Australian Government
National Health and Medical Research Council

Public consultation: draft *Australian guidelines to reduce health risks from drinking alcohol*

Personal details

Full name NOFASD Australia
[NHMRC has removed personal information]

Submission reflects

Organisation / Individual	An organisation
Organisation Name	NOFASD Australia

Questions

1. **Please indicate which format you read the guideline in.**
   PDF report
2. **The draft guidelines are presented in a new IT platform, MAGICapp. Please indicate how strongly you agree with the following statement: *The draft Australian Guidelines to Reduce Health Risks from Drinking Alcohol are easy to navigate in MAGICapp.***
   Strongly disagree
3. **Please indicate how strongly you agree with the following statement: *The Plain English summary is clear, simple and easy to understand*.**
   Neither agree nor disagree
4. **Do you have any comments on how the *Plain English summary* could be improved?**
   - There is a difference in the language and word choices in Guidelines 1 and 2, to the detriment of the wording in Guideline 3 which uses more modifiers and qualifiers. For example, words and phrases like “potential”, “not enough evidence” “pre-cautionary”, “risk of harm” ……”likely to be slight”, “hard to predict level of risk” contrast with Guideline 2 “there is no safe or no risk level of drinking alcohol”.
   - Extract
     Young people are at increased risk of the harmful effects of alcohol because of their developing brain, a smaller lean muscle mass (for some), and inexperience with the effects of drinking. When this is combined with a greater likelihood of risk-taking behaviour, young people are at greater risk of physical injury, including through alcohol poisoning, self-harm and unsafe sexual behaviour. The evidence suggests that adolescent drinking to intoxication is also associated with reduced cognitive performance and increased risk of mental health problems and suicidal behaviours.

All of the above extract from Guideline 2 applies to FASD, can be demonstrated by evidence and should be stated. The stronger language is evident when compared with Guideline 3.

- Australian research consistently points to large numbers of health professionals not being confident in approaching women about alcohol consumption in pregnancy. Clear language will better empower health professionals to provide information.

5. **Do you have any comments on how the *Introduction* could be improved?**

   No comment

6. **Do you have any comments on how the *Background* could be improved?**

   The description of the scope and approach to the review is helpful and illustrates the challenges that there were to ensure that the very best evidence-based advice is provided and that the advice is presented in an informative and effective way.

   The National Organisation for Fetal Alcohol Spectrum Disorder (NOFASD Australia) has a very specific interest in Fetal Alcohol Spectrum Disorder – prevention, diagnosis, recognition, research, intervention, outcomes over the lifespan, and management.

   In terms of health equity, pre-natal exposure to alcohol is one of the most inequitable starts to life which can be imagined.

   Throughout the document there are many sections in which the information provided is appropriate and the document is comprehensive and thorough. However, there are places where this is not the case. Ideally, each part of the document and messages should 'stand-alone' and not require the reader to explore further to seek a more accurate or clear message.

   For example, the opening email with the goal of reducing complex information, uses stronger language with less modifiers when providing summary information about consumption of alcohol by people younger than 18.

   When addressing alcohol and pregnancy the opening email does not consider unplanned pregnancy, yet on page 57 the document indicates that 50% of Australian pregnancies are unplanned. Based on the statement that 77.5% of Australians consume alcohol, the harms of pre-natal alcohol exposure (PAE) are consistently being neglected in this phase of the life-cycle.

   Extract

   Risks to babies during pregnancy and after birth: Alcohol crosses the placenta and readily enters the bloodstream of the fetus. Drinking alcohol while pregnant increases the risk of a range of birth defects and growth and developmental problems, comprising Fetal Alcohol Spectrum Disorder, the effects of which may persist into adulthood.

   The general implication of this extract from the Background is vague and creates the possibility that identified concerns may also disappear in adulthood. The permanent nature of brain damage and the known negative outcomes for adults with FASD are in conflict with this implied message.

   Extract

   Alcohol also enters the breast milk, and can interfere with breastfeeding and infant behaviour.

   PAE also interferes with breastfeeding and infant behaviour and many other areas of a child's life. Therefore, the last sentence when included related to alcohol and breastfeeding risks minimising PAE.

7. **Please indicate how strongly you agree with the following statement: *The Understanding risk section is clear, simple and easy to understand*.**

   Neither agree nor disagree

8. **Do you have any comments on how the *Understanding risk* section could be improved?**

No comment - other than comments in other sections related to the risks associated with pre-natal alcohol exposure which are being modified by less explicit and clear language choices and sentence structure.

9. **Do you have any comments on how the evidence has been used to develop the recommendation for Guideline One?**
   No comment
10. **Is there any evidence relevant for this guideline that has been missed? If so, please provide the citation(s).**
    No comment
11. **Do you have any editorial or readability comments on the sections that make up Guideline One?**
    No comment
12. **Do you have any comments on how the evidence has been used to develop the recommendation for Guideline Two?**
    No comment
13. **Is there any evidence relevant for this guideline that has been missed? If so, please provide the citation(s).**
    No comment
14. **Do you have any editorial or readability comments on the sections that make up Guideline Two?**
    No comment
15. **Do you have any comments on how the evidence has been used to develop the recommendation for Guideline Three?**
    The guideline does not address women who are able to conceive, not using birth control, consuming alcohol and are sexually active – nearly 50% of pregnancies are unplanned and this advice excludes these.
    There is a significant amount of illustrative literature which appears not to have been referenced. Some more recent publications may have missed the time frame for consideration.
    These missing pieces include the 4 city US mainstream prevalence led by May and Chambers, the Popova Greater Toronto prevalence study, the award winning Muggli et al. study which identified that subtle craniofacial changes were evident to a fetus with what has been previously viewed as low-risk drinking, the evidence of highly negative outcomes for those diagnosed in the Thanh and Jonsson study which identified that the average age of death for a person with FASD (diagnosed as FAS – the US diagnostic descriptor) was 34 years of age. There has been a study done which identified over 400 co-morbid conditions which are known to occur with FASD. Tables like 5.3.1 and 5.3.2 could have been prepared for FASD. Other studies and reports demonstrate the severity of mental health and substance use disorders amongst those living with FASD and their escalated risk of suicide. These studies are all available on CanFASD's website. NOFASD has in-house copies but does not have the rights to distribute.
    Preferences and values
    This section is incomplete. There are assumptions made about parenting – that two people are involved. There are other preferences and values which have not been addressed and which impact on PAE. There is a widespread preference to consume alcohol and continued widespread sharing of the NHMRC Guidelines which were replaced in 2009 which outlined amounts of alcohol which could be consumed safely. These guidelines continue to be re-hashed and shared often by health professionals. It can be argued that there is a preference for these guidelines, which necessitates the revised guidelines being even more clear about the risk of lifelong harm caused by PAE.
    Resources and other considerations
    Citing the Burns prevalence estimates is concerning and should be placed in context. There are no mainstream Australian prevalence studies. The prevalence studies which have been completed in countries where alcohol

use patterns and other cultural factors are similar to Australia estimate prevalence at 4% and state that this figure is conservative. There are Canadian, US and UK prevalence studies. It is a gap in Australia's research agenda that a mainstream prevalence study has not been undertaken. This gap does not justify serious underestimation of prevalence. Where there is alcohol there is FASD and Australia is in the early stages of recognising the extent of the problem.

The existence of the Banksia Hill detention study has been invaluable for advancing awareness of FASD in custodial settings but without a mainstream study this study reinforces a negative stereotype that people with FASD are offenders. Arguably, the Bower study does not indicate over-representation of children with "more severe FASD" in the justice system. The Bower study indicates that undiagnosed and unsupported young people with FASD have an increased risk of incarceration. Only one of the young people in the study had been previously diagnosed. Research informs us that 80% of people diagnosed with FASD have been previously incorrectly diagnosed with other disorders for example Autism Spectrum Disorder, Attention Deficit Hyperactivity Disorder and other conduct disorders, reported by Stevens, Nash, Koren and Rove in 2013. Therefore, the assumption that it is the more severely affected individuals with FASD who are in custody cannot be made.

The incorrect term "Fetal Alcohol Syndrome Disorder" is used in this section on page 49. This is a common problem in Australia and underlines the need to increase the widespread use of the full correct term and the abbreviation. There are many myths about FASD which are a constant issue for the NOFASD Helpline. These include the wide-spread belief among health professionals and others that those affected with FASD have visible bio-markers (only 17% of those affected have these identifiers), the invisibility of the disorder in that it is often noted through behavioural issues and then described as poor parenting, the failure to recognise that FASD is a lifespan disorder and not a condition which those affected can grow out of. Also, it is very common for people to believe that FASD will only occur in cases where the mother has a substance use disorder, likely to be described as alcoholic.

This section, if read in isolation, gives no indication that there are serious lifelong health issues. However, it is one of the few places in the document where unplanned pregnancy is vaguely addressed by use of the term "might become pregnant".

These draft guidelines appear to have been very careful to avoid reinforcing the myth that FASD is only found amongst communities of Indigenous Australians. This is very important, and the work on these Guidelines should be commended for this.

16. **Is there any evidence relevant for this guideline that has been missed? If so, please provide the citation(s).**

Yes.

These have been documented in the preceding text.

The research evidence base relevant to FASD is growing rapidly and requires additional attention to ensure that the most up-to-date emerging information has been captured. Some significant studies appear to have been left out - though possibly this was due to publication dates.

17. **Do you have any editorial or readability comments on the sections that make up Guideline Three?**

This has been documented in the preceding text.

7.5 The Practical info

Uses language modifiers, does not address the possibility of being pregnant and consuming alcohol because the pregnancy has not been recognised. Why state the risks are low when this is not known. Multiple animal model research indicate changes even with low threshold consumption – as has the Muggli birth cohort study.

18. **Do you have any comments on how the *Drinking frequency* section could be improved?**

No comment

19. **Do you have any comments on how the *Administrative report* could be improved?**
    No comment
20. **Are there any additional terms that should be added to the *glossary*?**
    Pre-natal Alcohol Exposure PAE
    An extended definition of FASD would be useful - given that terms like FASD/Fetal Alcohol Syndrome Disorder and other variations which are incorrect - are often used. Terms like FAS should be fully explained because they have historical relevance to the topic. The issues around assumptions that people affected by FASD have visible facial features which can be identified persist in sectors where this information should be known. These guidelines will become a source of information for professional Australians in relevant sectors.
21. **Are there any additional abbreviations or acronyms that should be added to this section?**
    PAE
22. **Do you have any comments on how the *Australian standard drinks* section could be improved?**
    No comment.

Disclaimer I have read the security warning/disclaimer below and accept the risks and conditions outlined.

Permission to publish yes