Topic proposal Development of Guidelines for the Early Diagnosis and support of Children with FAS and FASD

1.	What is the problem/need for a guideline/clinical scenario?
	Alcohol consumption in women of child bearing age, especially younger women most at risk of unplanned pregnancies, has increased rapidly in recent years. The lifelong effects of alcohol use in pregnancy have only been systematically researched over the past 40 years but this research indicates that fetal damage due to alcohol use in pregnancy has the potential to be of major concern in Scotland. [1] [2] [3] Paediatric clinical experience indicates that, in Scotland, more babies are harmed each year by alcohol than were ever harmed by thalidomide.[4] Fetal Alcohol Disorder (FAS) and Fetal Alcohol Spectrum Disorder (FASD) are now better defined, and many countries have successfully adopted a standardised approach to the diagnosis. In countries where good recognition, diagnostic processes, and recording exist FASD is considered to be common. It is estimated worldwide that alcohol detrimentally affects1:100 live births[5]. In Scotland we are failing to identify correctly and therefore adequately support these children. Currently poor awareness and lack of training in available accredited standardised diagnostic and screening tools for health care staff, results in the failure to recognise these children. Additionally alcohol use is often overshadowed by other substance abuse.[6] Children affected by maternal alcohol use are often diagnosed as ADHD or Autistic spectrum disorder, or other neuro-developmental and behavioural disorders, and the role of alcohol fails to be recognised. This may contribute to an adverse outcome for the child, but also misses the opportunity to protect subsequent pregnancies. With the development of better, more targeted, educational and social support programmes for these children and their families there is an urgent need to make the appropriate diagnosis at the earliest opportunity. Medical evidence confirms that early diagnosis and intervention from birth and in the first 3 years of life can make significant differences to the developmental progress of the affected child, and the better understanding of the condition can help parents and professionals cope more appropriately with the child's difficulties[7][8].The developing brain, if appropriately stimulated, may adapt and compensate for some of the damage caused by the maternal alcohol consumption in pregnancy. Children with FASD are affected lifelong and if difficulties are not anticipated and understood, they will often fail to optimise their educational opportunities and some will become involved in

[1] Beattie JO, Day RE, Cockburn F, Garg RA. Alcohol and the fetus in the west of Scotland. *Brit Med J* 1983;287:17-20

[2] Plant M. Drinking in pregnancy and fetal harm: Results from a Scottish prospective study *Midwifery* 1986; 2:81-85

[3] Sulaiman ND, Florey CDuV, Taylor DJ, Ogston SA. Alcohol consumption in Dundee primagravidas and its effect on outcome of pregnancy. *Brit Med J 1986;296:1500-1503*

[4] Cockburn F, McClure J, Watts M. Written evidence to House of Commons Health Committee: Alcohol Session 2008-09

[5] Jonsson E et al. "The International Charter on Prevention of Fetal Alcohol Spectrum Disorder" May P. A. Et al. "Prevalence and epidemiological characteristics of FASD from various research methods with an emphasis on recent in-school studies Dev Disabil Res Rev 2009 15: 176-190).

[6] Streissguth AP, Bookstein FL, Barr HM, Sampson PD, O'Malley K, Young JK. Risk factors for adverse life outcomes in fetal alcohol syndrome and fetal alcohol effects. J Dev Behav Pediatr. 2004;25(4):228–238.

[8] Paley B., O'Connor M.J. (2009) "Intervention for individuals with fetal alcohol spectrum disorders: Treatment approaches and case management" *Ment Retard Dev Disabil Res Rev* 15. 3. 258-267.

	criminal activity, develop mental health problems and have a higher risk of becoming addicted to alcohol and other drugs, thus continuing the cycle.[9] They are also more likely to die prematurely from violence, accident or suicide.[10] **Health Economics** During the course of 2010, Scottish Government analysts undertook modelling to estimate the public sector financial impacts of failing to invest in the early years of a child's life. The project identified the potential short, medium and long-term public sector cost savings from intervening early. These savings took the form of reduced health, justice and social work/care costs, as well as impacts on the tax/benefits system. The approach involved characterising hypothetical life trajectories for three different profiles of children. For each trajectory, analysts developed a narrative describing a typical set of life events and the associated demand upon public services and transfer payments. Children with no additional needs were identified as the base case with access to universal services, while the pathways of those with moderate and severe additional needs were costed relative to the universal base case. The services drawn upon by the hypothetical individuals over their lives were mapped based on Scottish evidence of the costs of interventions/programmes[11]. The modelling estimates that the lifetime public sector cost of an individual whose severe additional needs are not addressed effectively early in life can be up to 9 times greater than that of an individual who has few support needs and benefits solely from universal provision. As part of the work, analysts identified maternal health/health during pregnancy as one of three example policy areas and the additional cost to the public purse for a child with a limiting long term illness due to a mother's substance misuse during pregnancy (acute outcomes) was calculated. Specific modelling has also been undertaken in Canada with three interations of the model, all demonstrating the greatly increased cost to society of a child with FASD. Recent Canadian studies suggest the lifetime cost may be as great as $1million /affected child[12][13][14]
2.	**Burden of the condition**
	Mortality There is no current information on mortality specifically related to the condition. However, research shows that children with FASD conditions are more likely to have mental health problems and to have addiction problems in adulthood, suggesting that they may contribute to mortality from alcohol addiction and suicide. Also damage to the areas of the brain responsible for assessing and judging risk suggests they may be at higher risk of death due to accident or trauma.

[9] Rasmussen C. et al "Neurobehavioural outcomes of children with FASD : a Canadian perspective". Paediatr Child health 2008 13: 185-191 ; Popova S et al " Fetal Alcohol Spectrum Disorder prevalence estimates in correctional systems : a systematic literature review. Can J Public Health 2011 ; 102: 336-340)

[10] (Easton, Brian, et al. "The cost of lost productivity due to fetal alcohol spectrum disorder-related premature mortality." Journal of population therapeutics and clinical pharmacology= Journal de la thérapeutique des populations et de la pharamcologie clinique 22.1 (2015): e3.)

[6] http://www.scotland.gov.uk/Topics/Research/by-topic/children-and-young-people/FinancialImpactEarlyYears

[12] What Do We Know about the Economic Impact of Fetal Alcohol Spectrum Disorder? A Systematic Literature Review Svetlana Popova , Brenda Stade , Dennis Bekmuradov , Shannon Lange , Jürgen Rehm DOI: http://dx.doi.org/10.1093/alcalc/agr029 490-497 First published online: 22 April 2011]

[13] Cost of fetal alcohol spectrum disorder in Canada *www.cfp.ca/content/53/8/1303.full}*

[14] (Popova, Svetlana, Shannon Lange, Larry Burd, and Jürgen Rehm. "Health care burden and cost associated with fetal alcohol syndrome: based on official Canadian data." *PloS one* 7, no. 8 (2012): e43024.)

	Incidence There is currently no standard reporting or recording system for data capture on the incidence of FAS or FASD in either Scotland or the UK. It is, however, acknowledged that this condition is under-diagnosed and under-recorded. The incidence of FASD worldwide is considered to be around 1 in 100 live births[15] FAS, the full syndrome, which includes the sentinel facial features, caused by teratogenic exposure to alcohol during the first trimester of pregnancy, is considered to have a similar incidence to that of Down's syndrome (around 1:1,000 live births). A five year passive surveillance programme was funded by the Chief Scientists Office and Child and Maternal Health Division. This was to determine the rate of diagnosis by paediatricians in Scotland of FAS– the most readily recognised and clearly defined condition in the FASD spectrum. This programme has so far identified, 44 with a definite diagnosis. In the context of 60,000 births annually in Scotland, this is a gross underestimate of the number of affected children. The reasons for this include: • Failure to eliminate prenatal effects of alcohol as a possible major underlying cause of neuro-developmental delay / learning disability • Lack of standardised diagnostic approach and training, • Lack of expertise and/or confidence in making the diagnosis, • Non-referral of children to the paediatric service, for this diagnosis to be considered. • Reluctance to make the diagnosis as this is perceived as unhelpful or more damaging than not making it.
	Prevalence While there is incomplete evidence on the true prevalence of FAS and FASD in Scotland, international evidence on the incidence of FAS and FASD among similar populations is suggestive of a rate at birth in Scotland of between 58 and 444 for the more severe FAS, and of between 547 and 2432 for FASD per annum. These numbers are derived from estimates in Europe and North America, where rates of alcohol consumption in the general population are in some cases considerably lower than in Scotland. The above figures are therefore likely to be underestimates.
3.	**Variations**
	In practice in Scotland Significant large variation in practice relating to diagnosis is seen across Scotland. Paediatricians consider and report the condition sporadically. Diagnosis is not made in a standardised way and therefore it appears that professionals are not confident in making the diagnosis.[16] Australian studies also give evidence of this. [17] The diagnosis is more actively considered in Looked After and Accommodated (LAAC) children, because of increasing awareness. However the diagnostic approach from clinicians is not uniform and foster and adoptive parents are particularly frustrated by this.
	In health outcomes in Scotland Because we have very poor identification of children with FAS/FASD in Scotland and no consistent reporting system, many of these children are misdiagnosed and included in outcome figures for children with a learning disability, ADHD, Autistic spectrum disorders or

[15]7[15] Sampson PD, Streissguth AP, Bookstein FL, Little RE, Clarren SK, Dehaene P et al. Incidence of fetal alcohol syndrome and prevalence of alcohol-related neurodevelopmental disorder. Teratology 1997; 56(5):317-326

[16] Watts ,M Health Needs assessment for fetal alcohol syndrome report for Part 2 of the MPH examination.

[17] Watkins, Rochelle E., Elizabeth J. Elliott, Raewyn C. Mutch, Jane Latimer, Amanda Wilkins, Janet M. Payne, Heather M. Jones et al. "Health professionals' perceptions about the adoption of existing guidelines for the diagnosis of fetal alcohol spectrum disorders in Australia." *BMC pediatrics* 12, no. 1 (2012): 69.

	other behavioural disorders. It will only be possible to look at true outcomes once we have reliable diagnostic data. International research, as referenced, suggests that educational progress and treatment for behavioural disorders is significantly improved when the underlying cause of the neuro-developmental problem is understood.[18] Additionally health outcomes for fetuses in subsequent pregnancies are improved, if the mother knows that the problems in a previous child are linked to alcohol intake in pregnancy. Information from New Zealand and Canada suggests that this can be a potent motivator to mothers for abstention from alcohol in subsequent pregnancies.[19]
4.	**Areas of uncertainty to be covered**
	Key question 1 Do we screen adequately/positively for FASD in Scotland? Currently we know from populations similar to our own, but with a lower alcohol intake, and less damaging patterns of alcohol use, that we might expect 58-444 FAS and 547-2432 for FASD per annum. Our only study so far with paediatricians reporting cases suggested < 50. So we have a major need to identify cases adequately. The national support needs coding system (SNS)can be used in Scotland to record cases identified , but currently no standardised screening approach is used by clinicians.
	Key question 2 What is the best diagnostic tool to use to appropriately diagnose FAS and FASD conditions? World wide. a variety of diagnostic tool kits have been developed for the condition, and clinicians' confidence in making the diagnosis would be greatly increased if a standardised approach, with available training on the method, was agreed for Scotland. Improved outcomes for children due to earlier identification and intervention has been demonstrated in other countries where a standardised diagnostic tool is used. [20]
	Key question 3 When is the best time to screen for FASD to achieve optimum benefit to the child? Will increased awareness and earlier diagnosis of pre-natal alcohol affected children lead to better advice to parents and optimisation of the child's development, and . the reduction in secondary health sequelae suffered by this group of children, particularly mental health problems?
5.	**Areas that will not be covered**
	Screening at birth of all babies regardless of maternal history – mothers who have taken alcohol in pregnancy may be flagged through the universal child surveillance system. This guideline will concentrate on improving the accurate diagnosis of children with FAS/FASD. Programs have been developed and are already in place to increase awareness of the importance of alcohol abstinence during pregnancy (the NO Alcohol NO Risk campaign) and midwives trained in the importance of accurate alcohol intake recording for pregnant mothers.
6.	**Aspects of the proposed clinical topic that are key areas of concern for patients, carers and/or the organisations that represent them** (please describe how these issues have been identified eg reports or surveys from patient organisations, qualitative studies, telephone

[18] Paley B., O'Connor M.J. (2009) "Intervention for individuals with fetal spectrum disorders: Treatment approaches and case management" *Ment Retard Dev Disabil Res Rev* 15. 3. 258-267

[19] May, P. A et al (2013). Case management reduces drinking during pregnancy among high risk women. The international journal of alcohol and drug research, 2(3), 61.

[20] Astley S. "Profile of the first 1,400 patients receiving diagnostic evaluations for fetal alcohol spectrum disorder at the Washington State Fetal Alcohol Syndrome Diagnostic and Prevention Network. Can J Clin Pharmacol 17(1) : e 132-e164

	help line statistics, testimonies from patients or other means).
	Often birth mothers are reticent in identifying themselves, because of the stigma attached to the diagnosis, but those brave enough to present their views publicly, identify that they would have been better able to manage their child's difficulties if they had understood the underlying brain damage that the child had sustained, and that education staff might have been more supportive if they had known that the child had alcohol related pre-natal brain damage and was not' just a troublemaker'. They also identify the need to have a diagnosis at the earliest stage to have the opportunity to avoid similar damage occurring in subsequent pregnancies. We know from caregivers of children who are looked after and accommodated, (LAAC) that they feel strongly that they should have had more information before adoption or long term fostering, and it appeared that it was only after pushing health professionals and exploring many possible reasons for challenging behaviours that FASD was considered. This is because awareness of FASD with health professionals is still low, based on the numbers diagnosed with FAS, and there is a lack of confidence in making this diagnosis. Parent groups feel strongly that their children have been disadvantaged and adversely affected by the failure to make a correct diagnosis. This has been a consistent view from the parent groups who have been involved with the FASD pathway discussion groups over the past year, and is reiterated in the FASD-UK Facebook group. r. Education and social work colleagues have also expressed concern that health colleagues are reluctant and lacking in skills to support them in confirming or refuting the diagnosis of FASD. With the emergence of educational programs tailored to better meet the needs of this group there is a need for health care professionals to improve their diagnostic approach. Preliminary research by Sleep Scotland (a charity set up to support families through sleep counselling programs) has suggested that sleep disorders are seen more frequently in this group of children. Reaching the child and their parent at an earlier stage would improve the sleep patterns of both the child and their parents, allowing them to avoid secondary limitation of their learning through sleep deprivation.
7.	**Population**
	Included The diagnostic guidelines would be developed to be appropriate for children Birth-primary school leaving age. Future extension and adaptation for post transition to secondary teenagers could be developed.
	Not included Post primary children and adults with FASD
8.	**Healthcare setting**
	Included: • All sectors of health involved with the care of children and pregnant mothers would need to be aware of the Guidelines and how they could contribute to the diagnostic process. • Primary care (GPs and practice nurses) • Antenatal appointments Midwifery services • Addiction Support services • Paediatric and neonatal settings (Hospital and Community based) • Health visitor services – home and surgery visits, to include Family Nurse Practitioners • Speech and Language Therapists and/or Occupational Therapists • CAMHS service Clinical psychologists • Adoption and Fostering Medical advisors

	Not included • Adult health services for the care of adults with FAS/FASD
9.	**Potential**
	Potential to improve current practice • Standardisation of diagnostic practice and accurate recording of affected children. • Recognition of importance of diagnosis to advise treatment planning • To utilise the opportunities presented by the Children and Young Peoples (Scotland) Act 2014 – as well as the Additional Support for Learning (Education) (Scotland) Act 2004 (amended 2009) legislation (GIRFEC) to ensure interagency planning and support, subsequent to diagnosis
	Potential impact on important health outcomes (name measureable indicators) Because of the nature of the disorders and frequently co-occurring disorders, treating FASD is complicated. Large-scale studies of interventions have not been conducted in Scotland. Many children are currently receiving health support with alternative diagnoses e.g. ADHD or ASD, or undiagnosed learning disability. Canada, which also has a publicly funded healthcare system, provides a model for Scotland in its approach to these conditions. Much of what is known is based on "wisdom of practice" gained through trial and error by parents, educators, clinicians and others working with individuals prenatally exposed to alcohol. However, as with most disabling conditions, **early intervention is important** and has been shown to result in improved outcomes.[21] The personal and socio-economic costs associated with FASD are considerable and persistent. Secondary disabilities in those affected by FASD are common, severe and affecting multiple sectors of society. In Streissguth et al's 2004 study[22] reported the following features were observed in individuals with FASD in the US population: • 60% suffer a disrupted school experience; • 60% experience trouble with the law; • 50% experience confinement on mental health or justice grounds; • 50% exhibit inappropriate sexual behaviour on repeated occasions • 35% suffer alcohol/drug problems. There is scope for prevention of these secondary disabilities – protective factors include early diagnosis, stable home environment and eligibility for support services.[23]
	Potential impact on resources (name measureable indicators) Initially there may be increased pressure on developmental paediatricians to see children to consider the diagnosis. This is already beginning to happen as awareness of the importance of making the diagnosis is being raised with all staff caring for children and their parents. However currently these children are already in the 'system' so they are not a new population

[21] Streissguth AP, Barr HM, Kogan J et al. 1996 Understanding the occurrence of secondary disabilities in clients with fetal alcohol syndrome (FAS) and fetal alcohol effects (FAE). Final report to the Centers for Disease Control and Prevention (CDC). University of Washington, Fetal Alcohol and Drug Unit Tech Rep No 96-06

[22] Streissguth, AP et al. Risk Factors for Adverse Life Outcomes in Fetal Alcohol Syndrome and Fetal Alcohol Effects. *Journal of Developmental and Behavioral Pediatrics* 2004; 25(4) 228-238

[23] Community Mental Health Journal February 2012, Volume 48, Issue 1, pp 12-21 08 Aug 2010 The Effectiveness of a Community-Based Intervention Program for Women At-Risk for Giving Birth to a Child with Fetal Alcohol Spectrum Disorder (FASD)Carmen Rasmussen, Katrina Kully-Martens, Kennedy Denys, Dorothy Badry, Dorothy Henneveld,Katy Wyper, Therese Grant

	of children and often are being seen for multiple problems and returning for a diagnosis and inappropriately being seen in multiple clinics. A more stream lined and standardised approach may well save time and resources in the future. If Guidelines were available this should lead to better identification of the FAS/FASD group, a re-alignment, and better targeting of resources. Scottish Government have already agreed to provide training to health professionals in a standardised diagnostic approach, if a national model could be agreed through the SIGN process.. Alcohol histories are being taken as a routine by midwives and health visitors, as part of their refreshed framework. Recording is available through the national Child Health surveillance system and the SNS national Support Needs System. GIRFEC meetings are to be used in all areas of the country so no new resources will be needed to facilitate discussions regarding early support and support through the ASL legislation. There may be early pressure on Children and Adolescent Mental Health Services (CAMHS), however earlier identification of the potential for secondary mental health problems may result in earlier more pro-active treatment for these children, resulting in better use of available resources. Again this is not a new population of children, but currently a hidden group. **Measurable indicators.** Number of health professionals trained to use the standardised diagnostic process Number of children with developmental problems potentially related to alcohol in utero identified through the child health surveillance program. Number of children where the agreed diagnostic guideline/process to consider FAS/FASD as a cause of their developmental delay was used. Increased number of children recorded with FAS/FASD on the SNS Decrease in number of those children listed as undiagnosed aetiology for learning disability and/or behavioural problems.(These 2 figures should begin to balance out) Improved parental satisfaction with diagnostic services, initially in the LAAC group of parents, and then for all parents. Development of targeted programmes in education and social care for the children.
10.	**What evidence based guidance is currently available?**
	None Currently there are no UK Guidelines on this topic The Canadian Guidelines have just been reviewed.
	Out-of-date (list)
	Current (list)
11.	**Relevance to current Scottish Government policies**
	• A Refreshed Framework for Maternity Care in Scotland • Children and Young People (Scotland) Act 2014 • Commission on the Future Delivery of Public Services in Scotland • Education (Additional Support for Learning) (Scotland) Act 2004 • Equally Well • Getting it Right for Every Child (GIRFEC) • Healthcare Quality Strategy

	• Early Years Collaborative • National Guidance for Child Protection in Scotland • National Parenting Strategy • "No Alcohol No Risk" • The Early Years Framework • These are Our Bairns Scottish Government is committed to ensuring reduction in harm from alcohol to all sectors of the Scottish population, including children. Many of the policies above emphasise the need for early identification of difficulties in childhood to better support the child and their family and to optimise their developmental progress. The Children and Young People's (Scotland) Act 2014 sets out the obligation of all agencies involved with the care of the child to share information and co-ordinate services so that the needs of that child can be best met and their opportunities to progress optimised. The Refreshed Framework for Maternity Care and the Early Years Framework have allowed the opportunity to increase awareness of the need to consider alcohol as a significant possible causative factor in neuro-developmental delay in children and the need to pro-actively, routinely, record maternal intake in pregnancy. All of these policies will increase the need for standardised diagnostic guidelines for clinicians to confirm or refute the diagnosis. The availability of better alcohol histories will also greatly assist in making a confident diagnosis. The recognition of FAS/FASD as specific entities and the development of specialist educational programs[24] [25]means that the clear, early, identification of these children will ensure that they are offered appropriate support through the ASL legislation.
12.	**Who is this guidance for?**
	Primarily all Health professionals involved with the care of pregnant women and those caring for children with neurodevelopmental and/ or behavioural problems. Non-health professionals should also be informed by the guidance on how to access the diagnostic pathway using the GIRFEC process now available to all children in Scotland. Parents (birth and adoptive) also need to be aware of the guidelines in order to understand the diagnostic process and how their child could benefit.
13.	**Implementation**
	Links with existing audit programmes Audit of number of children with neurodevelopmental problems identified by the national Pre-School Surveillance program. It is planned that maternal alcohol intake during pregnancy will be recorded routinely, as well as the child's developmental status. Use of the national Support Needs System (SNS) Reed codes to identify children with FAS or FASD, and audit annual figures for new and existing cases.
	Existing educational initiatives: • FASD toolkit • Training for Midwives and Health Visitors on how best to obtain maternal alcohol history. • NHS Education for Scotland Fetal Alcohol Harm e-learning resource. The resource was developed to support a range of activity led by the Scottish Government to substantially reduce the harm caused by alcohol consumption in pregnancy across Scotland. The content was developed by 'Children in Scotland' with input from the child and maternal

[24] Carpenter,B.Ashdown,R.&Bovair,K(2001) Enabling access:Effectiveteaching and learning for children with learningdifficulties.London: David Fulton.

[25] Blackburn,C.,Carpenter,B.,&Egerton ,J.(2010) 'Shaping the Futurefor children with foetal alcoholspectrum disorders',Support for Learning,25(3),139-145

	health team at NES and the Scottish Government Fetal Alcohol harm national working group. • Conferences to increase awareness and knowledge level about FASD have been organised for health(GPs Midwives Paediatricians) Social work and Third sector , and Education colleagues and USB sticks to education and GP's, health visitors and midwives • Training sessions for Paediatricians, AHPs, Education and Social work professionals in Scotland, by an expert FASD Clinic group from Canada have been sponsored by Scottish Government to improve diagnostic ability and confidence in supporting parents and children at the time of diagnosis. • Specific practical training in best diagnostic practice has been arranged for Paediatricians.
	Strategies for monitoring implementation • Number of children reported to the Support Needs national Register with FAS and FASD • Number of children referred to Specialist FASD Review groups for further consultation • Number of paediatricians in Scotland who are trained in the standardised diagnostic approach • Improvement in satisfaction of LAAC parents in relation to information sharing and access to FASD diagnostic process. • Reduction in length of time for diagnosis to be made • Reduction in age at which diagnosis is made and appropriate early educational support is offered. • Reporting requirements and accountability measures in both the ASL Act and C&YP Act.
14.	**Primary contact for topic proposal**
	Dr Patricia D. Jackson
15.	**Group(s) or institution(s) supporting the proposal**
	RCPCH Scottish Committee SACCH Scottish Association of Community Child Health RCN (Midwives and Health Visitor colleagues) FASD Scotland Research Advisory Group for Children who are Looked after and Accommodated Aberlour Action for Children Alcohol Focus Scotland BAAF Barnardos - CELCIS Research Advisory Group for Children who are Looked after and Accommodated Children in Scotland SHAAP WAVE Trust NO-FAS UK Sleep Scotland Royal College of General Practitioners Royal College of Psychiatrists(Children and Young People's Mental Health Scottish Division)

Declaration of Interests

Please complete all sections and if you have nothing to declare please put 'N/A

Having read the attached SIGN Policy on Declaration of Competing Interests I declare the following competing interests for the previous year, and the following year. I understand that this declaration will be retained by the SIGN Programme Lead.	
Signature:	Patricia D. Jackson
Name:	Dr Patricia D Jackson
Relationship to SIGN:	Topic proposal primary contact
Date:	6th April 2015
Date received at SIGN:	07/04/2015

Personal Interests

Remuneration from employment

	Name of Employer and Post held	Nature of Business	Self or partner/ relative	Specific?
Details of employment held which may be significant to, or relevant to, or bear upon the work of SIGN	N/A			

Remuneration from self employment

	Name of Business	Nature of Business	Self or partner/ relative	Specific?
Details of self employment held which may be significant to, or relevant to, or bear upon the work of SIGN	Clinical Lecturer for charities	Charities are Sleep Scotland Down Syndrome International		

Remuneration as holder of paid office

	Nature of Office held	Organisation	Self or partner/ relative	Specific?
Details of office held which may be significant to, or relevant to, or bear upon the work of SIGN	N/A			

Remuneration as a director of an undertaking

	Name of Undertaking	Nature of Business	Self or partner/ relative	Specific?
Details of directorship held which may be significant to, or relevant to, or bear upon the work of SIGN	N/A			

Remuneration as a partner in a firm

	Name of Partnership	Nature of Business	Self or partner/ relative	Specific?
Details of Partnership held which may be significant to, or relevant to, or bear upon the work of SIGN	N/A			

Shares and securities

	Description of organisation	Description of nature of holding (value need not be disclosed)	Self or partner/ relative	Specific?
Details of interests in shares and securities in commercial healthcare companies, organisations and undertakings	N/A			

Remuneration from consultancy or other fee paid work commissioned by, or gifts from, commercial healthcare companies, organisations and undertakings

	Nature of work	For whom undertaken and frequency	Self or partner/ relative	Specific?
Details of consultancy or other fee paid work which may be significant of to, or relevant to, or bear upon the work of SIGN	N/A			

Details of gifts which may be significant to, or relevant to, or bear upon the work of SIGN	N/A			

Non-financial interests

	Description of interest	Self or partner/ relative	Specific?
Details of non-financial interests which may be significant to, or relevant to, or bear upon the work of SIGN	• Trustee for Family Fund. • Vice Convener Children in Scotland.		

Non-personal interests

	Name of company, organisation or undertaking	Nature of interest
Details of non-personal support from commercial healthcare companies, organisations or undertakings	N/A	

Please return to
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t: **0131 623 4735**
e:**roberta.james@nhs.net**

Initial screen

Purpose: initial screening by SIGN Senior Management Team to exclude proposals that are neither clinical, nor multi-professional, nor appropriate for the SIGN process.

1.	**Is this an appropriate clinical topic for a SIGN guideline?** Is it a clinical topic, what is the breadth of the topic and is there a need for the guideline as identified in the proposal?	
	YES	
2.	**Is there a suitable alternative product which would address this topic?** Would another Healthcare Improvement Scotland product better address the topic?	
	No	
3.	**Has this topic been considered before and rejected?** What were the reasons for rejection and are they still applicabl3	
	No	
4.	**Outcome**	
	Go forward to the next stage of topic selection	**YES**
	Reject	

Suitability screen

Purpose: screening by the Guideline Programme Advisory Board to select applications suitable for inclusion in the SIGN topic selection process.

1.	**Is there an owner for the project?** (preferably an individual)
	Yes
2.	**Is this a clinical priority area for NHSScotland?**
	Alcohol misuse is a problem in Scotland as is the knock-on effect for the next generation. Recommendations on screening for FASD are needed to allow good management of affected children.
3.	**Is there a gap between current and optimal practice? OR Is there wide variation in current practice?** (is this an area of clinical uncertainty)
	Yes, there is huge variation in practice in terms of screening.
4.	**Is there a suitable guideline already available that could be adapted?** (not necessarily by SIGN)
	There is a Canadian guideline which may not be entirely relevant as the populations differ. There is no guidance from NICE.
5.	**Is there adequate literature to make an evidence-based decision about appropriate practice?** (is effective intervention proven and would it reduce mortality or morbidity)
	There is a body of evidence.
6.	**Would the proposed practice change result in sufficient change in outcomes** (health status, provider and consumer satisfaction and cost) **to justify the effort?**
	Yes, through screening, healthcare professionals are more aware of the potential problems and interventions. Early assessment of educational and developmental needs have an impact and can avoid wrong diagnoses.
	How big is the gap?
	The gap is very large
	How much effort will it take to close the gap?
	The guideline may need good awareness raising rather than a major implementation strategy as there may not be many cases coming through.
7.	**Is there a perceived need for the guideline, as indicated by a network of relevant stakeholders?**
	Good interest from relevant stakeholders. The topic is very multidisciplinary and touches on social care aspects.
8.	**Is there a reasonable likelihood that NHS Scotland could implement the change?**
	There is Government support for this initiative although any potential guideline would have implications for education/specialist education.

9.	**Does the proposer have any conflicts of interest? If so how will these be managed?**	
	The proposer does not have any conflicts of interest.	
10.	**Outcome**	
	Go forward to the next stage of topic selection	**YES**
	Reject	
11.	**Decision**	
	Ratified by SIGN Council for inclusion on the SIGN guideline development programme	**Date**
	Comment	**10/02/16**

Scope of recent evidence

Scoping report: fetal alcohol syndrome (carried out August 2015)

- Guidelines found = 12 *(page 1)*
- HTAs found=5 *(page 6)*
- Guidelines identified through non guideline sites (Google Scholar and Epistemonikos) =11 *(page 8)*
- Sifted SRs=36 *(page 13)*
- Extra papers found regarding consensus methodology re fetal alcohol syndrome that may be of interest =5 *(page 31)*

Guidelines found (n=12):

CR185. Alcohol and Brain Damage in Adults: With reference to high-risk groups. 2014. url: http://www.rcpsych.ac.uk/files/pdfversion/CR185.pdf [Accessed

This report calls for clinical commissioning groups to support services that provide specialist care for patients with alcohol-related brain damage (ARBD). It highlights how alcohol abuse can cause changes to people's brain function and intellect, even though many will not be aware of it. However, carers, relatives and others may notice this and it can jeopardise work, family relationships and cause domestic and financial problems. It has been published in association with the Royal College of Physicians (London), the Royal College of General Practitioners and the Association of British Neurologists. The report reviews the literature relating to the definition, epidemiology, information on the neurobiological changes associated with ARBD and implications for medical treatments, service organisation and provision, assessment, and psychosocial interventions. The expert panel has reviewed the evidence and derived recommendations for commissioners and service providers. Specific recommendations are presented in the context of four specialist settings: alcohol treatment services, prisons, acute hospitals and pregnancy/fetal alcohol spectrum disorder (FASD). The report provides examples of service delivery models couched in the context of a team within a mental health trust, accessing clinicians across clinical teams, an ARBD team closely affiliated with the alcohol treatment services and a team embedded within an early onset dementia team. In the absence of significant research (except in a minority of areas), the evidence is derived from descriptive studies and clinical reviews. This guideline represents the best evidence available and it provides a source document for both commissioners and service providers in the assessment and management of this stigmatised and neglected group of patients.

Guidelines for the identification and management of substance use and substance use disorders in pregnancy. World Health Organization (WHO); 2014. url: http://apps.who.int/iris/bitstream/10665/107130/1/9789241548731_eng.pdf [Accessed

AHRQ - Agency for Healthcare Research + Quality (2010). Alcohol use and pregnancy consensus clinical guidelines. Society of Obstetricians and Gynaecologists of Canada. NGC:008007.

Bertrand J, Floyd L,Weber MK. Guidelines for identifying and referring persons with fetal alcohol syndrome. MMWR Recommendations and reports: Morbidity and mortality weekly report Recommendations and reports/Centers for Disease Control 2005;54(RR-11):1-14

Carson G, Cox LV, Crane J, Croteau P, Graves L, Kluka S, et al. Alcohol use and pregnancy consensus clinical guidelines. Journal

of obstetrics and gynaecology Canada : JOGC = Journal d'obstetrique et gynecologie du Canada : JOGC 2010;32(8 Suppl 3):S1-31

OBJECTIVE: to establish national standards of care for the screening and recording of alcohol use and counselling on alcohol use of women of child-bearing age and pregnant women based on the most up-to-date evidence. EVIDENCE: published literature was retrieved through searches of PubMed, CINAHL, and the Cochrane Library in May 2009 using appropriate controlled vocabulary (e.g., pregnancy complications, alcohol drinking, prenatal care) and key words (e.g., pregnancy, alcohol consumption, risk reduction). Results were restricted to literature published in the last five years with the following research designs: systematic reviews, randomized control trials/controlled clinical trials, and observational studies. There were no language restrictions. Searches were updated on a regular basis and incorporated in the guideline to May 2010. Grey (unpublished) literature was identified through searching the websites of health technology assessment (HTA) and HTA-related agencies, national and international medical specialty societies, clinical practice guideline collections, and clinical trial registries. Each article was screened for relevance and the full text acquired if determined to be relevant. The evidence obtained was reviewed and evaluated by the members of the Expert Workgroup established by the Society of Obstetricians and Gynaecologists of Canada. The quality of evidence was evaluated and recommendations were made according to guidelines developed by the Canadian Task Force on Preventive Health Care. VALUES: the quality of evidence was rated using the criteria described by the Canadian Task Force on Preventive Health Care (Table 1). SPONSOR: the Public Health Agency of Canada and the Society of Obstetricians and Gynaecologists of Canada. ENDORSEMENT: these consensus guidelines have been endorsed by the Association of Obstetricians and Gynecologists of Quebec; the Canadian Association of Midwives; the Canadian Association of Perinatal, Women's Health and Neonatal Nurses (CAPWHN); the College of Family Physicians of Canada; the Federation of Medical Women of Canada; the Society of Rural Physicians of Canada; and Motherisk. SUMMARY STATEMENTS: 1. There is evidence that alcohol consumption in pregnancy can cause fetal harm. (II-2) There is insufficient evidence regarding fetal safety or harm at low levels of alcohol consumption in pregnancy. (III) 2. There is insufficient evidence to define any threshold for low-level drinking in pregnancy. (III) 3. Abstinence is the prudent choice for a woman who is or might become pregnant. (III) 4. Intensive culture-, gender-, and family-appropriate interventions need to be available and accessible for women with problematic drinking and/or alcohol dependence. (II-2). RECOMMENDATIONS: 1. Universal screening for alcohol consumption should be done periodically for all pregnant women and women of child-bearing age. Ideally, at-risk drinking could be identified before pregnancy, allowing for change. (II-2B) 2. Health care providers should create a safe environment for women to report alcohol consumption. (III-A) 3. The public should be informed that alcohol screening and support for women at risk is part of routine women's health care. (III-A) 4. Health care providers should be aware of the risk factors associated with alcohol use in women of reproductive age. (III-B) 5. Brief interventions are effective and should be provided by health care providers for women with at-risk drinking. (II-2B) 6. If a woman continues to use alcohol during pregnancy, harm reduction/treatment strategies should be encouraged. (II-2B) 7. Pregnant women should be given priority access to withdrawal management and treatment. (III-A) 8. Health care providers should advise women that low-level consumption of alcohol in early pregnancy is not an indication for termination of pregnancy. (II-2A).

Chudley AE, Conry J, Cook JL, Loock C, Rosales T,LeBlanc N. Fetal alcohol spectrum disorder: Canadian guidelines for diagnosis. Canadian Medical Association Journal 2005;172(5 suppl):S1-S21

THE DIAGNOSIS OF FETAL ALCOHOL SPECTRUM DISORDER (FASD) is complex and guidelines are warranted. A subcommittee of the Public Health Agency of Canada's National Advisory Committee on Fetal Alcohol Spectrum Disorder reviewed, analysed and integrated current approaches to diagnosis to reach agreement on a standard in Canada. The purpose of this paper is to review and clarify the use of current diagnostic systems and make recommendations on their application for diagnosis of FASD-related disabilities in people of all ages. The guidelines are based on widespread consultation of expert practitioners and partners in the field. The guidelines have been organized into 7 categories: screening and referral; the physical examination and differential diagnosis; the neurobehavioural assessment; and treatment and follow-up; maternal alcohol history in pregnancy; diagnostic criteria for fetal alcohol syndrome (FAS), partial FAS and alcohol-related neurodevelopmental disorder; and harmonization of Institute of Medicine and 4-Digit Diagnostic

Code approaches. The diagnosis requires a comprehensive history and physical and neurobehavioural assessments; a multidisciplinary approach is necessary. These are the first Canadian guidelines for the diagnosis of FAS and its related disabilities, developed by broad-based consultation among experts in diagnosis.

Clarren S, Lutke J,Sherbuck M. The Canadian guidelines and the interdisciplinary clinical capacity of Canada to diagnose fetal alcohol spectrum disorder. Journal of population therapeutics and clinical pharmacology= Journal de la therapeutique des populations et de la pharamcologie clinique 2010;18(3):e494-9

BACKGROUND: In 2005, the CMAJ published the Fetal alcohol spectrum disorder: Canadian guidelines for diagnosis. The intent of this publication was to encourage a more consistent interdisciplinary team approach and diagnostic procedure for FASD diagnoses. That same year, the Canada Northwest FASD Research Network (CanFASD Northwest) determined the locations and capacity for interdisciplinary FASD diagnosis across Canada. Six years later, we wondered how successfully these Guidelines had been in bringing consistency to FASD clinical work. METHOD: All clinical programs in Canada that routinely performed FASD evaluations were identified through membership in either our Network Action Team on FASD Diagnosis, professional meetings, organizational memberships, websites, programs lists available from Provincial or Federal offices or by word of mouth. Surveys were sent to all of the programs identified. RESULTS: A total of 55 clinics had been identified in seven provinces and one territory in 2005 that did FASD multidisciplinary diagnostics. In 2011 only 44 clinics were identified in six provinces and one territory using the same methodology. Survey responses were completed by 89% of these 44 clinics identified in 2011. The Guidelines were well known to all programs and actively referred to by most. Only 46% of respondents had a full staff of professionals on site for diagnosis, however 90% did use the team approach in determining final FASD diagnosis, while 79% used the team to help in developing a treatment plan. Among the clinics reporting, 74% of them used the new diagnostic schema proposed in the Guidelines and another 12% report using both the Guidelines and another system for diagnosis. INTERPRETATION: The Guidelines have become well known to the medical community. They have contributed to increased consistency in approach and in diagnosis. The variations in clinical ability to fully staff themselves, and the 20% decline in clinic numbers suggest important funding gaps. Many provinces and territories still have no local interdisciplinary programs for FASD diagnosis, and the need across Canada is still many times greater than what is currently available.

Goh YI, Chudley AE, Clarren SK, Koren G, Orrbine E, Rosales T, et al. Development of Canadian screening tools for fetal alcohol spectrum disorder. The Canadian journal of clinical pharmacology= Journal canadien de pharmacologie clinique 2007;15(2):e344-66

BACKGROUND: Fetal alcohol spectrum disorder (FASD) is the most common cause of neurobehavioural handicap in North America. Screening for FASD may facilitate diagnosis and hence management of these children. We present a variety of screening tools for the identification of children at risk for FASD. METHODS: We critically reviewed and evaluated published and practiced methods for their potential of screening suspected cases, their epidemiological characteristics (sensitivity, specificity, positive and negative predictive values) [Phase I], as well as their feasibility [Phase II]. RESULTS: The following five tools were selected for the FASD screening toolkit: screening fatty acid ethyl esters in neonatal meconium, the modified Child Behaviour Checklist, Medicine Wheel tool, Asante Centre Probation Officer Tool, and maternal history of drinking and drug use. CONCLUSIONS: The toolkit for FASD screening aims at screening different populations, from the newborns to youth and at-risk mothers. It is anticipated that the toolkit will facilitate diagnosis of FASD.

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Methods: A steering group in Munich and a consensus group consisting of representatives of the German Federal Ministry of Health, the German Professional Societies and other FAS experts have been established in 2011. Representatives of the Patient Support Group FASworld are also members of the consensus group. For the methodological guidance the AWMF (Consortium of the scientific medical societies) is responsible and the literature evaluation is conducted by the ÄZQ

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Peadon E,Elliott EJ. Distinguishing between attention-deficit hyperactivity and fetal alcohol spectrum disorders in children: clinical guidelines. Neuropsychiatric disease and treatment 2010;6(509

Fetal alcohol spectrum disorders (FASD) are the physical and neurodevelopmental outcomes of fetal alcohol exposure. The behavioral phenotype of children with FASD includes difficulties with executive function, memory, planning, processing speed, and attention. Although attention deficit hyperactivity disorder (ADHD) is diagnosed in up to 94% of individuals with heavy prenatal alcohol exposure, the exact relationship between FASD and ADHD is unclear. There is some evidence that ADHD in FASD may be a specific clinical subtype and thus may require a different treatment approach. Although traditional behavioral observation scales may not distinguish between the two groups, there is evidence that children with FASD have a different profile on the four-factor model of attention than children with ADHD who do not have FASD. There is a paucity of good scientific evidence on effective interventions for individuals with ADHD and FASD. There is weak evidence that children with FASD and ADHD may have a better response to dexamphetamine than methylphenidate. There is a strong need for larger, high quality studies to examine the relationship between ADHD and FASD and identify effective treatments because management of inattention and hyperactivity may improve learning and ameliorate the common secondary disabilities associated with FASD.

Watkins RE, Elliott EJ, Mutch RC, Payne JM, Jones HM, Latimer J, et al. Consensus diagnostic criteria for fetal alcohol spectrum disorders in Australia: a modified Delphi study. BMJ open 2012;2(5):e001918

Objective To evaluate health professionals' agreement with components of published diagnostic criteria for fetal alcohol spectrum disorders (FASD) in order to guide the development of standard diagnostic guidelines for Australia. Design A modified Delphi process was used to assess agreement among health professionals with expertise or experience in FASD screening or diagnosis. An online survey, which included 36 Likert statements on diagnostic methods, was administered over two survey rounds. For fetal alcohol syndrome (FAS), health professionals were presented with concepts from the Institute of Medicine (IOM), University of Washington (UW), Centers for Disease Control (CDC), revised IOM and Canadian diagnostic criteria. For partial FAS (PFAS), alcohol-related neurodevelopmental disorder (ARND), and alcohol-related birth defects (ARBD), concepts based on the IOM and the Canadian diagnostic criteria were compared. Setting/participants 130 Australian and 9 international health professionals. Results Of 139 health professionals invited to complete the survey, 103 (74.1%) responded, and 74 (53.2%) completed one or more questions on diagnostic criteria. We found consensus agreement among participants on the diagnostic criteria for FAS, with the UW criteria most commonly endorsed when compared with all other published criteria for FAS. When health professionals were presented with concepts based on the Canadian and IOM diagnostic criteria, we found consensus agreement but no clear preference for either the Canadian or IOM criteria for the diagnosis of PFAS, and no consensus agreement on diagnostic criteria for ARND. We also found no consensus on the IOM diagnostic criteria for ARBD. Conclusions Participants indicated clear support for use of the UW diagnostic criteria for FAS in Australia. These findings should be used to develop guidelines to facilitate improved awareness of, and address identified gaps in the infrastructure for, FASD diagnosis in Australia.

Watkins RE, Elliott EJ, Wilkins A, Latimer J, Halliday J, Fitzpatrick JP, et al. Fetal alcohol spectrum disorder: development of consensus referral criteria for specialist diagnostic assessment in Australia. BMC pediatrics 2014;14(1):178

Fetal alcohol spectrum disorder (FASD) is known to be under-recognised in Australia. The use of standard methods to identify when to refer individuals who may have FASD for specialist assessment could help improve the identification of this disorder. The purpose of this study was to develop referral criteria for use in Australia. Method An online survey about

FASD screening and diagnosis in Australia, which included 23 statements describing criteria for referral for fetal alcohol syndrome (FAS) and FASD based on published recommendations for referral in North America, was sent to 139 health professionals who had expertise or involvement in FASD screening or diagnosis. Survey findings and published criteria for referral were subsequently reviewed by a panel of 14 investigators at a consensus development workshop where criteria for referral were developed. Results Among the 139 health professionals who were sent the survey, 103 (74%) responded, and 90 (65%) responded to the statements on criteria for referral. Over 80% of respondents agreed that referral for specialist evaluation should occur when there is evidence of significant prenatal alcohol exposure, defined as 7 or more standard drinks per week and at least 3 standard drinks on any one day, and more than 70% agreed with 13 of the 16 statements that described criteria for referral other than prenatal alcohol exposure. Workshop participants recommended five independent criteria for referral: confirmed significant prenatal alcohol exposure; microcephaly and confirmed prenatal alcohol exposure; 2 or more significant central nervous system (CNS) abnormalities and confirmed prenatal alcohol exposure; 3 characteristic FAS facial anomalies; and 1 characteristic FAS facial anomaly, growth deficit and 1 or more CNS abnormalities. Conclusion Referral criteria recommended for use in Australia are similar to those recommended in North America. There is a need to develop resources to raise awareness of these criteria among health professionals and evaluate their feasibility, acceptability and capacity to improve the identification of FASD in Australia. Keywords: Fetal alcohol spectrum disorder; Referral; Consensus

HTAs found (many on the Cochrane database followed through to dead links, so these are the ones where there are actual reports available) n=5 HTAs found

Andalusian Agency for Health Technology A. Efficacy of continuous electronic heart rate monitoring for antepartum fetal assessment in risk pregnancy - review. HTA Database 2005;

RECORD STATUS: None CITATION: Andalusian Agency for Health Technology Assessment. Efficacy of continuous electronic heart rate monitoring for antepartum fetal assessment in risk pregnancy - review. Seville: Andalusian Agency for Health Technology Assessment (AETSA). 2004

Elliott L, Coleman K, Suebwongpat A,Norris S. Fetal Alcohol Spectrum Disorders (FASD): systematic reviews of prevention, diagnosis and management. 2008;1(9):

Fetal Alcohol Spectrum Disorders (FASD) is an umbrella term used to describe the spectrum of disabilities (and diagnoses) associated with prenatal exposure to alcohol (Public Health Agency of Canada, 2005). This group of disorders encompasses fetal alcohol syndrome (FAS), fetal alcohol effects (FAE), alcohol-related birth defects (ARBD) and alcohol-related neurodevelopmental disorders (ARND) (Striessguth and O"Malley, 2000). The most clinically recognisable form of FASD, FAS, is the leading cause of non-genetic intellectual disability in the Western world (British Medical Association, 2007). FAS consists of measurable deficits including characteristic facial malformations, brain and central nervous system disorders, and growth retardation. Other associated conditions can include heart and kidney defects, hearing and eyesight impairments, skeletal defects and immune system deficiencies. The teratogenic actions of alcohol can occur at any stage during pregnancy. In particular, exposure to alcohol during the first three weeks post conception can damage early development and neural tube elaboration (O"Leary, 2002). Exposure between the fourth and nine weeks is the critical period for malformations of the brain and other cranial structures. The pattern of drinking is critical; binge drinking is associated with an increased rate of FAS-related abnormalities compared with drinking the same about of alcohol over an extended period of time (BMA Board of Science, 2007). Existing evidence on the adverse irreversible effects of low to moderate prenatal alcohol exposure 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 (BMA Board of Science, 2007). Estimates of FAS and FASD incidence and prevalence rates vary between countries. FASD is more common in populations that experience high degrees of social deprivation and poverty, such as indigenous groups. The difficulty in determining the incidence of FASD is due to the lack of accurate and routine data collection. Accurate reporting is further complicated by the lack of uniformly accepted diagnostic criteria and poor knowledge of FASD among primary care providers. The true extent of the incidence

and prevalence of FASD in New Zealand is unknown. There are no nationally consistent definitions or diagnostic criteria for FASD and children are not routinely screened in infancy or early childhood. Alcohol Healthwatch estimate that based on overseas incidence rates of 3 per 1000 live births, at least 173 babies are born with FASD every year in New Zealand (Alcohol Healthwatch, 2007). This can be compared to cystic fibrosis at 0.3 per 1000 live births, Down Syndrome at 1 per 1000 and cerebral palsy at 1-2.6 per 1000 (Alcohol Advisory Council and Ministry of Health, 2001). However other studies have estimated higher FASD incidence rates in New Zealand, with Curtis et al., (1994) estimating that 360 babies are born with FASD each year, and Leversha and Marks (1995) estimating that there are between 200 and 3540 babies born with FASD each year. The New Zealand Paediatric Surveillance Unit (NZPSU) collected data on the incidence and prevalence of FAS in New Zealand from July 1999 to December 2001. In 2000, 29 cases of suspected or definite FAS were reported. The incidence of FAS was found to be 2.9 per 100,000 children below 15 years of age, per year. The report notes that the incidence of FAS was low compared to other countries, possibly because only a small number of New Zealand paediatricians were diagnosing children with FAS (NZPSU, 2000). By comparison, the incidence of FAS in the state of Western Australia has been reported as 0.18 cases per 1000 births (Bower et al., 2000). Significantly higher incidence rates have been reported in Aboriginal children (2.76/1000 births) compared with non-Aboriginal children (0.02/1000 births). FASD is associated with irreversible damage to neural development and leads to lifelong consequences for the individual, their family and society. FASD is therefore a significant contributor to the burden of disease, to the burden of social costs and to health inequalities. Both primary disabilities (resulting from organ and central nervous system deficits) and secondary disabilities (developed over time because of the lack of interventions) associated with FASD are 100% preventable if women abstain from alcohol use during pregnancy. The financial implications of FAS and FASD have never been assessed in New Zealand but anecdotal evidence and financial estimates from overseas suggest it is a significant financial burden (Alcohol Healthwatch, 2007). Using a prevalence rate of 3 cases per 1000 live births (using the estimated incidence rate as a proxy), these cases would conservatively be costing New Zealand taxpayers an extra $3.46 million per annum. If lifetime care costs for FAS and FASD were calculated together with a higher estimated prevalence rate (which is likely given the current drinking culture in New Zealand), then it can be assumed that FASD is costing New Zealand a substantial amount of avoidable expenditure. There are a number of strategies that may be utilised to help reduce the burden of FASD. These include the use of effective screening, prevention and management programs, and accurate methods of diagnosing FASD.

Fröschl B, Brunner-Ziegler S,Wirl C. Prevention of fetal alcohol syndrome (Structured abstract). Health Technology Assessment Database. 2013; 3. [cited: url: http://onlinelibrary.wiley.com/o/cochrane/clhta/articles/HTA-32011001393/frame.html

Health Council of the Netherlands G. Risks of alcohol consumption related to conception, pregnancy and breastfeeding. HTA Database 2005;

RECORD STATUS: None CITATION: Health Council of the Netherlands Gezondheidsraad. Risks of alcohol consumption related to conception, pregnancy and breastfeeding. The Hague: Health Council of the Netherlands/Gezondheidsraad (GR). 2004/22. 2005

Mundy L, Hiller J, Braunack-Mayer A,Merlin T. MRI for the detection of foetal abnormalities. HTA Database 2007;

RECORD STATUS: This is a bibliographic record of a published health technology assessment from a member of INAHTA. No evaluation of the quality of this assessment has been made for the HTA database. CITATION: Mundy L, Hiller J, Braunack-Mayer A, Merlin T. MRI for the detection of foetal abnormalities. Adelaide: Adelaide Health Technology Assessment (AHTA). 2007

Guidelines found through Google Scholar and Epistemonikos (n=11)

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Methods: A steering group in Munich and a consensus group consisting of representatives of the German Federal Ministry of Health, the German Professional Societies and other FAS experts have been established in 2011. Representatives of the Patient Support Group FASworld are also members of the consensus group. For the methodological guidance the AWMF (Consortium of the scientific medical societies) is responsible and the literature evaluation is conducted by the ÄZQ (Center for Quality in Medicine). Results: The consensus group defined a key question and specific issues for the literature search. The evaluation of the literature is in progress. The methodological quality of the international and especially the German publications about the diagnostic criteria are rather poor. Most of the existing international guidelines for the diagnosis of FAS are consensus but not evidence-based. Conclusion: There is great need for a standardized, multidisciplinary, quality assured and implementable prevention of FAS in Germany. The first step is the establishment of evidence- and consensus-based diagnostic criteria for children with FAS which will be approved and presented in 2012.

Peadon E,Elliott EJ. Distinguishing between attention-deficit hyperactivity and fetal alcohol spectrum disorders in children: clinical guidelines. Neuropsychiatric disease and treatment 2010;6(509

Fetal alcohol spectrum disorders (FASD) are the physical and neurodevelopmental outcomes of fetal alcohol exposure. The behavioral phenotype of children with FASD includes difficulties with executive function, memory, planning, processing speed, and attention. Although attention deficit hyperactivity disorder (ADHD) is diagnosed in up to 94% of individuals with heavy prenatal alcohol exposure, the exact relationship between FASD and ADHD is unclear. There is some evidence that ADHD in FASD may be a specific clinical subtype and thus may require a different treatment approach. Although traditional behavioral observation scales may not distinguish between the two groups, there is evidence that children with FASD have a different profile on the four-factor model of attention than children with ADHD who do not have FASD. There is a paucity of good scientific evidence on effective interventions for individuals with ADHD and FASD. There is weak evidence that children with FASD and ADHD may have a better response to dexamphetamine than methylphenidate. There is a strong need for larger, high quality studies to examine the relationship between ADHD and FASD and identify effective treatments because management of inattention and hyperactivity may improve learning and ameliorate the common secondary disabilities associated with FASD.

Watkins RE, Elliott EJ, Mutch RC, Payne JM, Jones HM, Latimer J, et al. Consensus diagnostic criteria for fetal alcohol spectrum disorders in Australia: a modified Delphi study. BMJ open 2012;2(5):e001918

Objective To evaluate health professionals' agreement with components of published diagnostic criteria for fetal alcohol spectrum disorders (FASD) in order to guide the development of standard diagnostic guidelines for Australia. Design A modified Delphi process was used to assess agreement among health professionals with expertise or experience in FASD screening or diagnosis. An online survey, which included 36 Likert statements on diagnostic methods, was administered over two survey rounds. For fetal alcohol syndrome (FAS), health professionals were presented with concepts from the Institute of Medicine (IOM), University of Washington (UW), Centers for Disease Control (CDC), revised IOM and Canadian diagnostic criteria. For partial FAS (PFAS), alcohol-related neurodevelopmental disorder (ARND), and alcohol-related birth defects (ARBD), concepts based on the IOM and the Canadian diagnostic criteria were compared. Setting/participants 130 Australian and 9 international health professionals. Results Of 139 health professionals invited to complete the survey, 103 (74.1%) responded, and 74 (53.2%) completed one or more questions on diagnostic criteria. We found consensus agreement among participants on the diagnostic criteria for FAS, with the UW criteria most commonly endorsed when compared with all other published criteria for FAS. When health professionals were presented with concepts based on the Canadian and IOM diagnostic criteria, we found consensus agreement but no clear preference for either the Canadian or IOM criteria for the diagnosis of PFAS, and no consensus agreement on diagnostic criteria for ARND. We also found no consensus on the IOM diagnostic criteria for ARBD. Conclusions Participants indicated clear support for use of the UW diagnostic criteria for FAS in Australia. These findings should be used to develop guidelines to facilitate improved awareness of, and address identified gaps in the infrastructure for, FASD diagnosis in Australia.

Watkins RE, Elliott EJ, Wilkins A, Latimer J, Halliday J, Fitzpatrick JP, et al. Fetal alcohol spectrum disorder: development of consensus referral criteria for specialist diagnostic assessment in Australia. BMC pediatrics 2014;14(1):178

Fetal alcohol spectrum disorder (FASD) is known to be under-recognised in Australia. The use of standard methods to identify when to refer individuals who may have FASD for specialist assessment could help improve the identification of this disorder. The purpose of this study was to develop referral criteria for use in Australia. Method An online survey about FASD screening and diagnosis in Australia, which included 23 statements describing criteria for referral for fetal alcohol syndrome (FAS) and FASD based on published recommendations for referral in North America, was sent to 139 health professionals who had expertise or involvement in FASD screening or diagnosis. Survey findings and published criteria for referral were subsequently reviewed by a panel of 14 investigators at a consensus development workshop where criteria for referral were developed. Results Among the 139 health professionals who were sent the survey, 103 (74%) responded, and 90 (65%) responded to the statements on criteria for referral. Over 80% of respondents agreed that referral for specialist evaluation should occur when there is evidence of significant prenatal alcohol exposure, defined as 7 or more standard drinks per week and at least 3 standard drinks on any one day, and more than 70% agreed with 13 of the 16 statements that described criteria for referral other than prenatal alcohol exposure. Workshop participants recommended five independent criteria for referral: confirmed significant prenatal alcohol exposure; microcephaly and confirmed prenatal alcohol exposure; 2 or more significant central nervous system (CNS) abnormalities and confirmed prenatal alcohol exposure; 3 characteristic FAS facial anomalies; and 1 characteristic FAS facial anomaly, growth deficit and 1 or more CNS abnormalities. Conclusion Referral criteria recommended for use in Australia are similar to those recommended in North America. There is a need to develop resources to raise awareness of these criteria among health professionals and evaluate their feasibility, acceptability and capacity to improve the identification of FASD in Australia. Keywords: Fetal alcohol spectrum disorder; Referral; Consensus

Systematic reviews identified through Cochrane, OVID, EBSCO, Google Scholar limited to last 10 years/English language n=36

Burd L, Deal E, Rios R, Adickes E, Wynne J,Klug MG. Congenital heart defects and fetal alcohol spectrum disorders. Congenital Heart Disease 2007;2(4):250-5

OBJECTIVE: Review of the prevalence of congenital heart defects (CHD) and fetal alcohol spectrum disorder (FASD).
DESIGN: We conducted a search of the Medline and Pubmed databases to identify papers reporting the association. We then searched the reference lists of the papers and reference books for additional sources.
RESULTS: We found 29 studies that met our inclusion criteria. In the 12 case series studies of subjects with FASD, the proportion of cases with a CHD (atrial [ASD] and ventricular [VSD] septal defects, other defects, or unspecified CHD) ranged from 33% to 100%. From the 14 retrospective studies, the rate of septal defects was 21%, other structural defects 6% and unspecified defects was 12%. For the 2 case-control studies, the odds of CHD ranged from 1.0 (subjects with fetal alcohol effect) to 18.0 (subjects with fetal alcohol syndrome). In the 1 prospective study of CHD the OR for a child to have CHD and FASD was 1.0.
KEY CONCLUSION: Pediatric cardiologists may have frequent contact with children with FASD and increased levels of attention to prenatal alcohol exposure as a potential etiology of CHD is indicated. [References: 47]

Burd L, Peterson L,Kobrinsky N. Fetal alcohol spectrum disorders and childhood cancer: a concise review of case reports and future research considerations. Pediatric Blood & Cancer 2014;61(5):768-70

We reviewed the published literature on the relationship between childhood cancer and fetal alcohol spectrum disorders (FASD). A Pub Med search identified 12 subjects with the co-occurrence of FASD and cancer. We included an additional case from the author's institution. Neuroblastomas comprised 6 of the 13 (46%) case reports, yet neuroblastomas comprise only about 10% of childhood cancers ($z = 4.1$; $P < 0.001$). Other than rhabdomyosarcoma, no other cancer was reported more than once. Few cases of childhood cancer associated with FASD were identified likely due to under ascertainment of FASD.

D'Angiulli A, Grunau P, Maggi S,Herdman A. Electroencephalographic correlates of prenatal exposure to alcohol in infants and children: a review of findings and implications for neurocognitive development. Alcohol 2006;40(2):127-33

In this paper, we reviewed all existing studies using electroencephalography (EEG) in infants and children with known prenatal exposure to alcohol (PEA). The guiding purposes of the review were to determine if (1) EEG is a useful neuroimaging technique for investigating the brain correlates of PEA in infants and children, (2) there are indeed consistent EEG correlates of PEA in literature, and (3) these EEG correlates can be framed within a coherent picture of emerging implications for the study of PEA and its effects. The review confirms that EEG techniques have proven useful in indicating evidence of differential effects of patterns of PEA and timing in early fetal development and impairment of brain maturation in older children. In general, these techniques could be important in functional assessment of the brain of children affected by PEA, especially if used in conjunction with other neuroimaging techniques. The reviewed studies also suggest that although the impact on sensory and cognitive functions may involve extensive neural networks, there are EEG correlates of PEA which may in the future lead to the identification of neurophysiologic markers. A consistent aspect that emerges from the EEG data is that converging evidence from the study of different systems and processes suggests that PEA may almost invariably have consequences for later neurocognitive development.

Doney R, Lucas BR, Jones T, Howat P, Sauer K,Elliot EJ. Fine motor skills in children with prenatal alcohol exposure or fetal alcohol spectrum disorder. Journal of Developmental and Behavioral Pediatrics 2014;35(9):598-609

Objective: Prenatal alcohol exposure (PAE) can cause fetal alcohol spectrum disorders (FASD) and associated neurodevelopmental impairments. It is uncertain which types of fine motor skills are most likely to be affected after PAE or which assessment tools are most appropriate to use in FASD diagnostic assessments. This systematic review examined which types of fine motor skills are impaired in children with PAE or FASD; which fine motor assessments are appropriate for FASD diagnosis; and whether fine motor impairments are evident at both “low” and “high” PAE levels. Methods: A systematic review of relevant databases was undertaken using key terms. Relevant studies were extracted using a standardized form, and methodological quality was rated using a critical appraisal tool. Results: Twenty-four studies met inclusion criteria. Complex fine motor skills, such as visual-motor integration, were more frequently impaired than basic fine motor skills, such as grip strength. Assessment tools that specifically assessed fine motor skills more consistently

identified impairments than those which assessed fine motor skills as part of a generalized neurodevelopmental assessment. Fine motor impairments were associated with “moderate” to “high” PAE levels. Few studies reported fine motor skills of children with “low” PAE levels, so the effect of lower PAE levels on fine motor skills remains uncertain. Conclusions: Comprehensive assessment of a range of fine motor skills in children with PAE is important to ensure an accurate FASD diagnosis and develop appropriate therapeutic interventions for children with PAE-related fine motor impairments. (PsycINFO Database Record (c) 2015 APA, all rights reserved). (journal abstract)

Esper L,Furtado E. Identifying maternal risk factors associated with Fetal Alcohol Spectrum Disorders: a systematic review. European Child & Adolescent Psychiatry 2014;23(10):877-889

To identify the demographic, psychological, and social maternal risk factors associated with the development of Fetal Alcohol Spectrum Disorders (FASD). A bibliographic search was conducted in PubMed, SciELO, Lilacs, Web of Knowledge, and PsycINFO. The Newcastle-Ottawa Quality Assessment Scale (NOS) was used to evaluate the quality of the studies with case-control design. Articles were selected based on their relevance and presentation of data related to statistical comparisons of at least one or more demographic, psychological, or social maternal risk factors for FASD. 738 references were identified, of which 15 met the criteria to be included in the present review. Mothers of FASD children tend to: be older at the time of birth of the affected child, present lower educational level, have other family relatives with alcohol abuse, have other children with FASD, present a pattern of little prenatal care and a distinguishing pattern of alcohol consumption (alcohol use before and during pregnancy, failure to reduce alcohol use during pregnancy, and frequent episodes of binge drinking). Application of the NOS scale of methodological quality indicated that 8 studies (53 %) met the criterion for selection, 4 (27 %) were suitable for the criterion for comparability and only 4 studies were suitable for the exposition criterion. Mothers of FASD children have a distinctive pattern of drinking and accumulate several social risk factors. Maternal age at birth of the child seems to accentuate the risk. There are, however, few controlled studies that are adequate according to the NOS requirements for methodological quality. Fewer are based on the verification of a theoretical model. Clinicians should be aware of the relevance of preventive assessment of FASD risk mothers.

Esper LH,Furtado EF. Identifying maternal risk factors associated with Fetal Alcohol Spectrum Disorders: a systematic review. European Child & Adolescent Psychiatry 2014;23(10):877-89

To identify the demographic, psychological, and social maternal risk factors associated with the development of Fetal Alcohol Spectrum Disorders (FASD). A bibliographic search was conducted in PubMed, SciELO, Lilacs, Web of Knowledge, and PsycINFO. The Newcastle-Ottawa Quality Assessment Scale (NOS) was used to evaluate the quality of the studies with case-control design. Articles were selected based on their relevance and presentation of data related to statistical comparisons of at least one or more demographic, psychological, or social maternal risk factors for FASD. 738 references were identified, of which 15 met the criteria to be included in the present review. Mothers of FASD children tend to: be older at the time of birth of the affected child, present lower educational level, have other family relatives with alcohol abuse, have other children with FASD, present a pattern of little prenatal care and a distinguishing pattern of alcohol consumption (alcohol use before and during pregnancy, failure to reduce alcohol use during pregnancy, and frequent episodes of binge drinking). Application of the NOS scale of methodological quality indicated that 8 studies (53 %) met the criterion for selection, 4 (27 %) were suitable for the criterion for comparability and only 4 studies were suitable for the exposition criterion. Mothers of FASD children have a distinctive pattern of drinking and accumulate several social risk factors. Maternal age at birth of the child seems to accentuate the risk. There are, however, few controlled studies that are adequate according to the NOS requirements for methodological quality. Fewer are based on the verification of a theoretical model. Clinicians should be aware of the relevance of preventive assessment of FASD risk mothers.

Heller M,Burd L. Review of ethanol dispersion, distribution, and elimination from the fetal compartment. Birth Defects Research 2014;100(4):277-83

BACKGROUND: This study is a review of alcohol dispersion into and elimination from the fetal compartment. METHODS: PubMed searches were conducted for all years and all languages for relevant papers. We also hand searched the

reference list of papers and text books for additional references.

RESULTS: Alcohol concentration is determined by body water (49% for women), grams of ethanol consumed, and duration of drinking. The fetus has very limited metabolic capacity and transfer from the fetal compartment to maternal circulation is the major pathway to reduce fetal exposure. Vasoconstriction of the placenta-umbilical unit from alcohol and smoking decreases rates of alcohol elimination from the fetal compartment. By 20 weeks of gestation, keratinization of fetal skin reduces the permeability of fetal skin to very low levels, increasing the duration of fetal exposure and complicating alcohol elimination from the fetal compartment. Two reabsorption pathways, the intramembranous pathway and fetal swallowing, create a recycling system where much of the ethanol the fetus excretes will be reabsorbed back into its circulatory system. Fetal re-excretion of ethanol into the amniotic fluid occurs by means of fetal urine, breathing movements, and nasal excretions. Amniotic fluid then functions as a reservoir for ethanol, prolonging fetal exposure.

CONCLUSION: While the fetus has the ability to metabolize some ethanol, removal from the fetal-maternal unit relies primarily on maternal metabolic capacity. The alcohol elimination rate from the fetal compartment is approximately 3% to 4% of the maternal rate. We conclude with examples of the clinical relevance of information from this review.

Henderson J, Gray R,Brocklehurst P. Systematic review of effects of low-moderate prenatal alcohol exposure on pregnancy outcome. BJOG: An International Journal of Obstetrics & Gynaecology 2007;114(3):243-52

OBJECTIVE: The aim of this study was to review systematically the available evidence on studies in humans on the effects of low-moderate levels of prenatal alcohol consumption (up to 10.4 UK units or 83 g/week) compared with consumption of no alcohol on pregnancy outcome.

DESIGN: Systematic review.

POPULATION: Pregnant women or women who are trying to become pregnant.

METHODS: The search strategy included Medline, Embase, Cinahl and PsychInfo for the years 1970-2005. Titles and abstracts were read by two researchers and inclusion/exclusion being decided according to prespecified criteria. All the included articles were then obtained and read in full by the two researchers to decide on inclusion. The articles were assessed for quality using the Newcastle-Ottawa Quality Assessment Scales.

MAIN OUTCOME MEASURES: Outcomes considered were miscarriage, stillbirth, intrauterine growth restriction, prematurity, birthweight, small for gestational age at birth and birth defects including fetal alcohol syndrome.

RESULTS: The search resulted in 3630 titles and abstracts, which were narrowed down to 46 relevant articles. At low-moderate levels of consumption, there were no consistently significant effects of alcohol on any of the outcomes considered. Many of the reported studies had methodological weaknesses.

CONCLUSIONS: This systematic review found no convincing evidence of adverse effects of prenatal alcohol exposure at low-moderate levels of exposure. However, weaknesses in the evidence preclude the conclusion that drinking at these levels during pregnancy is safe. [References: 56]

Hosenbocus S,Chahal R. A review of executive function deficits and pharmacological management in children and adolescents. Journal of the Canadian Academy of Child and Adolescent Psychiatry 2012;21(3):223-229

Kodituwakku PW,Kodituwakku EL. From research to practice: an integrative framework for the development of interventions for children with fetal alcohol spectrum disorders. Neuropsychology Review 2011;21(2):204-23

Since fetal alcohol syndrome was first described over 35 years ago, considerable progress has been made in the delineation of the neurocognitive profile in children with prenatal alcohol exposure. Preclinical investigators have made impressive strides in elucidating the mechanisms of alcohol teratogenesis and in testing the effectiveness of pharmacological agents and dietary supplementation in the amelioration of alcohol-induced deficits. Despite these advances, only limited progress has been made in the development of evidence-based comprehensive interventions for functional impairment in alcohol-exposed children. Having performed a search in PubMed and PsycINFO using key words, interventions, treatment, fetal alcohol syndrome, prenatal alcohol exposure, and fetal alcohol spectrum disorders, we

found only 12 papers on empirically-based interventions. Only two of these interventions had been replicated and none met the criteria of "well-established," as defined by Chambless and Hollon (Journal of Consulting and Clinical Psychology 66(1):7-18, 1998). There has been only limited cross-fertilization of ideas between preclinical and clinical research with regard to the development of interventions. Therefore, we propose a framework that allows integrating data from preclinical and clinical investigations to develop comprehensive intervention programs for children with fetal alcohol spectrum disorders. This framework underscores the importance of multi-level evaluations and interventions.

Koren G, Sarkar M, Rosenbaum C,Orrbine E. The maternal drinking history guide: development of a national educational tool. Journal of Population Therapeutics & Clinical Pharmacology 2013;20(1):e42-3

BACKGROUND: The National Taskforce for the development of screening tools for FASD has identified maternal drinking as a critical area that should be screened. We describe the steps of development and implementation of a knowledge translation program for health care providers. The slide presentation is attached in English and French to allow its maximal use.

METHODS: In 2010, the National Taskforce for the development of screening tools for FASD identified maternal drinking as a critical area that should be screened. The systematic review and associated recommendations have been published and were included in the toolkit developed by the Canadian Association of Paediatric Health Centres with funding support from the Public Health Agency of Canada. Effective inquiry of maternal drinking can be conducted at three levels: Primary level, as part of practice-based screening; Level 2 use of structured questionnaires; and Level 3 laboratory-based screening.

CONCLUSION: It was acknowledged that most physicians do not ask women of reproductive age questions regarding their drinking habits, and the Taskforce was seriously concerned that even an effective guide may not change practice at the primary level. To that end, the Taskforce developed a three phase Knowledge Translation plan, to ensure that the educational program developed will be optimally effective for Canadian healthcare providers.

Landgraf MN, Nothacker M,Heinen F. Diagnosis of fetal alcohol syndrome (FAS): German guideline version 2013. European Journal of Paediatric Neurology 2013;17(5):437-46

BACKGROUND: Fetal alcohol syndrome (FAS) belongs to the umbrella of fetal alcohol spectrum disorders (FASD) and affects 0.02-0.8% of all annual births with a high number of undetected cases. FAS has severe and life determining consequences for the affected individual and his family.

AIM: The aim of the German guideline version 2013 is to provide objectively evaluated, evidence-based, clinically relevant and easily applicable diagnostic criteria for the full picture FAS.

METHODS: A systematic literature review (2001-2011), analysis of international guidelines and focused hand search were performed. Based on the evidence-assessed literature the multidisciplinary guideline group (14 German Professional Societies, the patient support group "FASD Germany" and 15 additional experts) consented recommendations for the diagnosis of FAS.

RESULTS: The following diagnostic criteria for FAS resulted: at least one deficit of growth, three defined facial characteristics and one functional or structural anomaly of the central nervous system. Confirmation of intrauterine alcohol exposure is not considered as a prerequisite for FAS diagnosis.

CONCLUSION: The German guideline presented here constitutes an unbiased evidence-based approach to the diagnosis of patients with fetal alcohol syndrome. It includes a practical pocket guide FAS for a quick overview of the diagnostic workup in everyday clinical work.

Landgraf MN, Nothacker M, Kopp IB,Heinen F. The diagnosis of fetal alcohol syndrome. Deutsches Arzteblatt International 2013;110(42):703-10

BACKGROUND: The estimated prevalence of fetal alcohol syndrome (FAS) is 8 for every 1000 live births. FAS has serious, lifelong consequences for the affected children and their families. A variety of professionals deal with persons who have FAS, including pediatricians, general practitioners, neurologists, gynecologists, psychiatrists, and psychotherapists.

Early diagnosis is important so that the affected children can receive the support they need in a protective environment.

METHODS: A multidisciplinary guideline group has issued recommendations for the diagnosis of FAS after assessment of the available scientific evidence. This information was derived from pertinent literature (2001-2011) retrieved by a systematic search in PubMed and the Cochrane Library, along with the US-American and Canadian guidelines and additional literature retrieved by a manual search.

RESULTS: Of the 1383 publications retrieved by the searches, 178 were analyzed for the evidence they contained. It was concluded that the fully-developed clinical syndrome of FAS should be diagnosed on the basis of the following criteria: Patients must have at least one growth abnormality, e.g., short stature, as well as all three characteristic facial abnormalities-short palpebral fissure length, a thin upper lip, and a smooth philtrum. They must also have at least one diagnosed structural or functional abnormality of the central nervous system, e.g., microcephaly or impaired executive function. Confirmation of intrauterine exposure to alcohol is not obligatory for the diagnosis.

CONCLUSION: Practical, evidence-based criteria have now been established for the diagnosis of the fully-developed FAS syndrome. More research is needed in order to enable uniform, evidence-based diagnostic assessment of all fetal alcohol spectrum disorders and optimize supportive measures for the children affected by them.

Lange S, Shield K, Koren G, Rehm J,Popova S. A comparison of the prevalence of prenatal alcohol exposure obtained via maternal self-reports versus meconium testing: a systematic literature review and meta-analysis. BMC Pregnancy & Childbirth 2014;14(127

BACKGROUND: Maternal self-reports, used for the detection of prenatal alcohol exposure (PAE), may lack validity, necessitating the use of an objective biomarker. The detection of fatty acid ethyl esters (products of non-oxidative ethanol metabolism) in meconium has been established as a novel biomarker of PAE. The purpose of the current study was to compare the prevalence of PAE as reported via maternal self-reports with the results of meconium testing, and to quantify the disparity between these two methods.

METHODS: A systematic literature search for studies reporting on the prevalence of PAE, using maternal self-reports in combination with meconium testing, was conducted using multiple electronic bibliographic databases. Pooled prevalence estimates and 95% confidence intervals (CI) were calculated based on eight studies, using the Mantel-Haenszel method, assuming a random effects model. A random effects meta-regression was performed to test for a difference.

RESULTS: The pooled prevalence of PAE as measured by meconium testing was 4.26 (95% CI: 1.34-13.57) times the pooled prevalence of PAE as measured by maternal self-reports. Large variations across the studies in regard to the difference between estimates obtained from maternal self-reports and those obtained from meconium testing were observed.

CONCLUSIONS: If maternal self-reports are the sole information source upon which health care professionals rely, a number of infants who were prenatally exposed to alcohol are not being recognized as such. However, further research is needed in order to validate existing biomarkers, as well as discover new biomarkers, for the detection of PAE.

Lange S, Shield K, Rehm J,Popova S. Prevalence of fetal alcohol spectrum disorders in child care settings: A meta-analysis. Pediatrics 2013;132(4):e980-e995

Latimer J, Pinto RZ, Ferreira ML, Doney R, Lau M, Jones T, et al. Gross motor deficits in children prenatally exposed to alcohol: A meta-analysis. Pediatrics 2014;134(1):e192-e209

Lucas BR, Latimer J, Pinto RZ, Ferreira ML, Doney R, Lau M, et al. Gross motor deficits in children prenatally exposed to alcohol: a meta-analysis. Pediatrics 2014;134(1):e192-209

BACKGROUND AND OBJECTIVES: Gross motor (GM) deficits are often reported in children with prenatal alcohol exposure (PAE), but their prevalence and the domains affected are not clear. The objective of this review was to characterize GM impairment in children with a diagnosis of fetal alcohol spectrum disorder (FASD) or "moderate" to "heavy" maternal alcohol intake.

METHODS: A systematic review with meta-analysis was conducted. Medline, Embase, Allied and Complementary Medicine

Database, Cumulative Index to Nursing and Allied Health Literature, PsycINFO, PEDro, and Google Scholar databases were searched. Published observational studies including children aged 0 to <18 years with (1) an FASD diagnosis or moderate to heavy PAE, or a mother with confirmed alcohol dependency or binge drinking during pregnancy, and (2) GM outcomes obtained by using a standardized assessment tool. Data were extracted regarding participants, exposure, diagnosis, and outcomes by using a standardized protocol. Methodological quality was evaluated by using Strengthening the Reporting of Observational Studies in Epidemiology guidelines.

RESULTS: The search recovered 2881 articles of which 14 met the systematic review inclusion criteria. The subjects' mean age ranged from 3 days to 13 years. Study limitations included failure to report cutoffs for impairment, nonstandardized reporting of PAE, and small sample sizes. The meta-analysis pooled results (n = 10) revealed a significant association between a diagnosis of FASD or moderate to heavy PAE and GM impairment (odds ratio: 2.9; 95% confidence interval: 2.1-4.0). GM deficits were found in balance, coordination, and ball skills. There was insufficient data to determine prevalence.

CONCLUSIONS: The significant results suggest evaluation of GM proficiency should be a standard component of multidisciplinary FASD diagnostic services.Copyright © 2014 by the American Academy of Pediatrics.

Minozzi S, Amato L, Bellisario C, Ferri M,Davoli M. Maintenance agonist treatments for opiate-dependent pregnant women. Cochrane Database of Systematic Reviews. 2013; 12. [cited: url:
http://onlinelibrary.wiley.com/doi/10.1002/14651858.CD006318.pub3/abstract
http://onlinelibrary.wiley.com/store/10.1002/14651858.CD006318.pub3/asset/CD006318.pdf?v=1&t=idlpfcjx&s=3a16848596afd40ed81a978eed03c650291ca874

Background: The prevalence of opiate use among pregnant women can range from 1% to 2% to as high as 21%. Heroin crosses the placenta and pregnant, opiate-dependent women experience a six-fold increase in maternal obstetric complications such as low birth weight, toxaemia, third trimester bleeding, malpresentation, puerperal morbidity, fetal distress and meconium aspiration. Neonatal complications include narcotic withdrawal, postnatal growth deficiency, microcephaly, neuro-behavioural problems, increased neonatal mortality and a 74-fold increase in sudden infant death syndrome.Objectives: To assess the effectiveness of any maintenance treatment alone or in combination with psychosocial intervention compared to no intervention, other pharmacological intervention or psychosocial interventions for child health status, neonatal mortality, retaining pregnant women in treatment and reducing the use of substances.Search methods: We searched the Cochrane Drugs and Alcohol Group Trials Register (September 2013), PubMed (1966 to September 2013), CINAHL (1982 to September 2013), reference lists of relevant papers, sources of ongoing trials, conference proceedings and national focal points for drug research. We contacted authors of included studies and experts in the field.Selection criteria: Randomised controlled trials assessing the efficacy of any maintenance pharmacological treatment for opiate-dependent pregnant women.Data collection and analysis: We used the standard methodological procedures expected by The Cochrane Collaboration.Main results: We found four trials with 271 pregnant women. Three compared methadone with buprenorphine and one methadone with oral slow-release morphine. Three out of four studies had adequate allocation concealment and were double-blind. The major flaw in the included studies was attrition bias: three out of four had a high drop-out rate (30% to 40%) and this was unbalanced between groups.Methadone versus buprenorphine: the drop-out rate from treatment was lower in the methadone group (risk ratio (RR) 0.64, 95% confidence interval (CI) 0.41 to 1.01, three studies, 223 participants). There was no statistically significant difference in the use of primary substance between methadone and buprenorphine (RR 1.81, 95% CI 0.70 to 4.69, two studies, 151 participants). For both, we judged the quality of evidence as low. Birth weight was higher in the buprenorphine group in the two trials that could be pooled (mean difference (MD) -365.45 g (95% CI -673.84 to -57.07), two studies, 150 participants). The third study reported that there was no statistically significant difference. For APGAR score neither of the studies which compared methadone with buprenorphine found a significant difference. For both, we judged the quality of evidence as low. Many measures were used in the studies to assess neonatal abstinence syndrome. The number of newborns treated for neonatal abstinence syndrome, which is the most critical outcome, did not differ significantly between groups. We judged the quality of evidence as very low.Methadone versus slow-release morphine:

there was no drop-out in either treatment group. Oral slow-release morphine seemed superior to methadone for abstinence from heroin use during pregnancy (RR 2.40, 95% CI 1.00 to 5.77, one study, 48 participants). We judged the quality of evidence as moderate.Only one study which compared methadone with buprenorphine reported side effects. For the mother there was no statistically significant difference; for the newborns in the buprenorphine group there were significantly fewer serious side effects.In the comparison between methadone and slow-release morphine no side effects were reported for the mother, whereas one child in the methadone group had central apnoea and one child in the morphine group had obstructive apnoea.Authors' conclusions: We did not find sufficient significant differences between methadone and buprenorphine or slow-release morphineto allow us to conclude that one treatment is superior to another for all relevant outcomes. While methadone see s superior in terms of retaining patients in treatment, buprenorphine seems to lead to less severe neonatal abstinence syndrome. Additionally, even though a multi-centre, international trial with 175 pregnant women has recently been completed and its results published and included in this review, the body of evidence is still too small to draw firm conclusions about the equivalence of the treatments compared. There is still a need for randomised controlled trials of adequate sample size comparing different maintenance treatments.

Montag A, Clapp JD, Calac D, Gorman J,Chambers C. A review of evidence-based approaches for reduction of alcohol consumption in native women who are pregnant or of reproductive age. The American Journal of Drug and Alcohol Abuse 2012;38(5):436-443

Background: Fetal alcohol spectrum disorders (FASDs) are the leading preventable cause of developmental disabilities in the United States and likely throughout the world. FASDs can be prevented by avoiding alcohol use during pregnancy; however, efforts to prevent risky alcohol consumption in women of childbearing potential have not been universally successful. Objectives: Data suggest that successful interventions may require tailoring methods to meet the needs of specific populations and cultures. Key findings of interventions previously tested among American Indian and Alaskan Native (AI/AN) women who are or may become pregnant, data gaps, and promising ongoing interventions are reviewed. Methods: A systematic review of the current literature on empirically based interventions among AI/AN women was conducted. Selected alternative approaches currently being tested in AI/AN settings are also described. Results: Similar to findings among other populations of women in the United States, a number of interventions have been implemented; however, only a small number have measured results. Approaches have included standard interventions involving hospitalization, inpatient, or outpatient care; wellness education; traditional approaches; and case management for high-risk women. An ongoing Screening, Brief Intervention, and Referral to Treatment (SBIRT) protocol comparing the effectiveness of a web-based culturally adapted tool, or a peer health educator model to standard clinical practice is described. Conclusion: Translation of successful interventions from other settings to AI/AN populations holds promise. Scientific Significance: FASDs represent a significant health issue with high personal and societal costs. Improvement of interventions to prevent prenatal alcohol consumption in specific populations, including AI/AN women, is a critical public health need. (PsycINFO Database Record (c) 2012 APA, all rights reserved). (journal abstract)

Montag A, Clapp JD, Calac D, Gorman J,Chambers C. A review of evidence-based approaches for reduction of alcohol consumption in Native women who are pregnant or of reproductive age. American Journal of Drug & Alcohol Abuse 2012;38(5):436-43

BACKGROUND: Fetal alcohol spectrum disorders (FASDs) are the leading preventable cause of developmental disabilities in the United States and likely throughout the world. FASDs can be prevented by avoiding alcohol use during pregnancy; however, efforts to prevent risky alcohol consumption in women of childbearing potential have not been universally successful.

OBJECTIVES: Data suggest that successful interventions may require tailoring methods to meet the needs of specific populations and cultures. Key findings of interventions previously tested among American Indian and Alaskan Native (AI/AN) women who are or may become pregnant, data gaps, and promising ongoing interventions are reviewed.

METHODS: A systematic review of the current literature on empirically based interventions among AI/AN women was conducted. Selected alternative approaches currently being tested in AI/AN settings are also described.

RESULTS: Similar to findings among other populations of women in the United States, a number of interventions have been implemented; however, only a small number have measured results. Approaches have included standard interventions involving hospitalization, inpatient, or outpatient care; wellness education; traditional approaches; and case management for high-risk women. An ongoing Screening, Brief Intervention, and Referral to Treatment (SBIRT) protocol comparing the effectiveness of a web-based culturally adapted tool, or a peer health educator model to standard clinical practice is described.

CONCLUSION: Translation of successful interventions from other settings to AI/AN populations holds promise.

SCIENTIFIC SIGNIFICANCE: FASDs represent a significant health issue with high personal and societal costs. Improvement of interventions to prevent prenatal alcohol consumption in specific populations, including AI/AN women, is a critical public health need.

Nabhan Ashraf F,Aflaifel N. High feedback versus low feedback of prenatal ultrasound for reducing maternal anxiety and improving maternal health behaviour in pregnancy. Cochrane Database of Systematic Reviews. 2015; 8. [cited: url: http://onlinelibrary.wiley.com/doi/10.1002/14651858.CD007208.pub3/abstract

http://onlinelibrary.wiley.com/store/10.1002/14651858.CD007208.pub3/asset/CD007208.pdf?v=1&t=idlpevhp&s=c1b44fd43e27f7677a8a531f9acd59c3d7487be6

Background: Prenatal ultrasound is one of many techniques used in screening and diagnosis. It gives parents instant access to the images of the fetus. Receiving information promotes knowledge and understanding, but it may also increase maternal anxiety.Objectives: To compare high feedback versus low feedback during prenatal ultrasound for reducing maternal anxiety and improving maternal health behaviour.Search methods: We searched the Cochrane Pregnancy and Childbirth Group's Trials Register (12 May 2015), the Central Register of Controlled Trials (The Cochrane Library 2015, Issue 5), MEDLINE (January 1966 to 12 May 2015), and the ISRCTN Registry (12 May 2015). We handsearched citation lists of relevant publications. We did not apply any language or date restrictions.Selection criteria: Randomised controlled trials (RCTs) of high feedback (women can see the monitor screen and receive detailed visual and verbal explanations) versus low feedback (women can not see the monitor screen and women are given only a summary statement of the scan) during prenatal ultrasound. The primary outcome measure was maternal state anxiety.Data collection and analysis: Two review authors independently assessed trials for inclusion and risk of bias, extracted data and checked for accuracy. We have expressed results as risk ratio (RR) or mean differences (MD), together with their 95% confidence intervals (CI).Main results: We included four studies (365 women). Three RCTs (346 participants) reported the effect of high versus low feedback during ultrasound on state anxiety scores (mean difference (MD) 0.92, 95% confidence interval (CI) -0.58 to 2.43; participants = 346; three studies, low quality evidence). Two trials (148 participants) reported women's views of the level of feedback. They do not show that women in the high feedback groups are more likely to choose very positive adjectives to describe their feelings after the scan (risk ratio (RR) 3.30; 95% CI 0.73 to 14.85). Women who had a high feedback during ultrasound were more likely to stop smoking during pregnancy (RR 2.93, 95% CI 1.25 to 6.86; participants = 129; one study; low quality evidence) and to avoid alcohol during pregnancy (RR 2.96, 95% CI 1.15 to 7.60; participants = 129; one study; low quality evidence). Downgrading of evidence was based on the unclear risk of bias of included studies, wide CI crossing the line of no effect or presence of heterogeneity.Authors' conclusions: There is insufficient evidence to support either high or low feedback during a prenatal ultrasound to reduce maternal anxiety and promote health behaviour.

Naumann DN, Reynolds JN, McColl MA,Smith HD. Environmental scan of programs for Fetal Alcohol Spectrum Disorder in Eastern Ontario. Journal on Developmental Disabilities 2013;19(3):29-50

Fetal Alcohol Spectrum Disorder (FASD) is a leading cause of developmental disability in Canadian children. The majority of Canadians with FASD are not identified: FASD is diagnosed in less than 1% of Canadians, when it may occur in as high as 2–5% of the school-aged population. This discrepancy is due in part to a lack of harmonized policy and service coordination at national and provincial levels. Failure to provide appropriate interventions for individuals with FASD results in the development of debilitating secondary effects that impact individuals, families and communities. Ontario is the most

populated Canadian province with an emerging provincial strategy for FASD that is challenged by additional barriers to effective service provision and utilization. The Eastern Ontario region represents a population of 3 million residents that are particularly underserviced. This environmental scan used formal and informal sources to explore, summarize, and map out current services for FASD in order to present a comprehensive review of service accessibility. The results inform residents, policymakers, service providers, and program developers on the scope and nature of services for FASD located in the Eastern Ontario region in 2012. (PsycINFO Database Record (c) 2014 APA, all rights reserved). (journal abstract)

O'Leary CM,Bower C. Guidelines for pregnancy: What's an acceptable risk, and how is the evidence (finally) shaping up? Drug and Alcohol Review 2012;31(2):170-183

Issues: The lack of consensus about whether low to moderate levels of prenatal alcohol exposure are a risk factor for fetal development has generated considerable debate about what advice policies and guidelines should provide. Approach: This paper reviews the evidence from systematic reviews and meta-analyses examining the risk from low and moderate levels of prenatal alcohol exposure, along with the results of articles published 2009–2010, after the reviews. Key Findings: The reported significant effects from low levels of prenatal alcohol exposure are likely due to methodological issues such as confounding and/or misclassification of exposure or outcome and there is no strong research evidence of fetal effects from low levels of alcohol exposure. However, harm is well-documented with heavy exposure and moderate levels of exposure, 30–40 g per occasion and no more than 70 g per week, have been demonstrated to increase the risk of child behaviour problems. Implications: With such a small margin before there is increased risk to the fetus, it would be morally and ethically unacceptable for policies and guidelines to condone consumption of alcohol during pregnancy. Not all women will follow this advice and some women will inadvertently consume alcohol prior to pregnancy awareness requiring non-judgmental counselling and the provision of rational advice about the likelihood of risk to the fetus. Conclusions: The policy advice that 'the safest choice for pregnant women is to abstain from alcohol during pregnancy' should be maintained. However, the abstinence message needs to be presented in a balanced and rational manner to prevent unintended negative consequences. (PsycINFO Database Record (c) 2012 APA, all rights reserved). (journal abstract)

Peadon E, Rhys-Jones B, Bower C,Elliott EJ. Systematic review of interventions for children with Fetal Alcohol Spectrum Disorders. BMC Pediatrics 2009;9(35

BACKGROUND: Children with Fetal Alcohol Spectrum Disorders (FASD) may have significant neurobehavioural problems persisting into adulthood. Early diagnosis may decrease the risk of adverse life outcomes. However, little is known about effective interventions for children with FASD. Our aim is to conduct a systematic review of the literature to identify and evaluate the evidence for pharmacological and non-pharmacological interventions for children with FASD.

METHODS: We did an electronic search of the Cochrane Library, MEDLINE, EMBASE, PsychINFO, CINAHL and ERIC for clinical studies (Randomized controlled trials (RCT), quasi RCT, controlled trials and pre- and post-intervention studies) which evaluated pharmacological, behavioural, speech therapy, occupational therapy, physiotherapy, psychosocial and educational interventions and early intervention programs. Participants were aged under 18 years with a diagnosis of a FASD. Selection of studies for inclusion and assessment of study quality was undertaken independently by two reviewers. Meta-analysis was not possible due to diversity in the interventions and outcome measures.

RESULTS: Twelve studies met the inclusion criteria. Methodological weaknesses were common, including small sample sizes; inadequate study design and short term follow up. Pharmacological interventions, evaluated in two studies (both RCT) showed some benefit from stimulant medications. Educational and learning strategies (three RCT) were evaluated in seven studies. There was some evidence to suggest that virtual reality training, cognitive control therapy, language and literacy therapy, mathematics intervention and rehearsal training for memory may be beneficial strategies. Three studies evaluating social communication and behavioural strategies (two RCT) suggested that social skills training may improve social skills and behaviour at home and Attention Process Training may improve attention.

CONCLUSION: There is limited good quality evidence for specific interventions for managing FASD, however seven randomized controlled trials that address specific functional deficits of children with FASD are underway or recently completed.

[References: 39]

Pei J, Denys K, Hughes J,Rasmussen C. Mental health issues in fetal alcohol spectrum disorder. Journal of Mental Health 2011;20(5):473-483

Background. High numbers of individuals with Fetal Alcohol Spectrum Disorders (FASD) have been described as having mental health problems. Aims. This article summarizes research about mental health problems in FASD and considers related developmental and environmental issues. Method. A computer-based literature search was conducted in the databases Medline, PsycINFO, Google Scholar, Academic Search Complete, and Education Resources Information Centre for articles addressing the prevalence and types of mental health issues in individuals affected by FASD. Results. High rates of mental disorders within the FASD and prenatal alcohol exposure (PAE) population were found to be consistently reported for both internalizing and externalizing disorders. Moreover, problems that emerge in childhood may reflect a convergence of genetic, environmental, and neurophysiological factors that persist into adulthood. Conclusions. Researchers are beginning to document the impacts of PAE on later mental health development. Further longitudinal study is needed to determine whether there is an increasing severity of mental health deficits and consequences with age, and whether any such changes reflect increasingly deteriorating environmental factors or brain-based factors. Additionally, research is needed to design interventions to better address the unique mental health needs of this population.

Pei J, Denys K, Hughes J,Rasmussen C. Mental health issues in fetal alcohol spectrum disorder. Journal of Mental Health 2011;20(5):438-48

BACKGROUND: High numbers of individuals with Fetal Alcohol Spectrum Disorders (FASD) have been described as having mental health problems.

AIMS: This article summarizes research about mental health problems in FASD and considers related developmental and environmental issues.

METHOD: A computer-based literature search was conducted in the databases Medline, PsycINFO, Google Scholar, Academic Search Complete, and Education Resources Information Centre for articles addressing the prevalence and types of mental health issues in individuals affected by FASD.

RESULTS: High rates of mental disorders within the FASD and prenatal alcohol exposure (PAE) population were found to be consistently reported for both internalizing and externalizing disorders. Moreover, problems that emerge in childhood may reflect a convergence of genetic, environmental, and neurophysiological factors that persist into adulthood.

CONCLUSIONS: Researchers are beginning to document the impacts of PAE on later mental health development. Further longitudinal study is needed to determine whether there is an increasing severity of mental health deficits and consequences with age, and whether any such changes reflect increasingly deteriorating environmental factors or brain-based factors. Additionally, research is needed to design interventions to better address the unique mental health needs of this population.

Popova S, Lange S, Bekmuradov D, Mihic A,Rehm J. Fetal alcohol spectrum disorder prevalence estimates in correctional systems: a systematic literature review. Canadian Journal of Public Health Revue Canadienne de Sante Publique 2011;102(5):336-40

OBJECTIVES: The objective of this study was to conduct a systematic search of the literature for studies that estimated the prevalence/incidence of Fetal Alcohol Spectrum Disorder (FASD) in correctional systems in different countries and, based on these data, to estimate a) the number of people with Fetal Alcohol Syndrome (FAS)/FASD within the criminal justice system population, and b) the relative risk of becoming imprisoned for individuals with FAS/FASD compared with those without FAS/FASD.

METHOD: A systematic world literature review of published and unpublished studies concerning the prevalence/incidence of FASD in correctional systems was conducted in multiple electronic bibliographic databases.

SYNTHESIS: Very little empirical evidence is available on the prevalence of FASD in correctional systems. There were no studies estimating the prevalence/incidence of FASD in correctional systems found for any country other than Canada and the

USA. The few studies that have identified incarcerated individuals with FASD estimate that the number of undiagnosed persons in correctional facilities is high. Based on available Canadian data, this study estimates that youths with FASD are 19 times more likely to be incarcerated than youths without FASD in a given year.

CONCLUSION: More studies investigating the prevalence/incidence of alcohol-affected people in the criminal justice system are required. There is an urgent need to raise awareness about the prevalence and disabilities of individuals with FASD in the criminal justice system and about appropriate responses. The criminal justice system is an ideal arena for intervention efforts aimed at the rehabilitation and prevention or reduction of recidivism in this unique population.

Popova S, Stade B, Bekmuradov D, Lange S,Rehm J. What do we know about the economic impact of Fetal Alcohol Spectrum Disorder? A systematic literature review. Alcohol and Alcoholism 2011;46(4):490-497

Aims: The objective of this study was to conduct a systematic review of the literature related to the measurement of the economic impact of Fetal Alcohol Spectrum Disorder (FASD) in different countries and to categorize the available literature. Methods: A systematic literature search of the studies concerning the economic impact of FASD was conducted using multiple electronic bibliographic databases. Results: The literature on the economic burden of FASD is scarce. There are a limited number of studies found in Canada and the USA, and data from the rest of the world are absent. Existing estimates of the economic impact of FASD demonstrate significant cost implications on the individual, the family and society. However, these estimates vary considerably due to the different methodologies used by different studies. Conclusion: Limitations and gaps in the existing methodologies of calculating the economic costs of FASD are discussed. It is evident that there is an urgent need to develop a comprehensive and sound methodology for calculating the economic impact of FASD to the society. (PsycINFO Database Record (c) 2013 APA, all rights reserved). (journal abstract)

Popova S, Stade B, Bekmuradov D, Lange S,Rehm J. What do we know about the economic impact of fetal alcohol spectrum disorder? A systematic literature review. Alcohol & Alcoholism 2011;46(4):490-7

AIMS: The objective of this study was to conduct a systematic review of the literature related to the measurement of the economic impact of Fetal Alcohol Spectrum Disorder (FASD) in different countries and to categorize the available literature.

METHODS: A systematic literature search of the studies concerning the economic impact of FASD was conducted using multiple electronic bibliographic databases.

RESULTS: The literature on the economic burden of FASD is scarce. There are a limited number of studies found in Canada and the USA, and data from the rest of the world are absent. Existing estimates of the economic impact of FASD demonstrate significant cost implications on the individual, the family and society. However, these estimates vary considerably due to the different methodologies used by different studies.

CONCLUSION: Limitations and gaps in the existing methodologies of calculating the economic costs of FASD are discussed. It is evident that there is an urgent need to develop a comprehensive and sound methodology for calculating the economic impact of FASD to the society.

Popova S, Yaltonskaya A, Yaltonsky V, Kolpakov Y, Abrosimov I, Pervakov K, et al. What research is being done on prenatal alcohol exposure and fetal alcohol spectrum disorders in the Russian research community? Alcohol & Alcoholism 2014;49(1):84-95

AIMS: Although Russia has one of the highest rates of alcohol consumption and alcohol-attributable burden of disease, little is known about the existing research on prenatal alcohol exposure (PAE) and Fetal Alcohol Spectrum Disorders (FASDs) in this country. The objective of this study was to locate and review published and unpublished studies related to any aspect of PAE and FASD conducted in or using study populations from Russia.

METHODS: A systematic literature search was conducted in multiple English and Russian electronic bibliographic databases. In addition, a manual search was conducted in several major libraries in Moscow.

RESULTS: The search revealed a small pool of existing research studies related to PAE and/or FASD in Russia (126: 22 in English and 104 in Russian). Existing epidemiological data indicate a high prevalence of PAE and FASD, which underlines the strong negative impact that alcohol has on mortality, morbidity and disability in Russia. High levels of alcohol consumption

by women of childbearing age, low levels of contraception use, and low levels of knowledge by health and other professionals regarding the harmful effects of PAE put this country at great risk of further alcohol-affected pregnancies.

CONCLUSIONS: Alcohol preventive measures in Russia warrant immediate attention. More research focused on alcohol prevention and policy is needed in order to reduce alcohol-related harm, especially in the field of FASD.

Premji S, Benzies K, Serrett K,Hayden KA. Research-based interventions for children and youth with a Fetal Alcohol Spectrum Disorder: revealing the gap. Child: Care, Health & Development 2007;33(4):389-97; discussion 398-400

BACKGROUND: Alcohol use during pregnancy can result in a continuum of effects including growth deficits, dysmorphology and/or complex patterns of behavioural and cognitive difficulties that influence an individual's functioning throughout their lifespan. We conducted a systematic review to identify research-based interventions for children and youth with a Fetal Alcohol Spectrum Disorder and areas for future study.

METHODS: We identified the substantive literature by searching 40 peer-reviewed and 23 grey literature databases, as well as reference lists. We hand-searched eight relevant journals, and undertook a systematic search of Internet sites and review of reports and documents received from key stakeholders. Two reviewers independently assessed eligibility and quality, and extracted data. Given the small number of studies that met all inclusion criteria, both experimental and quasi-experimental studies were included.

RESULTS: Ten intervention studies were identified, of which three were experimental or quasi-experimental, and four were non-experimental. Despite multiple attempts, three studies (two in foreign languages and one unpublished) could not be acquired. A meta-analysis could not be undertaken because the included studies examined different interventions or outcomes. Interventions targeted in the included studies were as follows: (i) psychostimulant medications (methyphenidate, pemoline and dextroamphetamine); and (ii) Cognitive Control Therapy. The identified studies were limited by very small sample sizes and weak designs.

CONCLUSION: There is limited scientific evidence upon which to draw recommendations regarding efficacious interventions for children and youth with a Fetal Alcohol Spectrum Disorder. Clinicians, researchers, service providers, educators, policy makers, affected children and youth and their families, and others need to urgently collaborate to develop a comprehensive research agenda for this population. [References: 52]

Premji S, Benzies K, Serrett K,Hayden KA. Research-based interventions for children and youth with a Fetal Alcohol Spectrum Disorder: revealing the gap (Structured abstract). Child: Care, Health and Development. 2007; 33: 4. [cited: url: http://onlinelibrary.wiley.com/o/cochrane/cldare/articles/DARE-12008103588/frame.html

Rehm J, Baliunas D, Borges GL, Graham K, Irving H, Kehoe T, et al. The relation between different dimensions of alcohol consumption and burden of disease: an overview. Addiction 2010;105(5):817-43

AIMS: As part of a larger study to estimate the global burden of disease and injury attributable to alcohol: to evaluate the evidence for a causal impact of average volume of alcohol consumption and pattern of drinking on diseases and injuries; to quantify relationships identified as causal based on published meta-analyses; to separate the impact on mortality versus morbidity where possible; and to assess the impact of the quality of alcohol on burden of disease.

METHODS: Systematic literature reviews were used to identify alcohol-related diseases, birth complications and injuries using standard epidemiological criteria to determine causality. The extent of the risk relations was taken from meta-analyses.

RESULTS: Evidence of a causal impact of average volume of alcohol consumption was found for the following major diseases: tuberculosis, mouth, nasopharynx, other pharynx and oropharynx cancer, oesophageal cancer, colon and rectum cancer, liver cancer, female breast cancer, diabetes mellitus, alcohol use disorders, unipolar depressive disorders, epilepsy, hypertensive heart disease, ischaemic heart disease (IHD), ischaemic and haemorrhagic stroke, conduction disorders and other dysrhythmias, lower respiratory infections (pneumonia), cirrhosis of the liver, preterm birth complications and fetal alcohol syndrome. Dose-response relationships could be quantified for all disease categories except for depressive disorders, with the relative risk increasing with increased level of alcohol consumption for most diseases. Both average volume and drinking pattern were linked causally to IHD, fetal alcohol syndrome and unintentional and intentional injuries.

For IHD, ischaemic stroke and diabetes mellitus beneficial effects were observed for patterns of light to moderate drinking without heavy drinking occasions (as defined by 60+ g pure alcohol per day). For several disease and injury categories, the effects were stronger on mortality compared to morbidity. There was insufficient evidence to establish whether quality of alcohol had a major impact on disease burden.

CONCLUSIONS: Overall, these findings indicate that alcohol impacts many disease outcomes causally, both chronic and acute, and injuries. In addition, a pattern of heavy episodic drinking increases risk for some disease and all injury outcomes. Future studies need to address a number of methodological issues, especially the differential role of average volume versus drinking pattern, in order to obtain more accurate risk estimates and to understand more clearly the nature of alcohol-disease relationships. [References: 278]

Stade Brenda C, Bailey C, Dzendoletas D, Sgro M, Dowswell T,Bennett D. Psychological and/or educational interventions for reducing alcohol consumption in pregnant women and women planning pregnancy. Cochrane Database of Systematic Reviews. 2009; 2. [cited: url: http://onlinelibrary.wiley.com/doi/10.1002/14651858.CD004228.pub2/abstract http://onlinelibrary.wiley.com/store/10.1002/14651858.CD004228.pub2/asset/CD004228.pdf?v=1&t=idlpezzl&s=122bb508013dd81e69c7be7f6d58019922aee700

Background: It is estimated that more than 20% of pregnant women worldwide consume alcohol. Current research suggests that alcohol intake of seven or more standard drinks (one standard drink = 13.6 grams of absolute alcohol) per week during pregnancy places the baby at risk of serious, lifelong developmental and cognitive disabilities. Psychological and educational interventions may help women to reduce their alcohol intake during pregnancy.Objectives: To determine the effectiveness of psychological and educational interventions to reduce alcohol consumption during pregnancy in pregnant women or women planning pregnancy.Search methods: We searched the Cochrane Pregnancy and Childbirth Group's Trials Register (August 2008), CENTRAL (The Cochrane Library 2007, Issue 4), MEDLINE (1966 to November 2007), EMBASE (1980 to November 2007), CINAHL (1982 to November 2007), Counsel.Lit (1980 to November 2007), PsycLIT (1974 to November 2007) and PsycINFO (1967 to November 2007) and checked cited references from retrieved articles.Selection criteria: Randomized controlled trials examining the effectiveness of psychological and educational interventions for reducing consumption of alcohol among pregnant women, or women planning for pregnancy.Data collection and analysis: At least two review authors independently extracted information from the results sections of the included studies.Main results: Four studies met the inclusion criteria (715 pregnant women), and reported on at least one of the outcomes of interest. We performed no meta-analyses as the interventions and outcomes measured in the studies were not sufficiently similar. For most outcomes there were no significant differences between groups; and results relating to abstaining or reducing alcohol consumption were mixed. Results from individual studies suggest that interventions may encourage women to abstain from alcohol in pregnancy. There was very little information provided on the effects of interventions on the health of mothers and babies.Authors' conclusions: The evidence from the limited number of studies suggests that psychological and educational interventions may result in increased abstinence from alcohol, and a reduction in alcohol consumption among pregnant women. However, results were not consistent, and the paucity of studies, the number of total participants, the high risk of bias of some of the studies, and the complexity of interventions limits our ability to determine the type of intervention which would be most effective in increasing abstinence from, or reducing the consumption of, alcohol among pregnant women.

Thanh NX, Jonsson E, Salmon A,Sebastianski M. Incidence and prevalence of fetal alcohol spectrum disorder by sex and age group in Alberta, Canada. Journal of Population Therapeutics & Clinical Pharmacology 2014;21(3):e395-404

OBJECTIVES: To estimate incidence and prevalence of FASD by sex and age in Alberta, Canada.

METHODS: We included all patients recorded in the Alberta provincial health databases of inpatients, outpatients, and practitioner claims from 2003 to 2012. The number of people with FASD were calculated from available data on FAS (ICD-9 code 760.71; ICD-10 codes Q86.0 and P04.3) and estimated prevalence of FASD among individuals diagnosed with 21 FASD-related conditions (identified by a literature review) for which there are ICD codes, such as learning disability, mental retardation, and nervous system defects (Table 1). Fractions of FASD-related diagnoses that can be attributed to alcohol

use during pregnancy were estimated by a systematic review. The incidence was measured as the number of new cases per 1000 births. The prevalence was measured as the number of cases per 1000 population in 2012.

RESULTS: Annually, 739 to 1884 people were born with FASD in Alberta establishing an incidence of 14.2 to 43.8 per 1000 births, depending on the length of follow-up. There were about 46,000 people living with FASD in Alberta 2012, including 6,000 FAS cases and 40,000 FASD-related cases. The prevalence of FASD was 11.7 (range 8.2 to 15.1) per 1000 population. The incidence and prevalence varied greatly by sex and age group. Generally, male and younger outnumbered female and older.

CONCLUSION: This study suggests new incidence and prevalence of FASD, which are higher than what has been commonly used (1%), and its variations among sex and age groups.

Watkins RE, Elliott EJ, Halliday J, O'Leary CM, D'Antoine H, Russell E, et al. A modified Delphi study of screening for fetal alcohol spectrum disorders in Australia. BMC Pediatrics 2013;13(13

BACKGROUND: There is little reliable information on the prevalence of fetal alcohol spectrum disorders (FASD) in Australia and no coordinated national approach to facilitate case detection. The aim of this study was to identify health professionals' perceptions about screening for FASD in Australia.

METHOD: A modified Delphi process was used to assess perceptions of the need for, and the process of, screening for FASD in Australia. We recruited a panel of 130 Australian health professionals with experience or expertise in FASD screening or diagnosis. A systematic review of the literature was used to develop Likert statements on screening coverage, components and assessment methods which were administered using an online survey over two survey rounds.

RESULTS: Of the panel members surveyed, 95 (73%) responded to the questions on screening in the first survey round and, of these, 81 (85%) responded to the second round. Following two rounds there was consensus agreement on the need for targeted screening at birth (76%) and in childhood (84%). Participants did not reach consensus agreement on the need for universal screening at birth (55%) or in childhood (40%). Support for targeted screening was linked to perceived constraints on service provision and the need to examine the performance, costs and benefits of screening.For targeted screening of high risk groups, we found highest agreement for siblings of known cases of FASD (96%) and children of mothers attending alcohol treatment services (93%). Participants agreed that screening for FASD primarily requires assessment of prenatal alcohol exposure at birth (86%) and in childhood (88%), and that a checklist is needed to identify the components of screening and criteria for referral at birth (84%) and in childhood (90%).

CONCLUSIONS: There is an agreed need for targeted but not universal screening for FASD in Australia, and sufficient consensus among health professionals to warrant development and evaluation of standardised methods for targeted screening and referral in the Australian context. Participants emphasised the need for locally-appropriate, evidence-based approaches to facilitate case detection, and the importance of ensuring that screening and referral programs are supported by adequate diagnostic and management capacity.

Extra papers found regarding consensus methodology re fetal alcohol syndrome that may be of interest n=5

Clarren S, Lutke J,Sherbuck M. The Canadian guidelines and the interdisciplinary clinical capacity of Canada to diagnose fetal alcohol spectrum disorder. Journal of population therapeutics and clinical pharmacology= Journal de la therapeutique des populations et de la pharamcologie clinique 2010;18(3):e494-9

BACKGROUND: In 2005, the CMAJ published the Fetal alcohol spectrum disorder: Canadian guidelines for diagnosis. The intent of this publication was to encourage a more consistent interdisciplinary team approach and diagnostic procedure for FASD diagnoses. That same year, the Canada Northwest FASD Research Network (CanFASD Northwest) determined the locations and capacity for interdisciplinary FASD diagnosis across Canada. Six years later, we wondered how successfully these Guidelines had been in bringing consistency to FASD clinical work. METHOD: All clinical

programs in Canada that routinely performed FASD evaluations were identified through membership in either our Network Action Team on FASD Diagnosis, professional meetings, organizational memberships, websites, programs lists available from Provincial or Federal offices or by word of mouth. Surveys were sent to all of the programs identified. RESULTS: A total of 55 clinics had been identified in seven provinces and one territory in 2005 that did FASD multidisciplinary diagnostics. In 2011 only 44 clinics were identified in six provinces and one territory using the same methodology. Survey responses were completed by 89% of these 44 clinics identified in 2011. The Guidelines were well known to all programs and actively referred to by most. Only 46% of respondents had a full staff of professionals on site for diagnosis, however 90% did use the team approach in determining final FASD diagnosis, while 79% used the team to help in developing a treatment plan. Among the clinics reporting, 74% of them used the new diagnostic schema proposed in the Guidelines and another 12% report using both the Guidelines and another system for diagnosis. INTERPRETATION: The Guidelines have become well known to the medical community. They have contributed to increased consistency in approach and in diagnosis. The variations in clinical ability to fully staff themselves, and the 20% decline in clinic numbers suggest important funding gaps. Many provinces and territories still have no local interdisciplinary programs for FASD diagnosis, and the need across Canada is still many times greater than what is currently available.

Landgraf M,Heinen F. Development of an evidence-and consensus-based guideline for the diagnosis of fetal alcohol syndrome in Germany. Neuropediatrics 2012;43(02):FV13_06

Methods: A steering group in Munich and a consensus group consisting of representatives of the German Federal Ministry of Health, the German Professional Societies and other FAS experts have been established in 2011. Representatives of the Patient Support Group FASworld are also members of the consensus group. For the methodological guidance the AWMF (Consortium of the scientific medical societies) is responsible and the literature evaluation is conducted by the ÄZQ (Center for Quality in Medicine). Results: The consensus group defined a key question and specific issues for the literature search. The evaluation of the literature is in progress. The methodological quality of the international and especially the German publications about the diagnostic criteria are rather poor. Most of the existing international guidelines for the diagnosis of FAS are consensus but not evidence-based. Conclusion: There is great need for a standardized, multidisciplinary, quality assured and implementable prevention of FAS in Germany. The first step is the establishment of evidence- and consensus-based diagnostic criteria for children with FAS which will be approved and presented in 2012.

Watkins RE, Elliott EJ, Mutch RC, Latimer J, Wilkins A, Payne JM, et al. Health professionals' perceptions about the adoption of existing guidelines for the diagnosis of fetal alcohol spectrum disorders in Australia. BMC pediatrics 2012;12(1):69

Background: Despite the availability of five guidelines for the diagnosis of fetal alcohol spectrum disorders (FASD), there is no national endorsement for their use in diagnosis in Australia. In this study we aimed to describe health professionals' perceptions about the adoption of existing guidelines for the diagnosis of FASD in Australia and identify implications for the development of national guidelines. Methods: We surveyed 130 Australian and 9 international health professionals with expertise or involvement in the screening or diagnosis of FASD. An online questionnaire was used to evaluate participants' familiarity with and use of five existing diagnostic guidelines for FASD, and to assess their perceptions about the adoption of these guidelines in Australia. Results: Of the 139 participants surveyed, 84 Australian and 8 international health professionals (66.2%) responded to the questions on existing diagnostic guidelines. Participants most frequently reported using the University of Washington 4-Digit Diagnostic Code (27.2%) and the Canadian guidelines (18.5%) for diagnosis. These two guidelines were also most frequently recommended for adoption in Australia: 32.5% of the 40 participants who were familiar with the University of Washington 4-Digit Diagnostic Code recommended adoption of this guideline in Australia, and 30.8% of the 26 participants who were familiar with the Canadian guidelines recommended adoption of this guideline in Australia. However, for the majority of guidelines examined, most participants were unsure whether they should be adopted in Australia. The adoption of existing guidelines in Australia was perceived to be limited by: their lack of evidence base, including the appropriateness of established reference standards for the Australian population; their complexity; the need for training and support to use the guidelines; and the lack of an interdisciplinary and interagency model to support service delivery in Australia. Conclusions: Participants indicated some support for the

adoption of the University of Washington or Canadian guidelines for FASD diagnosis; however, concerns were raised about the adoption of these diagnostic guidelines in their current form. Australian diagnostic guidelines will require evaluation to establish their validity in the Australian context, and a comprehensive implementation model is needed to facilitate improved diagnostic capacity in Australia.

Watkins RE, Elliott EJ, Mutch RC, Payne JM, Jones HM, Latimer J, et al. Consensus diagnostic criteria for fetal alcohol spectrum disorders in Australia: a modified Delphi study. BMJ open 2012;2(5):e001918

Objective To evaluate health professionals' agreement with components of published diagnostic criteria for fetal alcohol spectrum disorders (FASD) in order to guide the development of standard diagnostic guidelines for Australia. Design A modified Delphi process was used to assess agreement among health professionals with expertise or experience in FASD screening or diagnosis. An online survey, which included 36 Likert statements on diagnostic methods, was administered over two survey rounds. For fetal alcohol syndrome (FAS), health professionals were presented with concepts from the Institute of Medicine (IOM), University of Washington (UW), Centers for Disease Control (CDC), revised IOM and Canadian diagnostic criteria. For partial FAS (PFAS), alcohol-related neurodevelopmental disorder (ARND), and alcohol-related birth defects (ARBD), concepts based on the IOM and the Canadian diagnostic criteria were compared. Setting/participants 130 Australian and 9 international health professionals. Results Of 139 health professionals invited to complete the survey, 103 (74.1%) responded, and 74 (53.2%) completed one or more questions on diagnostic criteria. We found consensus agreement among participants on the diagnostic criteria for FAS, with the UW criteria most commonly endorsed when compared with all other published criteria for FAS. When health professionals were presented with concepts based on the Canadian and IOM diagnostic criteria, we found consensus agreement but no clear preference for either the Canadian or IOM criteria for the diagnosis of PFAS, and no consensus agreement on diagnostic criteria for ARND. We also found no consensus on the IOM diagnostic criteria for ARBD. Conclusions Participants indicated clear support for use of the UW diagnostic criteria for FAS in Australia. These findings should be used to develop guidelines to facilitate improved awareness of, and address identified gaps in the infrastructure for, FASD diagnosis in Australia.

Watkins RE, Elliott EJ, Wilkins A, Latimer J, Halliday J, Fitzpatrick JP, et al. Fetal alcohol spectrum disorder: development of consensus referral criteria for specialist diagnostic assessment in Australia. BMC pediatrics 2014;14(1):178

Fetal alcohol spectrum disorder (FASD) is known to be under-recognised in Australia. The use of standard methods to identify when to refer individuals who may have FASD for specialist assessment could help improve the identification of this disorder. The purpose of this study was to develop referral criteria for use in Australia. Method An online survey about FASD screening and diagnosis in Australia, which included 23 statements describing criteria for referral for fetal alcohol syndrome (FAS) and FASD based on published recommendations for referral in North America, was sent to 139 health professionals who had expertise or involvement in FASD screening or diagnosis. Survey findings and published criteria for referral were subsequently reviewed by a panel of 14 investigators at a consensus development workshop where criteria for referral were developed. Results Among the 139 health professionals who were sent the survey, 103 (74%) responded, and 90 (65%) responded to the statements on criteria for referral. Over 80% of respondents agreed that referral for specialist evaluation should occur when there is evidence of significant prenatal alcohol exposure, defined as 7 or more standard drinks per week and at least 3 standard drinks on any one day, and more than 70% agreed with 13 of the 16 statements that described criteria for referral other than prenatal alcohol exposure. Workshop participants recommended five independent criteria for referral: confirmed significant prenatal alcohol exposure; microcephaly and confirmed prenatal alcohol exposure; 2 or more significant central nervous system (CNS) abnormalities and confirmed prenatal alcohol exposure; 3 characteristic FAS facial anomalies; and 1 characteristic FAS facial anomaly, growth deficit and 1 or more CNS abnormalities. Conclusion Referral criteria recommended for use in Australia are similar to those recommended in North America. There is a need to develop resources to raise awareness of these criteria among health professionals and evaluate their feasibility, acceptability and capacity to improve the identification of FASD in Australia. Keywords: Fetal alcohol spectrum disorder; Referral; Consensus

Fetal Alcohol Syndrome/Spectrum Results (August 2015)

GIN: *(searched alcohol and fetal separately)*	2 results	1 english language
NICE: 2 *(Antenatal care http://www.nice.org.uk/guidance/qs22 no specific detail about fetal alcohol syndrome) http://www.nice.org.uk/guidance/cg62 2008 - again not mentioned*		
National Guidelines Clearinghouse:	2 results	
Epistemonikos.org (all) first 10 pages:	23 results	
GoogleScholar last 10 years, first 10 pages (search FASD, Fetal alcohol and guidelines/evidence based/toolkit)	18 results	

Cochrane Library SRs:	5 results	4 sifted
Cochrane Library trials:	84 results	36 sifted
Cochrane HTA:	9 results	sifted
Cochrane Economic Evaluations:	4 results	4
OVID (Medline and Medline in process, Embase, ERIC, MIDIRS) SRs	74 results	32 sifted
OVID (Medline and Medline in process, Embase, ERIC, MIDIRS) RCTs	236 results	30 sifted
EBSCO: Cinahl, PsychInfo and Pyschology and Behavioural Sciences Collection 7SRs, 9RCTs		

British Society for Maternal and Fetal Medicine SMFM: *no relevant materials accessible*

Royal College of Midwives: *no relevant materials accessible, cannot access publications list*

Royal College of Obs and Gyn: *no relevant materials accessible – superseded by NICE on antenatal care*

Royal College of Paediatrics and Child Health: *no relevant materials accessible*

Royal College of General Practitioners: *links to Mencap toolkit on FASD https://www.mencap.org.uk/FASD, no other relevant materials accessible*

Royal Coll of Psychiatrists: 1 report - CR185. Alcohol and Brain Damage in Adults: With reference to high-risk groups *(this includes a section on FASD)*

Royal Australian and New Zealand College of Obstetricians and Gynaecologists: *no relevant materials accessible*

Results are pre-sifting – there was a large number of overlapping records, Cochrane had a large number of "dead" records for HTAs where the link went no where