RACGP
Royal Australian College *of* General Practitioners

Healthy Profession.
Healthy Australia.

9 December 2019

Committee Secretary
Senate Standing Committees on Community Affairs
PO Box 6100
Parliament House
Canberra ACT 2600

Via email: community.affairs.sen@aph.gov.au

Dear Committee Secretary,

The Royal Australian College of General Practitioners (RACGP) thanks the Senate Community Affairs References Committee for the opportunity to provide a submission to the inquiry into *Effective approaches to prevention, diagnosis and support for Fetal Alcohol Spectrum Disorder*.

Fetal Alcohol Spectrum Disorder (FASD) is a preventable cause of disability, and can lead to significant difficulties throughout the lifespan. FASD is under-recognised and underdiagnosed in Australia, leading to patients and their families feeling unsupported and overwhelmed, resulting in substantial health and social costs.[1-3]

The RACGP provides the following responses to the Terms of Reference:

(a) the level of community awareness of risks of alcohol consumption during pregnancy;

FASD is not restricted to disadvantaged or low socioeconomic populations, and occurs throughout all sections of society.[4] According to the Australian Institute of Health and Welfare (AIHW), adults living in the least disadvantaged areas are 1.3 times more likely to exceed alcohol consumption guidelines, in comparison those living in the most disadvantaged areas.[5] Therefore, it is important that awareness campaigns extend to women in higher socioeconomic communities.

Studies suggest many Australian women are unaware of the potential harm and risk of FASD.[6] A multifaceted approach to improve awareness of FASD and to reduce drinking in pregnancy is required for women of childbearing age, their family and community members, whose support is vital for women at risk of drinking during pregnancy. Clearer labels on alcoholic drinks that warn against drinking in pregnancy should also be considered, as part of this multifaceted approach.

Improved support for general practitioners (GPs) and other health professionals is required to improve their capacity to educate and assist patients at risk of drinking during pregnancy. It is particularly important for rural and regional communities to appropriately target information and education, due to limited resources and support, and variable accessibility to specialists.

(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;

Information on general prenatal advice (not just on alcohol) should be widely available, promoted and expanded to ensure all women of childbearing age receive this information prior to pregnancy to empower them to plan and prepare accordingly.

The RACGP produces clinical resources for GPs and other health professionals.

The RACGP recommends:

- alcohol screening for women who are pregnant or planning a pregnancy,[1, 7, 8] with intervention or referral where appropriate.[1] This includes providing contraceptive advice to reduce unplanned pregnancy, as women may drink prior to pregnancy recognition.[9]

- information about alcohol use be also offered to women who are breastfeeding.[1, 10]

(c) barriers that may prevent women receiving accurate, timely and culturally/ethnically appropriate information and advice on alcohol and pregnancy;

Patient barriers

- Timing of information to patients - Approximately 60% of Australian women have drunk alcohol between conception and pregnancy recognition.[9] Ideally, information should be provided to women prior to pregnancy. Information should be holistic, and not only focus on alcohol consumption, but also provide overall maternal health information.

- Patient stigma - The stigma felt by patients can be a barrier to diagnosis and management of FASD. It is likely to be associated with feelings of guilt or grief.[1, 3] Therefore, these mothers need to be supported sensitively and without judgement.

- Language and cultural barriers - While cultural differences and language can be a barrier to prevention of FASD,[9] lack of awareness among professionals of culturally appropriate resources[4] as well as the short-term nature of the campaigns can compound issues in this space. More resources for men, grandmothers and aunties to help support pregnant women in their families has been recommended for Aboriginal and Torres Strait Islander patients.[4]

- Other individual and societal factors - Many complex contributing factors can lead to an increased risk of drinking during pregnancy. These include addiction, poor mental health, isolation, stress, low self-esteem, adverse early life experiences, racism, pre-pregnancy alcohol consumption and exposure to violence and abuse.[9] Other factors include living with a partner who consumes alcohol during pregnancy, lack of social support, social motives for drinking and social exclusion.[9]

Health system barriers

- Accessibility in remote and regional areas - Patients who live in remote and regional areas may face barriers in terms of limited accessibility to health professionals, travel and financial barriers.[9]

- Lack of resources for both health professionals and patients - Available resources need to be further promoted and implemented to ensure widespread awareness by people who work with women at risk of FASD. Advice for health professionals on how to have these often difficult conversations is also important.[4]

- Diagnosis of FASD - Patients may present to their GP with a range of symptoms and there may be concerns that a label of FASD will stigmatise the mother and their child. Some clinicians may also believe that there is currently little support available to alleviate the effects of FASD.[1] Further training and resources are required to assist health professionals in supporting patients and their families with a diagnosis of FASD.[2]

- Lack of funding for research and diagnosis - More funding needs to be provided to primary care and primary care research to assist patients with FASD effectively and provide patients and their families with appropriate support services.

(d) provision of diagnostic services in Australia including capacity, training, integration and diagnostic models in current use;

Children who may have borderline FASD can be difficult to diagnose. They tend to be diagnosed with mild or moderate intellectual delay and oppositional defiant disorder (ODD). There is also difficulty in diagnosing children who have been removed from their families, given the lack of access to family history to ascertain substance use. A delay in diagnosis may result in these children being disadvantaged and missing out on aide time or National Disability Insurance Scheme (NDIS) funding.

A diagnosis of FASD requires a team approach. Ideally, members of the multidisciplinary team (in addition to the GP), would include a paediatrician, neuropsychologist, occupational therapist, speech and language pathologist and a social worker. However, this is not always possible, given the limited availability and wait time for these services, particularly in rural and remote areas. In these cases, the RACGP recommends a more streamlined approach to diagnosis.[1]

The RACGP Guidelines for preventive activities in general practice and National guide to a preventive health assessment for Aboriginal and Torres Strait Islander people recommend the Alcohol Use Disorders Identification Test – Consumption (AUDIT-C) approach to screening for alcohol use. This assesses levels of drinking, dependency and experience of harm in circumstances where time is limited. Although AUDIT-C has not yet been reliably validated for use in Aboriginal and Torres Strait Islander populations, it is currently the most commonly used tools for these patients.[1]

There has been limited Australian studies on the screening and brief intervention for women who are pregnant and use alcohol[1].

(e) the prevalence and nature of co-occurring conditions and of misdiagnosis of FASD; As above often difficult to assess.

FASD can be difficult to diagnose due to many overlapping or co-occurring conditions. Overlapping conditions can include attention deficit hyperactivity disorder (ADHD), autism spectrum disorder (ASD), speech and language disorders, mental health disorders, conduct disorder, and oppositional defiant disorder (ODD)[1]. Conditions that can present similarly neurodevelopmentally to FASD include early life trauma or neglect, some genetic abnormalities or acquired brain trauma.

Certain patient groups may be at higher risk of missed diagnosis, including children in foster or adoptive care, and children who have come into contact with the law.[1]

(f) international best practice in preventing, diagnosing and managing FASD;

The RACGP recommends:

- Medication should be tailored to individual requirements (as some symptoms may coexist with other conditions) while still complying with appropriate guidelines.[1]

- Identified interventions should also be integrated into the home environment, schooling, and any other intervention services.[1]

Systematic reviews have indicated the importance of general public education campaigns combined with targeted approaches to women at risk of FASD.[9]

(g) awareness of FASD in schools, and the effectiveness of systems to identify and support affected students;

There is limited awareness of FASD in the school system, and more often a diagnosis of autism is suspected. It can be a difficult issue to raise in schools, particularly when the child is still in the care of their biological parents. If children have been diagnosed formally, they may be able to go to a mild intellectual disability class, where their needs are better catered for. However, children without a formal diagnosis may struggle both behaviourally and intellectually, and consequently, often suspended or expelled.

(h) the prevalence of, and approaches to, FASD in vulnerable populations, including children in foster and state care, migrant communities and Indigenous communities;

Effects of colonisation

It is important to understand how colonisation, dispossession and the forced removal of children have affected the health of Aboriginal and Torres Strait Islander people. Aboriginal and Torres Strait Islander women may not admit to alcohol use during pregnancy due to fear of government intervention.[1]

Cultural differences

It is important to be aware and sensitive to the historical context and cultural differences of Aboriginal and Torres Strait Islander peoples in Australia. This goes beyond language and overcoming health access issues in remote Australia, and includes understanding lived histories, the impact of cultural dislocation and intergenerational trauma.[1, 9] Therefore, it is especially important that any work is taken in conjunction with local communities with a particular focus on community capacity building, in order to be successful and respectful.[1]

Important role of family and community

The role and support of family and community is particularly important for Aboriginal and Torres Strait Islander women. Educational resources to assist men, grandmothers and aunties to support pregnant women is important as they have influence over decisions to drink alcohol during pregnancy and can become vital community advocates.[4]

Other vulnerable populations

It is estimated that the prevalence of FASD for children in out-of-home care and in youth justice systems is high, although there is no current data.[2] Screening for FASD in important for these vulnerable children is important to ensure they are appropriately supported throughout placements and in the judicial system. This is particularly the case in the youth justice system where individuals with undiagnosed FASD may be more likely to reoffend.[2]

(i) the recognition of, and approaches to, FASD in the criminal justice system and adequacy of rehabilitation responses;

There is little awareness of both classical and borderline cases of FASD in the Australian judicial system. It can be particularly difficult to make a diagnosis of FASD in adults, owing to the fact there is usually no access to maternal intake history.

It is important that individuals are assessed for FASD prior to sentencing to ensure they are adequately supported throughout court processes.[1]

(j) the social and economic costs of FASD in Australia, including health, education, welfare and criminal justice;

There are many ongoing costs of FASD in Australia, both to society and to individuals. More broadly, FASD may contribute to the chronic disease burden[2] in addition to mental health.[3] On an individual level, people with FASD may find they encounter difficulties in their work, education and social life.[3]

(k) access, availability and adequacy of FASD support available through the National Disability Insurance Scheme, including access to effective and early intervention services for individuals diagnosed with FASD;

While there are mainstream therapy programs available in Australia that can assist with the domain-specific impairments commonly seen in FASD, there are not many FASD-specific therapy programs or providers.[1] It can be difficult to obtain funding for a person with FASD, owing to the difficulty in diagnosing FASD, particularly in adult cases.

(l) support for adults with FASD and for parents and carers of children with FASD;

Required support for adults with FASD

There is little support for adults with FASD. Adults with FASD may benefit from supported living arrangements, personalised workforce training and vocational support.[1]

Support for parents of children with FASD

Studies show that parents of children with FASD:

- experience stress and social isolation
- are concerned for their child's future and their capacity to be a successful lifelong parent (as they recognise that their children are likely to need lifelong support)
- feel as though living with a child with FASD affects the whole family
- are worried about the stigma and judgement from society when their child is diagnosed with FASD, while also experiencing relief because it provides an explanation of their child's behaviour.[3]

Small studies suggest that parents of children with FASD may benefit from respite care[3] although further research into this is required. Unless there is a comorbid diagnosis, children with FASD and families do not receive any additional support as a result of their diagnosis.[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;

No comment.

(n) the effectiveness of the National FASD Action Plan 2018-2028, including gaps in ensuring a nationally co-ordinated response and adequacy of funding;

No comment.

(o) the need for improved perinatal data collection and statistical reporting on FASD and maternal drinking;

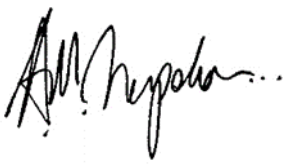
Further research into FASD is required. This includes the prevention, diagnosis, interventions and supports required. We not currently have estimates of the prevalence of FASD in Australia, which is needed to inform and evaluation prevention efforts and need.[2]

(p) any other related matters.

No comment.

We look forward to hearing about this Committee's progress and outcomes. For queries on this submission, please contact Mr Stephan Groombridge, Manager, eHealth and Quality Care on 03 8699 0544 or at stephan.groombridge@racgp.org.au

Yours Sincerely



Dr Harry Nespolon
President

References

1. National Aboriginal Community Controlled Health Organisation and The Royal Australian College of General Practitioners. National guide to a preventive health assessment for Aboriginal and Torres Strait Islander people. 3rd edn. East Melbourne, Vic: RACGP, 2018.

2. Reid, N. Fetal alcohol spectrum disorder in Australia: What is the current state of affairs? Drug and Alcohol Review, 2018; 37: 827–830. doi: 10.1111/dar.12855

3. Domeij H, et al. Experiences of living with fetal alcohol spectrum disorders: a systematic review and synthesis of qualitative data. Dev Med Child Neurol. 2018;60(8):741-752. doi: 10.1111/dmcn.13696.

4. Popova S, Lange S, Probst C, et al. Global prevalence of alcohol use and binge drinking during pregnancy, and fetal alcohol spectrum disorder. Biochemistry and Cell Biology, 2018;96:237-240. doi: https://doi.org/10.1139/bcb-2017-0077

5. Australian Institute of Health and Welfare. Risk factors to health [Internet]. Canberra: Australian Institute of Health and Welfare, 2017 [cited 2019 Dec. 5]. Available from: https://www.aihw.gov.au/reports/risk-factors/risk-factors-to-health

6. Williams HM, Percival NA, Hewlett NC, et al. Online scan of FASD prevention and health promotion resources for Aboriginal and Torres Strait Islander communities. Health Promot J Austral. 2018;29:31–38. doi: https://doi.org/10.1002/hpja.8

7. The Royal Australian College of General Practitioners. Guidelines for preventive activities in general practice. 9th edn. East Melbourne, Vic: RACGP, 2016.

8. Smoking, nutrition, alcohol, physical activity (SNAP): A population health guide to behavioural risk factors in general practice, 2nd edn. Melbourne: The Royal Australian College of General Practitioners 2015

9. Symons M, Pedruzzi RA, Bruce K, et al. A systematic review of prevention interventions to reduce prenatal alcohol exposure and fetal alcohol spectrum disorder in indigenous communities. BMC Public Health 2018 18:1227. doi: https://doi.org/10.1186/s12889-018-6139-5

10. Giglia RC, Reibel T. Has a national policy guideline influenced the practice of raising the topic of alcohol and breastfeeding by maternal healthcare practitioners? Aust J Prim Health. 2019; 25: 275-280. doi: 10.1071/PY1810