Foundation for Alcohol Research & Education

SUBMISSION:

Senate Community Affairs Reference Committee

Inquiry into effective approaches to prevention, diagnosis and support for Fetal Alcohol Spectrum Disorder

DECEMBER 2019

Foundation for Alcohol Research & Education

The Foundation for Alcohol Research and Education (FARE) is an independent, not-for-profit organisation working to stop the harm caused by alcohol. Alcohol harm in Australia is significant. Nearly 6,000 lives are lost every year and more than 144,000 people are hospitalised making alcohol one of our nation's greatest preventative health challenges.

As a leading advocate of evidence-based research, FARE contributes to policies and programs that support the public good, while holding the alcohol industry to account. FARE works with leading researchers, communities, governments, health professionals and frontline service providers to bring about change and reduce alcohol harm.

If you would like to contribute to FARE's important work, call us on (02) 6122 8600 or email info@fare.org.au.

STOPPING HARM CAUSED BY ALCOHOL

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Abbreviations

ABV	alcohol by volume
ACM	Australian College of Midwives
ACT	Australian Capital Territory
AIHW	Australian Institute of Health and Welfare
AUDIT-C	Alcohol use disorder identification test – consumption
BI	Brief intervention
DoH	Australian Government Department of Health
FARE	Foundation for Alcohol Research and Education
FAS	Fetal Alcohol Syndrome
FASD	Fetal Alcohol Spectrum Disorder
FSANZ	Food Standards Australia New Zealand
GP	general practitioner
HED	heavy episodic drinking
LBW	Low birth weight
MDAF	Ministerial Drug and Alcohol Forum
MUP	Minimum unit price
NACCHO	National Aboriginal Community Controlled Health Organisation
NCDs	noncommunicable diseases
NDSHS	National Drug Strategy Household Survey
NHMRC	National Health and Medical Research Council
NDSC	National Drug Strategy Committee
NPDC	National Perinatal Data Collection
NSW	New South Wales
PTB	Pre-term birth
RACGP	Royal Australian College of General Practitioners
RANZCOG	Royal Australian and New Zealand College of Obstetricians and Gynaecologists
SA	South Australia
SBI	Screening and brief interventions
SGA	Small for gestational age
WA	Western Australia
WHO	World Health Organization

Introduction

The Foundation for Alcohol Research and Education (FARE) welcomes the opportunity to provide a submission to the Senate Community Affairs Reference Committee inquiry into *Effective approaches to prevention, diagnosis and support for Fetal Alcohol Spectrum Disorder* (the Inquiry). This Inquiry provides an opportunity to investigate the progress made on addressing the issue of Fetal Alcohol Spectrum Disorder (FASD) since the previous inquiry by the House of Representatives Standing Committee on Social Policy and Legal Affairs, undertaken from September 2011 to November 2012. It also provides an opportunity to identify gaps in the current response and make recommendations for the future. This submission focuses on the aspects of prevention of harm caused by alcohol exposure during pregnancy, particularly, but not exclusively, FASD.

The need for a comprehensive prevention program forms the core of FARE's submission. Effective prevention efforts need to incorporate awareness raising, and the submission considers the essential aspects for such a program to be successful. FARE has been a lead organisation in awareness raising and prevention efforts centred on alcohol consumption during pregnancy. Since the 2011 inquiry, FARE has developed and implemented the public awareness campaign *Pregnant Pause* and the educational program aimed at health professionals *Women Want to Know*.

Submitted with this substantive submission are three appendices and three attachments of highly relevant material that align with and expand on key points. These include FARE's submission to the House of Representatives inquiry,[1] FARE's *Australian Fetal Alcohol Spectrum Disorder Action Plan 2013–2016*,[2] and a review by the Deeble Institute published in 2018,[3] in which approaches and recommendations to prevention are set out.

The problem

FASD is a potential consequence of the exposure of a fetus to alcohol in utero, through the consumption of alcohol during pregnancy.[4] Alcohol is a teratogen; a substance known to cause birth defects. Alcohol passes freely across the placenta and the fetus has minimal ability to metabolise the substance due to its size and development. There is no safe time, no safe amount, and no safe type of alcohol a woman can consume during pregnancy. Other adverse pregnancy and infant outcomes include miscarriage, stillbirth, low birth weight (LBW), small for gestational age (SGA), and pre-term birth.[5,6,7]

FASD is the leading cause of preventable developmental disability in Australia. FASD is a diagnostic term that describes a range of neurodevelopmental impairments caused by alcohol exposure before birth, when alcohol is consumed during pregnancy.[8] Estimates show that FASD affects five per cent of the Australian population, with a potential range between two to nine per cent of babies born each year. Aboriginal and Torres Strait Islander communities are disproportionately affected by FASD, with a rate of up to 12 per cent of births in some remote communities.[9] Furthermore, a recent study screened juveniles in detention in Western Australia and found that 36 per cent had FASD.[10] However, the impact of alcohol consumption on the fetus is indiscriminate; FASD occurs in all parts of Australian society where alcohol is consumed.

Without diagnosis and appropriate intervention, people with FASD have a higher likelihood of secondary disabilities such as requiring greater education, health and mental health support, problems with parenting, problems gaining employment, homelessness, and alcohol and other drug misuse.[11] With the many comorbid conditions people with FASD experience,[12] the medical and social costs to society are great. In Australia, the annual cost of the condition in 2018 was estimated to $1.18 billion.[13]

By international standards Australia has high rates of alcohol consumption during pregnancy.[14] In 2018, the Deeble Institute for Health Policy Research released an issues brief: *Reducing harms related to alcohol use in pregnancy: Policy and practice recommendations*. The brief outlined three key factors contributing to

high rates of prenatal alcohol use: lack of awareness of the National Health and Medical Research Council (NHMRC) Alcohol Guidelines and awareness of risk; limited use of screening and brief interventions (SBI) in antenatal care; and lack of standardised data collection and monitoring. [15] However, wider sociocultural factors play a part and the social environment around the pregnant woman is important, as are her own attitudes and beliefs.[16] Research has also shown that levels of alcohol consumption prior to the pregnancy and experience of intimate partner violence increase the likelihood of women using alcohol during pregnancy.[17]

The causes of FASD, therefore, are complex and prevention initiatives require a range of efforts to inform and support pregnant women to stop or reduce their alcohol intake. This includes:

- universal prevention through wide-reaching awareness raising
- primary prevention addressing alcohol with women of childbearing age
- secondary prevention in providing support to women identified as being at risk of consuming alcohol during pregnancy or subsequent pregnancies
- tertiary prevention to support new mothers staying healthy and support to those women who were unable to modify their alcohol consumption during pregnancy.[18]

It is important to acknowledge the wider sociocultural context in which alcohol consumption and creation of families occurs. Prevention efforts need to include interventions specific to the time of pregnancy, and also efforts which focus on the alcohol consumption of those around the woman, such as partners, family, and the wider community. Efforts focused on a woman's community, through population-wide awareness campaigns, are therefore needed to create an environment where women are supported to abstain from alcohol or reduce their consumption during pregnancy.

The World Health Organization (WHO) *Global Strategy to reduce the harmful use of alcohol* acknowledges that whole-of-population approaches to alcohol policy, targeting the price, promotion and availability of alcohol, are the best policy buys to reduce overall population consumption and alcohol harm, including FASD.[19] A greater commitment to these policies is critical to reducing FASD throughout Australia.

Terms of reference covered in this submission

The focus of FARE's submission to the Senate Community Affairs Reference Committee is on preventing harm caused by alcohol exposure during pregnancy. This submission therefore focuses on the following terms of reference only. Each term of reference is outlined in Table 1, cross-referenced with the corresponding section of the submission.

Table 1. Terms of reference covered in the submission

TERM OF REFERENCE	DEFINITION	SECTION OF SUBMISSION
A	The level of community awareness of risks of alcohol consumption during pregnancy	4.1
B	The adequacy of the health advice provided to women planning a pregnancy, pregnant women and women who are breastfeeding, about the risks of alcohol consumption	5.1-5.2 6.2-6.3
C	Barriers that may prevent women receiving accurate, timely and culturally/ethnically appropriate information and advice on alcohol and pregnancy	4.3 5.2 6.2-6.3
F	International best practice in preventing, diagnosing and managing FASD (addressed in relation to prevention only)	2
M	Progress on outstanding recommendations of the House of Representatives Standing Committee on Social Policy and Legal Affairs report, *FASD: The Hidden Harm*, tabled on 29 November 2012	1 and Appendix A
N	The effectiveness of the National FASD Action Plan 2018–2028, including gaps in ensuring a nationally coordinated response and adequacy of funding	1
O	The need for improved perinatal data collection and statistical reporting on FASD and maternal drinking	6.6.2

Recommendations

The submission has been broken into sections, which present: a background to the issue, an outline of key achievements in Australia's policy response to FASD, and an outline of issues and solutions to these. FARE makes the following recommendations to the Community Affairs Reference Committee:

1. Implement a national and comprehensive prevention program to reduce the overall level of alcohol consumption during pregnancy. This program should include interventions that target both pre-pregnancy contraception and alcohol consumption before and during pregnancy and incorporate best practice elements from international examples.
2. That a national awareness campaign focused on public education is implemented that:
    a. educates the general public, and women in particular, to improve societal-level awareness about the need for zero alcohol consumption during pregnancy and reduce pressure on women to drink in social settings
    b. educates the general public, and women in particular, on the range of adverse consequences that can occur if a woman consumes alcohol during pregnancy
    c. has co-designed resources for at risk Aboriginal and Torres Islander populations
    d. includes resources targeted to women prior to pregnancy, as well as during and in future pregnancies
    e. highlights what those around the woman can do to support her during pregnancy and beyond, particularly the pregnant woman's partner if she has one.
3. That all health professionals are educated on alcohol harms during pregnancy and training is incorporated into all General Practitioner (GP), midwifery, obstetrics and Aboriginal health worker education.
4. All university medical education (such as midwifery and medical degrees) includes curriculum on FASD and alcohol consumption during pregnancy.
5. Support and training to health professionals is provided, to increase skills in asking women about alcohol consumption, providing advice that is consistent with the Alcohol Guidelines, and recognising and responding to women at risk.
6. Continued funding for the *Women Want to Know* project, to ensure continuity in promotion to train health professionals about the risks of alcohol consumption during pregnancy.
7. That approaches to prevention and care for pregnant women are trauma-informed and conducted in a way aimed at reducing stigma.
8. The Australian Government (the Government) cease involvement with any DrinkWise programs and materials.
9. The Government commit to not funding the alcohol industry, including DrinkWise, to produce health education materials.
10. That Government-funded materials provided in health care are evidence-based and developed by public health and/or medical bodies and are free from alcohol industry influence.
11. A guide is created for media on how to accurately report on alcohol use during pregnancy without the use of stigmatising language, so as to not blame women or victimise individuals with FASD.
12. That mandatory pregnancy warning labels on packaged alcohol products are introduced into Australia without delay. These labels should include both pictogram and warning text situated within a box with the words HEALTH WARNING in bold, the label should also appear in red and black on a white background.

13. That immediately prior to the mandatory application of the pregnancy warning label, a comprehensive public education campaign be undertaken to inform consumers about the changes. This should be funded and implemented by the Government.
14. That all pregnant women are asked about their alcohol consumption and pregnant women with alcohol use disorders are provided with specialist support services and have access to treatment services. This should be tied in with wider maternity care frameworks ensuring continuity of care.
15. That the Government support the Australian Institute of Health and Welfare (AIHW) in implementing mandatory recording of alcohol use during pregnancy and invest in research to assess the feasibility, appropriateness and response from women. Evaluating the use of AUDIT-C should be included, especially with the lens of that many women may under-report.
16. That mandatory recording is regularly monitored and reported on, along with research into the implications of implementation and potential unintended consequences.
17. That the Government makes further commitment to reduce harm by implementing effective alcohol policy measures in line with global frameworks.

1. Australian responses to FASD prevention

1.1 *Hidden Harm* – the turning point for FASD

The year 2011 should be seen as a turning point in Australia's response to the issue of FASD. The 2011 inquiry served as a catalyst for the work that has taken place since, which has greatly increased the awareness of FASD among the general public, health professionals and decision-makers. In this section FARE has outlined a condensed timeline of significant policy announcements and achievements to provide background to the issue.

In January 2011, the final review of food labelling laws, known as *Labelling Logic*, was released. This made a specific recommendation that pregnancy warning labels be mandated to be applied to all alcohol products to inform consumers about the risks of consuming alcohol during pregnancy.

In September 2011, the Australian Federal Parliament, through the House of Representatives Standing Committee on Social Policy and Legal Affairs, commenced an inquiry into the prevention, diagnosis and management of FASD. The inquiry tabled its final report *FASD: The Hidden Harm – Inquiry into the prevention, diagnosis and management of Fetal Alcohol Spectrum Disorders (the Hidden Harm)* on 29 November 2012.[20]

The Hidden Harm inquiry made 19 recommendations, most with clear timeframes. An outline of the progress made against all of the recommendations is outlined in Appendix A. Of the recommendations:

- three have been met (one since discontinued)
- four partially met
- twelve have not been met or implemented at all.

The three recommendations that have been met are recommendation 1 (release of a National Plan of Action), recommendation 2 (establishment of FASD Reference Group – note this has now been disbanded) and recommendation 15 (publications of Australian FASD Diagnostic tool).

The *Hidden Harm* inquiry was followed by a West Australian Parliamentary inquiry into FASD (*FASD: the invisibility disability)*[21] in 2012 and a Northern Territory Parliamentary inquiry *(FASD: the preventable disability)*[22] commenced in 2014 and was completed by February 2015.

FARE's submission to *The Hidden Harm* inquiry provided the impetus for the development of the first Australian FASD Action Plan 2013 to 2016, published by FARE. This plan was developed in consultation with parents and carers, FASD researchers, and clinicians, and was launched at Parliament House in Canberra in September 2012. This plan is available at http://fare.org.au/wp-content/uploads/FARE-FASD-Plan.pdf.

On the ground there has been array of work across Australia over the last decade that should be recognised. This has included (but is not limited to): the first prevalence study that took place in Fitzroy Crossing, Western Australia, known as the Lililwan study; the Marulu strategy which followed from that; the launch of *Women Want to Know* and *Pregnant Pause* by FARE (education campaigns for health professionals and the general public); and the publication of the *Australian Guide to the Diagnosis of Fetal Alcohol Spectrum Disorder (FASD)*.

There has been a vast increase in diagnostic capacity across Australia, commencing with the first clinic at the Children's Hospital at Westmead in New South Wales (NSW). There has been research into the needs of families and into the knowledge and attitudes towards FASD by criminal justice professionals in Western Australia (WA) and Queensland. This work has been followed by research into FASD among those in juvenile detention. Numerous journal articles, television programs, media articles and video resources have been created, from Tristan's Story to an investigation by SBS's Insight program into FASD in 2013.

Australia released its second National FASD Strategic Action Plan in November 2018 and the Australian Government has made a strong commitment over that time to addressing FASD. However, as outlined in this submission there is substantial work that still needs to take place to make a real impact on the level of alcohol consumption during pregnancy and increase people's awareness of the harms.

Other events of strategic importance to FASD policy from 2011 to 2019 are outlined in Appendix B and FARE's submissions relating to FASD are outlined in Appendix C.

1.2 Australian Government funding commitments

The Australian Government released *A Commonwealth Action Plan: Responding to the Impact of FASD in Australia in 2013*. This plan committed $20 million in funding, commencing 2013-14, and covered five priority areas: prevention, secondary preventions for alcohol dependent women, diagnosis and management, prevention of FASD within Indigenous communities, and coordination and workforce support. Unfortunately, this version of the plan is no longer publicly available.[a]

However, before the National Action Plan could be implemented, Australia had a general election in September 2013, and when the *National Strategy to tackle FASD 2013-14 to 2015-16* was re-released in August 2014 the funding had been reduced to $9.2 million.[23,24] The differences in funding allocations between the two versions of National Action Plans is outlined in Table 2.

a FARE is able to provide a copy to the Committee if relevant.

Table 2: Funding differences between versions of the National FASD Action Plans released in 2013 and released again in 2014

FASD ACTION PLAN PRIORITY AREAS	2013 FUNDING	2014 FUNDING
1. Enhancing efforts to prevent FASD	$5.0 million	$0.6 million
2. Secondary prevention targeting women with alcohol dependency	$4.8 million	$3.1 million
3. Diagnosis and management	$0.5 million	$0.5 million
4. Targeted measures supporting prevention and management of FASD within Indigenous communities and families in areas of social disadvantage	$5.9 million	$4.0 million
5. National coordination, research and workforce support	$4.0 million	$0.1 million
Total	**$20.2 million**	**$9.2 million**

Since the initial funding of $9.2 million, the Australian Government has released two further funding rounds. These include the *Taking more action to prevent FASD announcement 2017* with $10.5 million in funding and the *National FASD Strategic Action Plan 2018–2028* with $7.2 million in funding.

The most recent funding, under the National FASD Strategic Action Plan 2018-2028 has been allocated to:

- $1.47 million for prevention-related activities, including new consumer resources and general awareness activities, and support for National FASD Awareness Day, translation and promotion of alcohol consumption guidelines and point of sale promotion activities.
- $1.2 million for new screening and diagnosis activities, which will include reviewing existing tools and guides and developing new tools and referral pathways to assist professionals in non-health settings.
- $1.2 million for management and support activities including tailored resources for people working in educational, justice and policing sectors.
- $1.27 million for priority group activities including cultural adaptation of best practice resources that meet local needs.
- $1.55 million to continue some of the existing activities which have been demonstrated as effective.[25]

Overall, across these funding rounds the Australian Government has committed close to $27 million towards FASD since 2014. This funding has created momentum for the great work that occurred over those years and has changed lives, showing the potential for funding in this area to be transformational. Considering the successes of the funding, and the unmet need in areas of prevention, diagnosis and support, there is a strong case for additional funding, proportionate to the scale of the need and its impacts.

As a comparison, the most recent allocation of $7.2 million for FASD is smaller than the amount allocated to the Australian Government Wine Tourism Cellar Door Grants. The grants are capped at $10 million each financial year and aim to support wine producers to attract visitors to wine regions.[26] This highlights the uneven funding allocations made to address the harms caused by alcohol, including the prevention, diagnosis and management of FASD, in comparison with funding to support the alcohol industry.

It should also be noted that significant investment by state and territory governments is virtually non-existent. The only jurisdiction with a dedicated FASD Action Plan is the Northern Territory, released in 2018.[27] WA launched a Model of Care in 2010, followed by an implementation framework in 2013. FASD is also referenced within the *WA Alcohol and Drug Interagency Strategy 2018-2022.*[28] Some local areas have commenced their own FASD action plans, these include the Marulu strategy in Fitzroy Crossing as well as the Hedland and Pilbara FASD research projects. Other areas such as Newcastle and Alice Springs are part of the *Making FASD history: multi-site prevention program*.[29]

2. International best practice in preventing FASD

Internationally, the prevention of FASD has become an increasing priority. In 2014, the first conference on the prevention of FASD took place in Canada. The conference had representatives from 35 countries and was attended by 700 participants. The *International Charter on Prevention of Fetal Alcohol Spectrum Disorders* was published following the conference. This Charter noted that key obstacles for prevention have been:

- the lack of recognition of FASD
- lack of knowledge by the general public on the risks associated with alcohol use during pregnancy
- the conflicting advice and misinformation that women receive about alcohol and pregnancy.

The Charter also called for recognition of the reasons why women may drink while pregnant and the importance of support from partners, families and health professionals to assist women during pregnancy.[30]

The WHO has also undertaken a number of activities over the last decade specifically focused on alcohol use during pregnancy. The World Health Assembly Resolution WHA 58.26, under which the *Global strategy to reduce the harmful use of alcohol* was adopted, specifically emphasised certain contexts where the risks of alcohol consumption are greater, including during pregnancy.[31] In Europe, the *European Action Plan to reduce the harmful use of alcohol 2012–2020* outlines specific actions to reduce alcohol harm, including within maternity care. This Action Plan noted that all women should be offered information about alcohol use during pregnancy.[32]

The WHO also released in 2014 *Guidelines for the identification and management of substance use and substance use disorders in pregnancy*. The guidelines reviewed the evidence for interventions, and outline the clinical management of women who are pregnant and using substances (including alcohol) alongside recommendations for care.[33] These guidelines make a 'strong' recommendation that all pregnant women be asked about their alcohol use in early pregnancy and at subsequent appointments.

The guidelines recommend that women who report using alcohol should be provided with a brief intervention (BI) to support the cessation or reduction of their alcohol consumption in order to minimise harm both to themselves and the fetus. The guidelines also note that women who are unable to stop or cut down their alcohol consumption should be offered a comprehensive assessment and have a tailored care plan, which may include referral to a specialist service if necessary.

In 2016, the WHO European Region released *Prevention of harm caused by alcohol exposure during pregnancy,* which was a rapid review of interventions to prevent harm caused by alcohol use during pregnancy. This report summarised interventions for pregnant and non-pregnant women and highlighted that interventions that target both contraception and alcohol consumption have shown to be effective in reducing the risk that a woman may consume alcohol during pregnancy. It recommended that these be considered when establishing comprehensive prevention programs.

The report also summarised case studies from European Member States, where examples of national awareness campaigns, clinical care, and screening for FASD prevalence were demonstrated. For example, in 2007 Norway undertook a comprehensive national awareness campaign which was evaluated in 2013. The evaluation showed that between 2009 and 2013 there was a 20 per cent reduction (from 40 per cent at baseline) in the number of people in the general public who believed pregnant women could consume "some alcohol with dinner". The Norwegian campaign is an example of how multifaceted, consumer-tested campaigns that focus on empowering women to not consume alcohol during pregnancy, can have a positive impact on attitudes towards alcohol use in pregnancy.[34]

3. Population awareness of Alcohol Guidelines and risks of alcohol consumption during pregnancy

3.1 Awareness of the NHMRC Alcohol Guidelines

Australia's national Alcohol Guidelines were published in 2009 by the NHMRC. These were a significant departure from the previous version published 2001. There are currently four Guidelines, covering short-term risk, long-term risk, pregnant women and children under 18 years.

The current Alcohol Guidelines are being reviewed with the expected draft available for public comment and consultation in December 2019. This review includes an examination of the evidence on alcohol harms for both the general population and sub-populations such as pregnant women, and contains four guidelines, for general population on risk of short-term and long-term harm, and for sub-populations of those under 18 and pregnant women.[35]

Despite the Alcohol Guidelines being in place for ten years, awareness of their content is low in the general population in Australia. This is in large part due to the lack of promotion. Since publication, there has been no national campaign to bring the Guidelines and their content to the public's attention. A study conducted before and after their implementation (in 2007 and 2010, respectively) found that less than five per cent of respondents could accurately state the correct low-risk limits for short- and long-term effects on health. Only 21.1 per cent of men and 14.9 per cent of women were able to accurately report the correct limit for low-risk limits for long-term harm (<2 drinks per day). Even fewer (only 2.5 per cent of men and 2.6 per cent of women) were able to state the accurate limits for single occasion drinking (>4 drinks per occasion).[36]

Similarly, an analysis of six waves of data from the NDSHS showed that accurate knowledge of the low-risk limits declined between 2007 and 2010. Prior to 2010, around 50 per cent of respondents accurately stated the low-risk limit. In the most recent three waves (2010, 2013 and 2016), including 2010, accurate knowledge was 32.6 per cent, 35.5 per cent, and 39.6 per cent, respectively.[37]

3.2 Awareness of the alcohol pregnancy guideline

Guideline four of the Alcohol Guidelines recommends that the safest option for women who are pregnant, planning pregnancy or breastfeeding is to abstain completely from alcohol.[38]

This abstinence message has been in place for ten years now and it would be expected that community awareness of the advice to avoid alcohol would be high. However, the data demonstrates that this not the case. Community-wide polling conducted by Galaxy YouGov, commissioned by FARE, shows that awareness of the 'zero alcohol' guidelines has slowly increased over time (Figure 1). In 2019, 78 per cent of both men and women were aware of the recommendation for pregnant women, which was higher among women than among men (84 per cent and 72 per cent, respectively). The awareness of this guideline has increased over time from 67 per cent in 2012, as demonstrated in Figure 1.

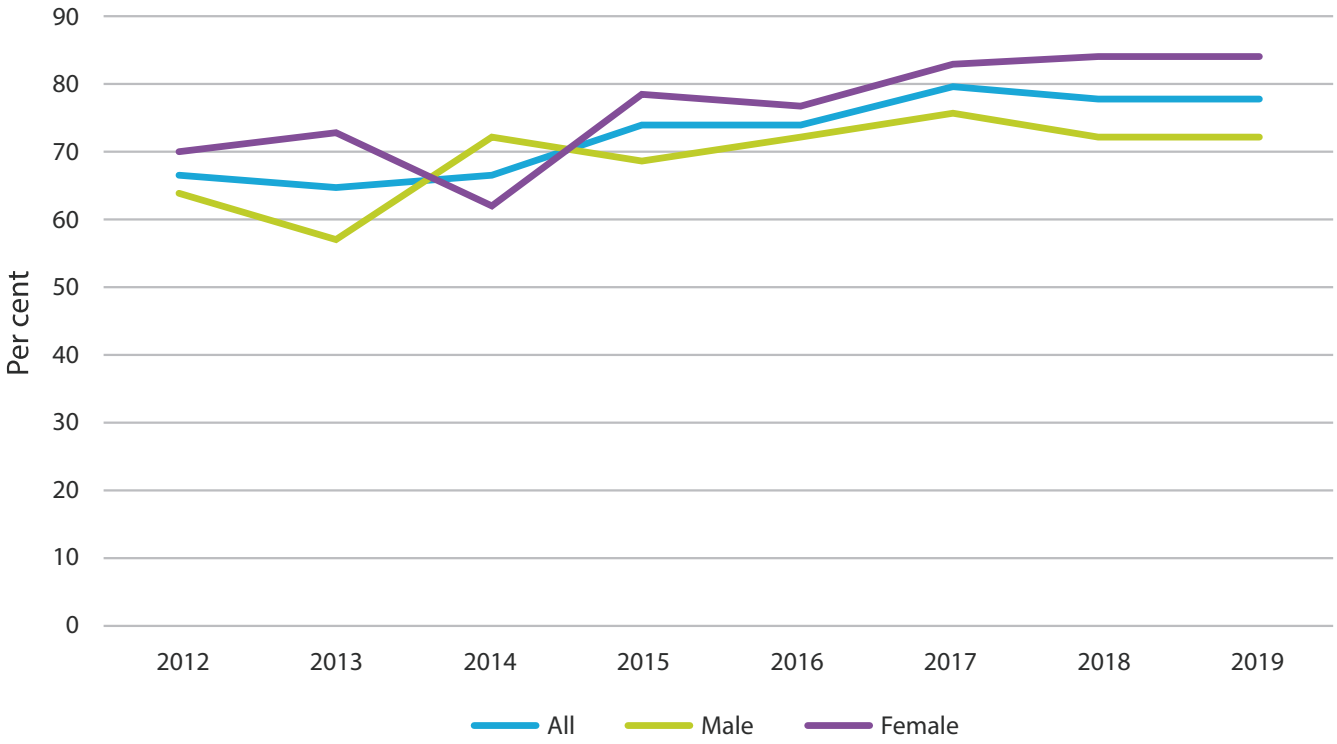

Figure 1. Awareness of 'zero alcohol' advice for pregnant women in the FARE Annual Poll 2012–2019, by gender. *Source: FARE Community Polls 2012–2019.*

4. Maternal alcohol consumption

In order to prevent alcohol-exposed pregnancies it is important to understand which women drink during pregnancy and their reasons for this. Understanding this can give insight into prevention strategies that may work for different women and their families.

4.1 Women's awareness of the risks of alcohol consumption during pregnancy

It is often presumed that Australian women are aware of the potential consequences of consuming alcohol during pregnancy. This assumption is seen in media articles on the issue, surveys of health professionals and in submissions by members of the alcohol industry most recently made to the public consultation on the mandatory application of pregnancy warning labels on packaged alcohol. An example is a submission by Alcohol Beverages Australia which states:

> The reasons we advocate for adopting the voluntary labelling scheme are there old (sic): 1) to minimise excessive costs to industry (and thus potentially to consumers or farmers) and 2) because awareness of the potential harm of alcohol for pregnant women is already at very high levels in the community (p.4).[39]

Contrast this to views by women themselves, who in focus groups undertaken by Hall and Partners Open Mind (commissioned by FARE) in 2018 said that alcohol consumption in pregnancy was seen as being at least somewhat acceptable. This perception was influenced by:

- the belief that alcohol consumption in pregnancy is a common practice (what others around them are doing)
- medical advice by health professionals seen as condoning and allowing for the consumption of some alcohol

- the feeling that there are no clear guidelines on alcohol for pregnant women, or that the evidence is conflicting
- the acceptability by older female family members and friends that some alcohol during pregnancy is without harm because they did it themselves with no apparent consequences
- having consumed alcohol during a previous pregnancy (or they had observed other pregnant women doing so) at low or high amounts prior to realising they were pregnant without apparent consequences for the baby or themselves.[40]

People's knowledge and understanding of the adverse consequences and reasons for not consuming alcohol during pregnancy are low. A nationwide survey, undertaken in 2010, examining women's knowledge, attitudes and practices of alcohol use during pregnancy in 2010 (N=1,103) showed that 38.5 per cent of women had not heard of any effects from alcohol on the developing fetus or the pregnancy itself. The most common effect listed among those aware of effects of alcohol was Fetal Alcohol Syndrome (FAS) (31.7 per cent), followed by low birth rate (LBW) (28.5 per cent) and brain damage (15.6 per cent). It is noteworthy that only 1.5 per cent of women reported miscarriage as a risk from alcohol consumption and only 0.3 per cent mentioned stillbirth.[41]

FARE's Annual Alcohol Poll has asked respondents about their awareness of FASD.[b] In 2015, half of the respondents reported being aware of FASD, which a higher proportion of women than men being aware of the condition (58 per cent and 42 per cent, respectively).[42] This has not increased significantly from 47 per cent of adults being aware of FAS in 2012. Those least likely to be aware were men (34 per cent), Gen Y (40 per cent), and regular drinkers (40 per cent).[43]

4.2 Who consumes alcohol during pregnancy in Australia?

By international standards, the consumption of alcohol during pregnancy in Australia is high. For example, a systematic review and meta-analysis, published in 2017, found that 35.6 per cent of women in Australia consume alcohol at some point during pregnancy (95% CI: 27.7per cent to 43.9 per cent), compared to a global prevalence of 9.8 per cent.[44]

However, Australia should be buoyed by the fact that alcohol consumption during pregnancy does appear to be on the decrease since the early 2000s. [45] Data from NDSHS shows that of all pregnant women, 34.7 per cent consumed alcohol either before or after they found out about the pregnancy. This is a decrease from 41.8 per cent in 2013. However, while there has been a decrease in women drinking before they knew they were pregnant (from 56.0 per cent in 2013 to 48.7 per cent in 2016), there has been no real change in women drinking after they found out they were pregnant[c] (26.1 per cent in 2013 to 25.2 per cent in 2016).[46]

Analysis of who drinks during pregnancy in the same study, analysing NDSHS data, shows that women of higher education were more likely to drink during pregnancy than all other women. However, women from lower socioeconomic groups were more likely to maintain pre-pregnancy levels or increase consumption.[47] This demonstrates the challenges of implementing 'one-size fits all' policies for all women during pregnancy.

There are also differences in alcohol consumption relative to age. A review undertaken in 2012 of NDSHS data showed that of women who drank before knowledge of their pregnancy, 91.3 per cent of women under the age of 25 stopped drinking after they became aware of the pregnancy. Only 8.7 per cent of this age group continued to drink after knowledge of the pregnancy. This compares to women aged over 36 years, of whom 51.3 per cent stopped drinking and 48.7 continued to drink after knowledge of the pregnancy.[48]

b Terminology used in the Annual Alcohol Poll changed from 'Fetal Alcohol Syndrome' to 'Fetal Alcohol Spectrum Disorder' in 2015

c It should be noted that survey questions have been modified over time, this has included separating out alcohol consumption to before and after knowledge of the pregnancy, and more recently questions have asked about separate occasions of alcohol consumption.

This issue of women who are older, and of higher socioeconomic status, continuing to drink during pregnancy (even after awareness of pregnancy) is not unique to Australia. A systematic review of published studies between 1999 and 2009 on predictors for alcohol use during pregnancy, found that of the 14 included studies, associations were found for women who are older, from higher socioeconomic status, screening positive for alcohol problems, and screening positive for psychiatric symptom. While the proportion of studies that found an association varied, two predictors were found to have a positive association in all studies that assessed them. These were exposure to intimate partner violence, and higher pre-pregnancy alcohol consumption.[49]

The available evidence for prevalence of FASD within Aboriginal and Torres Strait Islander communities show that the condition is significantly more common in these communities than the general population.[50] The higher rates in these communities suggest alcohol use during pregnancy is higher than in other populations. A study of a small sample of mothers (N=127) in a remote community in WA, of whom 95 per cent were Aboriginal women, found that 55 per cent consumed any alcohol during pregnancy. For women who had a valid AUDIT-C score and who reported drinking during their pregnancy (n=60), 95 per cent consumed alcohol at risky or at high-risk levels (as defined in the study as being an AUDIT-C score of 4-5 and ≥6 respectively). These findings also indicated that women consumed large quantities of alcohol and drank relatively frequently.[51] It should be acknowledged that any alcohol consumption during pregnancy carries some level of risk of harm to the fetus, not just higher or more frequent consumption. It is also important to note that the data collected on women's alcohol consumption was collected in 2010 but related to children who were born in 2002-03. This data was therefore retrospective and may not have been an accurate recollection of alcohol consumption during pregnancy.

4.3 Barriers women face in stopping or reducing their alcohol consumption during pregnancy

It is critical to understand and appreciate women's attitudes, intentions and behaviours towards alcohol consumption during pregnancy. Women's intention and actions to consume alcohol during pregnancy are influenced by their knowledge of the risks, their attitudes and beliefs about these risks, their life circumstances, previous pregnancies and those around her (partners, family, friends and wider community). A range of factors influence alcohol consumption during pregnancy, including:

- being unaware of the pregnancy
- being unaware of the extent and consequences of alcohol exposure on the fetus
- finding it difficult to abstain as alcohol consumption is normal within their social group
- using alcohol a way to cope with difficult life situations such as violence, depression, poverty and isolation
- having an alcohol use disorder
- having a partner who is drinking or not discouraging a women from drinking.[52,53]

Qualitative research, conducted through focus groups with women in Canberra in 2014, found that awareness of the Alcohol Guidelines was lacking. When made aware of the guidelines, women generally support their content. Some women were critical of the existence of the guidelines, suggesting it was a way to control women's bodily autonomy. However, most women believed that the choice to drink during pregnancy lies with the individual, and that this decision is informed and influenced by those around her, their experiences and the information available to them.[54]

Knowledge about risks appears important in relation to experience of having consumed alcohol in a previous pregnancy as well as intention to consume alcohol in a future pregnancy. A study of 1,103 Australian women found that disagreeing with the statement "Drinking alcohol during pregnancy can lead to life-long disabilities in a child" was associated with increased likelihood of having consumed alcohol

in a previous pregnancy and intending to consume alcohol in a future pregnancy. Women who disagreed with a statement "Drinking alcohol in pregnancy can affect the unborn child" also had higher likelihood of having consumed alcohol during a previous pregnancy. These women were also more likely to intend to consume alcohol in a future pregnancy. The highest likelihood for consuming alcohol during pregnancy was having consumed alcohol in a previous pregnancy.[55]

Life circumstances also impact on women's use of alcohol during pregnancy. These include, but are not limited to poor mental health, high life stress, poverty, housing and legal issues, concurrent drug use and exposure to violence such as domestic and family violence and trauma.[56] A study of 80 birth mothers of children with FASD by the University of Washington, found that all women had histories of alcohol use disorder, and 63 had a parent with an alcohol problem. The study also found that 96 per cent of the mothers had mental health disorders, 95 per cent had been physically or sexually abused in their life, and 80 per cent lived with men who did not want them to stop drinking during pregnancy.[57]

Therefore, prevention activities need to ensure that women are supported during pregnancy and that responses are trauma-informed. This means that an empathic approach is taken, moving from straight education (outlining the risks of alcohol consumption during pregnancy) to one that acknowledges a woman's life circumstances (she may or may not know the risks, but may need strategies to assist her). The Centre for Excellence for Women's Health and the CanFASD Research Network have done work in this area and Australia can learn from this experience.[58]

5. Health advice provided to women

5.1 Advice in antenatal care

The recommended advice by the WHO is that women are routinely screened for their alcohol consumption during pregnancy (using a standard screening tool), and provided a BI where necessary.[59]

All women, regardless of whether or not they drink alcohol should be advised that:

- no alcohol is the safest choice when pregnant or trying to get pregnant
- no safe level of alcohol consumption during pregnancy has been determined.

This advice was developed as part of the *Women Want to Know* project. This project has developed clear advice for health professionals in Australia to provide to women who are pregnant or planning pregnancy. The advice is based on an assessment of a woman's alcohol consumption (using AUDIT-C) both prior and during pregnancy. This advice should be tailored to the individual woman and acknowledge other information known about her, such as previous pregnancies, nutritional and smoking status, levels of stress and pregnancy support as well as experiences (current or past) of trauma, abuse, violence and alcohol and drug issues.

However, data on the advice women are provided with during pregnancy is mixed. Data from the FARE Annual Alcohol Poll 2018 indicates that among women who had ever been pregnant, only 46 per cent had been advised by a health professional that there is no safe limit of alcohol use during pregnancy.[60] Qualitative research from NSW and Queensland highlights that while most women received abstinence messages, some received advice that it was best to reduce their consumption rather than abstain from alcohol completely.[61] Further, women's interpretations of the messages were tempered by their understanding of risks associated with consuming smaller amounts of alcohol, particularly if they perceived that some alcohol was acceptable in moderate or limited occasions.[62]

These views were corroborated by qualitative research from South Australia (SA), where women reported having received information form a variety of sources, and that often was in conflict. In terms of antenatal

care, some women received information that did not clearly suggest complete abstinence and several had not received any information about alcohol. Some had experience of their midwife approving of the occasional glass of wine and many regarded the amount of information provided by the healthcare professional on the issue as limited. Some women reflected that the limited information could have been as a result of the health professional assuming that the woman was already not drinking.[63]

However, the acceptability among women about being asked about alcohol consumption is high.[64] Priority should be given to identify the best way to ensure that all women are being asked about their alcohol use and the most effective way for recording reported consumption (see further in section 6.6).

5.2 Barriers to health professionals providing appropriate advice

5.2.1 Systematic and individual barriers

The *Australian Clinical Practice Guidelines – Pregnancy Care* recommend that all women be asked about alcohol consumption during their first antenatal appointment and that a validated screening tool (AUDIT-C) is used to assess levels of alcohol consumption.[65]

However, while these guidelines were published in 2018, the chapter on Alcohol has not been updated since 2009. This was a significant failing and meant the information published in 2018 was significantly out of date, referring to the 2001 Alcohol Guidelines. Following the publication of the guidelines, academics and clinicians wrote to the Australian Government Department of Health to raise concerns about this issue. The chapter was amended to include information about use of AUDIT-C and links to resources. However, a full evidence review of this chapter is not scheduled until 2020.[66] This omission in updating the Alcohol chapter suggests that alcohol harm is not forefront of mind and that, despite significant achievements, the issue of alcohol and pregnancy is still under-prioritised by Australian governments and health officials.

Despite clear recommendations from the evidence and Government that women be asked about alcohol consumption, health professionals face a range of structural barriers in discussing alcohol consumption with women. This issue was examined during the development of the *Women Want to Know* project (see section 6.2). The *Audit and Literature Review* undertaken by IPSOS Social Research Institute at the start of the project highlighted that health professionals face: a lack a of knowledge of risk and consequences of alcohol consumption during pregnancy; a lack of skills and tools to intervene; fear of negative reaction; perceived lack of self-efficacy; preconceived ideas about who is at risk; and competing priorities.[67]

An evaluation undertaken of the *Women Want to Know* project found that alongside these, health professionals also mentioned other barriers such as:

- it was difficult to discuss alcohol if there were pregnancy complications
- an assumption that alcohol would be discussed by another health professional if the woman saw multiple health providers (such as between a GP and midwife)
- a desire to provide reassurance if a woman has consumed alcohol before pregnancy.[68]

Similarly, a focus group study with health professionals in WA showed that barriers to discussing alcohol included perceptions from midwives that women in general do not drink much or any alcohol, that women are already aware of recommendations to abstain, and that alcohol is not the main priority for women with other complex needs. Midwives' workloads and other public health issues taking priority, along with concerns for maintaining a good relationship with the woman and finding it difficult to ask about alcohol in a non-judgemental way were also barriers to discussing alcohol with women.[69] A literature review, published in 2013, recommended that: health professionals should be informed about FASD along with evidence for SBIs; structural practice barriers to discuss alcohol with pregnant women should be removed; and work done to ensure health professionals feel comfortable raising the topic.[70]

Wider approaches in antenatal care are also of importance in alcohol harm prevention. Continuity within maternity care services ensures that women are cared for by the same service provider throughout their pregnancy and supported by interventions to improve health.[71] Prevention of harm cause by alcohol exposure during pregnancy can be effective under this model due to the opportunity for the health care professional to build a trusting relationship with the woman over time.[72]

5.2.2 Knowledge barriers

The personal views and attitudes of health professionals about the consumption of alcohol and consumption during pregnancy can be prevailing factors as to whether women receive clear abstinence and harm reduction advice or not. These personal views can override any Government recommendation and unfortunately, too often health professional views are not informed by up-to-date evidence.

A survey of midwives in WA found that 91.4 per cent of midwives believed pregnant women should abstain from alcohol and 84.6 per cent believed women trying to get pregnant should abstain. However, despite the high proportion that agreed that pregnant women should abstain, 32.1 per cent believed that infrequent intake of one standard drink during pregnancy would not be harmful to the woman or the baby. The vast majority knew that alcohol use during pregnancy can result in FAS (93.9 per cent) or FASD (90.3 per cent), but knowledge of more specific conditions or effects had a lower proportion of midwives reporting awareness.[73]

Within the *Women Want to Know* project, a survey was undertaken with GPs, midwives and specialists to assess, among other things, awareness of risks associated with alcohol use during pregnancy. The most commonly reported outcome reported before the project was FAS/FASD (72 per cent), followed by intrauterine growth restriction (21 per cent), general harm to baby (20 per cent), and premature labour (12 per cent). Ten per cent reported that alcohol exposure can result in developmental delays or low IQ, ten per cent that it can cause miscarriage or stillbirth, ten per cent that it increases the risk of LBW/SGA, and another ten that it can cause congenital abnormalities.[74]

When open text fields to the *Women Want to Know* pre- and post-intervention surveys were investigated, myths about alcohol consumption and pregnancy were exposed. The advice provided by health professionals fit within three myths about alcohol use during pregnancy.[75] These myths and verbatim responses from health professionals are demonstrated in Table 3.

Table 3: Myths about alcohol consumption during pregnancy that persist and are perpetuated by some health professionals

MYTH	RESPONSES[d]
A 'safe time' – that a particular time in pregnancy in which alcohol can be consumed	"No alcohol in first trimester" "Keep third trimester alcohol to absolute minimum"
A 'safe amount' – that there is a level of alcohol consumption that might be safe	"No more than two drinks per day" "One drink a day or five a week is acceptable, moderation is the key" "Should be safe with less than nine drinks per week" "Avoid excessive use" "Never be unable to legally drive"
A 'safe type' of alcohol – that different types of alcohol have worse impact on the fetus	"Avoid spirits" "Permitted to have one glass of wine with main meal, usually with dinner once per day as a maximum"

d As demonstrated by answers to 'What advice do you generally give to women about alcohol consumption during pregnancy?' (open-ended response)

These results are substantiated by qualitative research from SA, in 2015 which has also shown that midwives are aware that alcohol is associated with risk of negative outcomes, but there appears to be a gap in knowledge of specific effects.[76,77] One study found that midwives were aware of the effects that alcohol can have on development in relation to physical as well as neurodevelopmental abnormalities. Knowledge of FASD as an outcome of alcohol use during pregnancy was widespread yet the specific knowledge of what the condition entails was limited. However, when it came to attitudes towards alcohol consumption during pregnancy several midwives expressed views divergent from the Alcohol Guidelines. They felt that small amounts of alcohol were unlikely to be harmful and some advised women that if they wanted an occasional drink, that would be acceptable.[78]

6. Solutions

6.1 Developing a comprehensive prevention program

Australia needs an overarching prevention program, developed in conjunction with experts. This should be informed by international examples of best practice, such as the four-tier prevention model developed in Canada[79]. This model is already being implemented in parts of Australia (Figure 2) by clinicians and researchers but has not been embraced by the Government as a strategic prevention program to reduce the harm caused by alcohol exposure during pregnancy under the National FASD Strategic Action Plan. For a national prevention program to be effective, clear responsibilities are required between federal, state and regional level governments to be implemented within specified timeframes. Adequate funding needs to be provided for such a program, for which principles already exist.

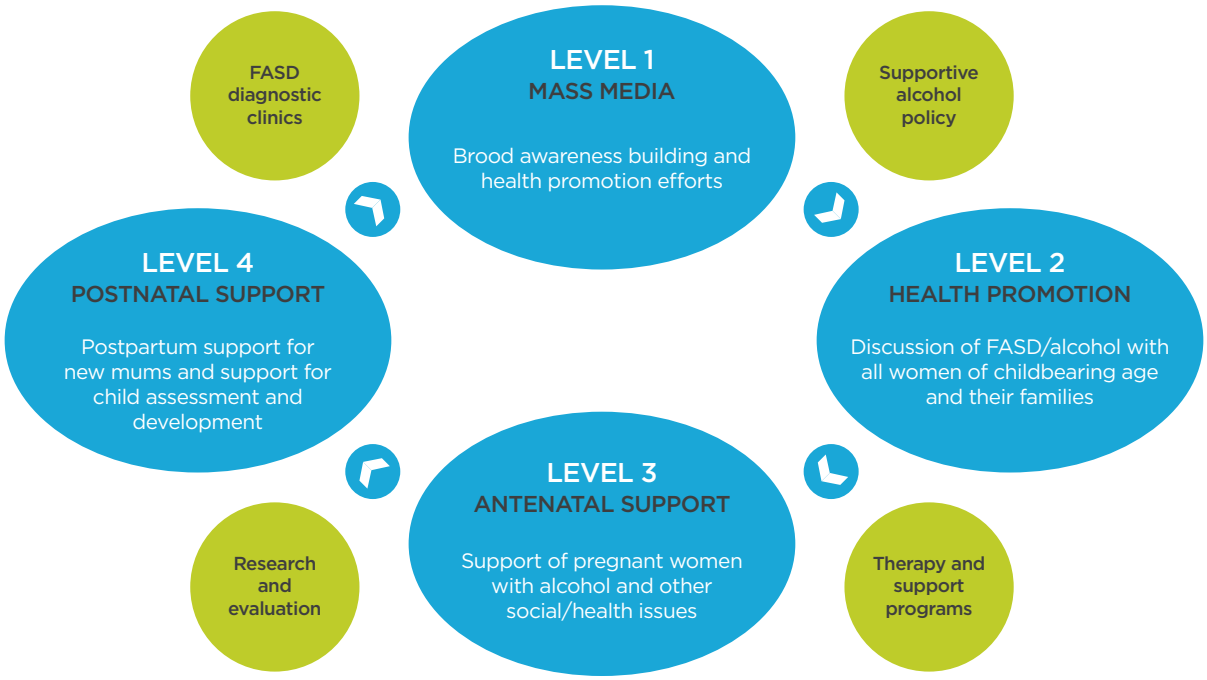

Figure 2. Australian FASD prevention model, adapted from the Canadian four-part prevention model. Source: Telethon Kids.[80]

As outlined in section 1, numerous inquiries have been undertaken, but the action in response has been limited. Activities that have been funded have been small scale, piecemeal and inconsistent. With such restrained commitment, these activities are not able to achieve their full potential. The report by the Deeble Institute released in September 2018 outlines that while some of the current funded activities (FASD Clinical Network and FASD Hub) have increase diagnostic capacity and improved clinical management of FASD, whole of population reductions in maternal alcohol consumption during pregnancy have not occurred.[81]

The report highlights that:

> Australian policymakers are therefore faced with both the challenge and the opportunity to reduce the burden associated with antenatal alcohol use in pregnancy through comprehensive and coordinated prevention approaches.

This report has done the work to outline the policy and practice recommendations to reduce harms caused by alcohol exposure during pregnancy. When developing a comprehensive prevention program, these comprehensive recommendations should be incorporated and should become the blueprint.

Recommendation

1. Implement a national and comprehensive prevention program to reduce the overall level of alcohol consumption during pregnancy. This program should include interventions that target both pre-pregnancy contraception and alcohol consumption before and during pregnancy and incorporate best practice elements from international examples.

6.2 Public education campaign

Despite low levels of knowledge around alcohol and pregnancy guidelines and, among pregnant women, limited knowledge on the risks to the developing baby from alcohol, to date, there has been no national public education awareness campaign on the issue.

Public awareness campaigns can challenge and change social norms.[82] The WHO explains that social norms are unspoken rules or expectations within societies about appropriate and inappropriate behaviour. These norms persist because of individuals' desire to conform, as well as expectations by others that people will conform.[83] Public education has been most successful in the tobacco control field, where social norms about the acceptability of smoking have changed dramatically. Research from the tobacco control field has found that public education campaigns are most successful when they are well-funded, repetitive, and ongoing.[84,85]

For public education to be effective, it must be multifaceted, free from alcohol industry influence and use a range of media to promote its key messages.[86] This includes broadcast media, digital media, and signage in and around licensed venues. An ideal campaign should be reinforced with more formal messaging in other settings, such as school-based education programs. The campaign rationale must clearly identify the target audience, and the behaviour change sought. Understanding the target audience includes securing information about their knowledge, attitudes and current behaviours relevant to the objective of the campaign.[87]

FARE first ran education campaigns on drinking during pregnancy in the Australian Capital Territory (ACT) through the *Pregnant Pause* campaign. This campaign was originally funded through an innovation grant from the ACT Government in 2014.[88] *Pregnant Pause* has a focus on the drinking of those around the woman, recognising that pregnancy and parenthood presents an opportunity for behaviour change. Research shows that while bearing and raising a child has an impact on women's alcohol use, at least until their child reaches five years old, becoming a parent does not greatly impact men's alcohol consumption.[89] We also know that the support of a partner is an important factor for alcohol cessation during pregnancy. A WA study of pregnant women reported that of those women who drank during pregnancy, 75 per cent did so with their partner, and that 40 per cent of the drinking occasions were initiated by their male partner.[90] This study found that women are more likely to abstain if supported by those around them.

Findings from evaluation of *Pregnant Pause* in the ACT showed that in its last year (2018), over 50 per cent of the adult population were aware of the campaign, and importantly, 61 per cent of women were aware of the campaign. In addition, the campaign outcomes indicated that awareness of the alcohol and pregnancy

guideline increased from 77 per cent (baseline) to 83 per cent. Over the three years of the campaign 436 individuals signed up, with the majority being parents-to-be. Large parts of the ACT population were reached through television commercials (3.6 million cumulative reach), radio advertising and a range of other strategies.

In 2017-18, FARE received further funding from the Australian Government Department of Health to promote *Pregnant Pause* at a national level. This grant allowed the campaign to be promoted through a broad range of strategies including:

- a radio campaign on leading Brisbane, Sydney and Melbourne radio stations (with a combined cumulative audience of 2.3 million listeners)
- consistent communication to 8,000 Facebook and Twitter followers
- sample resources to GP surgeries with information packs to 11,720 GPs and a television commercial that aired in over 2,500 GP surgeries
- mail-out to over 200 maternity services nationally.

The communication efforts resulted in 294 registrations, with 188 made in the first year of national promotion. Unfortunately, the impact of Pregnant Pause at a national level has been limited. Funding only provided for targeting of three eastern-state cities, and the campaign relied on social media.

To be holistic, the target group of Pregnant Pause should be expanded to include the health professions supporting women, such as professionals providing family planning and contraceptive advice, GPs, pharmacists, obstetricians, and gynaecologists. It could also expand opportunities for the message about alcohol-free pregnancies through universities, childcare groups and other places where women frequent.

It is important that a public education campaign on alcohol and pregnancy be extended to women of childbearing age seeking contraceptive advice or family planning. Close of 50 per cent of pregnancies are unplanned and many women are unaware of their pregnancy for a number of weeks. This presents a key target group and time period in women's lives to focus on. The Health Promotion Agency of New Zealand has tried to address this through the 'Pre-testie Bestie,' campaign. Still in its early development, 'Pre-testie Bestie' aims to empower women's female peers to encourage women to stop drinking alcohol if there is any chance they could be pregnant (prior to pregnancy test).[91] The campaign is achieving cut-through and engagement with the desired target audience; each video has gathered over 100,000 views, over 500 comments on the issue.

Recommendation

2. That a national awareness campaign focused on public education is implemented that:
    a. educates the general public, and women in particular, to improve societal-level awareness about the need for zero alcohol consumption during pregnancy and reduce pressure on women to drink in social settings
    b. educates the general public, and women in particular, on the range of adverse consequences that can occur if a woman consumes alcohol during pregnancy
    c. has co-designed resources for at-risk Aboriginal and Torres Islander populations
    d. includes resources targeted to women prior to pregnancy, as well as during and in future pregnancies
    e. highlights what those around the woman can do to support her during pregnancy and beyond, particularly the pregnant woman's partner if she has one.

6.3 Increasing knowledge and awareness among health professionals

Aside from public education, programs have also been undertaken to improve knowledge and awareness among health professionals about the risks of alcohol consumption during pregnancy. In 2014, FARE launched the *Women Want to Know* campaign with funding support from the Australian Government. The campaign aims to encourage health professionals to discuss alcohol and pregnancy with women routinely and to provide advice that aligns with the Alcohol Guidelines.

The project involves two main components:

- Accredited online training available through Australian College of Midwives (ACM), Royal Australian College of General Practitioners (RACGP) and the Royal Australian and New Zealand College of Obstetricians and Gynaecologists (RANZCOG).
- Resources to support health professionals to discuss alcohol and pregnancy with women. This comprises of three leaflets for health professionals and one for patients, plus eight videos which were made available as part of the online training course, through the Department of Health (DoH) YouTube playlists.

An evaluation of the campaign was carried out in 2016 which showed that the project had successfully reached a reasonable proportion of health professionals in Australia on a small budget. The evaluation noted, in particular, the challenges in achieving any knowledge of the campaign or 'cut-through' to a group that is inundated with different health information and different campaigns each day. The training courses had positively impacted the attitudes and behaviour of participating professionals and encouragingly fewer midwives and obstetricians/gynaecologists reported not being aware of the Alcohol Guidelines. However, receiving accreditation for training completion was not sufficiently motivating on its own to prompt health professionals to take up the course.[92]

Since the evaluation in 2016, the training courses have been reviewed and incentive strategies to encourage training course completion have been implemented. Data supplied to FARE by the colleges demonstrates that the incentive promotions (such as competitions to win annual membership by completing the training) resulted in positive spikes in course completions.[93]

In 2017, further Australian Government funding allowed for revision of the online training courses updating terminology and in the case of the RACGP course, a major revision updated the course materials. This substantially reduced the time required to complete the training, which can now be completed in 30 minutes while still retaining Continuing Professional Development accreditation. In addition, a revision of a women's leaflet was undertaken to ensure it was suitable as a standalone resource. A range of measures were used to promote the training to health professionals - the most effective being offering of incentives. This resulted in increased numbers of course enrolments and completions. A survey of GPs as part of the evaluation of these measures indicated that finding time was the biggest barrier to undertaking training. GPs also expressed that they would be more likely to discuss the impact of low levels of alcohol consumption during pregnancy with women if there was new evidence about this. Few of the doctors surveyed had heard of the *Women Want to Know* project and none had completed this or similar training.[94]

The *Women Want to Know* project has provided quality evidence-based information and training to health professionals and women who are pregnant, planning pregnancy or breastfeeding, since its inception. Growth of the project would be supported by continued funding that allows consistent growth in training completions, not ones interrupted by pauses in the funding.

Other efforts to provide education to health professionals has been undertaken in WA, under the *Alcohol and Pregnancy Project* which aimed to change practice among health professionals around alcohol and pregnancy and FASD. Following distribution of educational resources, there was no increase in health professionals who routinely asked about alcohol, but 31 per cent more health professionals were

discussing risks associated with prenatal alcohol use in 2007 compared to 2002. Along with a change in practice, the project had a high reach and there were high levels of engagement with the developed resources.[95]

Comprehensive work to develop a practice change intervention is also being undertaken in NSW that will aim to improve leadership and management, guidelines and other resources to support practice, and systems for collecting information from pregnant women which will be monitored along with performance. This work can support future endeavours to improve the way maternity services address alcohol but may also be applicable to other settings.[96]

Recommendations

3. That all health professionals are educated on alcohol harms during pregnancy and training is incorporated into all GP, midwifery, obstetrics and Aboriginal health worker education.
4. All university medical education (such as midwifery and medical degrees) includes curriculum on FASD and alcohol consumption during pregnancy.
5. Support and training to health professionals is provided, to increase skills in asking women about alcohol consumption, providing advice that is consistent with the Alcohol Guidelines, and recognising and responding to women at risk.
6. Continued funding for the *Women Want to Know* project, to ensure continuity in promotion to train health professionals about the risks of alcohol consumption during pregnancy.
7. That approaches to prevention and care for pregnant women are trauma-informed and conducted in a way aimed at reducing stigma.

6.4 Health communication in the media and by industry

The media is an important source of information for a large number of people, with digital media increasing the possibility of sharing research or other newsworthy information at rapid speed. A media framing analysis conducted on Australian media found that commonly used frames around FASD and alcohol use during pregnancy included 'contested evidence and advice', 'FASD crisis', 'blame risk-taking mothers', and 'women's rights'. In interview, women expressed that alarmist or stigmatising messages did not resonate with them to have an influence on their behaviour. A recommendation from this study, therefore, was that public health information around alcohol and pregnancy should focus on 'women's rights' frames rather than negatively framed messages.[97]

A study undertaken in 2012 of Australian media showed that media framing on FASD focused on narratives that stigmatise both individuals living with FASD as well as mothers. Many articles included in the analysis cast blame on birth mothers for the harm their children experience, but offer little by way of solutions, though the Government was at times presented as not doing enough.[98] Stigmatising and blaming news media stories may impact on women who are consuming alcohol, hindering them from discussing their alcohol use with their health professional. Investing in a comprehensive and clear public awareness campaign, along with influencing media reporting to be informed by current guidelines and practices and not use stigmatising language, is therefore important.

Another important aspect of health communication that is important to consider is that produced by the alcohol industry. Research has shown that the industry has engaged in misrepresenting or omitting evidence on the alcohol-cancer link in their information around the association between alcohol consumption and cancer.[99] Such misrepresentation is not isolated to chronic harm but has also been shown to occur for alcohol and pregnancy. A study of alcohol and pregnancy information on industry and public health websites found that industry websites were significantly less likely to include information about fertility, planning a pregnancy, breastfeeding, FAS, and other risks. Furthermore, the industry's

framing of the information emphasised uncertainty around a safe limit of alcohol use, implying it may be safe as there is 'debate' or 'confusion' about the evidence.[100]

In Australia, the industry-funded body DrinkWise in 2018 promoted messages around alcohol and pregnancy in clinics around the country. These posters, however, included language which suggested that it is 'unknown' if alcohol is safe during pregnancy. After complaints, DrinkWise revised the posters but still failed to clearly inform about risks associated with alcohol use during pregnancy and did not strongly inform that abstinence is the safest choice.[101] Information about alcohol and pregnancy should be clearly laid out, risks should be made clear and recommendations within the Alcohol Guidelines should be promoted.

It is clear from the abovementioned examples that the industry and industry-funded bodies do not have health and prevention of harm in mind when designing their resources. Governments should therefore not engage with these bodies in relation to health communication, or in policy development. The DrinkWise materials still feature in clinics around Australia – a situation that needs to change in order to progress this public health issue and ensure accurate information are communicated through all channels.[102] This will also support those health professionals working with women who are pregnant or others who may engage in conversations about alcohol.

Recommendations

8. The Government cease involvement with any DrinkWise programs and materials.
9. The Government commit to not funding the alcohol industry, including DrinkWise, to produce health education materials.
10. That Government-funded materials provided in health care are evidence-based and developed by public health and/or medical bodies and are free from alcohol industry influence.
11. A guide is created for media on how to accurately report on alcohol use during pregnancy without the use of stigmatising language, so as to not blame women or victimise individuals with FASD.

6.5 Pregnancy warning labels

Consumers have a right to be informed about products that cause themselves or others, particularly their unborn child, harm. This is particularly the case for alcohol consumption during pregnancy. In Australia and New Zealand other teratogens (a substance known to cause birth defects), except for alcohol:

- are completely banned from use in products designed to be consumed by people, or
- are illegal, or
- can only be used when there is no better alternative, under medical supervision, or
- carry a warning label on the packaging.[103]

Despite this situation, consumer information messages about alcohol and pregnancy have only been voluntarily placed onto alcohol products by alcohol producers since mid-2011.

An evaluation by Siggins Miller in 2017, commissioned by the Australian Government, found that fewer than half (48 per cent) of all packaged alcoholic beverages available for sale in Australia had some type of pregnancy message.[104] This demonstrated that a significant proportion of the alcohol industry was not prepared to voluntarily warn people of the risks associated with drinking alcohol while pregnant. This failure to inform consumers was recognised by the MFFR which in October 2018 recommended: "a mandatory labelling standard for pregnancy warning labels on packaged alcoholic beverages should be developed and should include a pictogram and relevant warning statement".[105]

Information on alcohol products regarding alcohol content, standard drinks and risks to health comprise consumer information that, from a public health perspective, should be readily available.[106] According to data from the FARE 2019 Annual Alcohol Poll, 76 per cent of respondents supported health warning labels, in general, on alcohol products. A higher proportion of women than men were in favour of health warning labels (80 per cent and 71 per cent, respectively). Similarly, respondents were asked whether they supported consumers' right to know about risks to the unborn baby, to which 89 per cent responded that they are in favour. A slightly higher proportion of women believed that they have a right to know about risks to the unborn baby from alcohol use during pregnancy (91 per cent and 87 per cent, respectively).[107]

FARE's 2011 policy position on alcohol product labelling outlines that warning labels should include the text HEALTH WARNING, include both text and symbols, be consistent in size and font applied to all products, be placed on the front of the package, be of a size corresponding to a proportion of the container surface, be complemented with a comprehensive education campaign, and be evaluated.[108,109]

In 2019, Food Standards Australia New Zealand (FSANZ) published their proposed changes (the Proposal) to the *Food Standards Code* (the Code) regarding pregnancy warning labelling requirements.[110] This Proposal features the application of both a pictogram and warning text in a box prescribed in red, white and black, across most packaged alcohol products. FARE and other public health organisations have raised concerns with some of the proposed details, particularly the recommendation that the alcohol industry be given two years to implement.

A final proposal is expected to the FSANZ Board in December 2019 with Ministerial approval to follow shortly afterwards. It is essential that alongside the mandatory label there is a campaign to inform consumers about the changes to the Code. This should be done by health promotion experts and not the alcohol industry. In addition, the mandatory labelling scheme requires comprehensive evaluation and monitoring, including a clear enforcement and compliance plan.

Recommendations

12. That mandatory pregnancy warning labels on packaged alcohol products are introduced in Australia without delay. These labels should include both pictogram and warning text situated within a box with the words HEALTH WARNING in bold, the label should also appear in red and black on a white background.
13. That immediately prior to the mandatory application of the pregnancy warning labels, a comprehensive public education campaign be undertaken to inform consumers about the changes. This should be funded and implemented by the Australian Government.

6.6 Routine practice by health professionals

6.6.1 Screening and brief intervention

As noted in section 2, international guidelines recommend that SBI are consistently implemented to ensure all women are asked about their alcohol use and that women who are drinking are offered advice.[111] However, evidence suggests that implementation of these strategies can be variable and that this variability leads to inconsistent advice to pregnant women. This has been evidenced in Scotland, where implementation of a national SBI program led to a variety of approaches within regional health localities. A common theme, however, was how to have the conversation, which local knowledge suggested affected disclosure rates of alcohol use during pregnancy.[112]

Recent research from the Hunter New England Local Health District in NSW, which included a survey of 1,363 pregnant women attending antenatal care, showed that 88.8 per cent of women had been asked about alcohol at their first appointment and 64.3 per cent had been assessed according to AUDIT-C. At subsequent visits, 14.3 per cent had been asked about alcohol, but only 7.8 per cent had been assessed in line with AUDIT-C. The vast majority (98.7 per cent) felt that it was acceptable for their alcohol consumption to be assessed and 88.3 per cent agreed that it is acceptable to be asked on several occasions.

Approaches to addressing alcohol with pregnant women need to take into consideration the potential barriers for women to report whether they are drinking alcohol. Qualitative research from Victoria with pregnant women on their past and present alcohol consumption found several reasons for potential under-reporting. This included difficulty with remembering alcohol intake at certain points during pregnancy, or earlier in life, and not being able to accurately categorise types and frequency of consumption. Further, a detailed questionnaire, with many questions, appeared too complex for some participants and certain terms were perceived to be open to subjective interpretation. Women's preferred way of reporting, which they felt would encourage honest responses, was over anonymous questionnaire, including a wide range of drinks options with clear examples to help accurately estimate consumption. Women also wanted to know why questions were asked and what would be done with this information. For some women, fear of involvement of child protection or social services following reporting alcohol or drug use may prevent open discussion about substance use.[113]

Currently, there is no consistent implementation of SBI in maternity care in Australia; however, the data exists to support that there is a need for it. A comprehensive approach to addressing alcohol with pregnant women overlaps with data collection and monitoring – a well-functioning SBI program underpins subsequent collection of the most reliable data possible, which can be monitored over time to address certain groups of women who may be in need of greater support (see further section 6.6.2).

Recommendation

14. That all pregnant women are asked about their alcohol consumption and pregnant women with alcohol use disorders are provided with specialist support services and have access to treatment services. This should be tied in with wider maternity care frameworks ensuring continuity of care.

6.6.2 Data collection and monitoring

A lack of comprehensive data collection prevents monitoring of trends in alcohol use among pregnant women and identifying areas where the need for resources may be greater. Introduction of universal screening in antenatal care in Australia has been promoted to reduce stigma and aid health professionals' practice,[114] and would also enable establishing data collection and monitoring levels of alcohol use during pregnancy. This is particularly important given evidence that self-reported prenatal alcohol use may result in under-reporting, for various reasons, and that alcohol use among pregnant women has changed over time (see section 4.2).[115]

When collecting data on alcohol use during pregnancy it is important to capture not only use that may be at high levels, but any use of alcohol. A Canadian study explored collection of data on alcohol use during pregnancy across 12 pregnancy cohorts and found varying degree of details in questions regarding alcohol intake. The study showed that the number of questions ranged from two to 32, making it difficult to compare levels of consumption across cohorts.[116]

For alcohol to be recorded comprehensively and systematically, it should be added as an item within the National Perinatal Data Collection (NPDC). This has been discussed since 2010 and currently three states (ACT, NT and Tasmania (TAS)) collect data which is fed into NPDC, but not in a consistent way.[117] Systematic data collection for the NPDC has already been proposed by FARE in *The Australian Fetal Alcohol Spectrum Disorders Action Plan 2013-2016*.[118] Universal screening with mandatory reporting has the possibility to:

- make women aware of and reflect on their drinking
- identify women who are drinking at high levels or who are alcohol dependent
- remove subjective judgements by health professionals of when or who to ask about alcohol use during pregnancy, which can help health professionals as well as remove perceived stigma for women.[119]

For comprehensive data collection to be informative and useful, timing of consumption and amount consumed (including heavy episodic drinking (HED)) should be collected on more than one occasion throughout the pregnancy. A validated screening tool should inform such a process and it has been recommended that AUDIT-C should be used for this purpose.[120] Following review of 12 pregnancy cohorts in Canada, authors of the study recommended that systematic data collection should include a standardised measure of frequency (such as within AUDIT-C), quantity to be measures using standardised categories (such as AUDIT-C) with visual aids for what constitutes a standard drink, and questions for number of drinks per occasion to be asked in relation to exceeding low-risk drinking guideline threshold for HED. Furthermore, keeping questions and information consistent is important to make women aware of general drinking guidelines. The authors also recommended asking about alcohol use before pregnancy, that questions be sensitive to trauma and culture, and to ensure women feel safe to report alcohol use if they are trying to reduce consumption rather than abstain.[121]

The *Australian Fetal Alcohol Spectrum Disorders Action Plan 2013–2016* sets out that the lack of an accurate and comprehensive recording of alcohol use during pregnancy along with recorded data on diagnoses hinder prevention, management and service provision.[122] Introduction of standardised and mandatory recording, using a validated screening tool, is therefore imperative for making progress on FASD prevention. However, this needs evaluation and close monitoring as international evidence has suggested that the way questions are asked may influence on reported levels of alcohol use before or during pregnancy.[123]

In line with international evidence, proposing the use of AUDIT-C as a feasible screening tool for antenatal settings,[124] research from WA has shown acceptability of the use of AUDIT-C among women. However, while many midwives were aware of the tool, few used it routinely. Need for training on how to use it was noted and following the implementation of a capacity-building programme, there was an increase in medical records where AUDIT-C scores were reported from 16 per cent to 48 per cent.[125] While encouraging, evidence from the implementation of a universal SBI programme in Scotland found that local adaptation appeared important for implementation to be successful.[126] It therefore needs to be acknowledged that there may be adaptations needed locally, or regionally, to ensure implementation is optimised.

Recommendations

15. That the Government support the AIHW in implementing mandatory recording of alcohol use during pregnancy and invest in research to assess the feasibility, appropriateness and response from women. Evaluating the use of AUDIT-C should be included, especially with the lens of that many women may under-report.
16. That mandatory recording is regularly monitored and reported on, along with research into the implications of implementation and potential unintended consequences.

6.7 Wider population-level alcohol policy

While alcohol use during pregnancy is a particular issue, it is part of a wider public health issue related to the harm caused by alcohol in Australia. Each year, nearly 6,000 deaths and 144,000 hospital admissions are the result of alcohol.[127] As the national rates of alcohol-attributable deaths and hospitalisations have remained stable over time, and emergency department presentations have remained stable or increased over time,[128] there is a need for further action to reduce the harm caused by alcohol.

The *Global strategy to reduce the harmful use of alcohol* recommends: "establishing a system for specific domestic taxation on alcohol accompanied by an effective enforcement system".[129] The *Global Action Plan for the Prevention and Control of NCDs 2013–2020* further sets the direction for governments to respond to the increasing challenge of premature deaths and morbidity as a result of NCDs.[130]

Within these global frameworks, the 'Best buys' are evidence-based, cost-effective population-level interventions for alcohol control to reduce harm. As such, the 'Best Buys' are increasing excise taxes on alcoholic beverages; enacting and enforcing bans or comprehensive restrictions on exposure to alcohol advertising; and enacting and enforcing restrictions on the physical availability of retailed alcohol.[131]

In the Northern Territory, a minimum unit price (MUP) has been successfully introduced with subsequent reductions in alcohol-related violence, intimate partner violence (a predictor for alcohol use during pregnancy), and emergency department presentations (see further in Appendix A).[132]

The evidence shows that one of the strongest predictors for alcohol use during pregnancy is higher alcohol use before pregnancy.[133],[134] Population-level interventions, targeting the most effective measures, will have great impact not just on harm related to alcohol exposure during pregnancy but to the whole population.

Recommendation

17. That the Government makes further commitment to reduce harm by implementing effective alcohol policy measures in line with global frameworks.

7. Conclusion

Harm caused by alcohol exposure during pregnancy is part of a wider problem of alcohol-related harm in Australia. Alcohol consumption in the wider population and particularly among pregnant women, is an important modifiable risk factor. In order to prevent harm, prevention strategies need to adopt a whole-population approach to raise awareness of risks associated with alcohol use during pregnancy. Further, such efforts need to create a supportive environment for women who are pregnant or planning a pregnancy to stop drinking. However, for some women abstinence is not possible and for those women adequate support and access to specialist services need to be established.

Prevention strategies should be designed to address relevant social determinants of health that impact on alcohol use during pregnancy. In particular, services that engage with women who are pregnant or who may become pregnant should be trauma-informed and be developed with an understanding of why some women continue to drink alcohol during pregnancy.

This Inquiry presents an opportunity for the Australian Government to collate and synthesise the existing work and principles to create an Australian FASD prevention program informed by evidence. Australia has never had a nationwide awareness campaign on drinking during pregnancy, which is reflected by the low level of public awareness of FASD and other alcohol-related harm. Continued efforts to address the lack of awareness and increase the capacity for medical and other professionals to talk to women about the issue is also needed. Combined with positive reforms, such as mandatory pregnancy warning labels and a whole-of-government prevention program, this will allow Australia to become a world-leader in preventing FASD and other adverse consequences that arise from alcohol consumption during pregnancy.

References

1 Foundation for Alcohol Research and Education. (2011). Submission to the House of Representatives Standing Committee on Social Policy and Legal Affairs: Inquiry into Fetal Alcohol Spectrum Disorders. Canberra, Australia: Author. http://fare.org.au/wp-content/uploads/FASD-Inquiry-Submission.pdf

2 Foundation for Alcohol Research and Education. (2012). *The Australian Fetal Alcohol Spectrum Disorders Action Plan 2013–2016*. Canberra, Australia: Author. http://fare.org.au/wp-content/uploads/FARE-FASD-Plan.pdf

3 Finlay-Jones, A. (2018). *Reducing harms related to alcohol use in pregnancy: Policy and practice recommendations.* Canberra, Australia: Deeble Institute for Health Policy Research. https://ahha.asn.au/publication/health-policy-issue-briefs/deeble-issues-brief-no-28-reducing-harms-related-alcohol-use

4 McLean, S. & McDougall, S. (2014). *Fetal alcohol spectrum disorders Current issues in awareness, prevention and intervention.* CFCA Paper No 29. Melbourne, Australia: Child Family Community Australia. https://aifs.gov.au/cfca/sites/default/files/publication-documents/cfca-paper29-fasd.pdf

5 Patra, J., Bakker, R., Irving, H., Jaddoe, V., Malini, S. & Rehm, J. (2011). Dose–response relationship between alcohol consumption before and during pregnancy and the risks of low birthweight, preterm birth and small for gestational age (SGA)—a systematic review and meta-analyses. *BJOG: An International Journal of Obstetrics & Gynaecology*, 118, 1411-1421. doi: 10.1111/j.1471-0528.2011.03050.x

6 Albertsen, K., Nybo Andersen, A., Olsen, J. & Grønbæk, M. (2004). Alcohol Consumption during Pregnancy and the Risk of Preterm Delivery. *American Journal of Epidemiology*, 159(2), 155–161. doi: 10.1093/aje/kwh034

7 Jaddoe, V. W. V., Bakker, R., Hofman, A. Mackenbach, J. P., Moll, H. A., Steegers, E. A. P., Witteman, J. C. M. (2007). Moderate Alcohol Consumption During Pregnancy and the Risk of Low Birth Weight and Preterm Birth. The Generation R Study. Annals of Epidemiology, 17(10), 834-840. doi: 10.1016/j.annepidem.2007.04.001

8 Bower, C. & Elliott, E. J. (2016). On behalf of the Steering Group. Report to the Australian Government Department of Health: *Australian Guide to the diagnosis of Fetal Alcohol Spectrum Disorder (FASD)*. https://www.fasdhub.org.au/siteassets/pdfs/australian-guide-to-diagnosis-of-fasd_all-appendices.pdf

9 Fitzpatrick, J.P., Latimer, J., Carter, M. et al (2015). Prevalence of fetal alcohol syndrome in a population-based sample of children living in remote Australia: The Lililwan Project. Paediatrics and Child Health 51(4), 450-457.

10 Bower C, Watkins RE, Mutch RC, et al (2017). Fetal alcohol spectrum disorder and youth justice: a prevalence study among young people sentenced to detention in Western Australia BMJ Open 2018;8:e019605. doi: 10.1136/bmjopen-2017-019605

11 Streissguth, A. P., Barr, H. M., Kogan, J., & Bookstein, F. L. (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), Technical Report. No. 96-06. Seattle, WA: University of Washington, Fetal Alcohol and Drug Unit.

12 Popova, S., Lange, S., Shield, K., Mihic, A., Chudley, A. E., Mukherjee, R. A. S… Rehm, J. (2016). Comorbidity of fetal alcohol spectrum disorder: a systematic review and meta-analysis. *The Lancet*, 387(1022), 978-987. doi: 10.1016/S0140-6736(15)01345-8

13 Food Regulation Standing Committee (2018). Decision Regulatory Impact Statement: Pregnancy warning labels on packaged alcoholic beverages. https://tinyurl. com/yyymc8n6

14 Finlay-Jones, A. (2018). *Reducing harms related to alcohol use in pregnancy: Policy and practice recommendations*. Canberra, Australia: Deeble Institute for Health Policy Research. https://ahha.asn.au/publication/health-policy-issue-briefs/deeble-issues-brief-no-28-reducing-harms-related-alcohol-use

15 Finlay-Jones, A. (2018). *Reducing harms related to alcohol use in pregnancy: Policy and practice recommendations*. Canberra, Australia: Deeble Institute for Health Policy Research. https://ahha.asn.au/publication/health-policy-issue-briefs/deeble-issues-brief-no-28-reducing-harms-related-alcohol-use

16 Holland, K., McCallum, K. & Blood, R.W. (2015). Conversations about alcohol and pregnancy. Canberra: Foundation for Alcohol Research and Education. https://www.canberra.edu.au/research/faculty-research-centres/nmrc/publications/documents/Conversations-about-alcohol-and-pregnancy.pdf

17 Skagerström, J., Chang, G. & Nilsen, P. (2011). Predictors of Drinking During Pregnancy: A Systematic Review. *Journal of Women's Health*, 20(6), 901–913. doi: 10.1089/jwh.2010.2216

18 Poole, N. (2008). *Fetal Alcohol Spectrum Disorder (FASD) Prevention: Canadian Perspectives*. Ottawa, Canada: Public Health Agency of Canada (PHAC). https://www.canada.ca/en/public-health/services/health-promotion/childhood-adolescence/programs-initiatives/fetal-alcohol-spectrum-disorder-fasd/publications/canadian-perspectives.html#intro2

19 World Health Organization. (2010). *Global strategy to reduce the harmful use of alcohol*. Geneva, Switzerland: Author. https://apps.who.int/iris/bitstream/handle/10665/44395/9789241599931_eng.pdf;jsessionid=D0DFC8022ED81DBC4D14FF2E70D67F12?sequence=1

20 Department of the House of Representatives. (2012). *FASD: The Hidden Harm Inquiry into the prevention, diagnosis and management of Fetal Alcohol Spectrum Disorders*. Canberra, Australia: House of Representatives Standing Committee on Social Policy and Legal Affairs. https://www.aph.gov.au/Parliamentary_Business/Committees/House_of_Representatives_Committees?url=spla/fasd/report.htm

21 West Australian Parliament Education and Health Standing Committee. (2012). *Foetal Alcohol Spectrum Disorder: the invisible disability*. Report number 15, September 2012. Perth, Australia: Legislative Assembly Parliament of Western Australia. https://www.parliament.wa.gov.au/Parliament/commit.nsf/(Report+Lookup+by+Com+ID)/1740F63B37A1314A48257A7F000766DD/$file/Final%20FASD%20Report%20with%20signature.pdf

22 Select Committee on Action to Prevent Foetal Alcohol Spectrum Disorder. (2015). *The preventable disability. Legislative Assembly of the Northern Territory*. Darwin, Australia: Author. https://parliament.nt.gov.au/__data/assets/pdf_file/0005/363254/Final_FASD_Report.pdf

23 NOFASD. (2014, 1 September). *The Loop newsletter*. https://www.nofasd.org.au/the-loop-v2/issue-12-the-loop-01-sept-2014.html

24 King, C. (2014, June 26). *Abbott cuts funding for national Foetal Alcohol Spectrum Disorder*. [Press release]. https://www.catherineking.com.au/2014/06/26/abbott-cuts-funding-for-national-foetal-alcohol-spectrum-disorder-prevention/

25 Department of Health. (2018, 21 November). *$7 million for Fetal Alcohol Spectrum Disorder*. [Press release] https://www.health.gov.au/ministers/the-hon-greg-hunt-mp/media/7-million-for-fetal-alcohol-spectrum-disorder

26 Australian Government Department of Business. (2019). *Funding for wine producer cellar door sales*. https://www.business.gov.au/Grants-and-Programs/Wine-Tourism-and-Cellar-Door-Grant

27 Northern Territory Department of Health. (2018). *Addressing Fetal Alcohol Spectrum Disorder (FASD) in the Northern Territory 2018-2024*. Darwin, Australia: Northern Territory Government. https://digitallibrary.health.nt.gov.au/prodjspui/bitstream/10137/7232/1/DOH_FASD_Strategy_Web.pdf

28 Mental Health Commission (2018). *Western Australian Alcohol and Drug Interagency Strategy 2018-2022*. Perth, Australia: Government of Western Australia Mental Health Commission. https://www.mhc.wa.gov.au/media/2570/western-australian-alcohol-and-drug-interagency-strategy-2018-2022.pdf

29 Telethon Kids Institute. (2017). *Program summary – FASD History: A multi-site prevention program*. Perth, Australia: Telethon Kids Institute. https://alcoholpregnancy.telethonkids.org.au/siteassets/media-docs---alcohol-preg-fasd/making-fasd-history-multi-site-project_may-20182.pdf

30 Jonsson, E., Salmon, A. & Warren, K. R. (2014). The international charter on prevention of fetal alcohol spectrum disorder. *The Lancet Global Health*, 2(3), E135-E137. doi: 10.1016/S2214-109X(13)70173-6

31 World Health Organization. (2010). *Global strategy to reduce the harmful use of alcohol*. Geneva, Switzerland: Author. https://apps.who.int/iris/bitstream/handle/10665/44395/9789241599931_eng.pdf;jsessionid=D0DFC8022ED81DBC4D14FF2E70D67F12?sequence=1

32 World Health Organization Regional Officer for Europe. (2012). *European action plan to reduce the harmful use of alcohol 2012–2020*. Copenhagen, Denmark: Author. http://www.euro.who.int/__data/assets/pdf_file/0008/178163/E96726.pdf

33 World Health Organization. (2014). *Guidelines for the identification and management of substance use and substance use disorders in pregnancy*. Geneva, Switzerland: Author. https://apps.who.int/iris/bitstream/handle/10665/107130/9789241548731_eng.pdf?sequence=1

34 Schölin, L. (2016). *Preventing harm caused by alcohol use during pregnancy – Rapid review and case studies from Member States*. Copenhagen, Denmark: World Health Organization Regional Office for Europe. http://www.euro.who.int/__data/assets/pdf_file/0005/318074/Prevention-harm-caused-alcohol-exposure-pregnancy.pdf

35 National Health and Medical Research Council. (2019). *Revision of the Australian guidelines to reduce health risks from drinking alcohol 2009*. https://www.nhmrc.gov.au/about-us/news-centre/revision-australian-guidelines-reduce-health-risks-drinking-alcohol-2009

36 Livingston, M. (2012). Perceptions of low-risk drinking levels among Australians during a period of change in the official drinking guidelines. *Drug and Alcohol Review*, 31, 224–230. doi:10.1111/j.1465-3362.2011.00414.x

37 Islam, M. M., Hoffman, M. W. & Rahman, M. B. (2019). Knowledge of low-risk drinking and its relationship with a reduction in alcohol consumption: Results from six waves of an Australian national survey. *Addictive Behaviors*, 95: 172–177. doi: 10.1016/j.addbeh.2019.03.016

38 National Health and Medical Research Council. (2009). *Australian Guidelines to reduce health risks from drinking alcohol.* Canberra, Australia: Author. https://www.nhmrc.gov.au/about-us/publications/australian-guidelines-reduce-health-risks-drinking-alcohol#block-views-block-file-attachments-content-block-1

39 Alcohol Beverages Australia. (2019). *Submission to Food Standards Australia New Zealand public consultation: Proposal P1050, Pregnancy warning labels on alcoholic beverages.* Sydney, Australia: Author. Available from https://www.foodstandards.gov.au/code/proposals/Pages/P1050Pregnancywarninglabelsonalcoholicbeverages.aspx

40 Hall and Partners Open Mind. (2018). *Women Want to Know leaflet re-development: research report.* Unpublished report. Canberra, Australia: Foundation for Alcohol Research and Education/Hall and Partners.

41 Peadon, E., Payne, J., Henley, N., D'Antoine, H., Bartu, A., O'Leary, C… Elliot, E. (2010). Women's knowledge and attitudes regarding alcohol consumption in pregnancy: a national survey. *BMC Public Health*, 10(510). doi:10.1186/1471-2458-10-510

42 Foundation for Alcohol Research and Education. (2016). *Annual alcohol poll 2016*. Canberra, Australia: Author. http://fare.org.au/wp-content/uploads/FARE-ANNUAL-ALCOHOL-POLL-2016-REPORT-FINAL.pdf

43 Foundation for Alcohol Research and Education. (2012). *Annual Alcohol Poll 2012: Attitudes and Behaviours*. Canberra, Australia: Author. http://fare.org.au/annual-alcohol-poll-2012/

44 Popova, S., Lange, S., Probst, C., Gmel, G. & Rehm, J. (2017). Estimation of national, regional, and global prevalence of alcohol use during pregnancy and fetal alcohol syndrome: a systematic review and meta-analysis. *The Lancet Global Health*, 5(3), e290 - e299. doi: 10.1016/S2214-109X(17)30021-9

45 Stanesby, O., Cook, M., & Callinan, S. (2018). Examining trends in alcohol consumption during pregnancy in Australia, 2001 to 2016. Canberra, Australia: Foundation for Alcohol Research and Education. http://fare.org.au/wp-content/uploads/Examining-trends-in-alcohol-consumption-during-pregnancy-in-Australia_2001-2016-FINAL.pdf

46 Australian Institute of Health and Welfare. (2017). *National Drug Strategy Household Survey 2016: detailed findings – Data tables: Chapter 8 Specific population groups*. https://www.aihw.gov.au/reports/illicit-use-of-drugs/ndshs-2016-detailed/data#page2

47 Stanesby, O., Cook, M., & Callinan, S. (2018). Examining trends in alcohol consumption during pregnancy in Australia, 2001 to 2016. Canberra, Australia: Foundation for Alcohol Research and Education. http://fare.org.au/wp-content/uploads/Examining-trends-in-alcohol-consumption-during-pregnancy-in-Australia_2001-2016-FINAL.pdf

48 Callinan, S. & Room, R. (2012). Alcohol consumption during pregnancy: Results from the 2010 National Drug Strategy Household Survey. Melbourne, Australia: Centre for Alcohol Policy Research. http://fare.org.au/alcohol-consumption-during-pregnancy-results-from-the-2010-national-drug-strategy-household-survey/

49 Skagerström, J., Chang, G. & Nilsen, P. (2011). Predictors of Drinking During Pregnancy: A Systematic Review. *Journal of Women's Health*, 20(6), 901–913. doi: 10.1089/jwh.2010.2216

50 Popova, S., Lange, S., Shield, K., Burd, L., & Rehm, J. (2019). Prevalence of fetal alcohol spectrum disorder among special subpopulations: a systematic review and meta-analysis. *Addiction*, 114, 1150– 1172. doi: 10.1111/add.14598.

51 Fitzpatrick, J. P., Latimer, J., Ferreira, M. L., Carter, M., Oscar, J., Martiniuk, A. L… Elliott, E. J. (2015). Alcohol in pregnancy in remote Australia. *Drug & Alcohol Review*, 34, 329-339. doi:10.1111/dar.12232

52 McBride, N. & Johnson, S. (2016). Fathers' role in alcohol-exposed pregnancies: Systematic Review of Human Studies. *American Journal of Preventive Medicine*, 51(2), 240-248. doi: 10.1016/j.amepre.2016.02.009

53 Centre of Excellence for Women's Health. (2013). *Why do girls and women drink alcohol during pregnancy? Information for Service Providers.* http://bccewh.bc.ca/wp-content/uploads/2014/08/FASD-Sheet-1_Who-Drinks-Alcohol-during-Pregnancy.2013.pdf

54 Holland, K., McCallum, K. & Walton, A. (2016). 'I'm not clear on what the risk is': women's reflexive negotiations of uncertainty about alcohol during pregnancy. *Health, Risk & Society*, 18(1–2), 38–58. doi: 10.1080/13698575.2016.1166186

55 Peadon, E., Payne, J., Henley, N., D'Antoine, H., Bartu, A., O'Leary, C… Elliot, E. (2011). Attitudes and Behaviour Predict Women's Intention to Drink Alcohol During Pregnancy: The Challenge for Health Professionals. BMC Public Health, 11(1), 584. doi: 10.1186/1471-2458-11-584

56 Centre of Excellence for Women's Health. *Pregnancy, Alcohol, and Trauma-informed Practice: Information for Service Providers.* http://bccewh.bc.ca/wp-content/uploads/2014/08/FASD-Sheet-5_Alcohol-Pregnancy-Violence-TIP-Dec-6.pdf

57 Astley, S., Bailey, D., Talbot, C. & Clarren, S. (2000). Fetal Alcohol Syndrome (FAS) Primary Prevention through FAS diagnosis: II. A comprehensive profile of 80 birth mothers of children with FAS. *Alcohol & Alcoholism*, 35(5), 509-519. doi: 10.1093/alcalc/35.5.509

58 Centre of Excellence for Women's Health. (2016). *Women, Alcohol and FASD Prevention*. http://bccewh.bc.ca/category/post/alcohol-fasd-prevention/

59 World Health Organization. (2014). *Guidelines for the identification and management of substance use and substance use disorders in pregnancy.* Geneva, Switzerland: Author. https://apps.who.int/iris/bitstream/handle/10665/107130/9789241548731_eng.pdf?sequence=1

60 Foundation for Alcohol Research and Education. (2018). *Annual Alcohol Poll 2018 – Attitudes and Behaviours.* Canberra, Australia: Author. http://fare.org.au/wp-content/uploads/FARE-Annual-Alcohol-Poll-2018-web.pdf

61 Hocking, M., O'Callaghan, F. & Reid, N. (2019). Women's experiences of messages relating to alcohol consumption, received during their first antenatal care visit: An interpretative phenomenological analysis. *Women and Birth*, In Press, Corrected Proof. doi: 10.1016/j.wombi.2019.02.002

62 Hocking, M., O'Callaghan, F. & Reid, N. (2019). Women's experiences of messages relating to alcohol consumption, received during their first antenatal care visit: An interpretative phenomenological analysis. *Women and Birth*, In Press, Corrected Proof. doi: 10.1016/j.wombi.2019.02.002

63 Crawford-Williams, F., Steen, M., Esterman, A., Fielder, A. & Mikocka-Walus, A. (2015). "My midwife said that having a glass of red wine was actually better for the baby": a focus group study of women and their partner's knowledge and experiences relating to alcohol consumption in pregnancy. *BMC Pregnancy Childbirth*, 15(79). doi:10.1186/s12884-015-0506-3

64 Hall & Partners Open Mind. (2016). *Women Want to Know project evaluation*. Canberra, Australia: Foundation for Alcohol Research and Education. http://fare.org.au/wp-content/uploads/WWTK-Evaluation-Report-Final-September-2016.pdf

65 Department of Health. (2018). *Clinical Practice Guidelines: Pregnancy Care.* Canberra, Australia: Australian Government Department of Health. https://www.health.gov.au/sites/default/files/pregnancy-care-guidelines_0.pdf

66 Bower, C. (2018). *Australia's dangerously outdated health guidelines on alcohol and pregnancy.* Drink Tank. http://drinktank.org.au/australias-dangerously-outdated-health-guidelines-on-alcohol-and-pregnancy/.

67 Ipsos Social Research Institute. (2013). *Australian Guidelines to Reduce Health Risks from Drinking Alcohol 2009: Brief literature review and audit of resources.* Unpublished report. Canberra, Australia: Foundation for Alcohol Research and Education.

68 Hall & Partners Open Mind. (2016). *Women Want to Know project evaluation.* Canberra, Australia: Foundation for Alcohol Research and Education. http://fare.org.au/wp-content/uploads/WWTK-Evaluation-Report-Final-September-2016.pdf

69 France, K., Henley, N., Payne, J., D'Antoine, H., Bartu, A., O'Leary, C… Bower, C. (2010). Health Professionals Addressing Alcohol Use with Pregnant Women in Western Australia: Barriers and Strategies for Communication. *Substance Use & Misuse*, 45(10), 1474-1490. doi: 10.3109/10826081003682172

70 Ipsos Social Research Institute. (2013). *Australian Guidelines to Reduce Health Risks from Drinking Alcohol 2009: Brief literature review and audit of resources.* Unpublished report. Canberra, Australia: Foundation for Alcohol Research and Education.

71 Finlay-Jones, A. (2018). *Reducing harms related to alcohol use in pregnancy: Policy and practice recommendations.* Canberra, Australia: Deeble Institute for Health Policy Research. https://ahha.asn.au/publication/health-policy-issue-briefs/deeble-issues-brief-no-28-reducing-harms-related-alcohol-use

72 Reid, N., Gamble, J., Creedy, J. K. & Finlay-Jones, A. (2018). Benefits of caseload midwifery to prevent fetal alcohol spectrum disorder: a discussion paper. *Women & Birth*, 32: 5–5. doi: 10.1016/j.wombi.2018.03.002

73 Payne, J.M., Watkins, R.E., Jones, H.M. Reibel, T., Mutch, R., Wilkins, A… Bower, C. (2014). Midwives› knowledge, attitudes and practice about alcohol exposure and the risk of fetal alcohol spectrum disorder. *BMC Pregnancy Childbirth*, 14, 377. doi:10.1186/s12884-014-0377-z

74 Hall & Partners Open Mind. (2016). *Women Want to Know project evaluation*. Canberra, Australia: Foundation for Alcohol Research and Education. http://fare.org.au/wp-content/uploads/WWTK-Evaluation-Report-Final-September-2016.pdf

75 Walsh, A. (2014). Alcohol and Pregnancy. *O&G Magazine*, 16(3), 61. https://www.ogmagazine.org.au/16/3-16/alcohol-and-pregnancy/

76 Crawford-Williams, F., Steen, M., Esterman, A., Fielder, A., Mikocka-Walus, A. (2015). If you can have one glass of wine now and then, why are you denying that to a woman with no evidence: knowledge and practices of health professionals concerning alcohol consumption during pregnancy. *Women Birth,* 28(4), 329-335. doi: 10.1016/j.wombi.2015.04.003

77 Jones, S. C. & Telenta, J. (2011) What influences Australian women to not drink alcohol during pregnancy? *Australian Journal of Primary Health*, 18, 68-73. Doi: 10.1071/PY10077

78 Crawford-Williams, F., Steen, M., Esterman, A., Fielder, A., Mikocka-Walus, A. (2015). If you can have one glass of wine now and then, why are you denying that to a woman with no evidence: knowledge and practices of health professionals concerning alcohol consumption during pregnancy. *Women Birth*, 28(4), 329-335. doi: 10.1016/j.wombi.2015.04.003

79 Poole, N. (2008). *Fetal Alcohol Spectrum Disorder (FASD) Prevention: Canadian Perspectives*. Ottawa, Canada: Public Health Agency of Canada. https://www.canada.ca/en/public-health/services/health-promotion/childhood-adolescence/programs-initiatives/fetal-alcohol-spectrum-disorder-fasd/publications/canadian-perspectives.html#intro2

80 Telethon Kids. (N.D.). *Community success stories Making FASD History FASD diagnosis, prevention and interventions – evaluating and scaling up successful models in remote Australian communities.* http://www.amsant.org.au/apont/wp-content/uploads/2018/07/K.-James-Fitzpatrick-Top-End-FASD-Forum-Making-FASD-History.pdf

81 Finlay-Jones, A. (2018). *Reducing harms related to alcohol use in pregnancy: Policy and practice recommendations*. Canberra, Australia: Deeble Institute for Health Policy Research. https://ahha.asn.au/publication/health-policy-issue-briefs/deeble-issues-brief-no-28-reducing-harms-related-alcohol-use

82 Turning Point Social Marketing National Excellence Collaborative. (n. d.). *The basics of social marketing – How to Use Marketing to Change Behavior from the Social Marketing National Excellence Initiative*. Seattle, WA: Turning Point. http://socialmarketingcollaborative.org/smc/pdf/Social_Marketing_Basics.pdf

83 World Health Organization. (2009). Changing cultural and social norms that support violence. Violence prevention: the evidence. Geneva, Switzerland: World Health Organization. http://www.who.int/violence_injury_prevention/violence/norms.pdf

84 Durkin, S., Brennan, E. & Wakefield, M. (2012). Mass media campaigns to promote smoking cessation among adults: An integrative review. *Tobacco Control*, 21, 127-138.

85 Turning Point Social Marketing National Excellence Collaborative. (n. d.). *The basics of social marketing – How to Use Marketing to Change Behavior from the Social Marketing National Excellence Initiative*. Seattle, WA: Turning Point. http://socialmarketingcollaborative.org/smc/pdf/Social_Marketing_Basics.pdf

86 Turning Point Social Marketing National Excellence Collaborative. (n. d.). *The basics of social marketing – How to Use Marketing to Change Behavior from the Social Marketing National Excellence Initiative*. Seattle, WA: Turning Point. http://socialmarketingcollaborative.org/smc/pdf/Social_Marketing_Basics.pdf

87 Jones, S., Rees, L., Hall, D. & Tang, A. (2005). *Using market segmentation theory to select target markets for sun protection campaigns*. Faculty of Health and Behavioural Sciences – Papers, University of Wollongong. https://pdfs.semanticscholar.org/6ef0/59823e81eb1695c07f5bb97d9198d9972dc0.pdf

88 Foundation for Alcohol Research and Education. (2019). *Pregnant Pause – Swap the pub for your bub: Final evaluation*. Unpublished report. Canberra, Australia: Author.

89 Borschmann, R., Becker, D., Spry, E., Youssef, G.J., Olsson, C.A. & Hutchinson, D.M. (2019). Alcohol and parenthood: an integrative analysis of the effects of transition to parenthood in three Australasian cohorts. *Drug and Alcohol Dependence*, 197, 326-334. doi: 10.1016/j.drugalcdep.2019.02.004

90 McBride, N., Carruthers, S. & Hutchinson, D. (2012). Reducing alcohol use during pregnancy: listening to women who drink as an intervention starting point. *Global Health Promotion*, 19(2), 6–18. doi: 10.1177/1757975912441225

91 Health Promotion Agency. (2018). *Pre-testie Bestie*. https://www.alcohol.org.nz/alcohol-its-effects/alcohol-pregnancy/dont-know-dont-drink

92 Hall & Partners Open Mind. (2016). *Women Want to Know project evaluation*. Canberra, Australia: Foundation for Alcohol Research and Education. http://fare.org.au/wp-content/uploads/WWTK-Evaluation-Report-Final-September-2016.pdf

93 Foundation for Alcohol Research and Education. (2018). *Performance report: Pregnant Pause national campaign and the continued promotion of Women Want to Know training and resources*. Unpublished report.

94 Foundation for Alcohol Research and Education. (2019). *FARE's Women Want to Know: Survey of General Practitioners*. Unpublished report.

95 Payne, J. M., France, K. E., Henley, N., D'Antoine, H. A., Bartu, A. E., O'Leary, C.. Geelhoed, E. (2011). RE-AIM Evaluation of the Alcohol and Pregnancy Project: Educational Resources to Inform Health Professionals About Prenatal Alcohol Exposure and Fetal Alcohol Spectrum Disorder. *Evaluation & the Health Professions*, 34(1), 57–80. doi: 10.1177/0163278710381261

96 Kingsland, M., Doherty, E., Anderson, A.E. Crooks, K., Tully, B., Tremain, D… Wiggers, J. (2018). A practice change intervention to improve antenatal care addressing alcohol consumption by women during pregnancy: research protocol for a randomised stepped-wedge cluster trial. *Implementation Science*, 13, 112. doi:10.1186/s13012-018-0806-x

97 Holland, K., McCallum, K. & Blood, R.W. (2015). Conversations about alcohol and pregnancy. Canberra, Australia: Foundation for Alcohol Research and Education. https://www.canberra.edu.au/research/faculty-research-centres/nmrc/publications/documents/Conversations-about-alcohol-and-pregnancy.pdf

98 Eguiagaray, I., Scholz, B. & Giorgi, C. (2016). Sympathy, shame, and few solutions: News media portrayals of fetal alcohol spectrum disorders. *Midwifery*, 40, 49–54. doi: 10.1016/j.midw.2016.06.002

99 Petticrew, M., Maani Hessari, N., Knai, C. & Weiderpass, E. (2018). How alcohol industry organisations mislead the public about alcohol and cancer. *Drug and Alcohol Review*, 37, 293–303. doi:10.1111/dar.12596

100 Lim, A. W. Y., Van Schalkwyk, M. C. I., Maani Hessari, N. & Petticrew, M. (2019). Pregnancy, Fertility, Breastfeeding, and Alcohol Consumption: An Analysis of Framing and Completeness of Information Disseminated by Alcohol Industry-Funded Organizations. *Journal of Studies on Alcohol and Drugs*, 80(5), 522-533. doi: 10.15288/jsad.2019.80.524.

101 Koplin, J. (2018). Revised DrinkWise posters use clumsy language to dampen alcohol warnings. *The Conversation*. https://theconversation.com/revised-drinkwise-posters-use-clumsy-language-to-dampen-alcohol-warnings-102406

102 DrinkWise. (2019). *DrinkWise Fetal Alcohol Spectrum Disorder Awareness Program*. https://drinkwise.org.au/our-work/drinkwise-fasd-awareness-program-partners-with-federal-government-for-new-education-materials-featuring-deborah-mailman-and-aaron-pedersen/#

103 Food Regulation Standing Committee. (2018). *Policy options targeted consultation paper: Pregnancy warning labels on packaged alcoholic beverages* https://ris.pmc.gov.au/sites/default/files/posts/2018/07/consultation_regulation_impact_statement_-_pregnancy_warning_labels_on_packaged_alcohol_beverages.pdf

104 Siggins Miller. (2017). *Second evaluation of the voluntary labelling initiative to place pregnancy health warning on alcohol products*. https://www1.health.gov.au/internet/fr/publishing.nsf/Content/C35B5AC81AED240FCA2581EE001B80B0/$File/AU%202nd%20Evaluation%202017.pdf

105 Australia and New Zealand Ministerial Forum on Food Regulation. (2018). *Communiqué of outcomes from the Australia and New Zealand Ministerial Forum on Food Regulation meeting held on 11 October 2018*. https://foodregulation.gov.au/internet/fr/publishing.nsf/Content/forum-communique-2018-October

106 World Health Organization Regional Office for Europe. (2017). *Alcohol labelling – A discussion paper on policy options*. Copenhagen, Denmark: Author. http://www.euro.who.int/en/health-topics/disease-prevention/alcohol-use/publications/2017/alcohol-labelling-a-discussion-document-on-policy-options-2017

107 Foundation for Alcohol Research and Education. (2019). *2019 Annual Alcohol Poll – Attitudes & Behaviours*. Canberra, Australia: Foundation for Alcohol Research and Education. http://fare.org.au/wp-content/uploads/FARE-Annual-Alcohol-Poll-2019-FINAL.pdf

108 The Alcohol Education and Rehabilitation Foundation (the AER Foundation, now Foundation for Alcohol Research and Education). (2011). *Alcohol product labeling: Health warning labels and consumer information*. Canberra, Australia: The AER Foundation. http://fare.org.au/wp-content/uploads/AER-Foundation-Policy-Position-Paper-Alcohol-Health-Warning-Labels.pdf

109 Foundation for Alcohol Research and Education/Public Health Association. (2011). *Submission to the House of Representatives Standing Committee on Social Policy and Legal Affairs: Inquiry into Fetal Alcohol Spectrum Disorders*. Canberra, Australia: Author. http://fare.org.au/wp-content/uploads/FASD-Inquiry-Submission.pdf

110 Food Standards Australia New Zealand. (2019). *P1050 – Pregnancy warning labels on alcoholic beverages.* Food Standards Agency Australia New Zealand. http://www.foodstandards.gov.au/code/proposals/Pages/P1050Pregnancywarninglabelsonalcoholicbeverages.aspx

111 World Health Organization. (2014). *Guidelines for the identification and management of substance use and substance use disorders in pregnancy*. Geneva, Switzerland: Author. https://apps.who.int/iris/bitstream/handle/10665/107130/9789241548731_eng.pdf?sequence=1

112 Schölin, L. & Fitzgerald, N. (2019). The conversation matters: a qualitative study exploring the implementation of alcohol screening and brief interventions in antenatal care in Scotland. *BMC Pregnancy Childbirth*, 19, 316. doi:10.1186/s12884-019-2431-3.

113 Nathoo, T., Wolfson, L. & Poole, N. (2019). New Approaches to Brief Intervention on Substance Use during Pregnancy. *Canadian Journal of Midwifery Research and Practice*, 18(1), 10-21.

114 Finlay-Jones, A. (2018). *Reducing harms related to alcohol use in pregnancy: Policy and practice recommendations*. Canberra, Australia: Deeble Institute for Health Policy Research. https://ahha.asn.au/publication/health-policy-issue-briefs/deeble-issues-brief-no-28-reducing-harms-related-alcohol-use

115 Stanesby, O., Cook, M., & Callinan, S. (2018). Examining trends in alcohol consumption during pregnancy in Australia, 2001 to 2016. Canberra, Australia: Foundation for Alcohol Research and Education. http://fare.org.au/wp-content/uploads/Examining-trends-in-alcohol-consumption-during-pregnancy-in-Australia_2001-2016-FINAL.pdf

116 Poole, N., Schmidt, R. A., Bocking, A., Bergeron, J. & Fortier, I. (2019). The Potential for Fetal Alcohol Spectrum Disorder Prevention of a Harmonized Approach to Data Collection about Alcohol Use in Pregnancy Cohort Studies. *International Journal of Environmental Research Public Health*, 16(11). doi: 10.3390/ijerph16112019.

117 Finlay-Jones, A. (2018). *Reducing harms related to alcohol use in pregnancy: Policy and practice recommendations*. Canberra, Australia: Deeble Institute for Health Policy Research. https://ahha.asn.au/publication/health-policy-issue-briefs/deeble-issues-brief-no-28-reducing-harms-related-alcohol-use

118 Foundation for Alcohol Research and Education. (2012). *The Australian Fetal Alcohol Spectrum Disorders Action Plan 2013–2016*. Canberra, Australia: Author. http://fare.org.au/wp-content/uploads/FARE-FASD-Plan.pdf

119 Finlay-Jones, A. (2018). *Reducing harms related to alcohol use in pregnancy: Policy and practice recommendations*. Canberra, Australia: Deeble Institute for Health Policy Research. https://ahha.asn.au/publication/health-policy-issue-briefs/deeble-issues-brief-no-28-reducing-harms-related-alcohol-use

120 Finlay-Jones, A. (2018). *Reducing harms related to alcohol use in pregnancy: Policy and practice recommendations*. Canberra, Australia: Deeble Institute for Health Policy Research. https://ahha.asn.au/publication/health-policy-issue-briefs/deeble-issues-brief-no-28-reducing-harms-related-alcohol-use

121 Poole, N., Schmidt, R. A., Bocking, A., Bergeron, J. & Fortier, I. (2019). The Potential for Fetal Alcohol Spectrum Disorder Prevention of a Harmonized Approach to Data Collection about Alcohol Use in Pregnancy Cohort Studies. *International Journal of Environmental Research Public Health*, 16(11). doi: 10.3390/ijerph16112019.

122 Commonwealth of Australia Department of Health. (2018). *National Fetal Alcohol Spectrum Disorder Strategic Action Plan*. Canberra, Australia: Commonwealth of Australia. https://www.health.gov.au/sites/default/files/national-fasd-strategic-action-plan-2018-2028.pdf

123 Schölin, L. & Fitzgerald, N. (2019). The conversation matters: a qualitative study exploring the implementation of alcohol screening and brief interventions in antenatal care in Scotland. *BMC Pregnancy Childbirth*, 19, 316. doi:10.1186/s12884-019-2431-3.

124 Poole, N., Schmidt, R. A., Bocking, A., Bergeron, J. & Fortier, I. (2019). The Potential for Fetal Alcohol Spectrum Disorder Prevention of a Harmonized Approach to Data Collection about Alcohol Use in Pregnancy Cohort Studies. *International Journal of Environmental Research Public Health*, 16(11). doi: 10.3390/ijerph16112019.

125 Reibel, T., Giglia, R. & Fletcher, T. (2018). *Midwives and women AUDIT-C intervention project report: Critical review, qualitative data & post-intervention results*. Subiaco, Australia: Telethon Kids Institute, The University of Western Australia/Department of Health Western Australia. https://www.fasdhub.org.au/siteassets/pdfs/midwives-and-women-audit-c-projectfinal-report-2018.pdf

126 Schölin, L. & Fitzgerald, N. (2019). The conversation matters: a qualitative study exploring the implementation of alcohol screening and brief interventions in antenatal care in Scotland. *BMC Pregnancy Childbirth*, 19, 316. doi:10.1186/s12884-019-2431-3.

127 Lensvelt, E., Gilmore, W., Liang, W., Sherk, A. & Chikritzhs, T. (2018). *Estimated alcohol-attributable deaths and hospitalisations in Australia 2004 to 2015. National Alcohol Indicators, Bulletin 16*. Perth, Australia: National Drug Research Institute, Curtin University. http://ndri.curtin.edu.au/NDRI/media/document

128 Lensvelt, E., Gilmore, W., Gordon, E., Hobday, M., Liang, W. & Chikritzhs, T. (2015). *Trends in estimated alcohol-related emergency department presentations in Australia, 2005-06 to 2011-12*. National Alcohol Indicators Project, Bulletin 14. Perth: National Drug Research Institute, Curtin University. http://ndri.curtin.edu.au/NDRI/media/documents/naip/naip014.pdf

129 World Health Organization. (2010). *Global strategy to reduce the harmful use of alcohol.* Geneva, Switzerland: Author. https://apps.who.int/iris/bitstream/handle/10665/44395/9789241599931_eng.pdf;jsessionid=D0DFC8022ED81DBC4D14FF2E70D67F12?sequence=1

130 World Health Organization. (2013). *Global Action Plan for the Prevention and Control of NCDs 2013–2020*. Geneva, Switzerland: World Health Organization. https://apps.who.int/iris/bitstream/handle/10665/94384/9789241506236_eng.pdf;jsessionid=88898E8277229E8F6DA5F512CF9E3855?sequence=1

131 World Health Organization. (2017). *Tackling NCDs –'Best buys' and other recommended interventions for the prevention and control of noncommunicable diseases*. Geneva, Switzerland: Author. https://apps.who.int/iris/bitstream/handle/10665/259232/WHO-NMH-NVI-17.9-eng.pdf?sequence=1

132 Foundation for Alcohol Research and Education. (2019). *Northern Territory alcohol harm-reduction report*. Canberra, Australia: Author. http://fare.org.au/wp-content/uploads/NT-Alcohol-Harm-reduction-Report.pdf

133 Skagerström, J., Chang, G. & Nilsen, P. (2011). Predictors of Drinking During Pregnancy: A Systematic Review. Journal of Women's Health, 20(6), 901–913. doi: 10.1089/jwh.2010.2216. Holland, K., McCallum, K. & Walton, A. (2016). 'I'm not clear on what the risk is': women's reflexive negotiations of uncertainty about alcohol during pregnancy. *Health, Risk & Society*, 18(1–2), 38–58. doi: 10.1080/13698575.2016.1166186

134 Holland, K., McCallum, K. & Walton, A. (2016). 'I'm not clear on what the risk is': women's reflexive negotiations of uncertainty about alcohol during pregnancy. *Health, Risk & Society*, 18(1–2), 38–58. doi: 10.1080/13698575.2016.1166186

Appendix A: Review of progress of the recommendations from *Hidden Harm*

FARE has undertaken a review of progress on the 19 recommendations made by the House of Representatives inquiry into FASD in 2012, *FASD: The Hidden Harm - Inquiry into the prevention, diagnosis and management of Fetal Alcohol Spectrum Disorders* (the Inquiry).

FARE has considered whether these recommendations have been met, partially met or not met at all. FARE has also examined if the recommendations were achieved within the timeframe set by the Committee.

This review finds that only three recommendations from the Inquiry have been met. Most (12) have not been met or implemented and eight have had no work undertaken on them at all.

It should be noted that the Australian Government has not yet formally responded to the Inquiry.

SECTION	RECOMMENDATION	TIME FRAME	MET	ON TIME	COMMENT
Introduction	1. The actions set out in this report should constitute the Commonwealth Government's National Plan of Action for the prevention, diagnosis and management of Fetal Alcohol Spectrum Disorders (FASD). This FASD National Plan of Action should be publicly released by 1 June 2013.	1 June 2013	Yes	No	The National Action Plan 2013-14 to 2016-17 was first released in August 2013 under the Labour Government (with $20million in funding allocated) and then re-released in August 2014 under the Liberal Government (with $9.2 million in funding allocated).
	2. The Committee recommends that the Commonwealth Government immediately establish an ongoing Fetal Alcohol Spectrum Disorders (FASD) Reference Group reporting to the relevant Commonwealth Government Ministers, consisting of a select group of appointed practitioners, professionals and stakeholders who are experts in the field of prevention and management of FASD. The role of the FASD Reference Group would be to oversee and advise on the FASD National Plan of Action.	None given	Yes	–	The FASD Technical Network was established in 2014 to oversee the implementation of the National FASD Action Plan. The Network provided advice to the Australian Government on how Australia could achieve a strategic coordinated approach to FASD. The Australian Government disbanded the network in 2017.
	3. The Committee recommends that the Commonwealth Government publicly report: • within 12 months on the progress of the implementation of a national Fetal Alcohol Spectrum Disorders (FASD) diagnostic and management services strategy, a critical element of the FASD National Plan of Action, and • within five years on the progress towards eliminating FASD in Australia.	12 months 5 years	No	–	The current *National FASD Strategic Action Plan 2018–2028* outlines some of the achievements over the past decade responding to FASD. This includes the publication of the Australian Guide to the Diagnosis of FASD, the establishment of the Clinical Network and FASD Hub and creation of the National FASD Register. However, a national FASD diagnostic and management services strategy has not been undertaken and FARE is unaware of any work to progress this specific part of the recommendations.

SECTION	RECOMMENDATION	TIME FRAME	MET	ON TIME	COMMENT
Awareness and prevention	4. The Committee recommends that the Commonwealth Government work with the National Health and Medical Research Council and professional peak bodies to ensure that all health professionals are: • fully aware of the National Health and Medical Research Council Guidelines that advise women not to drink while pregnant; • have alcohol consumption impacts on pregnancy and the developing fetus incorporated into all general practice and midwifery training; • trained in discussing the National Health and Medical Research Council Guidelines and alcohol consumption with women; and • skilled in asking women about alcohol consumption and recognising and responding to women at risk. By 1 January 2014, all health professionals, including sexual health advisors, midwives, general practitioners and obstetric professionals should be promoting the consistent message that not drinking while pregnant is the safest option, in line with the National Health and Medical Research Council Guidelines.	1 January 2014	Partially	No	Funding was provided to FARE for the development and implementation of the *Women Want to Know* campaign, which aimed to encourage health professionals to speak to pregnant women and provide advice consistent with the National Health and Medical Research Council (NHMRC) Alcohol Guidelines. The primary target audience for *Women Want to Know* is health professionals who work with women who are pregnant or planning pregnancy, which includes midwives, obstetricians and gynaecologists and general practitioners. *Women Want to Know* was launched on 1 July 2014 and provides resources, including free online training to health professionals. *Women Want to Know* is currently unfunded and has been since January 2019. A Grant Opportunity was released in October 2019 by the Australian Government DoH of up to $550,000 over four years. To date (29 November 2019) no outcome has been given to the success or otherwise of the application. Funding has not been provided to target sexual health advisors. In addition, *Women Want to Know* was specifically asked to not develop resources for Aboriginal Health Workers or Aboriginal and Torres Strait Islander people as other grants were funded at the time in this area. Some of the *Women Want to Know* resources have been adapted for use by Aboriginal Health Workers or with Aboriginal people.

SECTION	RECOMMENDATION	TIME FRAME	MET	ON TIME	COMMENT
Awareness and prevention	5. The Committee recommends that the Commonwealth Government establish mechanisms for health professionals to record women's alcohol consumption during pregnancy, or at the time of birth for women who have not presented for prenatal care, and to ensure such information is recorded in midwives data collections or notifications across Australia.	-	No	-	In 2015, the NHMRC funded a research project in the Hunter New England region of NSW to implement a practice change strategy that collects information on women's alcohol consumption during pregnancy. This study is a stepped implementation of a systematic practice change intervention in how women's alcohol consumption during pregnancy is collected and recorded in that region. It includes the implementation of leadership support strategies, local clinical practice guidelines, electronic prompts and reminders, educational meetings and educational materials, and performance monitoring.[135] Within the National Core Maternity Indicators, alcohol is not included but tobacco use during pregnancy (before 20 weeks for all women giving birth and those reporting smoking also after 20 weeks) is.[136] Section 13.3 of the *Clinical Practice Guidelines – Pregnancy Care* provides a practice summary for midwives of what to cover with pregnant women but does not make a note of recording alcohol use before and after pregnancy recognition.[137] A qualitative studya a was undertaken by the Murdock Children's Research Institute, on behalf of the AIHW, with women and health professionals about women's perception about being asked questions about alcohol and health professionals' views on using a standardised screening tool (the Alcohol Use Disorder Identification Test, Consumption; AUDIT-C). The findings showed that incorporating AUDIT-C into routine practice was perceived as feasible by midwives and women felt that more individually tailored questions would make them feel comfortable discussing alcohol use with their health professional.[138] There has, however, been work undertaken to include alcohol within the perinatal data collection. Enhancing maternity data collection and reporting in Australia reports on developments to include psychosocial risk factors into the Perinatal National Minimal Data Set.[139] Collecting data not only of any exposure, but also timing of exposure, may be important to capturing the level of exposure and connecting it to the child's records in the case that a diagnosis needs to be made further on. The report states that: "it is recommended by the National Perinatal Epidemiology and Statistics Unit that alcohol use during pregnancy should be collected twice during pregnancy, before and after 20 weeks gestation." (p.17) In May 2019, AIHW released resources and links for health professionals about alcohol consumption during pregnancy.[140] Work on including alcohol questions in the perinatal data set (AIHW version of AUDIT-C comprised of the first two questions only) went to a development Committee in 2018 to be implemented nationally by 1 July 2019, first voluntary then mandatory. However, reports on its uptake will not to be available until 18 months post implementation.

a A summary of this study is available from the AIHW website, but the research report is not publicly available

SECTION	RECOMMENDATION	TIME FRAME	MET	ON TIME	COMMENT
Awareness and prevention	6. The Committee recommends that the Commonwealth Government implement a general public awareness campaign which promotes not drinking alcohol when pregnant or when planning a pregnancy as the safest option, consistent with the National Health and Medical Research Council Guidelines. Specific awareness campaigns should be developed to target youth and Indigenous communities. Nationwide campaigns should be started no later than 1 July 2013	1 July 2013	No	–	No national public awareness campaigns on alcohol and pregnancy have been funded or undertaken by the Australian Government. FARE has received a small amount of funding to promote its Pregnant Pause campaign at the national level. This included: • $220,000 from July 2017 to June 2018 • $135,000 in funding from July 2018 to December 2018 The campaign has included: • Distributing the *Pregnant Pause* TV Commercial to digital screens in GP surgeries in all states and territories • Undertaking radio campaigns across Melbourne, Sydney and Brisbane (this was undertaken through two bursts: September 2017 and January 2018) • Implementing social media promotion • Mail-out to GPs including both *Pregnant Pause* information and resources • Coordinate printing and mailing *Pregnant Pause* resources to GPs
	7. The Committee recommends that the Commonwealth Government mandate a health advisory label advising women not to drink when pregnant or when planning a pregnancy to be included on the packaging of all pregnancy and ovulation testing kits. These labels should be in place by 1 October 2013.	1 October 2013	No	–	FARE is unaware of any work undertaken on this recommendation.
	8. The Committee recommends that the Commonwealth Government raise with the States and Territories the critical importance of strategies to assist Indigenous communities in managing issues of alcohol consumption and to assist community led initiatives to reduce high-risk consumption patterns and the impact of alcohol.	-	No	–	FARE is unaware of any work undertaken on this recommendation.

SECTION	RECOMMENDATION	TIME FRAME	MET	ON TIME	COMMENT
Awareness and prevention	9. The Committee recommends that the Commonwealth Government work with State and Territory governments to identify and implement effective strategies for pregnant women with alcohol dependence or misuse.	–	Partially	–	The *National FASD Action Plan 2014-2017* key priority area was: 'Secondary Prevention targeting women with alcohol dependency'. The actions under this strategy included: "Undertake further research to develop best practice, compassionate interventions and guidelines for specialist drug and alcohol services and primary care organisations to provide greater support for at risk women, including those with FASD children, to help them reduce their substance misuse and reduce the risk of delivering a child with FASD and to ensure they have priority access to early intervention." In September 2014, the National Drug and Alcohol Research Centre published *Supporting pregnant women who use alcohol or other drugs: a review of the evidence*.[141] This was funded through the Substance Misuse in Pregnancy Resource Development Project from the Australian Government. However, no information has been found to establish if this evidence review is used by alcohol and other drug services, or what guidelines and best practice interventions have been developed or implemented.
	10. The Committee recommends that the Commonwealth Government seek to include health warning labels for alcoholic beverages, including a warning label that advises women not to drink when pregnant or when planning a pregnancy, on the Legislative and Governance Forum on Food Regulation's December agenda. The Commonwealth Government should determine the appropriate format and design of the labels by 1 March 2013, to assist the alcohol industry in adopting best practice principles and preparing for mandatory implementation.	1 March 2013	Partial met – currently ongoing	No	In October 2018, the Ministerial Forum on Food Regulation committed to the mandatory application of pregnancy warning labels on all packaged alcohol and tasked FSANZ with developing the labelling scheme. FSANZ consulted on the development of the labels throughout 2019 and released a proposed labelling scheme for public consultation on 4 October 2019. The proposed changes to the Food Standards Code are expected to go to the FSANZ Board in December 2019, with anticipated gazettal in March 2020.

SECTION	RECOMMENDATION	TIME FRAME	MET	ON TIME	COMMENT
Awareness and prevention	11. The Committee recommends that the Commonwealth Government mandate the range of health warning labels for alcoholic beverages as decided by the Legislative and Governance Forum on Food Regulation. • The warning labels should consist of text and a symbol and should be required to be displayed on all alcohol products, advertising and packaging by 1 January 2014; • The minimum size, position and content of all health warning labels should be regulated; and • The introduction of mandated warning labels should be accompanied by a comprehensive public awareness campaign.	1 January 2014	No	–	FARE is unaware of any work undertaken on this recommendation to date.
	12. The Committee recommends that the Commonwealth Government commission an independent study into the impacts of the pricing and availability of alcohol and the influence of these factors in the changing patterns of alcohol consumption across age groups and gender. The study should be completed by 1 October 2013.	1 October 2013	No	–	The Commonwealth Government has not commissioned an independent study into pricing and availability of alcohol. FARE is unaware of any work undertaken on this recommendation. However, on 1 October 2018 the Northern Territory Government introduced a minimum unit price (MUP) on alcohol. A preliminary assessment of the impacts of MUP, comparing data from the period prior to implementation (1 October 2017 to 31 July 2018) and post implementation (1 October 2018 to 31 July 2019), shows there has been a: • 26 per cent reduction in alcohol-related total assaults (3497 compared to 2582) • 21 per cent reduction in alcohol-related domestic violence (2228 compared to 1749).[142]
	13. The Committee recommends that the Commonwealth Government commission an independent study into the impacts and appropriateness of current alcohol marketing strategies directed to young people. The study should have regard to these strategies and the volume and frequency of alcohol consumption amongst young people, the links being made between alcohol and sport, the efficacy of efforts to promote responsible drinking behaviours, and the adequacy of current regulations to respond to marketing through digital platforms such as the internet, social media and smartphones. The study should be completed by 1 October 2013.	1 October 2013	No	–	FARE is unaware of any work undertaken on this recommendation.

SECTION	RECOMMENDATION	TIME FRAME	MET	ON TIME	COMMENT
Awareness and prevention	14. The Committee recommends that, following the completion of the study into the pricing and availability of alcohol and the study into alcohol marketing strategies, the Commonwealth Government develop a National Alcohol Sales Reform Plan aimed at reducing the harms caused by irresponsible alcohol consumption across Australia.	Following recommendation 12	No	–	FARE is unaware of any work undertaken by the Australian Government to develop a National Alcohol Sales Reform Plan or any intensions by the Australian Government to support or implement this recommendation. Alcohol sales data was previously collected by the Northern Territory (until 2011-12), WA (until 2011-12) and Queensland (until 2012-13), ACT and Victoria. This data was being analysed by the National Drug Research Institute as part of the National Indicators Project, however this ceased in 2016.
Diagnosis	15. The Committee recommends that the Commonwealth Government expedite the rollout of the Fetal Alcohol Spectrum Disorder (FASD) diagnostic instrument and the development of a training and user manual. These should be available for use by 1 October 2013. Following the rollout, the Commonwealth Government should establish a mechanism to collect and monitor diagnostic data in order to assess the effectiveness of prevention strategies and patterns of FASD occurrence.	1 October 2013	Yes	No	The Australian FASD Diagnostic Instrument was released in 2016 and online training on its use has been developed. It unknown what the uptake of this training has been.
	16. The Committee recommends that the Commonwealth Government develop and implement a national Fetal Alcohol Spectrum Disorders (FASD) diagnostic and management services strategy. This strategy should be monitored and informed by the FASD Reference Group, and should establish capacity by 1 July 2014 for the following: • awareness amongst all general practitioners and child and maternal health professionals of the causation and clinical features of FASD and the importance of early diagnosis and intervention; • establishment of a model for diagnostic services such that regional as well as metropolitan areas are properly serviced; and • identification of effective methodologies of management including international best practice.	1 July 2014	Partially	No	A National FASD Diagnostic and Management Services Strategy has not been established or achieved. However, a FASD Clinical Network was established by clinicians in 2015 and this received a small amount of funding in that year for the appointment of an administrator. This network communicates by email to disseminate resources among themselves.[143] In addition, in 2017 the Australian Government DoH funded the establishment of the FASD Hub to be a central repository of documents and resources.[144]

SECTION	RECOMMENDATION	TIME FRAME	MET	ON TIME	COMMENT
Management needs	17. The Committee recommends that the Commonwealth Government develop educational material to raise awareness about Fetal Alcohol Spectrum Disorders (FASD). These materials should be monitored and informed by the FASD Reference Group. In particular, targeted training and materials should be developed for: • special education teacher aides and class teachers; • parents, foster carers and foster care agencies; • police and court officials; • youth workers and drug and alcohol officers; and • officers in correctional facilities and juvenile detention centres.	–	No	–	FARE is unaware of any work undertaken by the Commonwealth Government on this recommendation. However, some work has been done by state and territory governments on FASD and the criminal justice system. Telethon Institute for Kids has also developed training materials: • for those working in juvenile detention • videos as part of the Understanding FASD: A Guide for Justice Professionals project.[145] A resource for teachers was developed in 2014 by the Kimberley Success Zone and published by National Curriculum Services.[146] This resource is designed to support school leaders, teachers, Aboriginal educators and the broader school community to recognise, understand and work effectively with students living with FASD in schools. As far as FARE is aware, this resource has not been promoted or available across Australia.

SECTION	RECOMMENDATION	TIME FRAME	MET	ON TIME	COMMENT
Management needs	18. The Committee recommends that the Commonwealth Government include Fetal Alcohol Spectrum Disorders in the List of Recognised Disabilities and the Better Start for Children with a Disability Initiative.	–	No	–	As far as FARE is aware the Commonwealth Government has not pursued any action on this recommendation or undertaken work to recognise FASD as a disability. The Better Start Initiative provided eligible children with up to $12,000 in funding to access early intervention services. FASD is not one of the recognised disabilities although microcephaly, hearing impairment and sight impairment are listed conditions.[147] Currently the National Disability Insurance Scheme only recognises Fetal Alcohol Syndrome under *List B: Congenital conditions* - cases where malformations cannot be corrected by surgery or other treatment and result in permanent impairment but with variable severity.[148] This does not recognise the updated diagnostic terminology in place since 2016, despite numerous submissions by organisations to the National Disability Insurance Agency to change and update this wording. The lack of change to the NDIS and recognition of FASD is disappointing given the Critical Review of the Literature commissioned by the National Disability Insurance Agency in 2015.[149] Individuals living with FASD aged 16 or older can access the Disability Support Pension, but only if their IQ is assessed as being low (IQ between 70 to 85). This has not changed since 2012 and are outlined under Table 9 of the Tables for the Assessment of Work-related Impairment for Disability Support Pension.[150] This ruling precludes many people with FASD who have IQs within the normal range. As FARE suggested in 2012, to remedy this FASD should be listed as a condition under 'Table 7: Brain Function' alongside "a person with Autism Spectrum Disorder who does not have a low IQ".[151]
	The Committee recommends that the Commonwealth Government recognise that people with Fetal Alcohol Spectrum Disorders have, amongst other disabilities, a cognitive impairment and therefore amend the eligibility criteria to enable access to support services and diversionary laws.	–	No	–	FASD is unaware of any work undertaken on this recommendation.

Appendix B: Timeline of events of strategic importance for FASD policy in Australia

YEAR	EVENT OF STRATEGIC IMPORTANCE FOR FASD POLICY IN AUSTRALIA
2009–2012	Fitzroy Valley in WA commenced the Lililwan FASD Prevalence Study, Australia's first FASD prevalence study. This study was conducted in partnership between Nindilingarri Cultural Health Services, Marinwarntikura Women's Resource Centre, The George Institute for Global Health and Sydney University. The work was featured in the 2010 Australian Social Justice Commissioner's Annual Report, presented at the United Nations Permanent Forum on Indigenous Peoples in 2011 and 2012, directly supported by the former Governor General of Australia, Ms Quentin Bryce. Parents and carers of 108 children born in 2002 and 2003 took part in the study.
2013	Launch of WA Model of Care implementation plan, which followed the release of the WA Model of Care in 2010. The Model of Care outlined a whole-of-government response to FASD.[152]
2013–2017	Following the completion of the Lililwan FASD Prevalence Study a comprehensive strategy was established to address the finding. The *Marulu strategy* included comprehensive prevention, diagnosis and management strategies to be undertaken and evaluated through the community partnerships and with the Telethon Institute for Kids.[153]
2014	*Pregnant Pause* commenced. This campaign was first created by FARE as a fund raising initiative in 2012 but received an ACT Health Innovation grant in 2014.
2014	FARE launched *Women Want to Know*, the first education campaign to follow the release of the 2009 NHMRC Alcohol Guidelines.154 This project provides health professionals with knowledge and skills to assist them to routinely ask pregnant women about their alcohol consumption, provide advice consistent with the guidelines, and refer to appropriate services.
2011–2014	FARE provided funding for six select tendered projects, including: • development of the first FASD assessment and diagnostic clinic in Australia (Children's Hospital at Westmead) • research on knowledge and attitudes towards FASD by criminal justice professionals in QLD and WA[155,156] • improved services for families affected by FASD[157] • research into services for women who are pregnant and alcohol-dependent[158] • completion and filming of Tristan's Story and the Story of alcohol use in pregnancy – video resources describing FASD and the impact of the condition on individuals.159,160
2014	Publication of *Supporting Pregnant Women who use Alcohol or Other Drugs Resource*.161 This resource was funded through the Substance Misuse in Pregnancy Resource Development Project from the Australian Government. It aims to assist health professionals to identify women struggling with alcohol and drug issues during pregnancy and respond to their needs. The document also outlines tools for screening, assessment, brief intervention, guidelines, training and other resources.
2015	*Pilbara FASD Strategy* 2015–2019
2015	The FASD Clinical network commenced to oversee the implementation of *National Strategy to tackle FASD 2013-14 to 2015-16*.
2014–2016	FARE assisted with achieving: • ongoing funding for the Children's Hospital Westmead clinic (2015) • funding for the establishment of the Goulburn Valley clinic in Shepparton (2014–2016)
2016	Publication of the *Australian Guide to the diagnosis of Fetal Alcohol Spectrum Disorder (FASD.)*[162]
2017	Launch of the FASD Hub.
2017	Provision of $2.7 million funding from the Coalition Government to Patches for diagnostic services across five states.[163]
2017	FASD prevention and health promotion resource published by the Menzies School of Health Research and including Ord Valley Aboriginal Health Service, National Aboriginal Community Controlled Health Organisation and Telethon Kids Institute.[164]
2018	The Forum on Food Regulation agreed on 11 October 2018 that based on the evidence, a mandatory labelling standard for pregnancy warning labels on packaged alcoholic beverages should be developed and should include a pictogram and relevant warning statement.
2018	Launch of National FASD Action Plan 2018–2028 in November 2018.
2019	Public consultation on the format of mandatory pregnancy warning labels (P1050) published on 4 October by the FSANZ.

Appendix C: Submissions by FARE related to FASD

YEAR	SUBMISSIONS ON FASD OR RELATED TO FASD
2011	House of Representatives Standing Committee on Social Policy and Legal Affairs inquiry into: Fetal Alcohol Spectrum Disorders.
2012	West Australian Legislative Assembly Education and Health Committee inquiry: Fetal Alcohol Spectrum Disorder: the invisible disability.
2012	American Psychiatric Association – Development of Diagnostic and Statistical Manual of Mental Disorders (DSM-5) and recognition of FASD within Neurobehavioural disorder associated with prenatal alcohol exposure.
2013	SA Parliament Social Development Committee inquiry into the sale and consumption of alcohol.
2014	House of Representatives Standing Committee on Indigenous Affairs inquiry into the harmful use of alcohol in Aboriginal and Torres Strait Islander communities.
2015	Northern Territory Select Committee on Action to Prevent Fetal Alcohol Spectrum Disorder.
2015	National Alcohol Strategy consultation and National Drug Strategy.
2017	National FASD Action Strategy 2018-2028.
2017	NHMRC Alcohol Guidelines.
2017	Northern Territory Review of alcohol policies and legislation: Alcohol harm reduction framework.
2018	National Alcohol Strategy.
2017	Targeted consultation by Food Regulation Standing Committee on policy options on pregnancy warning labels on packaged alcoholic beverage.
2018	National Strategic Approach to Maternity Services.
2018	Breastfeeding Guidelines.
2018	National Women's Health Strategy 2020-2030.
2019	Productivity Commission inquiry into mental health.
2019	Targeted consultation by FSANZ on P1050 mandatory pregnancy warning labels on packaged alcoholic beverages.
2019	Senate Community Affairs Reference Committee inquiry into FASD.

Appendices references

135 Kingsland, M., Doherty, E., Anderson, A., Crooks, K., Tully, B., Tremain, D... Wiggers, J. (2018). A practice change intervention to improve antenatal care addressing alcohol consumption by women during pregnancy: research protocol for a randomised stepped-wedge cluster trial. *Implementation Science*, 13, 112. doi: 10.1186/s13012-018-0806-x

136 Australian Institute of Health and Welfare. (2019). *National Core Maternity Indicators*, 2019. https://meteor.aihw.gov.au/content/index.phtml/itemId/717443.

137 Australian Government Department of Health. (2019). *Clinical Practice Guidelines: Pregnancy care*. Canberra, Australia: Australian Government Department of Health. https://www.health.gov.au/resources/pregnancy-care-guidelines

138 Australian Institute of Health and Welfare. (2017). *National data collection on alcohol in pregnancy: a qualitative study*. https://www.aihw.gov.au/reports-data/population-groups/mothers-babies/data-sources

139 Australian Institute of Health and Welfare. *Enhancing maternity data collection and reporting in Australia*. Canberra, Australia: Author. https://www.aihw.gov.au/getmedia/277cc590ebae-4162-bf03-3e536b5ffab1/18797.pdf.aspx?inline=true

140 Australian Institute of Health and Welfare. (2019). *Alcohol use during pregnancy*. https://www.aihw.gov.au/reports-data/population-groups/mothers-babies/resources-for-psychosocial-health-in-pregnancy/alcoholuse-during-pregnancy

141 Breen, C., Awbery, E. & Burns, L. (2014). *Supporting pregnant women who use alcohol and other drugs: a review of the evidence.* Sydney, Australia: National Drug and Alcohol Research Centre, UNSW Australia. https://ndarc.med.unsw.edu.au/resource/supporting-pregnant-women-who-use-alcohol-or-other-drugs-review-evidence

142 Foundation for Alcohol Research and Education. (2019). *Northern Territory alcohol harm-reduction report*. Canberra, Australia: Foundation for Alcohol Research and Education/People's Action on Alcohol. http://fare.org.au/wp-content/uploads/NT-Alcohol-Harm-reduction-Report.pdf

143 FASD Hub Australia. (2019). *Australian and New Zealand FASD Clinical Network*.

144 FASD Hub Australia. (2019). *FASD Hub Australia*. https://www.fasdhub.org.au

145 FASD Hub Australia. (2019). *FASD and Justice Videos*.

146 National Curriculum Services. (2014). *Understanding and addressing the needs of children and young people with fetal alcohol spectrum disorders in schools*. Abbotsford, Australia: National Curriculum Services. https://cdn.shopify.com/s/files/1/1502/9380/files/FASD_ResourceForTeachers.pdf?1298261825453872816

147 Better Start. (n.d.). *What is Better Start?* https://www.betterstart.net.au/what-is-better-start/

148 National Disability Insurance Agency. (2019). List B – Permanent conditions for which functional capacity are variable and further assessment of functional capacity is generally required.

149 Dudley, A., Reibel, T., Bower, C. &Fitzpatrick, J. (2015). *Critical Review of the Literature: Fetal Alcohol Spectrum Disorders*. Subiaco, Australia: Telethon Kids Institute. www.fasdhub.org.au/siteassets/pdfs/critical-review-of-the-literature-fetal-alcohol-spectrum-disorders-14jun2016.pdf

150 Australian Government Department of Social Services. *Social Security (Tables for the Assessment of Work-related Impairment for Disability Support Pension)* Determination 2011. https://www.legislation.gov.au/Details/F2011L02716

151 Foundation for Alcohol Research and Education. (2012). *The Australian Fetal Alcohol Spectrum Disorders Action Plan 2013–2016*. Canberra, Australia: Author. http://fare.org.au/wp-content/uploads/FARE-FASD-Plan.pdf

152 Department of Health, Western Australia. (2013). *Western Australian across sector, statewide Implementation Plan for the Fetal Alcohol Spectrum Disorder Model of Care 2013-2018*. Perth, Australia: Health Networks Branch, Department of Health, Western Australia. https://ww2.health.wa.gov.au/~/media/Files/Corporate/general%20documents/Health%20Networks/Child%20and%20Youth/FASD-Model-of-Care-Implementation-Plan.pdf

153 Marninwarntikura Women's Resource Centre (2012). *The Marulu Strategy: Making FASD History*. https://www.marulustrategy.com.au/pages/about-the-strategy

154 Foundation for Alcohol Research and Education (2014). *Women Want to Know*. http://fare.org.au/women-want-to-know/

155 Douglas, H., Hammill, J., Hall, W. & Russell, E. (2013). *Fetal Alcohol Spectrum Disorders (FASD) within the Criminal Justice Sector in Queensland*. Canberra, Australia: Foundation for Alcohol Research and Education. http://fare.org.au/wp-content/uploads/12-feb-version-3-Douglas-et-al-FINAL-REPORT.pdf

156 Mutch, R., Watkins, R., Jones, H. & Bower, C. (2013). *Fetal Alcohol Spectrum Disorder: Knowledge, attitudes and practice within the Western Australian justice system*. Canberra, Australia: Foundation for Alcohol Research and Education. https://alcoholpregnancy.telethonkids.org.au/SysSiteAssets/media-docs---alcohol-preg-fasd/projects/final-report-fasd-justice-system.pdf

157 Breen, C. & Burns, L. (2012). *Improving services to families affected by FASD*. Canberra, Australia: Foundation for Alcohol Research and Education. http://fare.org.au/wp-content/uploads/Improving-services-for-Families-affected-by-FASD.pdf

158 Burns, L. & Breen, C. (2013). *It's time to have the conversation: Understanding the treatment needs of women who are pregnant and alcohol dependent.* Canberra, Australia: Foundation for Alcohol Research and Education. https://ndarc.med.unsw.edu.au/sites/default/files/ndarc/resources/FARE%20final%20report%20-%20treatment%20needs%20of%20women%20who%20are%20pregnant%20&%20alcohol%20dependent.pdf

159 Hogan, M. (n.d.) *Tristan* [video file]. http://www.melaniehogan.com/tristan.html

160 Foundation for Alcohol Research and Education. (2014). *The story of alcohol use in pregnancy* [video fie]. https://vimeo.com/100859137

161 National Drug and Alcohol Research Centre. (n. d.). *Supporting pregnant women who use alcohol and other drugs – A guide for healthcare professionals*. Sydney, Australia: University of New South Wales. National Drug and Alcohol Research Centre. https://ndarc.med.unsw.edu.au/sites/default/files/ndarc/resources/Supporting%20Pregnant%20Women%20who%20use%20Alcohol%20or%20Other%20Drugs%20Resource.pdf

162 Bower, C. & Elliott, E. J. (2016). On behalf of the Steering Group. Report to the Australian Government Department of Health: *Australian Guide to the diagnosis of Fetal Alcohol Spectrum Disorder (FASD)*. https://www.fasdhub.org.au/siteassets/pdfs/australian-guide-to-diagnosis-of-fasd_all-appendices.pdf

163 Department of Health. *Remembering that alcohol and pregnancy don't mix*. [Press release] https://www.health.gov.au/ministers/the-hon-greg-hunt-mp/media/remembering-that-alcohol-and-pregnancy-dont-mix

164 Menzies School of Health Research, National Aboriginal Community Controlled Health Organisation, Telethon Kids Institute, Ord Valley Aboriginal Health Service. (2017). *FASD Prevention & Health Promotion Resources Project: Final Report*. Report prepared by Menzies School of Health Research for the Australian Government Department of Health, Canberra. https://www.fasdhub.org.au/siteassets/pdfs/fphpr-project-final-report.pdf

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