

National Indigenous FASD Resources Project SNAPSHOT FOR HEALTH PROFESSIONALS

Introduction

Fetal alcohol spectrum disorders (FASD) are a range of effects on the fetus resulting from maternal ingestion of alcohol that can have serious and lifelong implications for the health and wellbeing of the child¹⁻³. While FASD is a community-wide issue, the prevalence of harmful drinking among Aboriginal and Torres Strait Islander women aged between 25-34 years is higher than for non-Indigenous women, and this is despite the fact that fewer Aboriginal and Torres Strait Islander women drink alcohol than non-Indigenous women⁴. Research evidence indicates that health professionals working in Aboriginal and Torres Strait Islander health care settings need access to information on alcohol and pregnancy and FASD that is culturally secure and acceptable for themselves and their clients³.

The National Drug Research Institute (NDRI) at Curtin University was contracted by the Department of Health and Ageing (now Department of Health and hereinafter referred to as the Department of Health (DoH)), to consult with Aboriginal and Torres Strait Islander health professionals and community members across Australia, to gather their views on the range of information and kinds of resources focused on alcohol, pregnancy and FASD they believed would be most useful within their local communities. The outcome of these consultations informed the development of resources that would allow cultural and regional specificity, while also ensuring they were evidence based and nationally consistent. The resources, consistent with the Australian guidelines to reduce health risks from drinking alcohol (NHMRC 2009), aim to enhance strategies to reduce risks to women from drinking alcohol, and the risks to the fetus from maternal alcohol consumption while pregnant and to the infant when breastfeeding.

Review of the literature

The literature review examined published and 'grey' literature on Fetal Alcohol Spectrum Disorders (FASD), and provided an overview of existing resources designed for both national and international health professionals and communities. Nine databases and a range of Australian government, non-government and international websites were searched, using a defined set of search terms. In brief the literature notes:

- widespread agreement that drinking heavily during pregnancy and heavy episodic drinking are clearly implicated in FASD^{5, 6};
- the situation is less clear regarding drinking alcohol at lower levels⁶⁻⁸ but in Australia the recommended 'safest option' is to not drink (NHMRC 2009);
- estimates of prevalence of Fetal Alcohol



Syndrome (FAS) and FASD vary⁹⁻¹², and reported rates are likely to be under-estimations¹²⁻¹⁴;

- in Australia, initial cases of FASD were published in the early 1980s¹⁵;
- Australian and international policy responses to FASD generally recommend not drinking alcohol during pregnancy¹⁶⁻¹⁸; and
- a wide range of Australian and international resources exist around FASD, encompassing a number of different perspectives, but there are limited evaluations of these¹⁹⁻²¹, and very few well conducted primary studies of effective interventions^{22, 23}.

Methodology

The project comprised six main phases:

- establishment of a Reference Group, consisting of members from peak Aboriginal and Torres Strait Islander health organisations and services, Government, drug and alcohol service providers and consultants with expertise in Aboriginal and Torres Strait Islander service delivery, research and policy development;
- identification and review of existing FASD health promotion resources;
- identification of the processes required to develop templates for use in the creation of culturally secure and appropriate, evidence-based alcohol and pregnancy/FASD resources;
- extensive consultation with key stakeholders;
- workforce development; and
- evaluation of responses to the consultation process and resources.

These processes included:

- a workshop held with the project team and Reference Group members, where group members were asked to consider and advise

on the consultation process to be followed, and the appropriateness of a selected sample of Australian and international resources;

- developing a draft set of questions for health professionals and community members to guide the consultation process, and receiving and incorporating feedback on these from Reference Group members;
- sending consultation packs to all Aboriginal Community Controlled Health Services (ACCHS) who had indicated an interest in participating in the project;
- negotiating with individual services in each state and territory to secure consultations;
- project managers travelling to various locations for meetings with CEOs, managers, and health professionals to discuss the project; and
- project managers facilitating or assisting at consultations.

In total, 17 consultations were held. For comparative purposes, participants were prompted to provide responses to the same sets of questions across jurisdictions. The average length of consultations was three hours, with some extending up to five hours.

Data analysis

A coding scheme was used to ensure a systematic, comparative thematic analysis of the qualitative data collected. The coding scheme utilised the major categories developed to guide the focus group consultations. Qualitative data were extracted and entered into a database, with identifying markers removed and replaced with a case file number allocated to geographical areas. Data were then analysed using a pre-determined, standardised method to ensure consistency of approach, to identify and follow a chain of evidence, and increase accuracy of interpretation. Data were then reported on according to how individuals and groups responded to each question/topic, and how participants across all sites responded to each question/topic, to identify consistencies and differences across consultation sites.

Overall, the data supported the need and desire for ongoing education at all levels – for all groups in communities and for health professionals themselves – on issues around alcohol and pregnancy. People wanted to have access to locally relevant resources, which were evidence based but flexible to local need. Participants clearly wanted to be involved and engaged in the development of these strategies and resources, with the ability to utilise local knowledge and content highly valued by consultation participants rather than receiving resources developed externally that had limited local ownership and perceived relevance. It was apparent to the project team that there was more commitment to using these locally developed resources. Engaging local communities in developing responses has been argued as critically important in uptake and durability of interventions (24, 25). In response to these considerations

the decision was taken to develop an iPad/Web PosterMaker application that would allow local services to develop their own resources from a set of evidence-based data.

Workforce development

The workforce development component of the project included:

- a workshop attended by seven health professionals, representing each of the six jurisdictions in which consultations were held, where participants were shown the PosterMaker applications and provided feedback on them to project managers; and
- a series of training videos embedded within the PosterMaker app, covering each step in the design and production of posters to ensure ease of adoption by users.

Evaluation

Evaluation of the applications included:

- comment and suggestions from workshop participants;
- feedback on the PosterMaker application by staff of the Department of Health, Chief Investigators on the project and Reference Group members;
- providing commissioned illustrations to Aboriginal members of the research team and Reference Group for assessment of cultural appropriateness;
- providing poster templates to key Aboriginal health professionals to ensure acceptability and cultural appropriateness;
- inclusion in the PosterMaker application of a simple, voluntary and anonymous evaluation survey; and
- post-launch evaluation survey to be provided to users three months after launch.

Summary of results

Knowledge, awareness and raising the issues

The term 'Fetal Alcohol Spectrum Disorders' and its acronym 'FASD' is not well known by community members and, in some areas, health professionals were also unfamiliar with FASD as an umbrella term for issues around alcohol and pregnancy. Community members and health professionals were generally, however, in agreement as to the level of knowledge in the community around these issues: that is, community members have an understanding of the risks of drinking during pregnancy, but the effects of doing so are little known or understood. Lack of knowledge and information around drinking while breastfeeding was also raised across consultations. Across sites, there was considerable inconsistency between what health professionals believe they are conveying to clients and what community believe they are receiving by way of messages around alcohol and pregnancy.

Existence and appropriateness of available resources

While the majority of health professionals across consultation sites said they use some type of FASD resource, most community participants said they had not seen any such resources in their local communities. Where these had been noted by community members, they were located in health services and doctors' offices. Both health professionals and community members considered some of the resources they had seen as not useful, citing cultural and/or contextual/regional inappropriateness. Key concepts for the development of culturally safe and relevant resources included things such as: contextually and locally relevant, few words, simple language, image driven, and colourful.

The best and the worst advice to give someone about FASD

Health professionals and community members both believed telling women not to drink during pregnancy was the best advice that could be given, but for community members this message was best couched within advice around the consequences of drinking and possible effects on the child. The two groups differed substantially in their views on how such messages should be framed: health professionals preferred a less direct and confrontational approach, while community members across all sites called for messages that were hard-hitting, blunt and to the point.

In contrast, many health professionals felt that confronting people with worst outcome or hard-hitting messages was the worst advice that could be given, while community members believed that 'soft' messages do not serve community well or do not work to embed the seriousness and potentially lifelong health and social outcomes of drinking during pregnancy. Health professionals and community members did agree, however, that telling women "It's okay to have a couple of drinks" was the 'worst advice' that could be given.

The who, what and how of resources for Aboriginal and Torres Strait Islander communities

With the exception of two participants at one site, there was unanimous agreement across all consultation sites that there should be different resources targeting different groups in communities. Resources specifically directed to young people (pre-teen and upwards) were considered a key strategy in education about and prevention and/or reduction of alcohol consumption by young people. Many participants in both groups talked about the need for community-wide education and the development and availability of educational tools to address issues of alcohol and pregnancy with both sexes and all age groups. In each consultation, the possibilities for using new social media and technology to develop and disseminate resources were raised by participants. It was believed that

these technologies had the potential to reach a wider audience than more traditional resources, although traditional resources were supported where they were seen to be culturally appropriate. National advertising campaigns focused on the dangers of alcohol in pregnancy were strongly supported across consultation sites.

Limitations of the study

Study results are limited in their general application by the relatively small number of locations in which consultations were conducted. Further, while consultations were held with services in both metropolitan and regional locations in some states, no consultations were held in very remote locations. For various reasons, consultations could not be conducted in the Northern Territory. Consultations were not held in Western Australia because state government services were conducting their own FASD consultations; however, findings from these consultations were generally consistent with those from our project, suggesting confidence in the findings.

Discussion and conclusion

In the absence of a well-defined universally accepted evidence base to guide interventions aimed at reducing prenatal alcohol consumption, contemporary public health emphasises a community-based approach to health promotion and prevention strategies²⁶. There is an evidence base, however, on what works to overcome Indigenous disadvantage:

- community involvement and engagement in program design and decision making;
- commitment to doing projects with, not for, Aboriginal and Torres Strait Islander people;
- respect for language and culture;
- development of social capital;
- recognising underlying social determinants;
- creative collaboration²⁷.

The data gathered throughout these consultations essentially reflect these principles.

Certain themes emerged from the consultations across all jurisdictions:

- health professionals and community members are looking for consistency in the messages received and given regarding issues around alcohol, pregnancy and FASD;
- a recognition of the need for sensitivity in the provision of such information, but also of the need for messages that clearly and effectively demonstrate the dangers of drinking in pregnancy;
- effectiveness of such messages would be enhanced when embedded within a holistic approach to combatting the normalisation of alcohol use more generally, and to the social circumstances and determinants of health in their communities;
- evidence-based information around alcohol, pregnancy and FASD will have its greatest

effect when delivered to young people as part of a wider educational strategy around sex education and family planning issues;

- while most resources were seen as 'better than nothing', there was a strong desire to use more technology to gather and disperse information and education, both between and among health professionals, and out into communities; and
- people want to have a choice of culturally safe, generally positive materials to draw on so they can develop their own locally relevant resources, using artwork, colours, forms of words and local contacts.

These desires are consistent with the available evidence and the principles enunciated above for overcoming Indigenous disadvantage.

We have responded to this evidence, both from our own consultations and from other sources²⁸, by undertaking the development of an iPad/Web PosterMaker application intended primarily for health professionals to develop resources targeting staff and community members.

The PosterMaker application has a suite of pre-loaded, evidence based messages and culturally relevant images that can be combined with a database of colours, shapes and fonts to create locally-relevant posters. The PosterMaker also allows users to upload images and text, which are not available to others, but which the owner can utilise in their own posters. The application contains nine training videos covering all aspects of the use of PosterMaker, and includes a comprehensive 'More Information' section with links to FASD information from the Australian Government and other sources. PosterMaker can be used either from an iPad or on the Web. Health professionals can, for example, use PosterMaker on iPad in the field to create posters in concert with community members, or teachers could utilise PosterMaker in the classroom as an educational tool with young people.

FASD PosterMaker can be found in the Apple store or at www.fasdpostermaker.com.au.

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For further information about the National Drug Research Institute, visit www.ndri.curtin.edu.au.

The National Drug Research Institute at Curtin University is supported by funding from the Australian Government under the Substance Misuse Prevention and Service Improvement Grants Fund.

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