Alcohol, Pregnancy and Fetal Alcohol Spectrum Disorders: Resources for health professionals working in Aboriginal and Torres Strait Islander health care settings

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Preventing harmful drug use in Australia

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National Indigenous Fetal Alcohol Spectrum Disorders Project

Alcohol, pregnancy and Fetal Alcohol Spectrum Disorders

Resources for health professionals working in Aboriginal and Torres Strait Islander health care settings

Final Report

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Acronyms

ACCHO	Aboriginal Community Controlled Health Organisation
ACCHS	Aboriginal Community Controlled Health Services
ADAC	Aboriginal Drug and Alcohol Council (SA)
AHMRC	Aboriginal Health & Medical Research Council
AMA	Australian Medical Association
AMS	Aboriginal Medical Service
AOD	alcohol and other drugs
ARBD	alcohol-related birth defects
ARND	alcohol-related neurodevelopmental disorder
AUDIT	Alcohol Use Disorders Identification Test
CDC	Centers for Disease Control and Prevention
COAG	Council of Australian Governments
DAO	Drug and Alcohol Office (WA)
DoH	Department of Health
FARE	Foundation for Alcohol Research and Education
FAS	Fetal Alcohol Syndrome
FASD	Fetal Alcohol Spectrum Disorders
MoU	Memorandum of Understanding
NACCHO	National Aboriginal Community Controlled Health Organisation
NDRI	National Drug Research Institute
NEACA	National Expert Advisory Committee on Alcohol
NHMRC	National Health & Medical Research Council
NIAAA	National Institute on Alcohol And Alcoholism
NOFASARD	National Organisation for Fetal Alcohol Syndrome and Related Disorders
OATSIH	Office of Aboriginal and Torres Strait Islander Health
QAIHC	Queensland Aboriginal and Islander Health Council
RANZCOG	Royal Australian and New Zealand College of Obstetricians and Gynaecologists
RCOG	Royal College of Obstetricians and Gynaecologists
WHO	World Health Organization

Executive summary

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 child (Kyskan & Moore, 2005; O'Leary, Nassar, Kurinczuk, et al., 2010; Payne et al., 2005). While FASD is a community-wide issue, the prevalence of harmful drinking amongst Aboriginal and Torres Strait Islander women aged 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 women (ABS, 2006). 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 clients (Payne et al., 2005).

Project aim

The aim of the Project is to develop culturally appropriate resources to assist health professionals in Aboriginal and Torres Strait Islander health care settings address the issues of alcohol and pregnancy and FASD.

The National Drug Research Institute (NDRI) at Curtin University was contracted by 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.

Project objectives

- to collaborate with DAO to identify the processes required to develop culturally secure and appropriate resources for use across Australia to assist health professionals working in Aboriginal and Torres Strait Islander health care settings to discuss alcohol and pregnancy/FASD with Aboriginal and Torres Strait Islander women;
- to improve the capacity of Aboriginal and Torres Strait Islander health workers, staff in primary health care settings, and the alcohol and other drug workforce to address the issue of alcohol and pregnancy/FASD with Aboriginal and Torres Strait Islander women;
- to provide Aboriginal and Torres Strait Islander health workers, staff in primary health care settings, and the alcohol and other drug workforce in the jurisdictions included in this project with templates for use and adaptation to provide Aboriginal and Torres Strait Islander women and

men in their communities with culturally secure and appropriate resources about alcohol and pregnancy;
- to increase understanding of the risks of drinking alcohol, drinking alcohol while pregnant and breastfeeding;
- to assist Aboriginal and Torres Strait Islander women to stop drinking alcohol during pregnancy, or where this is not possible, to reduce their alcohol consumption; and
- to evaluate the response to the consultation process and the templates of resources.

Methodology

The project comprised of seven main phases:

- establishment of a Reference Group;
- 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;
- data analysis;
- 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 ACCHSs 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 four and five hours.

Development of iPad/Web PosterMaker app included:

- analysis of data (from all aspects of the methods – literature review, key informant interviews) leading to identification of several key themes considered integral to resources addressing the issues of alcohol, pregnancy and FASD;

- discussions with app developers on how best to respond to the outcomes of the consultations;
- contracted app developers to design and develop the iPad/Web FASD PosterMaker app;
- developed evidence-based statements, based on the literature review, that were trialled with the Reference Group before inclusion in the app. These statements are 'locked' so that the integrity of the message remains;
- contracted local illustrator to develop sets of images that reflect the themes considered appropriate and relevant to participants. These images were trialled with the Reference Group and Indigenous service providers to check for cultural security;
- developed poster templates as examples of completed images for users' ease;
- trialled at a workshop in Adelaide to check for cultural appropriateness, functionality, and evaluation and feedback; and
- finalised the app.

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 (Dell & Roberts, 2007; O'Leary & Bower, 2012);
- the situation is less clear in relation to drinking alcohol at lower levels (Kelly et al., 2010; O'Leary & Bower, 2012; Robinson et al., 2010) but in Australia the recommended 'safest option' is to not drink (NHMRC 2009);
- estimates of prevalence of Fetal Alcohol Syndrome (FAS) and FASD vary (Bower et al., 2000; Coyne et al., 2008; Elliott et al., 2007; Harris & Bucens, 2003), and reported rates are likely to be under-estimations (Burns et al., 2013; Elliott, Bower, et al., 2006; Harris & Bucens, 2003);
- in Australia, initial cases of FASD were published in the early 1980s (O'Leary, 2002);
- Australian and international policy responses to FASD generally recommend not drinking alcohol during pregnancy (Department of Health, 2009; Government of Canada, 2008; NH&MRC, 2009);
- a wide range of Australian and international resources exist around FASD, encompassing a number of different perspectives, but there is limited evaluation of these (McBride, Carruthers, & Hutchinson, 2008; Payne et al., 2011; Peadon et al., 2011), and very few well conducted primary studies of effective interventions (McBride, 2009; Wilson et al., 2010).

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 upon 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 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 that this would result in 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 (Allsop, 2008; Caswell, 2000). In response to these considerations the decision was taken to develop an iPad/Web PosterMaker app that would allow local services to develop their own resources from a set of evidence-based data.

The National Indigenous FASD resource
FASD PosterMaker is an easy to use app designed to enable the creation of Indigenous specific, locally relevant Fetal Alcohol Spectrum Disorders (FASD) resources for communities and health staff. This app provides pre-loaded messages and images to create informative and educational resources about the harms associated with consuming alcohol while pregnant and maintaining a healthy pregnancy.

Workforce development
The workforce development component of the project includes:

- a workshop attended by seven health professionals, representing each of the six jurisdictions in which consultations were held, in which participants were shown the PosterMaker app and provided feedback on it to the project managers;
- 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 of the workforce development workshop and PosterMaker App

Evaluation of the app includes:

- comment and suggestions from workshop participants;
- feedback on the PosterMaker app by staff of the Department of Health, Chief Investigators on the project, and Reference Group members;
- provision of commissioned illustrations to Aboriginal members of the research team and Reference Group for assessment of cultural appropriateness;
- provision of poster templates to key Aboriginal health professionals to ensure acceptability and cultural appropriateness;
- inclusion in the PosterMaker app of a simple, voluntary and anonymous evaluation survey;
- 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. A lack of knowledge and information around drinking while breastfeeding was also raised across consultations. Across sites, there was considerable inconsistency between what health professionals believed they were conveying to clients and what community believed they were 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 resources, the majority of 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 as reasons. 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 believed that a less direct and confrontational approach was to be preferred, 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 the community well or 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' they 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 in 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 with which to address issues of alcohol and pregnancy with both sexes and all age groups. In each consultation, the potential for using new social media and technology to develop and disseminate resources was 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.

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 strategies (World Health Organization (WHO), 2009). 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; and,
- creative collaboration (Al-Yaman & Higgins, 2011).

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 'traditional' resources were seen as 'better than nothing', there was a real desire to use 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 expectations 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 sources (Drug and Alcohol Office, 2011), by undertaking the development of an iPad/Web-based PosterMaker app aimed primarily for health professionals to develop resources targeting staff and community members.

The PosterMaker app 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 app 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 app 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 Australian government and other sources. PosterMaker can be used either on 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.

Dissemination strategy and evaluation

Dissemination

The project managers presented on the project to the Australasian Fetal Alcohol Spectrum Disorders Conference in Brisbane on 19 November 2013.

This was an opportunity for the project managers to demonstrate and promote the project and its outcomes to a key target audience.

Further dissemination strategies include:

- a media release targeting health professionals and other interested stakeholders;
- a link to the PosterMaker app sent via email to all relevant Indigenous and mainstream health and other organisations;
- 'snapshots' of the project aimed at health and other interested professionals and to participating communities; and
- Publication of peer-reviewed papers in relevant academic journals.

Evaluation

The iPad/Web PosterMaker app has an inbuilt voluntary and anonymous evaluation component where users are invited to comment on the app and elements of its use. The results of this evaluation will be collected and analysed by NDRI over the first three months post-launch and will be available to the DoH at that time.

Additionally, all participants in the consultation process will be forwarded an evaluation survey in relation to both the consultation process, as well as to the outcomes (the iPad/Web PosterMaker app) of that process three months post-launch of the apps. This information will be analysed and available to the DoH at that time.

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 child (Denzin & Lincoln, 1998; Kvale, 1996; Kvale & Brinkmann, 2009; Kyskan & Moore, 2005, Executive Summary; O'Leary, Nassar, Kurinczuk, et al., 2010; Payne et al., 2005; Peadon, O'Leary, et al., 2007; Shedlin & Schreiber, 1995). Trends in alcohol consumption and patterns of drinking in Australia indicate that potential for harm, including alcohol-exposed pregnancies and therefore for fetal damage, is increasing (Australian Medical Association, 2009). A 2005 survey of health professionals' knowledge, practice and opinions about Fetal Alcohol Syndrome (FAS) and alcohol consumption in pregnancy found that only 2% of health professionals perceived themselves very prepared to deal with FAS (Payne et al., 2005). Around 30% of the Aboriginal and Torres Strait Islander health professionals surveyed reported that they routinely asked about alcohol use in pregnancy or provided information to their clients, with over 70% of Aboriginal health workers indicating that they wanted information on alcohol and pregnancy/FAS for themselves and their clients.

The research evidence highlights the need for health professionals to have access to strategies and resources that reduce the prevalence of alcohol consumption in pregnancy (Alcohol and Pregnancy Project, 2009) and it is consistently noted that health professionals have an important role. While it is important to acknowledge that FASD is a community-wide issue, the prevalence of harmful drinking amongst Aboriginal and Torres Strait Islander women aged 25-34 is higher than for non-Aboriginal and Torres Strait Islander women, and this is despite the fact that fewer Aboriginal and Torres Strait Islander women drink alcohol than non-Indigenous women (ABS, 2006). This indicates that particular attention needs to be given to providing Aboriginal and Torres Strait Islander women with culturally appropriate information and interventions to assist and support them to stop or reduce their drinking when pregnant (Ministerial Council on Drug Strategy, 2006).

NDRI was contracted by the DoH to develop culturally appropriate resources to assist health professionals in Aboriginal and Torres Strait Islander health care settings to address the issues of alcohol and pregnancy and Fetal Alcohol Spectrum Disorders (FASD). Creating a collaborative approach to the issue, NDRI is the lead agency for a collaboration involving representatives from Aboriginal Community Controlled Health Organisations (ACCHOs), the DoH Drug Strategy Branch, the Office of Aboriginal and Torres Strait Islander Health (OATSIH), Indigenous clinical service providers, the WA Drug and Alcohol Office (DAO), and consultants with expertise in Aboriginal and Torres Strait Islander service delivery, research and policy development.

The primary purpose of this national project was to improve the capacity of Aboriginal and Torres Strait Islander health workers to address issues of alcohol and pregnancy/FASD within their communities through the provision of culturally secure and appropriate resources about alcohol and pregnancy.

To achieve this, health professionals and community groups across Australia (with the exception of Western Australia where a similar state-based consultation was being undertaken by the Drug and Alcohol Office) were consulted to determine:

- the extent of existing knowledge about alcohol and pregnancy and FASD;
- the level of knowledge and use of currently available health promotion resources;
- the range of information and resources required to assist health professionals and Aboriginal and Torres Strait Islander people to address alcohol and pregnancy issues; and,
- the key features that are required to adapt the resources in each location to ensure they are culturally acceptable.

As part of the consultation process, health professionals were provided with evidence-based information about alcohol and pregnancy and FASD that would assist them to discuss these issues with their clients and communities. The outcome of these consultations informed the development of templates that would allow regional and cultural specificity to resources that were nevertheless evidence based and nationally consistent. These resources 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 breastfeeding.

The project team at the NDRI included: Professor Sherry Saggers,[1] Professor Steve Allsop, Associate Professor Ted Wilkes, Professor Dennis Gray, Dr Colleen O'Leary, and Dr Nyanda McBride. These researchers have, amongst the team, considerable experience in Aboriginal and Torres Strait Islander health, alcohol and pregnancy research and policy development, and in the development of prevention and early intervention programs. Dr Kate Frances and Dr Lynn Roarty were appointed in August 2010 as joint project managers. The project began in August 2010, and was completed in November 2013.

[1] Professor Saggers retired from the University and from further participation in this project in early 2012.

Review of the literature

Introduction

The literature review examines the academic and 'grey' literature on Fetal Alcohol Spectrum Disorders (FASD), and provides an overview of existing resources designed for both national and international health professionals and communities.

Methodology

Literature and resources relating to FASD, including Fetal Alcohol Syndrome (FAS), were identified from academic and non-academic sources. Nine databases were searched,[2] using a wide range of search terms.[3] These terms were also used to search the internet more generally for national and international 'grey' literature, and to search Australian federal and state health departments for government publications and resources, and Aboriginal Medical Services (AMS) and other non-government organisation websites.

Definition of terms

The term FASD is an umbrella term encompassing the range of effects that can result from prenatal alcohol exposure, with differing degrees of malformations and dysfunction. FASD is not a diagnostic term; rather it includes the diagnostic terms of FAS, partial FAS, Alcohol-related Birth Defects (ARBD), and Alcohol Related Neurodevelopmental Disorder (ARND). These terms are considered to denote attribution of the outcomes of the impact of alcohol on the developing fetus (Sokol & Clarren, 1989). Guidelines for the diagnosis of these conditions have been published (Astley, 2004; Centers for Disease Control and Prevention (CDC), 1998; Chudley et al., 2005; Hoyme & et al, 2005).

What does the literature say about FASD?

Epidemiology

Prenatal exposure to alcohol produces a range of fetal effects, along a continuum from relatively minor behavioural and neurodevelopmental symptoms, to more serious and debilitating disabilities and to the clearly recognisable facial features that constitute FAS. A FAS-affected child will display facial dysmorphology, growth retardation, and dysfunction of the central nervous system (Astley, 2004; Centers for Disease Control and Prevention (CDC), 1998; Chudley et al., 2005; Hoyme & et al, 2005). FASD includes a range of other alcohol-related birth defects not diagnosed as FAS, such as structural defects of the heart, skeleton, kidneys, eyes and ears, as well as cognitive abnormalities that cause learning impairment and/or

[2] Proquest/Proquest Health & Medical Complete; Psychinfo/Psycharticles; Medline; ScienceDirect; ATSIHealth; Health & Society; Health Collection (Informit); PubMed; MedInfo.

[3] Fetal/Foetal Alcohol Syndrome/FAS, Fetal/Foetal Alcohol Spectrum Disorders (FASD), partial fetal/foetal alcohol syndrome (PFAS), alcohol-related neuro-developmental disorder (ARND), Alcohol Related Birth Defects (ARBD) AND resources, materials, culturally appropriate resources/materials, literature, service providers, Aboriginal and Torres Strait Islander (ATSI), health promotion/materials, harm minimiz/sation, government health services, drug & alcohol services, health care settings, and workforce development.

disordered or difficult behaviours (O'Leary, 2004; Peadon, O'Leary, et al., 2007; Stratton, Howe, & Battaglia, 1996).

The range of alcohol-related disorders encompassed within the term FASD are widely described as completely preventable, since alcohol is a teratogen, and FASD only affects those children whose mothers drank alcohol during pregnancy (Awopetu, Brimacombe, & Cohen, 2008; Blackburn & Whitehurst, 2010; Elliott et al., 2008; Kyskan & Moore, 2005; Peadon, O'Leary, et al., 2007). The notion that FASD is completely preventable is, however, complicated by the lack of clarity around a safe level of consumption, and by the complexities of the personal, social and economic realities of individual women and communities. The impact of alcohol use during pregnancy appears also to be dose-dependent (NH&MRC, 2009; O'Leary, Bower, et al., 2010) and to be mediated by maternal factors, including nutrition (Keen et al., 2010). Some studies in the relatively new fields of epigenetics/ecogenetics also point to the potential involvement of paternal, maternal and fetal genetic factors in risk vulnerability or as protective factors for FASD (Abel, 2004; Chambers & Jones, 2002; Haycock, 2009; Ouko et al., 2009; Warren & Li, 2005). Most recently, a large population-based birth-cohort study has drawn a link between IQ at age eight, fetal alcohol exposure, and genetic variants carried by both mother and fetus (Lewis et al., 2012). There is some evidence to suggest that older maternal age exacerbates the harmful effects on the fetus of drinking alcohol during pregnancy (Chiodo et al., 2010; Jacobson et al., 1998). This is of concern, since research shows that older women, at least in some cultures, are also more likely to drink alcohol while pregnant (US Department of Health and Human Services, 2007c).

There is widespread agreement in the literature that drinking heavily during pregnancy (more than 7 standard drinks a week)[4], and heavy episodic drinking (more than 4-5 standard drinks on any one occasion) (Dell & Roberts, 2007; US Department of Health and Human Services, 2007a), are clearly implicated in FASD, with risk to the fetus occurring throughout pregnancy (Boyles et al., 2010; Larroque et al., 1995; O'Leary, Bower, et al., 2010; O'Leary, Nassar, Zubrick, et al., 2010; Rosenthal, 1990). There is also evidence demonstrating that ingestion of 3-4 standard drinks (30-40 grams) on a single occasion increases the risk of fetal effects (O'Leary, Nassar, Zubrick, et al., 2010; Sayal, 2009). However, the situation is more complex than a simple one-to-one correspondence, as not all women who drink heavily during pregnancy will have a FASD-affected child (Astley et al., 2000; Centers for Disease Control and Prevention (CDC), 1998), and nor has the impact of light drinking during pregnancy, if any, been clearly established (Kelly et al., 2009; Kelly et al., 2010; O'Leary, Nassar, Zubrick, et al., 2010; Robinson et al., 2010; Sayal, 2007). The situation is further complicated by local variation in what is understood to be a 'standard' alcoholic drink (Abel, 1999; Colvin et al., 2007; Drug Info Clearinghouse, 2009; Witbrodt et al., 2007), the quantity of alcohol in a standard serve (Gill & Donaghy, 2004; Kerr et al., 2005), and reliance on maternal self-reporting in alcohol consumption (Ernhart et al., 1988; Hannigan et al., 2010).

[4] Defined as 10g alcohol in Australia, 12g in the USA, 13g in Canada, 8g in the UK.

There is debate around the effects of drinking alcohol at lower levels (1-2 standard drinks a week or per occasion) (Henderson, Gray, & Brocklehurst, 2007). For example, recent research reports no increased risk for behavioural or cognitive deficits in the children of light drinkers (1-2 drinks a week or per occasion) (Kelly et al., 2009; Kelly et al., 2010; Rodriguez et al., 2009) or for behavioural deficits in the children of light/moderate drinkers (between 2-10 standard drinks a week) (Robinson et al., 2010) or at 1-2 drinks per occasion and fewer than 7 drinks a week (O'Leary, Nassar, Zubrick, et al., 2010). However, behaviour problems have been reported following 3-4 standard drinks per occasion and no more than 7 standard drinks a week, indicating a relatively low threshold for fetal effects to occur (O'Leary, Nassar, Zubrick, et al., 2010).

Three of these studies (Kelly et al., 2009; Kelly et al., 2010; Robinson et al., 2010) reported a significant protective effect for child behaviour problems following low levels of prenatal alcohol exposure, generating considerable media interest and debate. Each of these three studies, and the predictable headlines they have attracted (see, for example, Boseley, 2010; Brooks, 2010a, 2010b), have drawn criticism for methodological issues and concern about the translation of the findings into a message that establishes light drinking in pregnancy as safe or even protective (Jacobson & Jacobson, 2010; Jaddoe, 2010; Sayal, 2009; Todorow, Moore, & Koren, 2010). However, their findings illustrate the contention surrounding the establishment of a safe lower level of alcohol ingestion in pregnancy.

A 2006 survey of 1103 Australian women of childbearing age found 24% would continue to drink if they fell pregnant, and 34% had continued to drink alcohol during a previous pregnancy (Peadon, Payne, et al., 2007). In Western Australia, a random sample of 4,839 non-Aboriginal women giving birth in 1995-1997 showed that 80% had consumed alcohol in the three months prior to falling pregnant, and 59% drank alcohol during at least one trimester. Fifteen per cent of women exceeded the recommended safe level of consumption in the first trimester of pregnancy, and 10% did so in the second and third trimesters (Colvin et al., 2007). Also in Western Australia, Zubrick and colleagues (2005) stated that in a survey of 5289 Aboriginal children and their families, 23% of mothers reported consuming alcohol during their pregnancy. The Public Health Agency of Canada reports that rates of alcohol use in pregnancy had declined over the 10-15 years up to 2007, with an approximation of less than 15% of Canadian women drinking while pregnant (Public Health Agency of Canada, 2007, p. 18). With regard to epidemiological studies conducted in Canada the report further notes:

> The focus on Aboriginal communities with high rates of alcohol abuse and regions with large concentrations of Aboriginal peoples has meant that Canada lacks epidemiological data regarding other populations, making it difficult to determine whether or not Aboriginal women are at greater risk than other groups (Public Health Agency of Canada, 2007, p. 24).

Rates of alcohol use statistics from the United States show that 1/30 women report high-risk drinking; 1/9 report heavy episodic[5] drinking in the first trimester; and more than 1/5 report alcohol use in the first trimester, 1/14 in the second trimester, and 1/20 in the third trimester (US Department of Health and Human Services, 2007c).

Prevalence/Incidence

Estimates of the incidence of FAS and FASD vary, since FAS is the most clinically recognisable form of FASD, consisting of measurable deficits (British Medical Association, 2007), whereas FASD itself extends to a more diverse and less easily clinically captured range of other fetal effects (see appendix A). Abel's earlier estimation of the prevalence of FAS worldwide (0.97/1000) (Abel, 1995), was "based almost entirely on [populations in] the USA" (Abel, 1998, p. 197). The 'American paradox' to which Abel refers in the title of his paper is the fact that the incidence of FAS in the US is higher than for all other countries in the study, while its per capita consumption of pure alcohol is relatively low.[6] A 1998 paper reported no cases of FAS per 1000 births in the UK, despite an estimation of the annual per capita consumption of pure alcohol in the UK at 7.3 litres. Reported figures were similar for a number of other western countries, including Germany, Italy, the Netherlands, Spain, Denmark, Canada, and Australia (Abel, 1998, p. 196).

In 2007, the British Medical Association noted that:

> Determining the incidence of FASD is complicated by a lack of reliable and consistent data collection, and the difficulty in diagnosing the range of disorders. Consequently, the incidence of FASD in the UK and internationally is not accurately known (British Medical Association, 2007, p. 1).

May and colleagues reviewed research into the epidemiology and prevalence of FAS and FASD in mainstream populations, with a particular focus on in-school studies. They concluded that the prevalence of FAS in "typical, mixed-racial, and mixed-socioeconomic populations of the US is at least 2 to 7 per 1,000" (May et al., 2009, p. 176). They further estimated the prevalence of FASD in younger school children in the US and some western European countries as high as 2-5% (May et al., 2009). Other recent research estimates the incidence of FASD in western countries as high as 9 per 1000 live births (Blackburn & Whitehurst, 2010).

In the United States, earlier research reported prevalence rates of FAS per 10,000 births for: Asians, 0.3; Hispanics, 0.8; Whites, 0.9; African Americans, 6.0; and Native Americans, 29.9 (Ma et al., 1998). A more recent publication of the US Department of Health and Human Services estimates that FASD affects nearly 40,000 newborns in the United States each year. The rate of FASD in the general population is estimated at 1% of all births, with rates of FAS between 0.5 and 2 per 1,000 births (US Department of Health and Human Services, 2007c), and between 1.5 and 2.5 per 1,000 births among

[5] Sometimes referred to as 'binge' drinking.

[6] Abel does however recognise the problems inherent in using per capita alcohol consumption as a proxy measure of the prevalence of alcohol consumption during pregnancy.

some Native American tribes (US Department of Health and Human Services, 2007b). The prevalence of FAS in Alaska is believed to be considerably higher, at 5.6 per 1000 live births for American Indians and Alaska Natives (US Department of Health and Human Services, 2007b).

In their report for the Public Health Agency of Canada, Dell & Roberts reported estimates of 2/1000 for FAS and 9/1000 for FASD in Canada, while noting that some studies "have suggested rates from 25 to 200 per 1,000 live births in some isolated northern communities" (Dell & Roberts, 2007, p. 5). Rates of FASD are said to be similarly elevated in some very high risk communities in South Africa, estimated to be as high as 40+ per 1000 (Molteno, 2008), and the rate of FAS/PFAS at 68.0-89.2 per 1000 (May et al., 2007). In Croatia, Petkovic and Barisic estimated a prevalence of 6.44/1000 for FAS, 34.33/1000 for PFAS and an overall prevalence of FAS/PFAS of 40.77/1000 (Petkovic & Barisic, 2010), based on a study of 466 primary school children (1st to 4th grade). A similar study of school children in two health districts in the Lazio region of Italy found a prevalence of FAS of 3.7-7.4 per 1000 children, and of FASD of 20.3-40.5 per 1000, estimated at 35 per 1,000 overall or between 2.3% and 4.1% of all children (May et al., 2006).

In Australia, reported rates of FASD vary by location and by Indigenous status. A Western Australian study linking data from the WA Birth Defects Registry and the Rural Pediatric Service found a prevalence of FAS of 0.02 per 1000 live births in non-Indigenous children, and 2.76 per 1000 live births in Indigenous children (Bower et al., 2000). Rates for FAS in the Indigenous population in the Northern Territory have been estimated to be 1.7 per 1000 live births, and for FASD 4.7 per 1000 live births (Harris & Bucens, 2003). Rates of FASD in far north Queensland were estimated at 15 per 1000 among Indigenous children (Coyne, et al., 2008). The national prevalence of FAS has been reported as 0.06 per 1000 live births (Elliott, et al., 2007).

It has been suggested that reported rates of the prevalence of FASD in Australia are likely to be underestimations (Burns et al., 2013; Elliott & Bower, 2004; Elliott, Payne, et al., 2006; Harris & Bucens, 2003; Kyskan & Moore, 2005). Elliott & Bower stated that accurate determination "is thwarted for a number of reasons" (2004, p. 8), among them: lack of access to antenatal care for women in rural, low socioeconomic and Indigenous communities; inadequate clinical data; the lack of validity of retrospective or self-reported alcohol consumption; and the difficulty and very low incidence of early diagnosis. In a later report, they noted results of a national study where just 6.5% of FAS-affected children were diagnosed at birth (Elliott et al., 2007) and of a Queensland study, where only 3% were diagnosed at birth (Coyne et al., 2008).

Commentary in the literature on FASD research

Some health professionals and sociologists have criticised the growing alarm over FASD, public policies recommending abstinence during or in the contemplation stage of pregnancy, and the growing tendency for society, in the US in particular, to hold women 'accountable' for 'fetal harm' as a result of various lifestyle choices (see also Annas, 1986; Armstrong, 2003; Armstrong,

1998; Armstrong & Abel, 2000; Daniels, 1996; Gavaghan, 2009; Lowe & Lee, 2010). Such criticisms revolve around four main arguments. First, that an exaggerated level of concern about FAS is an example of 'moral panic' (Armstrong & Abel, 2000). Second, that democratising the problem across class and ethnicity disguises the need for action to improve the personal, social, and economic circumstances of the most 'at-risk' mothers (Armstrong, 2003; Armstrong & Abel, 2000). Third, concern at the transformation of health advice into 'lifestyle rules', whereby the pregnant woman must self-consciously monitor both her behaviour and her choices, and be consciously aware of the prospective and potentially condemnatory scrutiny of her choices by others (Lowe & Lee, 2010). Finally, given the uncertainty in the evidence, that promoting abstinence as a blanket policy represents a 'paternalistic exception' unjustified within an accepted ethical convention of honesty and accuracy in detailing risk to patients (Gavaghan, 2009). It is important to note here that where we do not know safe levels of consumption for any other drug, there is much less contention to say the safest option is to not use. With alcohol, this pragmatic conservatism is often lost. However, while there is no ambiguity about the damaging effect of heavy drinking on fetal health, the equivocal evidence on the impact of light drinking, and the need to avoid stigmatising women, has suggested a nuanced approach to FASD health promotion.

The development of national and international responses to FASD

There are a number of sources referencing the origins of the recognition of the effects of prenatal alcohol exposure, and developments since the formal identification and widely published findings of FAS affected babies in 1973 in the United States by a team of doctors at the University of Washington, Seattle (Roberts & Nanson, 2000; Streissguth, 1997). For the purposes of this section of the review, we draw upon these secondary sources to provide an overview of the development of FASD as a health issue in the United States, Canada and Australia.

United States of America

It has been widely reported in America that the medical profession set in motion a huge research agenda on alcohol, pregnancy and FAS, which precipitated concern with “women’s alcohol problems, knowledge about threats to the fetus, research findings, and media attention” (Golden, 1999, p. 275). During the late 1970s and early 1980s this environment transformed FAS from a medical condition into a public health problem that concerned politicians, lawyers and public health advocates (Golden, 1999). While it has been noted that the medical researchers at the University of Washington (Jones & colleagues) have been key actors in the production of scientific knowledge about FAS – emphasising that the eight cases they originally presented came from three different ethnic groups with the common denominator being that each child had an “alcoholic mother” (Jones et al., 1973, p. 1270) – at the same time, they assumed advocacy roles for patients, embracing ideas around fetal rights and support services for families as part of their clinical and research strategies (Tait, 2003, p. 56).

In 1977, the National Institute on Alcohol and Alcoholism (NIAAA) held the first international research conference on FAS. Attendees "were so impressed with the findings to date that they collectively recommended that NIAAA issue the first government health advisory on FAS" (Warren, 2009, p. 20). The literature notes that this conference, and ensuing recommendations, soon caught the attention of the US Congress and the news media (who played an integral role in the education of parents) (Kyskan & Moore, 2005), and debate began on whether the risks of drinking during pregnancy warranted warning labels on alcoholic beverages (Warren, 2009). An infusion of federal funding in the United States for FAS research helped to support many new initiatives, leading to researchers in virtually every subspecialty of medicine responding to the new funding initiatives (Armstrong & Abel, 2000, p. 278). In turn, parents have pushed for diagnostic and remediation services (Kyskan & Moore, 2005).

Canada

The long-term relationship between members of the Washington group of medical researchers with their counterparts in Canada, especially with those from the University of British Columbia, is widely reported. This relationship partially explains why FAS has received significantly greater attention in the western provinces of Canada (Tait, 2003, p. 56), with policy implementation in these provinces noted as preceding a national policy agenda (Russell, 2007).

The Canadian approach to research, clinical and advocacy roles has been similar to that of the dominant model in the United States, and has influenced both policy and professional development (Tait, 2003). One of the major differences between the two countries would appear to be that of Canada's primary focus on the prevalence rates of FAS in First Nation communities, with the risk of FAS assumed to be much greater among pregnant Aboriginal women than among their non-Aboriginal counterparts (Tait, 2003).

In 1983, a National Symposium on FAS was held in Winnipeg, bringing together multi-disciplinary experts and representatives from different levels of government to discuss the problems associated with both prenatal alcohol exposure, and women and alcohol more generally (Tait, 2003, p. 112). The first FAS advocacy group was formed by medical professionals in British Columbia in 1985, comprising members from the fields of education, nursing, addictions and medicine (Robinson & Armstrong, 1988, p. 2). The central goals of the group were to raise awareness about the risks of prenatal alcohol exposure and to secure increased funding for FAS research across a broad spectrum of research questions (Robinson & Armstrong, 1988). This advocacy group organised the first Canadian conference on FAS in 1988, in conjunction with the University of British Columbia and the Sunny Hill Health Centre of Children (Robinson & Armstrong, 1988, p. 2). In 1994, following a parliamentary recommendation, the first FAS Resource Centre was established, under the banner of the National Clearinghouse on Substance Abuse, operated by the Canadian Centre on Substance Abuse (Russell, 2007).

In the early 1990s, grassroots activists/advocates – particularly parents (biological, adoptive and/or foster parents) – were mobilised through increasing knowledge about the teratogenicity of alcohol and its impact on babies and children. This knowledge began providing answers to the presenting behaviours of children in their care (Russell, 2007, p. 25).

Australia

While drug use in general in Australia has received a great deal of attention from the government, FASD has a shorter history of interest than in North America. Initial case reports of FAS in Australia were published in the early 1980s, identifying 27 children with FAS, of whom 18.5% had Aboriginal parents. All the mothers of these children had a history of heavy or heavy episodic drinking during the pregnancy or a history of chronic alcoholism (see, for example, O'Leary, 2002, p. 19).

In the late 1990s/early 2000s, the issue of FASD was progressing on three fronts: grassroots/community action, policy, and academic (for example, Bower et al., 2000). In 1999 the first advocacy/support non-government organisation, the National Organisation for Fetal Alcohol Syndrome and Related Disorders (NOFASARD), was incorporated. The incorporation of NOFASARD was precipitated by, among a range of other activities, the 1999 Prairie Province Conference on Fetal Alcohol Syndrome (Canada) and through concern about "the apparent lack of knowledge and education in our community about the damage that prenatal exposure can cause to babies" (Miers, 1999b, p. 14). A copy of this report was one of a suite of initiatives disseminated/initiated by NOFASARD to raise awareness of FAS at both the South Australian state and national levels (Miers, 1999a, 1999b, 2000).

Following on from these activities and outputs, the National Alcohol Strategy: A Plan for Action 2001 to 2003/4 (2001b) noted as a key strategy area how:

> Educational activities need to target adolescent girls and boys and women of childbearing age to inform them of the risks to the foetus of drinking to intoxication. Obstetricians, midwives, general practitioners, and other health professionals involved in providing antenatal care have the opportunity and should be encouraged to provide advice on low risk drinking during pregnancy (p. 10).

The background paper to this strategy, Alcohol in Australia: Issues and Strategies (2001a), specifically referenced 'fetal alcohol syndrome and related conditions' under the section 'chronic disease attributable to alcohol' (p. 9).

In 2001, the National Expert Advisory Committee on Alcohol (NEACA) instigated a review of the published scientific literature on FAS and ARND with the aim of giving the reader an understanding of FAS and related issues (O'Leary, 2002). The review noted how the NEACA "had become aware of the generation of new population data showing a high rate of FAS in [I]ndigenous communities, the efforts of FAS lobby groups, and the development of local prevention and education responses to FAS in a range of communities across Australia" (O'Leary, 2002, p. 3). Furthermore, an outcome of this review was the recommendation for a national workshop on FAS to be held, and the first

Australian Fetal Alcohol Syndrome National Workshop took place in 2002 (O'Leary, 2002, p. 3), representing the "first focus[ed] discussion on the effects of alcohol consumption on the fetus and development of the child in Australia" (Australian National Council on Drugs National Expert Advisory Committee on Alcohol, 2003, p. iv).

FASD is now much more widely researched in Australia (Burns et al., 2013; Elliott et al., 2013; Fitzpatrick et al., 2012; Hutchinson et al., 2013; Jones et al., 2013; O'Leary & Bower, 2012; Watkins et al., 2012). In September 2012, the Foundation for Alcohol Research and Education (FARE), in consultation with 33 leading FASD experts, released a National FASD Action Plan, incorporating a fully-costed design for addressing gaps in the prevention and management of FASD. The plan identified and addressed five priority areas: increase community awareness of FASD and prevent prenatal exposure to alcohol; improve diagnostic capacity for FASD in Australia; enable people with FASD to achieve their full potential; improve data collection to understand the extent of FASD in Australia; and close the gap on the higher prevalence of FASD among Aboriginal and Torres Strait Islander peoples (FARE, 2012).

FASD has also reached the formal agenda of the Australian Government, and the states and territories, across the areas of education, health, drug and alcohol services and child protection. Most recently, an inquiry has been conducted by the House of Representatives Standing Committee on Social Policy and Legal Affairs into Fetal Alcohol Spectrum Disorders. The report of this inquiry, entitled 'FASD: The Hidden Harm. Inquiry into the prevention, diagnosis and management of Fetal Alcohol Spectrum Disorders', was released on 29 November 2012 (House of Representatives Standing Committee on Social Policy and Legal Affairs, 2012). This report included 19 recommendations for a national plan of action on FASD, including a recommendation that such a national plan be publicly released by 1 June 2013. The Australian Government responded to this recommendation with the release of a Commonwealth FASD Action Plan on 6 August 2013 (Australian Government, 2013).

Policies on alcohol and pregnancy

O'Leary and colleagues (2007) reviewed policies on alcohol use during pregnancy in Australia and six other English-speaking countries in 2006 and found inconsistent messages across jurisdictions. In 2001, NH&MRC guidelines (NH&MRC, 2001) recommended that "women who are pregnant or might soon become pregnant" consume fewer than seven standard drinks per week, and no more than two standard drinks on any one day. In 2009, this recommendation was revised and now reads:

> For women who are pregnant or planning a pregnancy, not drinking is the safest option. For women who are breastfeeding, not drinking is the safest option ... It is not clear whether the effects of alcohol are related to the dose of alcohol and whether there is a threshold above which adverse effects occur (RCOG 2006). However, variation in effects can be due to the stage of development of the fetus at the time of exposure and to individual characteristics of the mother (NH&MRC, 2009, p. 67).

The NH&MRC guidelines later expand on this recommendation to state:

> Women who drank alcohol before they knew they were pregnant or during pregnancy should be reassured that the risk to the fetus is likely to be low if they had drunk at low risk levels (NH&MRC, 2009, p. 77).

Over the same period as the NH&MRC was developing its revised guidelines, parallel developments had been taking place among health and medical professional associations. The Royal Australian and New Zealand College of Obstetricians and Gynaecologists released a statement in June 2008 advising that, since a minimum safe level of alcohol use in pregnancy has not been established, it is "preferable that women avoid or minimise their intake of alcohol during pregnancy" (see, for example, RANZCOG, 2008). In a position statement released in 2009, the AMA advised, similarly:

> As there is no scientific consensus on a threshold below which adverse effects on the foetus do not occur, the best advice for women who are pregnant is to not consume alcohol (Australian Medical Association, 2009).

The United Kingdom also revised its advice in 2007, and recommended that:

> As a general rule, pregnant women or women trying to conceive should avoid drinking alcohol. If they do choose to drink, to protect the baby they should not drink more than 1 to 2 units of alcohol once or twice a week and should not get drunk (Department of Health, 2009).

In Canada the message is stronger, to the effect that "There is no safe amount or safe time to drink alcohol during pregnancy" (Government of Canada, 2008).

In the US, the policy about alcohol and pregnancy has stayed consistent since the early 1980s. The advice from the US Surgeon General is:

> 1. A pregnant woman should not drink alcohol during pregnancy. 2. A pregnant woman who has already consumed alcohol during her pregnancy should stop in order to minimize further risk. 3. A woman who is considering becoming pregnant should abstain from alcohol. 4. Recognizing that nearly half of all births in the United States are unplanned, women of childbearing age should consult their physician and take steps to reduce the possibility of prenatal alcohol exposure. 5. Health professionals should inquire routinely about alcohol consumption by women of childbearing age, inform them of the risks of alcohol consumption during pregnancy, and advise them not to drink alcoholic beverages during pregnancy (US Surgeon General, 2005).

Evaluations of interventions to reduce alcohol use during pregnancy

In a 2008 report of a systematic review of the international published evidence pertaining to the relative effectiveness of primary, secondary and tertiary strategies to reduce the burden of FASD, Elliott and colleagues (Elliott et al., 2008) found that:

- there is no strong evidence that any one primary prevention strategy[7] is more effective in reducing alcohol consumption during pregnancy. Evaluations of strategies included in the few papers that were identified were of warning labels on alcohol bottles, an educational campaign, and an alcohol ban (Elliot et al., 2008, p. 7). The most effective primary prevention strategy evaluated was alcohol prohibition. There was no evidence that warning labels on alcohol bottles or mass education campaigns reduce alcohol consumption in pregnant women (p. 132);
- of the 13 identified secondary prevention programs[8], a brief intervention involving education and behavioural modification components was found to have significantly reduced prenatal alcohol consumption. A third publication described pooled results from nine different drug treatment programs. The authors of the report note, however, that it is difficult to identify factors critical to the success of these interventions as many of the features of these programs were also present in studies which found no benefit from the intervention (p. 132); and
- of the 14 identified tertiary prevention programs[9], one significantly reduced prenatal alcohol consumption. This intervention was an intensive drug and alcohol prevention program evolving from a 4-5 hour a day, 5 days a week outpatient program to a 7-8 hours a day, 5 days a week onsite residential program. The authors note that it is likely that the success of this program was related to its comprehensive nature (p. 132).

They concluded that there is no strong evidence to suggest that any particular type of intervention is effective at reducing prenatal alcohol consumption. The authors noted, however, that interventions were generally more effective in women who consumed low levels of alcohol at study entry, with some evidence that providing pregnant women with any information about the risks of alcohol consumption during pregnancy (advice on not to drink, receiving a short pamphlet or given a brief alcohol assessment by a medical provider) resulted in reduced alcohol consumption (pp. 132/133). High-risk women, on the other hand, were noted as less able to change their drinking behaviour and interventions need to provide both information about alcohol use in pregnancy and alcohol dependence (pp. 132-133).

The authors reminded us that all of these results must be considered in the context of the small number of published studies identified and the low-level of evidence available, since lack of evidence is not the same as saying there is evidence that a strategy is not effective. McBride (McBride, 2009) also noted that in a systematic review of interventions to reduce alcohol use during pregnancy and breastfeeding (conducted on studies published between 1990 and June 2009) very few well conducted primary studies were identified. This has also been noted in other recent Cochrane Database reviews (Lui,

[7] Primary prevention referring to aiming to reduce the incidence of FASD in the general population.
[8] Secondary prevention referring to aiming to reduce the incidence of FASD in pregnant women.
[9] Tertiary prevention referring to aiming to reduce the incidence of FASD in women at high risk of having a child with FASD.

Terplan, & Smith, 2008; Nabhan & Faris, 2010; Stade et al., 2009). Wilson and colleagues (2010), in a paper on the harmful use of alcohol amongst Indigenous Australians, similarly note that the evidence for the effectiveness of alcohol intervention programs for Indigenous Australian populations is scant (Wilson et al., 2010, p. 10). The authors go on to note, however, that the available evidence does indicate that, for interventions to be effective, they should: have the support of and be controlled by local communities; be designed specifically for the needs of a particular community and sub-groups within the community; be culturally sensitive and appropriate; have adequate resourcing and support; provide aftercare; and, cater for complex presentations. Most importantly, they noted, a single intervention should not be seen as a quick fix, and a combination of harm minimisation strategies is most effective (Wilson et al., 2010, p. 12).

Prenatal screening tools

Elliott and colleagues' (2008) report on the seven publications included in their systematic review that had evaluated pregnancy specific screening tools, TWEAK and T-ACE. They noted that unlike general alcohol screening tools, which were designed to detect harmful alcohol use in the general population, TWEAK and T-ACE were specifically designed to detect the lower levels of alcohol consumption that may affect fetal development in pregnant women. All identified publications reported that the T-ACE[10] and TWEAK[11] were at least as effective as other general screening tools, such as the AUDIT or the MAST,[12] and were generally shorter and easier to administer. The authors noted that the combined evidence from the literature indicates that these are the most appropriate screening tools to use in the clinical setting (p. xiv). In the context of screening tools for use with Indigenous populations, Dawe and colleagues (2002) noted the growing awareness of the need to use culturally appropriate measures within alcohol and drug services, but caution that there have been few investigations of the reliability and validity of screening instruments within this population (Dawe et al., 2002, p. 47).

Evidence-base for the development of FASD resources

In the absence of a well-defined evidence base to guide intervention, contemporary public health emphasises a community-based approach to health promotion and prevention strategies (World Health Organization (WHO), 2009). Formative research, as part of that process, is key to improving the relevance, sustainability, and effectiveness of community-based public health programs and is used, among other purposes, to test concepts, product or message design and to pre-test materials with the target audience (Glanz, Rimer, & Lewis, 2002). This involves speaking directly with the target group (focus groups, surveys, in depth interviews) as programs that resonate with the target audience and meet their needs will be most effective in creating change (McBride et al., 2004). While a search of the literature on community-based formative research revealed a number of publications across the health and wellbeing spectrum, there has been some recently

[10] T-ACE is an acronym for Tolerance; Annoyed; Cut down; Eye opener.

[11] TWEAK is an acronym for Tolerance; Worried; Eye opener; Amnesia; (K) cut down.

[12] AUDIT is an acronym for Alcohol Use Disorders Identification Test; MAST is an acronym for Michigan Alcoholism Screening Test.

published Australian formative work specifically in the area of the development of FASD resources (McBride et al., 2008; Payne et al., 2011; Peadon et al., 2011) .

The most recently published study relates to the Alcohol and Pregnancy Project (Payne et al., 2011) on the evaluation of the uptake of the educational resources that were developed, produced and distributed to health professionals in Western Australia, and on the related paper 'Health Professionals Addressing Alcohol Use with Pregnant Women in Western Australia: Barriers and Strategies for Communication' (France et al., 2010). In the development phase of the project, the researchers synthesised the literature relevant to health professionals' practice and knowledge about the prevention of prenatal alcohol exposure and FASD, conducted formative research with health professionals (including Aboriginal health workers, allied health professionals, nurses working in the community, general practitioners, obstetricians and paediatricians), Aboriginal and non-Aboriginal women of childbearing age, and perspectives of Aboriginal and non-Aboriginal consumer and community representatives. Focus groups and in-depth interviews were conducted with 53 health professionals and 57 women of childbearing age to explore topics relating to the communication of information on alcohol consumption during pregnancy and its effects on the fetus (Payne et al., 2011, p. 60). Data were specifically collected to inform the development of written resources on alcohol use in pregnancy appropriate for Western Australian health professionals to enhance their knowledge and support their practice with pregnant clients (France et al., 2010). We are unclear if the formative research findings with Aboriginal and non-Aboriginal women of childbearing age have been included in these publications.

Importantly, the research identified barriers to health professionals addressing alcohol use with pregnant women and grouped the findings into four themes:

- how health professionals perceive their clients;
- how health professionals prioritise their practice;
- concern for the client and the health professional/client relationship; and
- health professionals' need for skills and resources to support their practice.

Based on the literature review and the formative research, four resources were developed, and the paper reports that of the responding health professionals who cared for pregnant women 54.6% used one or more of the resources (Payne et al., 2011, p. 72), and the majority of those who reported seeing the resources (79.6%) had used them (Payne et al., 2011, p. 76). It was also reported that of a sample of 593 health professionals who cared for pregnant women, there was no increase in the proportion of health professionals overall (and a small increase in obstetricians) who routinely asked pregnant women about alcohol use (Payne et al., 2011, p. 64).

Findings from a national survey on women's knowledge and attitudes regarding alcohol consumption in pregnancy were published in 2010 (Peadon et al., 2010) where it was reported that, of the study cohort, one in three

women of childbearing age said they did not know any adverse effects of alcohol consumption in pregnancy (p. 5). It was also found that while most study participants agreed that pregnant women should not drink alcohol and reported a negative attitude towards alcohol consumption in pregnancy, one-fifth had a neutral or positive attitude towards alcohol consumption in pregnancy (Peadon et al., 2010, p. 5). The authors acknowledge that the knowledge and attitudes regarding alcohol and pregnancy may be different in Indigenous women compared with non-Indigenous women and that a separate study of Indigenous women's knowledge and attitudes is warranted. For the study participants who had seen information about alcohol and pregnancy, the most common sources were: brochures or pamphlets (31%); traditional media, such as programmes or newspapers or magazine articles (26%); television advertising (19%); and health professionals (16%). Forty seven per cent of participants nominated health professionals as the best source of information with brochures coming in at 9%. Overall, it was reported that women's preferred information sources vary with age, with the authors suggesting that strategies to reduce fetal alcohol exposure and prevent FASD should include health professional education and clear guidelines delivered via the preferred media as identified by the study participants (Peadon et al., 2011).

While not specifically addressing the issue of FASD resources *per se*, McBride and colleagues (2008) identified that the most common settings for alcohol use by the study women was in either their own home (67.7%) or at a friend's house (15.4%). The authors suggest that the private nature of alcohol consumption by pregnant women provides important information to assist in defining the form and targets of potential interventions. However most obstetricians do not ask pregnant women about alcohol use (Elliott & Bower, 2008; Payne et al., 2005). In addition to refined obstetrician/health-carer intervention, interventions that target site and situation drinking may be important to generate change (McBride et al., 2008, p. 4).

Range of available resources/interventions

For the purposes of this project, Australian resources dealing with FASD have been sourced from all states and territories and internationally. Some states have produced considerably more internal resources than others, and we are aware of the existence of more locally produced resources than we have been able to obtain physical copies of (as suggested by personal communications from service providers). Internationally, resources are available from other English-speaking countries, including the UK, Ireland, the US, Canada, South Africa and New Zealand. As well, there are documents written in English available from the World Health Organization, Eurocare, the Netherlands and Sweden. From research on the worldwide web, there also appears to be resources available within some other European countries, however, these documents are written in the language of the country of origin and were thus not accessible for this review.

Most located resources are readily available on the worldwide web. Resources cover a number of different perspectives on the issue, including policy and strategy documents, guidelines and training materials for health

professionals, fact and information sheets for carers and FASD individuals, websites of support organisations, literature reviews, lists of resources and websites, and details and reports of conferences. There is also an extensive body of academic literature around FASD issues accessible via research databases. In terms of volume, literature from the United States and Canada continues to dominate the field, with a relatively small group of Australian researchers maintaining a significant presence. Relatively little of the academic literature is directed towards FASD individuals or families, with the vast majority directed toward informing governments and health professionals of the breadth of the problem and of the need for more attention to policy intervention and education around issues of alcohol and pregnancy. The extent to which the academic literature has influenced the development of resources for health professionals, particularly those being developed for and by Aboriginal Medical Services/non-governmental organisations, is unclear apart from the various presentations on FASD, where very often the literature is cited.

Given the uncertainty around establishing a safe lower level of alcohol consumption in pregnancy or while breastfeeding, the advice in the resources located for this study varies between the stronger message that pregnant women should not drink at all, and one that advises 'less drinking is better, no drinking is best'. Comprehensive but not exhaustive lists of national and international resources and their properties are included at Appendices A and B to this report.

Summary

In summary, the estimated prevalence of FASD, both overseas and in Australia, is relatively low in the general population, but is considerably higher among rural, lower socioeconomic and Indigenous groups. Research points to the prevalence of FASD being underestimated, due to a number of factors including: the difficulty of diagnosis, health professionals' lack of knowledge and/or resources around FASD, and hesitation in asking women about their alcohol use in pregnancy. There is limited published research that evaluates FASD resources for use by health professionals, and very few well-conducted primary studies of effective interventions. The ingestion of alcohol during pregnancy is necessary for the development of FASD, however, the personal, social, and economic factors in the lives of many women, as well as the social mores surrounding the drinking of alcohol, are recognised as component factors, mediating the potential for women to have a FASD-affected child.

The research literature clearly establishes the link between high alcohol intake and heavy episodic drinking and FASD, but there is much less certainty in the evidence around the effects of low and moderate drinking. As noted earlier, there is some criticism, in the literature around FASD, of the abstinence policy, as exemplifying a shift in the balance between the rights of mother and unborn child and as limiting women's choices and extending the social monitoring of pregnant women. Australian guidelines, and most other government and non-government bodies dealing with FASD issues recognise – and most state in their literature – that there are methodological issues with much of the research, and that the evidence base around a safe lower level of

alcohol consumption is unclear. That being so, both sectors have largely responded to this uncertainty by advising women who are pregnant or breastfeeding, or who are attempting to become pregnant, that the safest course is not to drink any alcohol at all. The varied and complex influences on women around their ingestion of alcohol, including their social situations and the influence of partners, friends and families, point to the need for the development of multi-level and multi-targeted policies, programs and resources that raise awareness of the issue of FASD and provide information and practical support for health professionals and for their diverse client groups throughout Australia.

The National Indigenous FASD resource

This project focused on establishing the types of resources around alcohol, pregnancy and FASD that are required by health professionals working with Aboriginal and Torres Strait Islander individuals and communities across Australia. The consultation process was designed to develop an understanding of the level of knowledge health professionals and community members have about FASD, and to determine what kinds of culturally safe and acceptable resources best suit local needs.

FASD PosterMaker is an easy to use app designed to enable the creation of Indigenous specific, locally relevant Fetal Alcohol Spectrum Disorders (FASD) resources for communities and health staff. This app provides pre-loaded messages and images to create informative and educational resources about the harms associated with consuming alcohol while pregnant and maintaining a healthy pregnancy.

Methodology

Introduction

The project comprised seven main phases:

1. the establishment of a Reference Group to oversee the project;
2. the identification and review of existing FASD health promotion resources, in particular those designed for Aboriginal and Torres Strait Islander health professionals and communities;
3. 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 for use with Aboriginal and Torres Strait Islander people across Australia and for the development of targeted FASD resources for specific communities;
4. extensive consultation with key stakeholders, including Aboriginal and Torres Strait Islander community controlled organisations and other peak Aboriginal organisations, including the Western Australian Drug and Alcohol Office (DAO), government and non-government organisations, Aboriginal health workers and Aboriginal women and men;
5. data analysis;
6. workforce development; and
7. evaluation of responses to the consultation process and templates of 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 ACCHSs 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.

Ethics

The research has a specific focus on resources for Aboriginal and Torres Strait Islander peoples. The project was guided by the National Health & Medical Research Council (NH&MRC) Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Health Research (2003), particularly those related to reciprocity, respect, quality, responsibility, survival and protection, and spirit and integrity. These values are relevant to all human groups, but especially to those with histories of marginalisation. The research approach, Participatory Action Research, necessitates close attention to and conformity with these values at all stages of the research process.

Formal ethics approval for the research was obtained from the Curtin University Human Research Ethics Committee on 12 November 2010 (HR 131/2010), the Aboriginal Health Research Ethics Committee of South Australia on 17 May 2011 (04-11-393), the Central Australian Human Research Ethics Committee on 20 May 2011 (2011.05.02), and the Aboriginal Health & Medical Research Council of New South Wales on 13 June 2011 (790/11). The project received support from both the Chair and interim Chief Executive Officer of the National Aboriginal Community Controlled Health Organisation (NACCHO), providing contact with NACCHO affiliates throughout the country. Consultations and data collection occurred between October 2011 and June 2012.

Reference Group

Terms of Reference for the National Aboriginal and Torres Strait Islander FASD Prevention Reference Group were finalised in October 2010 and the Reference Group was formed in early 2011. The Reference Group includes members from each state and territory, both Indigenous and non-Indigenous, with representatives from affiliates of the National Aboriginal Community Controlled Health Organisation (NACCHO), the Department of Health and Ageing Drug Strategy Branch, the Office of Aboriginal and Torres Strait Islander Health (OATSIH), Aboriginal and Torres Strait Islander community controlled service providers (ACCHS), clinical service providers, the WA Drug and Alcohol Office (DAO), academics and representatives from non-government organisations with expertise in issues around alcohol and pregnancy, and consultants with expertise in Aboriginal and Torres Strait Islander service delivery, research and policy development. Reference Group Terms of Reference and the list of Reference Group members can be found at Appendices C and D respectively.

Collaboration with WA DAO

A Memorandum of Understanding (MoU) between Curtin University through the NDRI and DAO was finalised in July 2011. The MOU formalised the

commitment towards collaboration between this project and the DAO Strong Spirit Strong Future project, funded by the Council of Australian Governments (COAG), in the development of culturally secure resources for health care professionals to address issues of alcohol, pregnancy and FASD. Members of the project teams have met regularly to exchange ideas and information.

Review of FASD resources

The review of FASD resources included both a desktop search of academic and 'grey' literature around alcohol, pregnancy and FASD, as well as sourcing available resources on these issues from national and international government and non-government organisation websites. Resources collected and reviewed included academic papers, policy documents, reports, training manuals for health professionals and trainers, resource packs and guides, action frameworks, conference reports, briefing papers, toolkits, websites, books, DVDs and rap songs, leaflets, brochures, posters and fact sheets. As previously noted, lists of these resources are included at Appendices A and B.

Identification of the processes required to develop templates

A workshop was held with Reference Group members and the research team in Perth on 31 March 2011, with 16 of the 17 Reference Group members attending.[13] The Reference Group was asked to consider and advise on:

1. the community consultation processes to be followed, including:
    - whether all states and territories should be included in the consultations;
    - the steps needed to ensure the consultation process was culturally safe and appropriate;
    - the processes for stakeholder identification and recruitment; and
    - what information should be provided in the consultation package.
2. a critical review of FASD resources used in various jurisdictions:
    - how acceptable they felt resources in use in various jurisdictions were;
    - whether any resources in use could be modified for other jurisdictions; and
    - what types and range of resources were appropriate in various jurisdictions.
3. a selected sample of resources designed for and in use in the general population, specifically designed for and in use in Aboriginal and Torres Strait Islander populations in Australia, and designed for and in use with Indigenous populations internationally.

The summary of outcomes from this workshop is included at Appendix E.

Consultations with key stakeholders

Engagement process

It was clear from discussions with the Reference Group that all states and territories (other than Western Australia) should be included in the consultation process. The research team initially followed a top-down

[13] The Reference Group was expanded to 18 in December 2011 to include a representative from the Aboriginal Health & Medical Research Council of NSW (AH&MRC).

approach, contacting peak Aboriginal and Torres Strait Islander organisations about the project and seeking their support and assistance. A letter of support for the project was provided by Mr Justin Mohamed, Chair of NACCHO, in March 2011, and information about the project was sent by NACCHO to its state and territory affiliates in April 2011. From the beginning of May 2011, research managers followed up by writing or calling directly those ACCHSs identified by NACCHO, and providing brief information sheets as an introduction to the project to all ACCHSs who responded.

At the same time, a draft set of questions for health professionals and community members was developed to guide the consultation process and to ensure that questions were standardised across all sites. This was provided to the Reference Group for feedback, which was received and incorporated by the end of June 2011. Consultation packs were sent out over the next two months to all ACCHs who had indicated an interest in participating in the project, and negotiations continued with services in each state and territory to recruit support for the consultations.

With the exception of South Australia, where the Aboriginal Drug and Alcohol Council (ADAC) had agreed to organise and facilitate consultations in that state, it had become clear by the end of August 2011 that attempts at recruiting relevant/interested Aboriginal Medical Services and other peak Aboriginal and Torres Strait Islander organisations via telephone and email, from Perth, were proving largely unproductive. While many of the services contacted were interested in the project, and willing to assist, they were finding what they were being asked to do – that is, to employ a local facilitator, and to organise and conduct the focus groups with local health professionals and community members – onerous. The research team met in early September to revisit the overall methodological approach, and agreed to a revised approach that included:

1. Enlisting the support of Coralie Ober from the Queensland Aboriginal and Islander Health Council (QAIHC) and Mark Saunders from the National Aboriginal and Islander Community Controlled Health Organisation (NACCHO) to provide us with contact names and introductions in as many jurisdictions as possible. The project managers and two Chief Investigators (Dennis Gray and Ted Wilkes) met with Coralie Ober and Mark Saunders in Canberra on 11 September 2011 to discuss engagement strategies and gather contact information for services and other key stakeholders in various jurisdictions.
    - Project managers received advice on the engagement process and were provided with contact details for key people in services in Queensland, Victoria, New South Wales, Tasmania and the Northern Territory.
2. Adopting an approach where project managers travelled to meet with CEOs/managers/health professionals in some locations to introduce the project in person and to secure interest from local services. As part of this approach, it was decided that interested services would be provided with the option of either being contracted to organise and facilitate the consultations (as envisaged in the project plan) or of participating in consultations organised and facilitated by the project managers. Where services chose the first

approach, it was agreed that the project managers would offer to attend these consultations to provide support and assistance for local organisers and facilitators.

- The project managers met with the manager of the social health team at one service in the Australian Capital Territory on 10 September to further discuss participation in the project, following from a number of phone conversations. Participation from this service was secured on the basis that the project managers assist with organisation where necessary and facilitate the focus groups.
- The project managers travelled to Brisbane in the week of 14 November, where Coralie Ober had organised a meeting/focus group with local health professionals. All three then travelled to Cairns, where introductions and meetings with local health professionals had been organised by Mr Bevan Ah Kee (QAIHC). Three further consultations, to be held in early 2012 – one in Brisbane and two in Cairns – resulted from these meetings.
- Between September 2011 and April 2012, participation in consultations was also secured from two services in New South Wales, two services in Victoria – one of which later declined participation due to a change in CEO and related issues – and from one service in Tasmania.
- Many of the services involved in the consultation process invited and included health professionals working in other services in the area in their consultations.

Consultation process

In total, 17 consultations were conducted, involving approximately 210 participants, across six of the seven jurisdictions covered by the project. Despite some protracted negotiations, due to a range of practical issues, including staff turnovers at key sites and local concerns around unrelated issues, it was not possible to secure any consultations in the Northern Territory. There were seven consultations with health professionals, five with community members, and five joint community/health professional consultations[14]. Many participants in the health professionals' consultations were also present as community members and comfortably moved between 'hats' in their responses to questions. The project managers attended and assisted local facilitators in all consultations, with the exception of three of the four consultations conducted in South Australia. These consultations were organised and managed by ADAC staff.

Table 1: Consultation key

Code	Location	Source	Participant nos
A1	Australian Capital Territory region #1	Community	21
A2	Australian Capital Territory region #1	Health professionals	
B1	New South Wales region #1	Community	15
B2	New South Wales region #1	Health professionals	
B3	New South Wales region #2	Community	15
B4	New South Wales region #2	Health professionals	
C1	Queensland region #1	Community	25

[14] Throughout this report, the term 'health professionals' refers to all participants attending health professionals' consultations, and includes early childhood and child care workers, AOD workers, sexual health workers and youth workers.

C2	Queensland region #1	Health professionals	
C3	Queensland region #2	Health professionals	20
C4	Queensland region #2	Health professionals	
D1	South Australia region #1	Community/ health professionals	66
D2	South Australia region #2	Community/ health professionals	
D3	South Australia region #3	Community/ health professionals	
D4	South Australia region #4	Community/ health professionals	
E1*	Tasmania region #1	Community	13
E2*	Tasmania region #1	Health professionals	
F1	Victoria region #1	Community	35
F2	Victoria region #1	Health professionals	
Totals	**Consultations: 17***		**210**

*Consultations with E1/E2 were conducted together but participants identified as either health consultants or community members and so responses were separated in the analysis process

All but one of the consultations followed a similar pattern. Most consultations began with introductions and a Welcome to or Acknowledgement of Country, followed by a short description of the project, the purpose of the consultation, and an overview of the consultation process. Facilitators and/or project managers then prompted participants to think about and provide responses to the same sets of questions across jurisdictions. These varied depending on whether they were directed at health professionals or community members, but both sets of questions primarily revolved first around issues of awareness, process, attitudes and needs, and then around responses to the same set of resources across all consultation sites. Question sheets were provided in consultations for participants to make notes against individual questions; in some places, participants chose to provide verbal answers only, which were transcribed by the project managers. With the permission of participants, the project managers took notes of responses, themes and discussions throughout all consultations they attended. The average length of consultations was three hours, but where time was available and participants wished to continue, were extended to four and, in one case, over five hours. Indirectly this substantial commitment of time illustrated the importance accorded the issue.

The single consultation where this process differed was a community consultation which took place at a ‘Mums and Bubs’ group. It was felt that the usual process needed to be adapted in this context, and so the project managers moved around among the children and activities and took the opportunity to speak to the mothers about their knowledge of and thoughts around alcohol and pregnancy, and to gather information about available services in the local area. The resources were only discussed in general terms in this consultation and, at just over two hours, this was the shortest of all consultations.

Although the focus of the consultations was on the standard questions and the resources, almost all consultations included more general discussion around alcohol use generally, and peoples' concerns for their communities. While no questions about individual alcohol consumption were asked, many participants – in the community consultations particularly – voluntarily made personal disclosures of their own or family members' relationships with alcohol, and of their concerns for some of the children in their own or others'

care. They spoke of a lack of awareness, both in the past and presently, around the dangers of alcohol in pregnancy and of the social issues that impact upon alcohol use within communities. Many participants asked to retain the resources used in the consultations and, at a number of consultations, the project managers were asked for and provided details of such things as website addresses where people could locate further materials.

Overwhelmingly, participants in the consultations were welcoming, interested in the project, and expressed a desire for more knowledge around Fetal Alcohol Spectrum Disorders to be made available to them. Importantly, almost without exception, health professional and community participants in the consultations were concerned that issues of alcohol related harm be addressed holistically, within a context of the wider spectrum of social determinants of health.

Data analysis

A coding scheme was developed to facilitate a systematic, comparative thematic analysis of the qualitative data collected during focus group consultations. The coding scheme drew upon the major categories developed to guide the focus group consultations; that is according to:

Community members' consultations:

- knowledge of FAS/FASD;
- attitude towards FASD messages;
- input on future resources;
- implementation of resources into the communities; and
- evaluation of resources

Health professionals' consultations:

- addressing the issue of alcohol use in pregnancy/breastfeeding and FASD;
- attitude towards FASD messages;
- input on future resources;
- implementation of resources; and
- evaluation of resources.

Qualitative data gathered at each of the focus group consultations were extracted and entered into an electronic database. Any identifying markers were removed and replaced with a case file number allocated to geographical areas. Data were analysed using a pre-determined method to ensure consistency of approach, to identify and follow a chain of evidence, and to increase accuracy of interpretation. Analysis included: stating the question; developing a matrix of response themes; describing the range of responses and categorising these responses; providing direct quotations to illustrate responses; and, providing interpretive discussion (Denzin & Lincoln, 1998; Kvale, 1996; Kvale & Brinkmann, 2009; Shedlin & Schreiber, 1995).

The data were then reported upon according to:

- how individuals and groups within their respective focus group consultation responded to each question/topic:
    - 'what are community saying?';

- ‘what are health professionals saying?’; and

- how participants across all sites responded to each question/topic to identify consistencies and differences:
  - ‘what are the similarities across communities?’;
  - ‘what are the similarities and divergences across community and health?’.

The major themes that emerged were then used to form the main areas for discussion in the report.

Development of iPad/Web PosterMaker app

Processes included:

- analysis of data leading to identification of several key themes considered integral to resources addressing the issues of alcohol, pregnancy and FASD;
- discussions with app developers on how best to respond to the outcomes of the consultations;
- contracted app developers to design and develop the iPad/Web FASD PosterMaker app;
- developed evidence-based statements, based on literature review, that were trialled with Reference Group before inclusion in the app. These statements are ‘locked’ so that the integrity of their message remains;
- contracted local illustrator to develop sets of images that reflect the themes considered appropriate and relevant to participants. These images were trialled with Reference Group and Indigenous service providers to check for cultural security;
- developed poster templates as examples of completed images for users’ ease;
- trialled at workshop in Adelaide to check for cultural appropriateness, functionality, and evaluation and feedback; and
- finalised the app.

Workforce development

Workshop

On 11 June 2013, the project managers held a one day training workshop in Adelaide for health professionals who had been involved in the consultation process. A total of seven health professionals, from New South Wales, Queensland (two participants), South Australia, Tasmania, Victoria and the Australian Capital Territory, attended the workshop. Each of the States/Territory where consultations were held were represented.

The purpose of the workshop was to trial the iPad app, to train participants in its use and to gain valuable feedback prior to its finalisation. The Senior Designer of the app also attended and was available to answer queries/questions as they arose. It was felt that his presence was very important, not least as the project managers had not had access to the app prior to the workshop.

The workshop was very successful and involved:

- a presentation/overview of the project, highlighting the key issues that emerged throughout the consultations;
- presentation of the app and its functionality;
- participant experimentation with the app;
- evaluation/feedback to the app, including to the textual and image-based content; and
- evaluation/feedback to the workshop overall.

Training videos

In our consideration of 'workforce development' as an ongoing requirement, it was understood that the workshop alone would not be sufficient to address the needs of a wider audience than those participating that day. Furthermore, while one of our briefs to the app designers was for a user-friendly and intuitive platform, we also recognised the need to provide the opportunity for users to access training in its use in a convenient way.

For this reason, we contracted the developers to produce a series of training videos to be embedded within the app. These training videos cover nine areas, set behind the 'how to' button, and cover:

- Introduction
- Using Templates
- Positioning Layers
- Background Layers
- Text Layers
- Image Layers
- Shape Layers
- Saving and Printing
- Syncing and Offline Use.

Evaluation of templates of resources

PosterMaker app

The workshop had been the first opportunity for the research team to trial the app; they had not had access to a full, working version prior to that day. Responses ranged in their scope and included suggestions for enhancements to the functionality/appearance of the app, including:

- make instruction keys darker;
- will we have the ability to wrap the text around an image?
    - since we have 'locked in' the key messages this is not possible. It is, however, possible for users to create and insert their own text where this will be an option;
- confusion around 'layers' – participants wondered if this was appropriate terminology
    - the training videos clarify the meaning of layers;
- a concern that any person in the world can, potentially, create a poster including 'mainstream' health professionals and there are no controls for this;
- very good idea for users to have the capacity to import their own images
    - all participants felt that there would be a big uptake of this option.

A diverse range of suggestions were made when asked for feedback on the text and images, highlighting the challenges inherent in the production of resources to suit all populations. Comments included:

> C*lothing [in one image] is dull in colour.*
>
> *Remove the book from the health professional's hands.*
>
> *Remove 'you are' and replace with 'you're'.*
>
> *Remove 'remember to' in the sentence 'remember to stay healthy throughout your pregnancy'.*

Overall, all participants confirmed that they would either use the app themselves and/or recommend its use to other health and related professionals. Examples of specific comments included:

> *Well done, you're on the money with this – it's the only way to go…*
>
> *Love it – it's exactly what we need. We can create what works for us.*
>
> *I'm going to show my colleagues at a workshop next week…*

All but one of the health professionals present at the workshop had attended at least one consultation each (the exception was new to her role since we had carried out the consultations with her colleague) and it was strongly expressed that the PosterMaker app was an appropriate outcome of the consultation process.

Further trialling of the app

Immediately following the training workshop held in Adelaide, invitations were sent to the Department of Health, all Reference Group members, and all Chief Investigators involved in this project for them to assess the functionality, efficacy and appropriateness of content of the iPad PosterMaker app prior to its finalisation. Since this first invitation, contact was maintained on a regular basis with the Department of Health and with Chief Investigators involving ongoing discussions around implementation of suggestions for enhancements.

Overall, the feedback received ranged in scope and included, among other things:

- recommendations and links to Indigenous artists as possible collaborators in designing the images;
- inclusion of additional pre-loaded templates to provide communities with a number of choices should they not have the capacity to create their own;
- some alterations in wording at various points throughout the app to provide maximum clarity for users; and
- 'locking in' the key evidence-based text to preserve its integrity.

Each suggestion received was accepted as important to the overall functionality, efficacy and appropriateness of the app and were implemented by the app designers.

In addition to the above, the research team designed a short and simple evaluation survey, which has been embedded in the app, for a wider participation in the evaluation process. This evaluation survey is anonymous and voluntary. All responses will be forwarded to the app developers' network/database and, having administrator access rights to this database, the research team can log in, search and export all evaluations received. It is proposed that this task be carried out on a monthly basis for the first six months after launch of the app.

'Man Up/Woman Up' apps

The apps were trialled with young people working at NDRI of different sex and cultural backgrounds, including an Indigenous woman. There was a range of responses, including:

> *Twenty questions are enough.*
>
> *Finesse the sex before marriage issue.*
>
> *Really good idea to make kids think about these issues…the end goal.*
>
> *I would suggest that the 'results' section provide a more informative response i.e., to get along better with women, you need to do xyz.*
>
> *The scoring is for what real purpose?*
>
> *Need an instruction page at the beginning.*

The developer also conducted a focus group of young Aboriginal men of school age and older in Alice Springs, and also undertook one-on-one testing with approximately 40 young people, involving a roughly even split of males and females.

The suggestions for enhancements to the apps were discussed among the research team and then put to the developer for implementation. Once this process had been completed the Department of Health, Reference Group members and Chief Investigators involved in this project were invited to trial the apps. Overall, the suggestions that were made included additions/alterations to functionality as well as to content:

- to include specific information on FASD
    - to satisfy this requirement, a series of questions/statements were developed to highlight the risks of drinking alcohol during pregnancy;
    - inclusion of three relevant website links;
- removal of the numerical scoring component of the apps
    - this was achieved and some rewording of the 'instructions' text made;

- capitalising the headings/links in one section;
- slight rewording of text and consistency of spelling ‘FETAL’;
- removal of the reference to the Department of Health; and
- including the ‘more information’ button in multiple places.

Despite these changes, after further discussion among the research team and with the Department of Health, it was determined that, as an ancillary output from the project with a limited focus on FASD, we would not move forward to public release of these apps.

The research team

At each step of the way, the research team has been closely involved in the development of the apps and has paid close attention both to the small detail (as in use of language, for example) as well as to the overall functionality of the apps.

Post-launch evaluation

All participants in the consultation process will be forwarded an evaluation survey, covering both the consultation process and the outcomes of that process (i.e., the apps), three months post-launch of the apps. This information will be analysed and available to the Department at that time.

RESULTS

What are health professionals saying?

Addressing the issue of alcohol use in pregnancy/breastfeeding and FASD

1. **What is the level of awareness in the community about effects of alcohol use in pregnancy?**

Across all consultation sites, health professionals told us that while women know not to drink alcohol during pregnancy, the rationale for this is not as clear as it should be – levels of awareness about the **effects** of alcohol use in pregnancy are generally very low:

> *They know they shouldn't [drink] but not the impact on the baby* (A2).
>
> *A lot of mothers don't understand that if mum drinks, so does baby…I don't think the younger generation have much awareness of the effects …prior to our project conducted with* [X], *not a lot of awareness. Still not a lot of community awareness* (B2).
>
> *Not sure specifically about FASD but community brush the issues of alcohol and pregnancy under the carpet…community are choosing to ignore the risks/issues…it is not uncommon for girls to drink during pregnancy but won't admit it* (B4).
>
> *90% of women here don't know what FASD is…need to get the messages out there early, education with young girls, otherwise it can be too late* (C1).
>
> *There is some awareness around women, but not men in* [X], *particularly around how men can support their partners…90% of women don't know what FASD is* (C2).
>
> *There is a high awareness that women shouldn't drink during pregnancy, but the effects of this is still not well known* (C3).
>
> *There is a low level of awareness of the actual effects of FASD…people know they shouldn't smoke and drink but don't know about effects. There is no info out there on when to stop* (C4).
>
> *There is nothing out there to inform us about FASD…I wasn't educated about it* (D3).
>
> *There is very limited awareness…people know they shouldn't drink but don't know the effects…some people think it's ok to drink up until 7/8 months pregnant, when they 'show' and then there's judgement around 'bump' so might drink differently, at home or in private* (E2).

A similar point was made by some health participants around lack of knowledge regarding the effects of alcohol use during breastfeeding:

> *Most people are aware of risks during pregnancy but not during breastfeeding* (A2).
>
> *Many clients I have worked with have no understanding of alcohol consumption during breastfeeding and how this affects baby* (C3).
>
> *There is a lack of understanding around alcohol and breastfeeding generally* (B4).

In contrast, we were also told that some "young women will not breastfeed because it prolongs abstinence" (E2):

> *Breastfeeding is decreasing because of alcohol messages…this is one of the unintended consequences* (C2).
>
> *Need to consider carefully how to do this kind of education* [alcohol and breastfeeding] – *there could be unintended consequences, for example, messages being taken on board by mums but they have then stopped breastfeeding rather than stopping drinking* (C3).

Participants at one consultation site told us they always advise "safest is no alcohol" (A2). At all health consultation sites, we were told that there is some confusion, or misinformation, around just how much alcohol is safe to drink during pregnancy. Participants told us that they regularly get asked whether 'a little bit of alcohol' is alright, and some provided anecdotal evidence that clients had reported being informed by their doctor that it is "ok to have one or two drinks per day" (B2). These participants were concerned that some young women were interpreting this to mean that they could, for example, 'save up' those one to two drinks a day for a 'session', or that they could have one to two drinks an hour, or even one to two six packs at a time, and this theme recurred across a number of consultation sites (B2; B4; C1; C3; D1). So there was concern around clients receiving conflicting messages, with some health professionals advising that it was safest to drink no alcohol, and others saying it was okay to have one or two drinks, as well as concern around the interpretations that were being placed on what constitutes 'one or two drinks'.

To compound these problems, we were also told that there were:

> *Misunderstandings around, for example, pre-mixed drinks in cans…people don't believe this is alcohol…mixed drinks not seen as 'drinking'* (F2).

There was acknowledgement in some communities that alcohol *per se* is so normalised that it is not perceived as a problem, with one telling us that:

> *Binge drinking is a huge problem here…whole point is they don't see alcohol as a problem…people thinking it's ok to drink but not to be an alcoholic* (E2).

At the same time there was acknowledgement of the difficulties facing some women in "saying no to alcohol" and the peer/family pressure to continue

drinking even during pregnancy (E2). Some consultation sites also referred to challenges in addressing these issues due to the:

- normalisation of alcohol-impaired behaviour generally in the wider community (B2; B4; C2; C3; F2);
- normalisation of alcohol-impaired behaviour around children and childrearing (F2); and
- normalisation of the behaviours associated with FASD-affected children (E2).

One consultation site reached further afield in their assessment of levels of awareness of FASD by referencing Marulu: The Lililwan Project and how:

> *The work in Fitzroy [Crossing] has meant there's an awareness of FASD out there – stigma has been taken away from talking about it…women acknowledging they've drunk during their pregnancies has destigmatised it. Can that same process be brought here?* (C4).

2. Do you ever raise the issue of alcohol use in pregnancy and FASD?

For participants in relevant roles, the majority across all consultation sites confirmed that they do raise the issue of alcohol use in pregnancy. Responses included:

> *Confirm that safest path is no alcohol…it's part of our program…discussed in men's group…systematically bring it up…always bringing it up/daily with groups; encourage discussion around it…talk about side effects…informal conversation; easier to bring it up as a casual thing, otherwise people shut down…if I have suspicions I will keep addressing it…*(A2; B2; B4; C1; C3; C4; D1; D2; E2; F2).

Health participants also acknowledged the challenges inherent in addressing these sensitive and complex issues:

> *It is extremely difficult to deal with – talk to health workers to attempt to protect future pregnancies…extremely difficult to raise with mothers so try to avoid blame* (C2).

> *Yes, but no point making people feel guilty…difficult to give the message, depends on the individual involved and relationships… raising the issue is fine when everything is going ok for the woman…alcohol is used for coping* (F2).

At one consultation site, the early childhood worker stated that it was the children attending who were telling her about alcohol consumption in their households (F2). At the community members' consultation in that same jurisdiction we were told that "kids know that grog is not good for their parents" (F1).

3. How do you raise the issue?

A combination of approaches was taken to raising the issue of alcohol, pregnancy and FASD depending on the setting (for example, in schools

versus in a health setting) and the participant's role (for example, a midwife versus a youth worker). Examples included:

- educational discussions/programs using, for example, the *Core of Life* program, existing pamphlets/other resources (A2; B2; C1; C2; C3; D2);
- with FAS dolls (C2; C3; C4; E2);
- during ante/post natal consultations (B4; C1; C3; C4); and
- screening tools, for example, the IRIS (A2; C1).

Participants at three consultation sites (B4; C1; E2) felt strongly the need to be "very blunt" about alcohol use during pregnancy as it is a "child safety issue/case" (C1), although the majority of participants did not agree with this approach (see *02.6best*).

For some the reality was also that they:

> *Often don't see mums til 24+ weeks into pregnancy – so the message is about minimising damage at that point* [and an opportunity for prevention for subsequent pregnancies](F2).
>
> *Midwives are talking about reduction when they know there is no chance of them giving up* (E2).

Referrals to appropriate services was an approach taken by some participants whose role precluded them from taking discussions any further themselves (A2; B2; C4; E2).

4. What do you think is the best advice to give someone about FASD?

There were several common themes running within and across consultation sites regarding what is perceived to be the best advice a health professional can give someone about FASD. These included:

- no alcohol at all during pregnancy and breastfeeding (B2; B4; C1; C3; D1; D2; E2; F2);
- there is no safe limit (A2; B2; B4; E2; F2);
- provide them with the facts/information; keep it simple (B2; C2; C3; C4; D3; F2);
- advise of services and supports in local area (C3; D1; D3); and
- less is best, none is better (B2; C4).

There were contrasting views on the best approach to adopt in giving this information to clients, with some participants wanting only positive messages imparted (A2; B2; C3; C4), while for others the need to 'take the hard line' (B4; C1; E2) was not negotiable. Between these two positions were a range of other approaches:

> *Some health professionals are talking about reduction when they know there is no chance of giving up* (E2).
>
> *Telling them about the difficulties FASD holds for parenting capacity (financially, emotionally, socially)* (C3).

Telling them the effects long term…features characteristic of FASD children (B2).

I explain that the alcohol goes across to the baby and they can't get rid of it, so it just goes around and around in their baby causing damage. I also explain that not all the damage can be immediately seen by us (C4).

There is pressure on health workers to ask the questions and then they are the ones who take the heat (C4).

I think the best advice to know would be in relation to what services and supports are available to families (C3).

5. What do you think is the worst advice to give someone about FASD?

As above, views and opinions differed and varied within and across consultation sites regarding what was considered to be the worst advice to give someone about FASD, but some common themes emerged, including:

Do not use 'scare tactics' (A2; B4; C3; C4):

If you are drinking, giving worst possible outcome isn't going to do it…language is important – no shame, no blame (A2).

Don't make threats about DOCS [Department of Community Services] (B4).

Blaming them and telling them that they've failed as a mum if they've consumed alcohol during pregnancy…I don't think you would want to try and scare anyone in relation to the condition or put blame or shame on anyone (C3).

Anything that entrenches shame and blames the person…the worst advice would be 'you are harming your baby' – people already know this (C4).

Do not advise that alcohol is ok in moderation/at all (B2; B4; C1; C3; D1; D2; D3; E2; F2):

Alcohol is ok in pregnancy in moderation (B2).

It's alright…you've only had one or two (this can also make them hide their drinking) (B4).

One or two, here and there, is ok (C1).

Advising client it's ok to still have one or two drinks (C3).

A little bit won't hurt (D2).

Alcohol is ok, just don't get drunk (E2).

Some participants felt that those in relevant roles should not ignore the issue (D1; F2):

> *If you ignore the issue of alcohol and pregnancy you are normalising the behaviour* (F2).

Attitude towards FASD messages

6. What types of messages do you think would be effective to engage community to raise the awareness of alcohol/pregnancy/FASD?

There is some overlap between responses to this question and to *02.6best* above. Here there were several consistent themes that emerged across consultation sites with regard to the types of messages thought to be effective to engage community to raise the awareness of alcohol/pregnancy and FASD, including:

- The direct approach:
  - *Show reality of effects/long term effects for all involved including affected/parents/siblings…show visual effects on fetus…basic and direct messages and not to soften the facts…depict true stories 'our people need to know the truth'…the facts need to be given…people need to see the effects of alcohol on the fetus, and after birth right through to adulthood* (A2; B4; C3; C4; D1; D2; E2; F2).

- Integrated and holistic health care/whole of community responsibility approach:
  - *It is everyone's responsibility to support pregnant women…address alcohol holistically – not just targeting FASD which would have greater chances of reaching risk groups…focus on the wellbeing of the baby and mother…address alcohol holistically – both Aboriginal and non-Aboriginal resources…target whole of community as supports for pregnant women* (A2; B2; C2; C3; C4; D1; E2).

- Incorporate messages for fathers:
  - *Need to encourage dads from refraining from alcohol prior to conception…we need to talk about the effects of alcohol on sperm; this needs to be made clear…if father's drinking is problematic too he should refrain for three to six months prior to conception, or when trying for a baby* (B2; C3; D1; E2).

Other suggestions for effective messages around these issues included:

- integrated into pre-pregnancy and pregnancy planning (C3; A2; E2);
- positive/caring messages – 'I embrace my responsibilities' (B2; C4: C2);
- preventative messages (A2; D3; E2);
- education strategies that target everyone (A2; E2);
- training of health and other workers (A2; E2);
- focus messages on the baby (E2); and

- information/stories from the affected children themselves (A2).

There was consensus across all consultation sites that messages need to be culturally appropriate and contextualised to suit local needs and preferences and incorporate the following:

- simple, everyday language;
- local language;
- easy to read;
- short, simple and effective;
- picture driven;
- image focused; and
- colours/colourful.

7. What resources do you currently use to inform/demonstrate to clients the dangers of alcohol use in pregnancy/breastfeeding?

Participants in some consultation sites reported they did not have access to, and/or were not aware of, any resources that address these issues (C3; C4; D1; F2).

The types of resources in use by others include:

- FAS dolls (B4; C2; C3; C4; D1; E2);
- posters (A2; B2; B4; D2; C2; E2);
- flipcharts (C3; D1; D2; C2; C3);
- (locally developed) brochures (B2; D1; F2);
- *Core of Life* education and training program (A2; C2; F2);
- locally developed PowerPoint presentations (C2; C3);
- baby baskets (C2);
- AOD pamphlets (F2); and
- DVDs (B2).

8. Do you find the resources that you currently use helpful?

Of the communities using resources, participants at three sites told us that they do not find the resources currently in use helpful. Reasons given varied, and included:

> *resources specifically for this State/Territory lacking…pregnancy pack is large, not* [X] *focused, and needs adapting* (A2); and
>
> *current standard resources, i.e. flipcharts and brochures, can have their usefulness with people with limited literacy but other than message sharing, don't think people would use much* (C3).

Some communities, however, did find resources helpful. Reasons included:

> *developed locally, target whole community…these resources, developed by* X [Aboriginal Medical Service] *can be amended by other services* (B2);
>
> *yes, no problems with any as I appreciate different approaches are needed to meet diverse personalities* (C3);

simple, picture driven (D2); and

FAS dolls can be effective (C4; E2).

9. Do you feel that your clients find these resources acceptable and appropriate?

At one consultation site, in particular, participants said that any resources they have seen are inappropriate for their particular context with, for example, no local referral details on them (A2). For another consultation site one objection was around the resources being "too wordy" (C4).

In terms of acceptability, participants at two consultation sites thought/knew that their clients would find the resources acceptable due to the nature of their development:

> *Yes, because we carried out comprehensive consultation around their development…community owned it…well accepted in the community…still in use* (B2).

> *Yes…they were workshopped and designed by communities which make them culturally appropriate* (D3).

Other observations by participants included:

> *It's all about what appeals to the individual…they will pick up those that grab them and ignore those that don't* (C3).

> *Yes. They are quite powerful flipcharts. We have had grannies in tears because they didn't know about FASD when they were pregnant. They have made the connection between alcohol and their children's behavioural issues. They have expressed gratitude that these* [support] *groups and resources exist for their own daughters* (C3).

Participants at one consultation site admitted that they didn't know how well resources work as "we haven't actually engaged the community for a response" (C3).

10. What kinds of resources would you like to have available to you to provide information on FASD?

The two key requirements across all consultation sites was for the development/availability of resources that can be used for educational purposes in a range of different settings and with different audiences – for example, the *Core of Life* education and training program was mentioned by a few communities as either a great resource that they are already using (A2; C2; F2) or one that they would like to use (E2) – and for health promotional purposes, with opportunities for the integration of broader health messages beyond a focus on alcohol, pregnancy and FASD:

> *Resources for use in schools; not FAS as such but integrated into sex education and education about risk-taking behaviour and the potential consequences* (A2).

> *Anything up-to-date, educational, holistic (covering emotional, social, physical and cognitive development)…resources that can be used to train workers…probably more resources that can be easily adapted for community education as well* (C3).
>
> *All resources to show messages to do with health* (C2).
>
> *Health promotion/education* (C1).
>
> *Education in schools…sex education in schools…Core of Life in schools* (E2).

Consultations yielded many suggestions on the types of resources that could deliver these educational/health promotional messages:

- pamphlets (A2; C2; C3; C4; D3);
- posters (C1; C3; C4; E2);
- T-shirts (A2; C1; C2; C4);
- brochures (E2; B2; D1);
- billboards (B4; C2);
- flipcharts (C2); and
- fridge magnets (C2).

FAS dolls were mentioned at three consultation sites (C3, C4, F2), although one participant cautioned that:

> *Dolls are ok but not entirely representative. Some babies look normal and problems may not emerge until puberty – this needs to be mentioned* (C3).

More innovative suggestions included:

> *…condoms and pregnancy test kits with messages such as 'prevention is better than cure'* (E2); and
>
> *beer goggles – give you the effect of being drunk; school kids would love that* (C1).

DVDs and videos were thought to be useful resources by 50 per cent of participatory sites, with different messages for different contexts:

> *Great resource might be DVD on screening…how to get support…showing people with FASD* (B2).
>
> *Rap DVD like the one produced in Tenants Creek (sic)…we saw that in Darwin recently…play it in doctor's surgery, clinics etc whilst they're waiting for their check-ups* (E2).

The use of/development of social media/digital platforms was suggested both as the best type of resource and as the best way to relay relevant information, to young people in particular, by the majority of consultation sites. Some suggestions included:

> *pop up messages on social media* (B2);

YouTube or something easily available to young women, for example, SMS (C3);

side bar on Facebook…Twitter… interactive – need to use things people rely on such as phones (E2);

interactive modules on the net (C1);

software/digital platforms that communities can pop their own messages/pictures into (C2);

phone apps (D1);

internet/social networks…all resources need to be cool and interactive…interactive apps on phones (E2);

a Tamagotchi type thing – virtual baby – one affected by smoking, one by alcohol, and one normal (E2); and

apps…one already exists on 'my baby's progress'(F2).

At one consultation site it was strongly felt by participants that "the issues go way beyond resources" – resources are not enough on their own, but that holistic action on the social determinants of health is required rather than tackling the issues of alcohol, pregnancy and FASD as a discrete issue:

…perhaps a big banner saying 'no alcohol during pregnancy' but really 'resources', posters, flyers etc are just not going to cut it…unfortunately, I think a lot of these problems are related back to the low socio-economic and associated issues in the community (B4).

11. Do you think there should be different resources for different groups in the community?

At all consultation sites it was judged essential that there should be different resources for different groups in the community, albeit with a consistent message across all resources. Some of the different groups included:

- different resources for Aboriginal and non-Aboriginal communities;
- teen dads;
- teen mums;
- groups at risk;
- young people;
- dads/men;
- teenagers;
- grandparents;
- carers/support people; and
- health professionals.

Overall, the majority of participants are calling for resources for "everyone, anyone":

Whole of community because alcohol is socially accepted and family related (B2).

Mums, dads, teenagers, young people, all of family, extended family (D1).

In addition, participants in several consultations talked of the need for resources that are tailored to different social contexts and to the various types of alcohol being consumed (and this might differ by age group).

12. What do you think are the key components of any resources on FASD for use in your community?

Across all consultation sites we were told that any approach to address issues of alcohol, pregnancy and FASD within Aboriginal and Torres Strait Islander communities must incorporate (in varying configurations):

- a holistic/integrated health approach;
- a cross sectoral approach; and
- a long-term, ongoing educational/awareness-raising effort .

Holistic/integrated approach

In the majority of consultation sites (A2, B2, B3, C1, C2, C3, C4, F2) participants specifically stated their belief that a holistic/integrated approach to the care and support of pregnant women was a key component in any resources on FASD:

Break down messages around 'social drinking' and associated harms, for example, violence etc and address the core issues, not just alcohol during pregnancy (B2).

AOD use is a huge problem here and you can't separate out alcohol from a whole range of other problems/disadvantages (B3).

Focus on alcohol, sex, relationships – need a whole/broader focus than just FASD within a holistic approach to care and support (C1).

Holistic education around health generally, with a focus on positive messages (C2).

Programs that address holistic health and social outcomes to give people more options and realistic, valuable strategies (C3).

Talking about healthy babies/pregnancy generally which then addresses alcohol but not specifically FASD…integrate resources into a continuum of care across the sectors i.e., education, health, antenatal etc. Integrate messages into everything people do i.e., cricket day (C4).

Need a whole program approach, not just a resource/sheet targeted at areas of high prevalence rates (C4).

In some of the consultation sites, participants also wanted to see messages that focused on/stressed the positives of the creation of healthy families and lifestyles:

> *Healthy families stay together…if drinking is the culture within the home then it's difficult. Need to stress that healthy lifestyle = no alcohol* (B2).

> *Need to emphasise the positiveness of being sober, for example: not buying alcohol saves money* (C1).

> *We need positive messages around 'not' drinking alcohol rather than focusing on the negatives* (C4).

> *Positive images and messages, for example: if you breastfeed, you will lose weight etc* (E2).

Similarly, participants at the majority of consultation sites considered that any attempts to address issues of alcohol, pregnancy and FASD must be contextualised within a long-term, ongoing educational/awareness-raising effort:

> *…depends on your client group – for me, can be tricky bringing in the resources to start discussion. Material has to be really educational for any meaningful discussion* (B2).

> *Need to consider carefully how to do this kind of education – there could be unintended consequences, for example, messages being taken on board by mums to stop drinking during pregnancy and breastfeeding but they have then stopped breastfeeding rather than stopping drinking* (C3).

> *Education needs to be incorporated into a program; the longer the program runs the better. Just leaving resources lying around won't be the answer* (C4).

> *Need a tiered approach to the development of resources that takes into account pre-pregnancy, post-pregnancy and aftercare – aftercare of mum, family and child (this is once a baby is born with suspected FASD)* (C4).

> *Will involve a long term process to change behaviour and, if you do drink while you're pregnant your child may need early intervention etc which is also a long term process* (E2).

There was consensus among all consultation sites that any and all resources developed have cultural appropriateness and relevance at their core. Key concepts talked about, and challenges around their incorporation, included:

Language

> *Simple, culturally appropriate language that is to the point* (D1).

Language is a barrier here at [B4] *and which ones to incorporate into resources.*

Word usage

How to decide on the kinds of words to use, for example, some women will use Indigenous language like 'grog' and some wouldn't (B4).

Clear, concise, simple language (C3).

Artwork

…needs to be inviting, visual and needs to look Aboriginal; will pick up in first instance even if they put it back down again (E2).

Artwork and colours should be specific to region (C3).

Message must not get lost in artwork (C3).

Visual

The visual is the most important thing (A2).

Pictures much more effective than words (C2).

Images are powerful (C3).

Graphic images of effects on baby and development – very important (F2).

Ongoing community involvement in both the development of the resources and their implementation in communities were seen as fundamental across consultation sites. In some instances, specific groups were selected as key players:

Give the voice to the youth…also see Elders as key to effective communication strategies (A2).

In others, whole of community engagement was considered key:

People from across the community (C1).

Need to involve members of the community at grass roots level, for example, Aunties talking with kids in the park (A2).

Community people should be doing the educating (E2).

The use of role models was mentioned at several consultation sites as an effective methodology, with some suggesting national role models such as sporting figures, and others suggesting local role models like musicians, would be beneficial. Conversely, issues of when/if that role model later engages in negative behaviours was raised as a risk in this context.

13. Can you identify any other gaps in your community for addressing the issues of alcohol, pregnancy and breastfeeding?

While there is some overlap between responses to this question and *02.12kind* above, we have included here as many of the identified gaps as possible to highlight the scarcity of resources, tools, education, and knowledge around these issues, the majority of which include broader, systemic gaps that create challenges for workers and community in addressing these issues:

- lack of diagnostic and screening tools and services;
- lack of resources in community generally and the associated lack of resources for men as well as women;
- national recognition of FASD as a disability;
- early intervention in early childhood as a pathway to prevention during later years;
- early intervention strategies for early childhood workers;
- FASD-trained workers and more training generally for health and other relevant sector workers; and
- for FASD to be 'put on the agenda' across communities and nationally and to include men within any resource/program/strategy.

In addition, the lack of consistency both in messages around alcohol consumption during pregnancy and/or in how various sectors are approaching these issues at state, territory and national levels, was considered detrimental to promoting understanding:

> *Need a really good national picture of the problem…at least if they can get a picture of who's doing what in* [State] *– what types of resources are available, a picture of referral network and so on – need cohesion across the State. At the moment, pockets of people are doing their own thing* (C3).
>
> *All health partners and agencies should be on the same page* (D1).
>
> *There are mixed messages from GPs and other health professionals and then again from family – need a clear, consistent message across the board* (E2).
>
> *The messages need to be out there – consistently, pervasively and not as an add-on program/strategy but one in its own right* (F2).

Other suggestions for filling some of the gaps included:

- information for the children themselves who are diagnosed with FASD (A2);
- alcohol, drugs and parenting need to be addressed together (B2);
- lack of understanding around alcohol and breastfeeding (B4);
- cross sectoral responses to the issues (B4; C2);
- teachers and early childhood workers as target groups for FASD training (C2; F1);
- the association between alcohol and other drug use generally and mental health issues, and the lack of support for their treatment (C3);
- better education of doctors, paediatricians and health professionals generally (this was raised as an issue across all consultation sites);

- effective intervention strategies to address these issues pre-pregnancy, post-pregnancy and during early childhood (C3);
- educational strategies in schools that address these issues (C3);
- information on how to work with this client group, for a generalist worker (C4);
- alcohol restrictions/responsible sale of alcohol (E2);
- posters/information at point of sale (bottle shops), in pubs, on the back of toilet cubicle door (E2);
- versatile, regional mobile team that can go round communities and assess/diagnose FASD (E2);
- universal/nationwide logo for FASD – nationwide competition for the design of the logo (E2);
- the need to involve men in discussions around alcohol, pregnancy and FASD (all consultation sites raised this issue as a significant gap); and
- lack of adequate funding to deliver message systematically, to as wide an audience as possible and on an ongoing basis (E2).

For some, there was a belief that until the normalisation of both alcohol consumption/risky drinking and of (suspected) FASD-affected children's behaviour are addressed, "not much will make a difference" (B4):

> *Don't believe much will make a difference – community sees FASD kids every day and it's normalised (B4).*
>
> *Inter-generational birth defects are normalised here* (E2).
>
> *There is a complacency around children's behaviour – affected children's behaviour is normalised (E2).*

The disparity between the ongoing focus on smoking during pregnancy and the lack of comparable attention to alcohol consumption during pregnancy was consistently raised as an issue throughout many consultation sites, with the *Quit Smoking* advertisements cited as an effective strategy, at least in its wide reaching effect (A2)*:*

> *Government are on the band wagon with tobacco but not alcohol…we are bombarded with smoking and alcohol/binge drinking – put FASD up there* (C1).

Ongoing education around not only alcohol, pregnancy, breastfeeding and FASD but across the spectrum of risky behaviours and/or healthy lifestyle choices was raised by health professionals in all communities (A2; B4; C1; C2; C3; C4; E2; F2; E2). "Proper parenting education for those with FASD children" was considered "really important" (F2). The need to keep talking about these issues, and for FASD to be put on the agenda across communities, is considered crucial to any possibility for behavioural change. For some communities, Elders were represented as the best 'resources' available and it was felt they should be provided with the tools to participate in 'conversations' around these issues (C2). Participants at another community felt the answer lay in "Doing it over and over and let it sink in – long term education" (C2). Another participant put it more succinctly: "Knowledge is power" (B2).

Health professionals at several consultation sites noted that the sheer magnitude of the problem of alcohol and/or other drugs across their communities was such that simply knowing where to begin tackling alcohol, pregnancy and FASD was a real issue (F2; B4). At one of these sites in particular practitioners expressed the belief that the whole community is "choosing to ignore the risks/issues, brushing the issues of alcohol, pregnancy and FASD under the carpet"(B4). At another, we were informed that alcohol, *per se*, is not seen as a problem and in some instances is seen as acceptable as long as one is not "an alcoholic" (E2).

Implementation of resources

14. From the resources you indicated are useful, how do you suggest that these are introduced and implemented into the community?

There were a range of suggestions on *how* resources should be implemented: health (including through health professionals) and other programs (B2; C1; C2; C3; C4; C4; D1; F2); youth group sessions and sporting groups (B4; C2); school teachers and Elders in the educational setting (C2; A2; C4; E2); role models and Elders (C2; C3), and through workshops and focus group discussions (D1; C1).

Regarding *where* the resources should be situated/positioned, suggestions were plentiful and ranged from the obvious ones such as in Indigenous and non-Indigenous health centres/clinical settings, through to the backs of toilet doors in pubs/alcohol outlets.

Importantly, the majority of consultation sites shared the view that ongoing community consultation and engagement with regard to both the development of the resources and their implementation was fundamental.

15. Do you feel resources such as T-shirts, brochures, posters etc are effective means to get the FASD messages across, or are there different methods such as TV or radio that you feel are effective?

This question overlaps considerably with *02.12kinds*, so we have focused here on data that addresses the need to incorporate digital media/social networking, both into the ways messages can be imparted and into the tools that can be used effectively to impart these messages, particularly for young people. National TV and local radio advertisements were also considered important media through which to get these messages across:

> *National TV ad campaign similar to the smoking ads but for FASD. NITV for ownership…would like to see a discussion of the issues on programs like Living Black* (A2).
>
> *TV and radio ads…social networking* (B2).
>
> *Pop-up messages on mobile phones/Facebook etc that will reach target populations as reminders/triggers to remember not to drink* (B2).
>
> *Facebook, Twitter, YouTube…advertising on TV* (B4).

For health professionals would like to use something like IBERA – a computer/digital health tool. They use it in the NT…for young people on the web/Facebook/YouTube (storyline, cartoon characters around effects of FASD (C1).

TV ads – positive messages (C2).

I think TV and radio would be very effective as long as it is well done, not demeaning to our people in the wider Australian community (C3).

Media campaigns would be more effective…I think all promotion mediums need to be explored but you need all aspects in targeting our audience including posters, brochures etc (C3).

TV, radio, Facebook (C4).

Facebook, SMS, radio…not just packages in clinics (C4).

We need to change the way all people drink…TV and radio ads would get the message to the wider community (D1).

All media avenues (D2).

All forms of media are good, however, the appropriateness for men and women should differ (D3).

TV commercials are effective (E2).

Social networking…iPhone apps/ringtones…sidebar on Facebook…TV ads are very impactful…Must be linked to technology; how about a standard free app on the iPhone? (E2).

YouTube…gestation apps…social media/Facebook…national ads on TV (F2).

Evaluation of resources

16. What would be the best way for communities to assess how effective these resources are?

Several consistent themes emerged from the data related to assessing the effectiveness of any resources including, in particular, increased levels of community awareness, and changing behaviours and attitudes with a corresponding decrease in FASD-affected children over time (B4; C2; C3; D1; D2; F2; E2).

Capacity building and community control and ownership were strong themes:

Building capacity for community to design, implement and evaluate initiatives for their own communities (C3).

Workers should be evaluating/learnt to evaluate as part of their skill set (C4).

Coming together as a community and consulting and communicating with community on a regular basis (D1).

What are community saying?

Knowledge of FASD

1. **What do you think when you hear the term FASD?**

While the majority of community participants in one consultation site (F1) acknowledged that they had never heard the term FASD, this was unrepresentative across consultation sites generally. At all other sites participants displayed some knowledge, with various responses to the question "What do you think of when you hear the term FASD" being:

- unhealthy babies;
- mentally and physically challenged;
- slow learners;
- sick babies;
- babies born with difficulties;
- problems with motor skills; and
- memory loss.

Site-specific comments included:

I think of my son, he's affected (A1).

They get frustrated…they are unsociable (B1).

They have physical defects…drinking during pregnancy…alcohol misuse…pregnant mums and babies at risk of alcohol related problems (D1).

Alcohol effect on unborn babies…when are they going to stop drinking? (D2).

Babies look funny…disorder that babies get when parents consume alcohol while pregnant…there are long term effects…mothers shouldn't drink (D4).

There are a lot of mothers here that do drink…a lot of stress here generally…[there is] a 'won't affect me kinda thing' (F1).

However, all community participants also suggested that the **effects** of maternal alcohol consumption during pregnancy are not well known or understood throughout the community:

Lots of people are unaware of FASD (A1).

A lot of community wouldn't know what FASD meant (B1).

FASD is a new word for community (D1).

Some have heard of it, some haven't (D2).

It's not really advertised, most people don't know about FASD (D4).

People here know risks of drinking alcohol but not the extent of those risks – they wouldn't know what FASD is…have never heard of it (F1).

2. Have you had any discussions etc on drinking alcohol, pregnancy and breastfeeding?

Each of the community consultation sites had some participants who said that they had never had discussions on drinking alcohol and pregnancy with a health professional:

No not really – not really discussed…yes, on alcohol and drugs but not on pregnancy and alcohol (D1).

The midwife should be talking to them about alcohol and pregnancy – never has (B3).

Other participants confirmed that such discussions were being/had been initiated by health professionals:

Yes, by the midwives (A1).

Yes, by the doctor or midwife (B1).

Yes, by [drug and alcohol service] (D1).

The overall consensus, however, was that although the issue might be raised it was in a cursory manner with little probing and/or further explanation of the risks associated with drinking alcohol while pregnant:

In high school briefly…with the health worker…most knowledge from parents (D4).

I was told while pregnant not to drink (D4).

The hospital/GP ask whether you drink, if you say no, they stop (B1).

The GP always asks – do you drink/smoke? (B1).

We were also told that the link between alcohol-related harm and breastfeeding was either not being made explicit to mothers (B1; D1; D4; F1) or was known by mothers and the (unintended) consequence of this knowledge was for the mother to stop breastfeeding as early as possible in order to resume drinking alcohol (D1).

3. Have you seen any resources about FASD?

Some participants in all but one of the consultation sites said that they have seen minimal to no resources on FASD in their community (A1; D1, D2, D4; B3 and F1). However, other participants in these and other sites went against this trend (B1; D1; D2; D4), reporting that FASD resources have a presence

"everywhere". One participant stated that "It's definitely out there…information/message on FASD" (B1), and it was believed that this is due to the local Aboriginal Medical Service/Aboriginal Drug and Alcohol Council undertaking an extensive community consultation process to develop and produce their own culturally appropriate and acceptable resources that address the issues of alcohol, pregnancy and FASD. Another participant commented that these resources "should also be advertised in more places like schools, community centres…rather than just in health settings" for the messages to reach as wide an audience as possible (B1). In contrast, participants at another consultation site in that same state/territory said that "there are no messages around this issue in the community at all" (B3). These comments reflect both the uneven distribution of resources within communities and the varying responses to those that are available.

The types of resources that were seen by some of the participants (three of the consultation sites where resources were seen – D1, D2 and D4 – are all situated in the same state/territory), include:

- posters (D1; D2; D4; B1; A1);
- flipcharts (D1; D4);
- booklets (D1; D4);
- brochures (D1; B1);
- T-shirts (D1);
- videos (D4); and
- FAS dolls (D1).

Several of the communities specifically mentioned that there are more resources on alcohol and other drug use generally (A1) and/or smoking and pregnancy (D1; F1) than on alcohol and pregnancy.

4. Where have you seen the resources?

Settings where resources have been sighted include:

- health settings (for example, Aboriginal Medical Services, doctors' surgeries, hospitals, antenatal clinics (B1; D1, D2, D4; A1);
- drug and alcohol services (D1, D2);
- internet (A1; D4);
- library (B);
- TV (A1);
- cultural centres (B1); and
- community workshops (D1).

Attitude towards FASD messages

5. Are the resources in your community 'liked' by you? What do you like about them?

Of those participants who had seen resources in their community, reasons cited for 'liking' them included:

- colours/colourful (B1; D1, D2);
- pictures/picture driven (B1; D1; D4);
- simple language (B1; D4);
- simple/appropriate wording (B1);

- culturally appropriate (B1);
- cultural connection (B1);
- relatable (B1);
- hard hitting (B1); and
- graphic (B1).

Some participants referred to their mere presence in their community as reason enough for 'liking' them:

They are a good warning for our people (D2).

They send a clear message not to drink alcohol when pregnant (D2).

I like the fact that they are out there (D1).

6. What did you think of the messages they were sending about drinking alcohol, pregnancy and breastfeeding?

Examples of the few responses to this question included:

Good – need more education though…eye opener…you don't realise at the time what alcohol can do…more pictures would be good…some parts of the local community think existing resources are discriminating to some Aboriginal mums (B1).

Very good messages…there is more awareness these days…it's good because it brings awareness of the consequences…it was positive (D2).

Good…informative…strong message…to prevent FASD, encourage women not to drink; educate them (D4).

Don't drink and be pregnant (D1).

7. If you didn't like the resources, can you tell us what it is about them that you don't think is ok?

There were several reasons given for thinking that existing resources are not acceptable, including:

some parts of the local community think existing resources are discriminating to some Aboriginal mums…People think that only Aboriginals do it, pointing the finger, make you feel bad (B1);

not hard hitting enough (B1); and

they didn't relate to the Aboriginal families and how we live and exist…we need more resources for Aboriginal people (D1).

In addition, participants at one consultation site specifically said that the limited resources available in their community are not culturally friendly (D4), while those at another site felt that the resources available in the community are not appropriate as they have not been adapted to the local context (A1).

8. What do you think is the best advice to give someone about FASD?

There was no shortage of views on what was considered to be the best advice to give someone about FASD, with some differences both across geographic boundaries as well as within communities. For clarity, the data has been aggregated into the several themes that emerged as the most prominent.

All consultation sites felt that telling people about the consequences of drinking and the effects on the baby is fundamental. The ways advice/messages need to be and/or are being relayed varied across consultation sites:

> *Talk about the consequences and how one drink leads to another* (A1).
>
> *Not to drink while pregnant, the baby can get FASD which can cause problems later in life through school-learning difficulties, motor skills and so on…contrast – show healthy baby and unhealthy baby* (B1).
>
> *We tell them to be mindful of the damage to baby and themselves* (D1).
>
> *Beware of the dangers of alcohol to the baby* (D2).
>
> *Tell them about the side effects…help them with information* (D4).
>
> *Need tough love before baby is born rather than waiting til after…they need to know* (F1).

Participants from five consultation sites wanted advice to be 'short, sharp and to the point'. Examples included:

> *Give up drinking because it affects the baby* (A1).
>
> *Don't touch alcohol, cigarettes or any form of chemicals which could harm your baby…Don't drink while pregnant, or use drugs* (B1).
>
> *You should not drink while pregnant* (D1).
>
> *Tell them not to be drinking while pregnant* (D2).
>
> *Not to drink while pregnant* (D4).

Other participants wanted the central focus to be placed specifically on the baby (A1; B1; F1):

> *Think about your baby.*
>
> *Pregnancy is not about you…emphasis should be on the baby's health and safety*
>
> *Healthy mum = healthy baby.*
>
> *If you want a healthy child, then don't drink, don't smoke.*

As well as the above, participants at one consultation site felt that the focus of attention should be on "our way…drinking is not the Aboriginal way…focus attention on that" (A1).

9. What do you think is the worst advice to give someone about FASD?

All consultation sites agreed that the worst advice to give someone about FASD is that 'it's ok to have a couple of drinks'. The major concerns expressed around people receiving this advice included:

- the (mis)interpretation of this advice as *carte blanche* to drink as much as one likes (for example, a couple every hour is ok; a couple of six packs is ok); and
- the difficulties for some people stopping at just 'a couple' - "there is no such thing as *one* drink…never say it's ok to have one or two" (A1).

Participants also said that "giving no advice to someone about FASD" (A1; B1) and "preaching/lecturing about alcohol and pregnancy" (B1; D4) were among the worst things one could do. At one consultation site, participants spoke of some community members advising the younger generation that 'it's a myth that alcohol and pregnancy is harmful':

> *They say "I smoked and/or drank with my baby and they're ok…so you* can *drink when pregnant"*(B1).

Input on future resources

10. Do you think there should be different resources for different groups in your community?

There was unanimous consensus across all consultation sites that there should be different resources for different groups in the community. Specificities included:

- different cultural groups from within same communities;
- targeting based on age, with some suggesting pre-teen boys and girls would benefit;
- targeting based on gender with a big emphasis on targeting dads/males; and
- different types of resources according to people's different levels of education.

Similarly, there was also the suggestion that information should be targeted at the stage/phase a person is at in their life – for example, a pregnant woman would need to know that 'no alcohol during pregnancy is the safest option', while a pre-pregnant/pre-teen group might need to know about the importance of safe sex and family planning.

11. What types of resources would you like to see in your community to address the issues of alcohol and pregnancy?

All communities talked about the need for community-wide education around issues of alcohol and pregnancy generally and for the development of educational tools with which to address these issues. The inter-relatedness of these two requirements is highlighted through both the lack of knowledge generally around the effects of maternal alcohol consumption on the fetus (as discussed in *01.1hear*) and the scarcity of resources in communities to

address these issues (as highlighted in *01.3seen*). The one consultation site (B1) that demonstrated a (comparatively) high degree of knowledge of FASD was also the one consultation site that had produced its own set of resources around these issues (B1).

In terms of educational tools, there were many ideas put forward as to what would be useful in specific contexts. Some participants talked about the value of using FAS dolls with school-aged young people (A1; F1) or at the first antenatal appointment (D4), while others talked about the value of utilising 'people as resources' to promote healthy lifestyle choices and/or sharing experiences/histories of the damaging effects of alcohol generally (A1; B1; B3; D2). In particular, some Elders felt this would be an optimal way for them to engage with/maintain their relationships with the younger generation, even suggesting taking 'discussions' into the school setting. As one Elder told us "there are people sitting here who can roll out programs on these issues" (A1). Others talked of recruiting other types of role models, such as:

> *sports players…Elders…people that have gone through it* (B1);
>
> *people are the resources…I tell mums they shouldn't drink* (B3); and
>
> *leadership programs, encourage role models* (A1).

Workshops and programs that address the dangers and risk factors of maternal alcohol consumption during pregnancy, contextualised within broader social determinants of health discussions, were also called for by all communities. As well, more Aboriginal workers in community and easier access to the workers were seen as key resource requirements by some participants (A1; D2).

Other resources suggested included:

- posters, brochures, pamphlets, flipcharts (B1; D1; D2; D4; F1);
- video/DVD/CD (A1; B1; D1; D4); and
- T-shirts, hats, fridge magnets, playing cards and so on (B1; D1).

Participants across all community consultation sites also quite simply stated that they would like 'anything and everything' that raises awareness, that educates, and that changes behaviour around these issues.

12. Who should each resource be targeted at?

There was general consensus across consultation sites that resources need to target 'all family members' and 'all community members' with comments such as "general community, we are all the same" (B1), or "young, old, male, female, health professionals, specific communities. Everyone!" (D1) Echoing a suggestion mentioned at *01.11groups* above, participants in one consultation discussed the importance of differentially targeting 'drinkers': for example, those who are alcohol dependent versus those who can give up when they learn that they are pregnant (F1).

Consultation site-specific suggestions included:

resources should be targeted at a younger age group – before high school…need to educate young people on STI [sexually transmitted infections], pregnancy and FASD (A1);

everything must revolve around and include family, including dads (A1);

resources should target adults first and foremost because they're responsible for enabling children's [drug and alcohol] *use (children as young as 10 here are drinking or smoking)* (B3);

young teenagers…all the family – we are all connected (D1), and

general community … high schools … everyone (D2).

13. What messages would you like to see for each resource which addresses the issues of alcohol, pregnancy and breastfeeding?

There were numerous answers and suggestions to this question from all consultation sites, many of them overlapping with other categories, in particular with *01.9best* above.

All communities wanted issues of alcohol, pregnancy and FASD to be situated within broader health messages that might also include topics such as:

sex education…(F1; A1; B1);

integrated messages on the issues including on STI, *pregnancy and FASD* (A1); and

safe births and healthy babies…good birth weight is important…healthy mums (D1).

The majority of community members felt very strongly that any messages addressing these issues must be "up front…confronting…blunt" (A1) (as mentioned at *01.9best*) (A1; B1; D1; D2; F1). Participants told us:

confronting presentations…'in your face'…they need to know the side effects, describe what the worse outcome will be…don't sugarcoat it (D2);

need to use shock tactics…straight to the point…hard hitting messages (B1);

want to see stark imaging…tough love messages…images similar to domestic violence campaigns/smoking ads (F1); and

no drinking while pregnant (D1).

Again, as already mentioned at *01.9best* above, all communities wanted messages that educate community around the consequences of drinking and the effects on the baby, as well as messages that show the effects across the life course for the FASD-affected individual (including secondary effects):

…side effects of drinking – it's important to know this…Get them to understand that all *alcohol affects the baby, not just beer but all alcohol* (D1);

need to know from start of life to finish how alcohol can affect babies (B1);

show side effects of drinking…show different effects of FASD (D4);

show facts with graphic illustrations (D1); and

causes and dangers for partners, parent and the kid (D2).

Participants in one community added, however, that:

Education is needed on how *to stop drinking not just being told to say 'no' to alcohol* (F1).

Unsurprisingly, all communities expressed a desire for messages that are culturally appropriate and contextualised to suit local needs and preferences, with consensus that all messages should:

- use simple language with minimal words, local language and local artwork;
- be visual, simple, eye-catching;
- be engaging, clear and straightforward; and
- should be something that people identify with.

Two of the consultation sites (A1; F1) talked about the need for messages to depict 'true' stories:

Something personal/true stories, depicting effects on the child as well as longer term/secondary effects of FASD (F1).

This is congruent with what some Elders said about there being "people sitting here who can roll out programs on these issues" (A1). While no questions were posed to participants around their own drinking behaviour and/or drinking history, many volunteered their personal stories. For some, this included having a FASD-affected child and/or grandchild, and the impact that alcohol consumption has had on their own lives and the lives of their families. On this basis, many felt that they are in the prime position of being able to educate others on the dangers of alcohol, pregnancy and FASD.

14. What other information would you like to see on each resource addressing the issues of alcohol, pregnancy and breastfeeding?

Again, this question overlaps with *01.9best* and *01.14messages,* so only those isolated suggestions that do not appear above are included here:

- language specific (B1);
- photos of real/normal people and/or the utilisation of real/normal people (including Aboriginal and non-Aboriginal people) in community/grassroots settings (A1; B1; D4; F1);
- product labelling/warnings on all alcoholic packaging, at all points of sale (B1; D2; F1);

- the issues presented as a whole of community issue/responsibility (A1; B1);
- development of a national FASD symbol (like the red cross symbol) that becomes instantly recognisable as: a warning to not drink alcohol during pregnancy; and/or a safe place to come and talk about the issues of alcohol, pregnancy and FASD (B1); and
- funding for FAS dolls (F1).

15. What other things do you think health workers should use or do to address the issues of alcohol, pregnancy and breastfeeding in your community?

While answers to this question may have already been mentioned elsewhere, they are listed again here to highlight communities' expectations around health workers' responsibilities in respect of these issues:

- ongoing, community-wide education and/or advice (A1; B1; D1; D2; D4; F1);
- more training/education overall (for health workers) around the issues and on how best to address/approach the issues (B1; D1; D2; D4; F1);
- address normalisation of alcohol consumption (A1; F1);
- emphasis on breastfeeding and alcohol (D1; D4);
- addressing alcohol in the same manner as tobacco (F1);
- be less judgemental/more empathetic towards clients (D4);
- provide intervention services at birth (A1); and
- specifically trained FASD health workers (D4).

16. How do you feel that resources should be implemented into the community?

One of the most important messages to come from the consultations was communities' requirement for their ongoing involvement in the development of any resources that seek to address these issues, with the following themes recurring across all consultation sites:

- cultural appropriateness;
- community-driven solutions;
- empowerment;
- community consultation and ownership; and
- tailored responses.

Other recurring themes across all consultation sites regarding resource implementation included:

- through ongoing community-wide education;
- through sex education being delivered in schools on a continual basis and for issues of alcohol, pregnancy and FASD to be embedded within broader health messages; and
- for the [Federal] government to initiate a national FASD awareness campaign for TV broadcasting.

17. What do you feel would be the best way for communities to assess how effective these resources are?

Communication was believed by all communities to be the best way to assess how effective any resources would be, including:

- through community consultations ('follow up…more information days like today') (B1; D2; D4);
- through working together and sharing information as a team (D1; D2);
- through surveys (B1; D1; D2; D4); and
- by how much it is being talked about (B1).

What are the similarities/divergences across community consultation sites?

This section provides as succinct a picture as possible of the most salient similarities and/or points of divergence across and between community member consultation sites that have emerged from the data.

Knowledge of FASD

1. **What do you think when you hear the term FASD?**

Participants at all community consultation sites acknowledged that while there is an understanding that one should avoid alcohol when pregnant, the **effects** of maternal alcohol consumption during pregnancy are not well known: the limited information/education community-wide around FASD generally equates with a lack of knowledge and/or awareness of FASD as a possible outcome of maternal alcohol consumption during pregnancy.

2. **Have you had any discussions etc on drinking alcohol, pregnancy and breastfeeding?**

While participants across four consultation sites said that discussions had been held between themselves and health professionals regarding the risks of alcohol consumption during pregnancy and breastfeeding (two referenced midwives/doctors, one referenced the local drug and alcohol council and one referenced a health worker), the general consensus across all sites was that very little or only cursory attention is given to these issues by health professionals. For one of the two sites referencing that this information is addressed by midwives/doctors (B1), we were also made aware of the extensive community consultation process that had been undertaken by the local Aboriginal Medical Service in that jurisdiction to produce their own resources addressing these issues; this process and the resources appeared to have contributed to an increased awareness of the importance for health professionals to address these issues with clients on an ongoing basis.

3. **Have you seen any resources about FASD?**

In two jurisdictions (B1 and D (including D1, D2 and D4)) the majority of participants had seen the resources produced by their respective Aboriginal-specific medical service/drug and alcohol council. In contrast, where resources had not been locally produced, the majority of participants had not been aware of/seen any resources addressing FASD.

4. **Where have you seen the resources?**

For those participants who had seen resources, the majority reported that they were located in health settings (for example, AMSs, doctors' surgeries, hospitals, antenatal clinics).

5. **What do you think is the best advice to give someone about FASD?**

All consultation sites felt that telling people about the consequences of drinking alcohol and the effects on the baby is fundamental. The differences lay in how messages are relayed, pointing to the necessity for local input into how messages are constructed/oriented.

6. **What do you think is the worst advice to give someone about FASD?**

While there were differing suggestions put forward as to the worst advice to give someone about FASD, these were not contradictory; rather, they reinforced the overall consensus that educating people around the facts and the potential outcomes of drinking alcohol during pregnancy is fundamental. Language use would be one way communities might differentiate their messages but the overall thrust of what was considered 'worst advice' was: 'It is ok to have one or two drinks while pregnant'.

7. **Do you think there should be different resources for different groups in your community?**

There was overall consensus across consultation sites that there should be different resources for different groups in communities. Most participants, both in community and in health professional consultations, felt that resources specifically targeting men, young people, and whole of community, as well as women of childbearing age, were essential to the educative process around issues of alcohol, pregnancy and FASD.

8. **What types of resources would you like to see in your community to address the issues of alcohol and pregnancy?**

All communities talked about the need for community-wide education and the development of educational tools to address the issues of alcohol and pregnancy. Education of young people (pre-teen and upwards) in particular was considered a key strategy at preventing/reducing consumption of alcohol during pregnancy across all consultation sites. The breadth of suggestions around the types of resources that would fulfil these requirements pointed to the varied ways it might be possible to address these issues. The primary finding from this is that there is no one way that these issues can be addressed both from within communities and across jurisdictions. The development of local resources, and ongoing community involvement in the development of resources that seek to address these issues, however, was raised at all consultation sites.

9. **Who should each resource be targeted at?**

As noted in 01.11 above, all consultation sites agreed that different resources need to be developed that target as many different groups within a community as possible.

10. **What messages would you like to see for each resource that addresses the issues of alcohol, pregnancy and breastfeeding?**

There were several major themes raised by all communities around the types of messages they would like to see for each resource that addresses issues of alcohol, pregnancy and breastfeeding including:

- situating these issues within broader health messages, including within messages around sex education generally and the benefits of healthy lifestyle choices;
- education around the consequences of drinking alcohol and the effects on the baby;

- up-front, confronting, and blunt messages; BUT also
- positive messages so that the women will not feel shame or guilt if she has been drinking during pregnancy; and
- a recognition that some pregnant women are unable to stop drinking, and so they need to be supported to cut down.

Importantly, all communities stressed the need for messages to be culturally appropriate and contextualised to suit local needs and preferences.

11. What other things do you think health workers should use or do to address the issues of alcohol, pregnancy and breastfeeding in your community? Gaps?

The major themes that participants identified as ways health workers should address issues of alcohol, pregnancy and breastfeeding included:

- ongoing community-wide education and/or advice;
- more training/education around the issues generally (for health workers);
- more training/education on how health workers could approach/address the issues; and
- the implementation and use of locally produced and locally relevant resources.

What are the similarities/divergences between health and community?

Questions posed to health professionals and community members during the consultations differed to take into account participants' differing levels of involvement with issues of alcohol, pregnancy and FASD. For ease, we have attempted to synthesise the data from questions that bear similarity to each other and to provide as succinct a picture as possible of the most salient points that have emerged.

Knowledge of FASD

1. Levels of community awareness about alcohol, pregnancy, breastfeeding and FASD

There would appear to be congruence between what health professionals' perceive communities' levels of awareness to be around the issues of alcohol, pregnancy and FASD and what community themselves have identified: community members know not to drink alcohol during pregnancy but the **effects** of doing so are little known/understood.

Lack of knowledge around alcohol use during breastfeeding was also raised as an issue across sites.

2. Raising the issue of alcohol use in pregnancy and FASD

While there were health professionals in relevant roles across all consultation sites reporting that they do raise the issue of alcohol use in pregnancy and FASD, community members' perceptions overall were that very little or only cursory attention is given to these issues by health professionals in their communities. This was a clear disparity between what health professionals believed they had conveyed and what community believed they had received by way of messages around alcohol and pregnancy. It is not possible to further extrapolate significant meaning from these data other than to highlight community participants' perceptions of the gaps in health professionals' approaches to these issues.

3. Existing FASD resources

Some participants from across the majority of health professional consultation sites use some type of FASD resources; in contrast, participants from across the majority of community consultation sites had not seen any FASD resources in their local community. Of those resources that are used/have been sighted, the majority of participants across both community and health find them acceptable. Where resources were not considered useful by both health professionals and community members, cultural and/or context inappropriateness were cited as reasons.

4. Appropriateness of existing resources

Health professionals appear to have a firm understanding of what community members consider appropriate and acceptable in both existing resources and/or in the development of future resources that address issues of alcohol, pregnancy and FASD. Key concepts noted by both groups were: contextually

relevant; culturally appropriate; few words; simple language; picture/image driven; and colourful.

5. The best advice to give someone about FASD

There were subtle differences between health professionals' and community members' views about what constitutes the 'best advice' to give someone about FASD. For health professionals, advising clients to not drink alcohol during pregnancy was a dominant theme. For community members, factual information informing people of the consequences of drinking and the effects on the baby was key, with advice to not drink alcohol during pregnancy embedded within those broader messages. There was a more significant difference, across consultation sites, around how these messages were delivered, with communities calling for 'hard hitting…blunt…to the point' messages, while the majority of health professionals preferred a less direct/less harsh approach.

6. The worst advice to give someone about FASD

The key commonality with regard to what was considered the 'worst advice' across both health and community consultations was:

- 'It's ok to have a couple of drinks' – participants across all consultations told us that this is unacceptable advice for clients to be given by any person operating in a professional capacity.

While this view was shared across community and health professional consultations as the single most worst advice that could be given, there was a clear divergence in views on how other messages around drinking and pregnancy should be framed. In contrast to community views that hard facts and hard hitting messages are the **best** advice that can be given, many health professionals felt that 'giving the worst possible outcome', or confronting people with 'hard hitting' messages, is the **worst** thing one can do. Many community members, on the other hand, suggested that providing people with 'softened' information or messages is worse, as they felt this does not serve the community well or work to embed the seriousness of potential health and social outcomes of drinking during pregnancy.

7. Resources for different groups in communities

With the exception of two participants (site D), there was unanimous agreement across all consultation sites that there should be different resources for different groups in communities.

8. Types of resources that address the issues of alcohol and pregnancy

At all consultation sites health professionals and community members talked about the need for community-wide education and the development/ availability of educational tools to address issues of alcohol and pregnancy. How that education is rolled out and with what tools would vary depending on the setting/target audience. Many health professionals and community members spoke of the potential for using new social media and technology in the development of educational and health promotion resources that could be accessed by a wider audience than more traditional resources, such as

pamphlets, posters etc. Poster and pamphlet type resources were also supported, but in particular where these were locally produced, locally relevant and culturally appropriate. At almost all consultations, participants spoke of national advertising campaigns as an effective resource.

9. Targeting resources

Resources targeting the education of young people (pre-teen and upwards) was considered a key strategy in preventing/reducing consumption of alcohol during pregnancy across all health and community consultation sites. There was also consensus across all health and community consultation sites that resources should target all population groups within communities (for example, young people; boys; girls; dads and so on) addressing as many situations/contexts as possible.

10. Messages for each resource which address the issues of alcohol, pregnancy and breastfeeding

As previously mentioned, opinions were divided regarding how messages are framed, particularly between some communities' desire for 'up-front', 'confronting' and 'blunt' messages, as against the majority of health professionals who suggested that a less direct approach would be more appropriate. Health professionals also suggested a range of other approaches that, while not expressly mentioned by community, fit in with communities' overall approach – in particular, that what is needed is a holistic approach to the care and support of pregnant women around a whole range of issues not limited to alcohol and pregnancy.

11. Other information on each resource addressing the issues of alcohol, pregnancy and breastfeeding

Owing to the breadth and depth of views expressed across all health and community consultation sites, it is clear that there are many potential possibilities for addressing these and associated issues. Context and local needs and preferences will guide any future outcomes.

12. Other things that health workers should use or do to address the issues of alcohol, pregnancy and breastfeeding in your community?

The primary issue here is really to highlight that there are so many ways these issues could be addressed at a local level and that the source of appropriate approaches and media to do so resides with community and health services continuing to work together in addressing the issues on an ongoing basis.

13. How do you feel that resources should be implemented into the community?

Overall, the data supports the need and desire for ongoing education around these issues as a key requirement.

Community want to continue to be involved and engaged in the development of any resources and/or in the educational process in addressing the issues. It was clear from consultations that the ability to include local content and local development of resources was highly valued by participants.

Discussion and conclusion

In the absence of a well-defined evidence base to guide interventions aimed at reducing prenatal alcohol consumption, contemporary public health emphasises a community-based approach to health promotion and prevention strategies (World Health Organization (WHO), 2009). There is an evidence base, however, on what works to overcome Indigenous disadvantage and it is these principles that the data gathered throughout the consultations essentially reflect:

- 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; and,
- creative collaboration (Al-Yaman & Higgins, 2011).

Community involvement and engagement

While, for privacy and ethical reasons, no questions were posed to participants around their own drinking behaviour and/or drinking history, many volunteered to share their personal stories. Typically, these were Elders talking of their own FASD-affected children or grandchildren, and in some cases their awareness of the intergenerational effects of alcohol consumed during pregnancy. These women spoke of the everyday and lifelong challenges and complexities involved, not only for the FASD-affected person, but also for others concerned in the child's/person's care.

Of the young women and (fewer) men who participated in this research, there was often robust discussion around the shared knowledge that drinking alcohol during pregnancy is harmful. That participants also acknowledged a lack of awareness generally about the effects of drinking alcohol during pregnancy highlights a significant gap in the less than optimal attention that this issue receives within the consultation sites and supports other research in this area. Findings from a national survey on women's knowledge and attitudes regarding alcohol consumption in pregnancy were published in 2010 (Peadon et al., 2010) and reported that, of the study cohort, one in three women of childbearing age said they did not know of any adverse effects of alcohol consumption in pregnancy (p. 5).

Health professionals taking part in the consultations have reported experiencing the kinds of challenges in addressing these issues that have also been reported elsewhere:

- concern for the client and the health professional/client relationship; and,
- health professionals' need for skills and resources to support their practice (Payne et al., 2011).

Across the consultation sites, there was recognition by health professionals and communities that genuine partnerships to address these issues will require an ongoing commitment by all concerned. The suggestion that local role models, Elders, artists, sporting figures and so on have a potential role to play in raising community awareness, in the ongoing development of resources and in their implementation was considered an important strategy. The significance of community involvement and engagement in creating local resources was evident at those consultation sites where this had taken place (B1; D1; D2; D4). Communities in these localities had a greater awareness of existing resources addressing these issues within their communities. The increased awareness of issues of alcohol, pregnancy and FASD in these communities was directly attributed to the community consultation processes that local Aboriginal services implemented in developing locally-relevant resources.

Commitment to doing projects with, not for, Aboriginal and Torres Strait Islander people

While the data point to many similarities in both health professional and community members' requirements for templates of resources that address issues of alcohol, pregnancy and FASD across all consultation sites, the differences that have arisen are more to do with participants' different ways of thinking about the problem than with irreconcilable differences of opinion in how these issues can be addressed. It was evident that there was a high demand for a range of locally developed and contextualised resources – and such an approach was consistent with what is considered effective and enduring community informed and based interventions (Allsop, 2008; Caswell, 2000). Any approach to these issues must therefore be accompanied by a flexible rather than 'one size fits all' approach, both within and across communities/jurisdictions.

The different approaches to addressing these issues that emerged from the consultations highlights how effective participation, in which individuals and communities define the problems and have the potential to develop community solutions, shifts the balance of power towards individuals and communities in the hope of achieving the penetration of interventions needed to satisfy the wide-ranging demands and requirements at the local level (Marmot, 2011).

One key difference, however, between community and health requirements for the ways messages about alcohol, pregnancy and FASD are constructed seems to reside in communities' insistence for messages that are blunt, up-front and direct. This is in direct contrast to how some health professionals have framed the appropriate approach, with a less direct, less confrontational style preferred. This could be interpreted as a somewhat paternalistic approach that could have the unintended consequence of denying Aboriginal and Torres Strait Islander peoples' and communities' ownership of knowledge and the associated empowerment processes that come with being able to make informed choices for oneself, determine one's own fate and acquire resources to support one's decisions (Marmot, 2011). As we were succinctly told: "Knowledge is power" (B2). While this does not argue against the need

for national approaches to health and social issues that affect the population as a whole – and indeed it is clear that there must be a firm core of fundamental messages, principles and practices around issues of alcohol, pregnancy and FASD that apply generally across the whole population – it does highlight the need for these national approaches to be sensitive to, and supplemented and supported by, local knowledge and local needs, particularly in those of our communities that are most disadvantaged. It also argues the need for a greater investment in educating and assisting communities to understand the available options, and evidence about what is and what is not effective, so they are fully informed about any interventions affecting them.

The data support the conclusion that some of the resources in use in some communities that address issues of alcohol, pregnancy and FASD are considered culturally inappropriate by some members of that community – "*some parts of the local community think existing resources are discriminating to some Aboriginal mums"* (B1). That the resources to which this participant was referring were produced by the local Aboriginal Medical Service highlights the importance of a flexible approach to targeting different requirements both across and within communities. Others clearly considered resources produced elsewhere to be regionally/contextually inappropriate.

Respect for language and culture

Across all consultation sites there was recognition that any resources developed to address these issues must have a solid foundation in cultural safety, security and appropriateness. Health professionals demonstrated a congruent understanding of requirements compared to community members.

Recognising underlying social determinants

While some of the health discourses employed throughout some of the consultations attributed risky alcohol consumption to individuals (Baum, 2007), there was general acknowledgment that the underlying social determinants and the link between ill-health and low socioeconomic status presented the greatest challenge to addressing alcohol, pregnancy and FASD. Thus, all consultation sites agreed that to separate out these issues from the factors underlying disadvantage is a major barrier to reducing the prevalence of FASD in communities. It is widely recognised in the literature that strategies to address the broader structural and social determinants of health, as well as the provision of services that are accessible, appropriate, affordable, and acceptable to Indigenous people (Gray, Saggers, & Stearne, in press, p. 12) must accompany any strategies to address the ill effects of alcohol consumption (Aboriginal Peak Organisations (NT) (APONT), 2011; Gray et al., in press).

Primary health care is thus fundamental to the prevention, early detection and management of chronic conditions and their risk factors, with the primary health care provider typically playing a central role in the coordination of care (Council of Australian Governments (COAG), 2009). While there was recognition by some health professionals throughout the consultations that some women experience access issues in relation to health services ("*don't*

see mums til 24+ weeks into pregnancy"), and that whatever barriers exist for any individual will, understandably, impact on the supports that can be provided *("so the message is about minimising damage at that point*"(F2)), there was a discrepancy between communities' perception of health professionals' involvement in addressing the issues of alcohol, pregnancy and FASD and the perceptions of health professionals overall. From communities' perspective, more could be done. This supports data from a previous study reporting that, of a sample of 593 health professionals who cared for pregnant women, there was no increase in the proportion of health professionals overall (and only a small increase in obstetricians) who routinely asked pregnant women about alcohol use (Payne et al., 2011, p. 64).

Education, as another social determinant of health, is one way to contribute towards achieving health equity for Aboriginal and Torres Strait Islander peoples and communities (Marmot, 2011, p. 512). Linking back to the previous section on community involvement and engagement, the templates and resources that are being developed as a result of this consultation process provide one way community and health professionals can further develop their knowledge, power and understanding of the issues in collaborative and informative ways; developing these links between individuals and groups at the local level, and in technologically contemporary ways, has the potential to increase participants' social capital within and between communities (Marmot, 2010).

Conclusion

Certain themes emerged from the consultations across all jurisdictions. People are looking for consistency in the messages they receive from health professionals regarding drinking alcohol during pregnancy. Health professionals also expressed the desire for their colleagues across the profession to take a consistent approach to the abstinence message in pregnancy. There was recognition of the need for sensitivity in providing information to those women who may have been drinking during their pregnancy, or who may be unable to abstain from alcohol (e.g. a pregnant woman who is alcohol dependent suddenly stopping drinking and going into withdrawal without clinical support). There is a need for messages informing both women and men about the effects of prenatal alcohol exposure on the baby, and of the lifelong impact that FASD has on the child, family, community and society as a whole. As well, participants in the consultation believed that messages around alcohol and pregnancy would be most effective if embedded within a holistic approach to combatting the normalisation of alcohol more generally, and to the social determinants of health in their communities.

At all consultation sites health professionals and community members talked about the need for community-wide education and the development/availability of educational tools to address the issues of alcohol, pregnancy and FASD. Education of young people (pre-teen and upwards) in particular was considered a key strategy at preventing/reducing consumption of alcohol during pregnancy across all consultation sites. It was believed that evidence-based information focused around alcohol, pregnancy and FASD

should be blended into existing sex education and family planning materials, and that these educational resources be made available to teachers and other professionals to enable them to approach these issues with young people likely to be or to become sexually active.

Participants across the country spoke of their desire for locally relevant and locally developed resources, but also spoke positively of the benefits of national advertising campaigns around issues that are of concern to all, such as smoking, drink driving, and domestic violence. There was an often expressed desire by participants in both community and health professional consultations to see a similar campaign run nationally around the dangers of drinking in pregnancy.

It was also very clear from discussions with people in communities in each locality that, while 'traditional' resources such as brochures, pamphlets, and posters were often viewed as 'better than nothing', there was a real desire to use technology to gather and disperse information and education, both between and among health professionals, and out into communities. There is a need both for lengthier pieces of explanatory and evidence-based text aimed at health professionals, and for the short, sharp messages that will capture the attention of the wider community. People want to have a choice of culturally safe, generally positive materials to draw on so that they can develop their own locally relevant resources, using appropriate artwork, colours, forms of words, and local contacts. These desires are consistent with the available evidence that a combination of culturally sensitive and appropriate harm minimisation strategies, designed specifically for the needs of particular communities, are the most effective interventions for Indigenous Australians (see, for example, Wilson et al, 2010). They also reflect the findings of the Western Australian Fetal Alcohol Spectrum Disorder (FASD) Prevention Aboriginal Consultation Forum 2010, which found:

> ...a general consensus that significant, broad based efforts to raise awareness of the harms associated with alcohol use in pregnancy and FASD were required. These messages then need to be adapted to suit individual communities and should encourage community ownership (Drug and Alcohol Office, 2011).

We have responded to this evidence both from our own consultations and from other sources by undertaking the development of what we have called 'templates' of resources, rather than through the production of a suite of 'finished products'. These templates consist of material reflecting areas of commonality across the country. For tailored responses, services may also upload their own, locally relevant images/photos. The database of both textual and image-based material addresses broader, more holistic issues around the social determinants of health, but has a specific focus on issues around alcohol and pregnancy. The 'template database' includes, for example, evidence-based messages ranging from longer clinical descriptions of the effects of FASD for health professionals, through to clear, concise messages for use with community. Content has been provided that is relevant to health professionals and to different groups within communities (that is, young

people, women, men and whole-of-community), from which services can choose to create a variety of locally relevant resources. In this way, those communities outside the consultation process will be enabled to have input into and take some ownership of the resources they may choose to create from the templates provided.

Health services and communities will be able to do this through accessing an iPad app or a web-based digital platform. The app and web-based platform can be used as educational tools through which individuals and groups may work with their local health or other sector provider and/or with fellow community members in producing their own posters. Community involvement and engagement in the creation of the resource (poster maker) will provide the opportunity for meaningful dialogue around relevant and associated issues, at the same time as investing decision-making and ownership in users' hands.

We also had developed an iPhone/Android phone app specifically aimed at engaging young people holistically in consideration of healthy lifestyles and the consequences of various life choices. The proposed purpose of this app was twofold: for parents, health professionals and other workers engaging with young people to use as an educational tool during their discussions/workshops, and for young people to educate themselves on these issues in a fun way. However, as has been noted above, the decision was taken not to release these apps.

Limitations

Of course, generalisability is limited by the number of locations where consultations were conducted. For a range of reasons, it was not possible to secure any consultations in the Northern Territory. While we did not conduct consultations within Western Australia, because state government services were conducting their own, we were informed by the outcomes of these latter consultations. Further, while consultations were held with services in both metropolitan and regional locations in some states, there were no consultations held with any services in very remote locations. On the other hand, it is evident that the findings are consistent with those obtained in the separate consultations conducted in WA by DAO, suggesting confidence in the findings.

A further limitation of this research project has been the under-representation of younger women and men generally in the consultation process, and particularly of young women who would be at the greatest risk of having a FASD-affected baby. Of those young (and sometimes pregnant) women who did attend the community consultations, most professed to be non or very light drinkers, and many said they had mothers or aunties who had advised them of the dangers of drinking while pregnant. Some were daughters or nieces of health professionals involved in the consultations. The majority of the men involved in the consultations were health professionals, although men, including some young men, did take part in a few of the community consultations. This of course is not an uncommon challenge – some of those in the target audience might be less likely to attend consultation processes.

These limitations provide even stronger impetus for the development of resources that are readily accessible, that provide information and evidence-based content, but are amenable to local adaptation and the inclusion of local content. It is expected that the digital platforms that will be developed as part of the project, containing templates that individual services can adapt (and potentially contribute to) to suit the needs and preferences of their own communities, will assist in overcoming these limitations.

Dissemination strategy and evaluation

The iPad/web-based app has the potential to be used in a variety of settings, including health, youth settings, community-based events, schools and so on to provide as far a reach, community ownership and involvement as possible.

Post-launch evaluation

The iPad/web PosterMaker app has an inbuilt voluntary and anonymous evaluation component where users are invited to comment on the app and elements of its use. The results from this evaluation will be collected and analysed by NDRI over the first three months post-launch, and will be available to the DoH at that time.

Additionally, all participants in the consultation process will be forwarded an evaluation survey covering both the consultation process and the outcomes of that process (that is, the iPad/Web PosterMaker app) three months post-launch. This information will be analysed and available to the DOH at that time.

Dissemination

The project managers presented on the project to the Australasian Fetal Alcohol Spectrum Disorders Conference in Brisbane on 19 November 2013. This was an opportunity for the project managers to demonstrate and promote the project and its outcomes to a key target audience that included:

- health professionals at all levels;
- allied and public health workers;
- Aboriginal health workers and community sector workers;
- AOD, mental health and related sector workers;
- policy makers;
- families and people with FASD, and parents and carers; and
- people working in the criminal justice system, child protection, and social and health services.

A media release has been developed, in consultation with NDRI's communication staff, targeting health professionals and other interested stakeholders, for example, NACCHO (for dissemination to their affiliate organisations), the project Reference Group members, Indigenous Health*Info*Net, and consultation participants/organisations.

A link to the PosterMaker app will be sent via email to all relevant Indigenous and mainstream health and other organisations, encouraging them to include it on their own websites.

Two 'snapshots' of the project have also been developed for dissemination: one of these provides a comprehensive overview aimed at health and other interested professionals, and the other is a short, plain-language overview of the project for dissemination where appropriate to community members. The

snapshots will also be provided to the AH&MRC as part of fulfilling our obligations for ethics approval from that body.

The research team will develop and seek to publish peer-reviewed papers in relevant academic journals.

A seminar on the project will be held at NDRI, in Perth, in early 2014.

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Appendix A: Australian resources

Resource #	Government	Place/ Funder	Date	Type of resource	Title/Description	Primary purpose	Primary audience
1	ACT Dept of Health	ACT	n.d.	Web-based information	Alcohol and Drug Program	Information/supports	General
2	Australian Gov't	ACT	n.d.	Poster – various	Various	Promotion of positive messages about strong culture, families and healthy choices	Young Indigenous men and women
3	Australian Institute of Family Studies	ACT	n.d.	Bibliography compiled from Australian Family & Society Abstracts database	Parenting and substance abuse	Information/ education	General
4	DoHA	ACT	2002	Literature review	Fetal Alcohol Syndrome – A Literature Review	To provide an understanding of FAS and the surrounding issues	Policy/service providers/health professionals
5	DoHA	ACT	2006	Clinical guidelines	National clinical guidelines for management of	Support for health care practitioners caring for women/families with AOD issues	Health care practitioners

					drug use during pregnancy, birth and early development years of newborn		
6	DoHA	ACT	2007	Guidelines	Alcohol treatment guidelines for Indigenous Australians	Information/ education/guidelines/management of FASD	Various
7	DoHA	ACT	2008	Web-based info on funding provided to community services to address binge drinking among young people	National Binge Drinking Strategy – Community Level initiative	Information	Various
8	DoHA	ACT	2009	Info sheet	New guidelines for alcohol consumption	Education	New mothers/breast-feeding mothers
9	DoHA	ACT	2009	Info sheet	New guidelines for alcohol consumption	Education	Pregnant women/child-bearing age women
10	DEEWR &	SA/	2009	Resource	Drug strategy	Education	General

	DECS, SA	Federal		sheet	resources		
11	Depts of Human Services & Community Services	NSW	n.d.	Program	Brighter futures	Education/ support	Aboriginal families
12	NSW Government	NSW	2003	Information re Alcohol Summit 2003 and links to information on FAS	NSW Alcohol Summit03	Information on the summit	General
13	NSW Department of Health	NSW	2006	Information sheet	Alcohol and Drugs in Pregnancy	Information	AOD using mothers
14	NSW Department of Health	NSW	2007	State-wide health plan	Healthy people NSW – Improving the health of the population	Improving the health of NSW population	Policy/service providers/health professionals
15	NSW Department of Health	NSW	2007	A worker's guide (cartoon booklet)	No Shame, No Blame – A workers guide for helping Aboriginal and Torres Strait Islander families affected by	Information/ education/to facilitate discussion of AOD use (not FASD)	Aboriginal and Torres Strait Islander families affected by AOD use

					alcohol and drugs		
16	NSW Department of Health	NSW	2007	State health plan	A new direction for NSW – State Health Plan towards 2010	Health priorities/strategies and targets towards 2010 and beyond (nothing specifically focusing on FASD)	Policy/service providers/health professionals
17	NSW Department of Health	NSW	2008	Clinical guidelines	Nursing & midwifery clinical guidelines – identifying and responding to AOD issues	Support for nurses and midwives involved with AOD clients	Clinical, nurses, midwives
18	NSW Department of Health	NSW	2009	Clinical guidelines	Aboriginal Family Health Workers – Operational Guidelines	The identification of specific requirements of the Aboriginal Family Health Workers	Aboriginal Family Health Workers
19	NSW Department of Health	NSW	2009	Factsheet	Alcohol Factsheet (not FASD)	Information/ education	General
20	NSW Dept Community Services (DOCS)	NSW	2009	Practice resource	Working with Aboriginal people and communities	Guide to improve service delivery	Health/service professionals, gov't, NGOs
21	NT Health Services, Gov't of NT	NT	2002	Book	The public health bush book: a	Information/ resources/education	Community workers

					resource for working in community settings in the NT		
22	NT Gov't Departments	NT	n.d.	Resource kit to address alcohol misuse. Includes flipchart, 2xDVDs, handouts, Indigenous Risk Impact Screening tool	Grog – making the change (not viewed)	Support	Frontline workers across health and community services
23	Queensland Government	QLD	n.d.	Leaflet	How Dads can help – growing strong: feeding you and your baby – section on effects of drinking	Information	Pregnant women and their partners
24	Queensland Health	QLD	2009	Information leaflet	Growing strong: feeding you and your baby. Alcohol, tobacco and	Information/ education/advocacy	Pregnant/women of childbearing age

					other drugs during pregnancy and breastfeeding. Shows picture of pregnant Aboriginal woman with hand out saying no to images of alcohol and cigarettes		
25	Children, Youth and Women's Health Service, Gov't SA	SA	n.d.	Posters	Pregnancy and alcohol don't mix – there is no safe time to drink alcohol during pregnancy – there is no safe amount of alcohol – alcohol can harm your baby for life	Information/ education	Pregnant women
26	Children, Youth and Women's	SA	n.d.	Factsheet	Alcohol – effects on unborn	Information/ education	Pregnant women

	Health Service, Gov't SA				children		
27	Drug Education Network (DEN)	TAS	n.d.	Links to resources	Prenatal exposure to alcohol and FASD resource site	Education/training/ networks/ referrals	General
28	DEN	TAS (DoHA)	2008	Newsletter	Foetal Alcohol Spectrum Disorder Community Building Newsletter	Information/ education	Community members
29	Tasmanian Gov't	TAS	2009	Report	Kids Come First Report 2009 – Outcomes for children and young people in Tasmania	Information/ outcomes framework	Policy makers/service providers
30	The Royal Women's Hospital	VIC	n.d.	Clinical guidelines	Alcohol & other drug issues in pregnancy: management	Information/ education	Health professionals
31	The Royal Women's Hospital	VIC	n.d.	Information/ fact sheet	Alcohol	Information/ education	Pregnant women

32	The Royal Women's Hospital	VIC	n.d.	Information/ fact sheet	Neonatal abstinence syndrome	Information/ education	AOD using pregnant women
33	The Royal Women's Hospital	VIC	2001	Guidelines	Three Centres Consensus Guidelines on Antenatal Care – October 2001	Guidelines on aspects of antenatal care (no FASD)	Health professionals
34	Victorian Dept of Human Services	VIC	2003	Alcohol and Drug Plan	The Koori Alcohol and Drug Plan 2003-2004	A report on the development of a Koori-specific drug strategy within the Victorian Drug Initiative	Policy/service providers
35	Drug Info Clearinghouse	VIC	2004	Fact sheet	Alcohol and other drug use by Australian Indigenous people: a snapshot	Information	For workers
36	Drug Info Clearinghouse	VIC	2004	Fact sheet	Drug prevention work with Indigenous Australian clients and communities	Information	For workers
37	Premier's Drug Prevention	VIC	2007	Literature review	Fetal Alcohol Syndrome: A literature	Research and awareness project/Background information for VACCHO	Policy/service providers/health professionals/

	Council, Dept of Human Services, Government of Victoria				review for the 'healthy pregnancies, healthy babies for Koori communities' project	project of same name/develop culturally appropriate information and training materials	community
38	Victorian Dept of Health	VIC	2007	Flip chart	Healthy Pregnancies, Healthy Babies for Koori Communities – our kids, our community, our responsibility	Education/information	Pregnant/child-bearing age Koori women, and men; community
39	Drug Info Clearinghouse /The Royal Women's Hospital	VIC	2009	Fact sheet	Pregnancy and alcohol	Information/ education	Pregnant/child-bearing age women
40	Drug Info Clearinghouse /ADF	VIC	2009	Fact sheet	Resources for workers in the drug and alcohol field who work with Indigenous communities	Information sheet	D&A workers
41	St Vincent's	VIC	2009	Booklet	The grog brain	Information/	Aboriginal people

	Hospital & Menzies School of Health Research				story	education about the effects of alcohol	
42	Healthway WA	WA	n.d.	Presentation	Alcohol use in pregnancy: should we be doing more?	Education/research findings	Researchers/health professionals
43	Pilbara Community Drug Service Team	WA Dept of Health/ BHP Billiton	n.d.	Presentation	Alcohol and pregnancy	Information/ education	Health/service providers
44	DAO	WA	2005	Guide	Strong spirit, strong mind: Aboriginal alcohol and other drugs worker resource: a guide to working with our people, families and communities	Information/ education	Aboriginal AOD workers
45	DAO	WA	2006	Information sheet	Strong spirit, strong mind: Aboriginal	Information/ education	Aboriginal people

					ways of reducing harm from alcohol and other drugs		
46	DAO	WA	2006	Information sheet	Strong spirit, strong mind: Strong babies	Information/ education	Aboriginal people
47	DAO	WA	2006	Information booklet	Strong spirit, strong mind: making sense and supporting change: a guide for our people	Information/ education	Aboriginal people
48	DAO	WA	2007	Information sheet	Strong spirit, strong mind: understanding low risk drinking	Information/ education	Aboriginal people
49	DAO	WA	2007	Presentation	Health professionals making a difference: Fetal Alcohol Spectrum Disorder, alcohol and substance use in pregnancy,	Education/ information/ strategies for intervention	Health professionals

					and breastfeeding		
50	Department for Child Protection	WA	2008	Matrix	FASD – Services and programs by state government agencies (CSDG), including all of DAO's projects	Overview of what's going on re FASD	Various
51	Dept of Health, Gov't of WA	WA	2010	Model of Care Guidelines	Fetal Alcohol Spectrum Disorder Model of Care	Recommendations for health professionals/policy makers when addressing the issues of alcohol and women's health or pregnancy	Health professionals/policy makers
52	WA Country Health Service, Gov't of WA	WA BHP Billiton	n.d.	Information/ Fact sheet	Alcohol and Pregnancy: what are the risks?	Education/ information	Pregnant women
53	University of Adelaide	SA	2009	Report	Preventing infant deaths among aboriginal and teenage women in SA – part 2	Inform/educate /further research/action required	Researchers/policy makers/
54	Rio Tinto	WA	2008	Report	Delivering	Progress on	Various

	Child Health Partnership				improvement in Aboriginal and Torres Strait Islander Child and Maternal Health	research/initiatives in awareness raising/support on FASD issues	
55	Telethon Institute for Child Heath Research (TICHR)	WA	2009	Booklet	Alcohol and pregnancy: a resource for health professionals	Support WA health professionals to address the issue of alcohol use in pregnancy with women	Health professionals
56	TICHR	WA	2009	Wallet card/ calendar	No alcohol in pregnancy is the safest choice	Reminder to pregnant women to think before drinking alcohol when pregnant	Pregnant women
57	TICHR	WA	2009	Factsheet	Alcohol and pregnancy and fetal alcohol spectrum disorder	Information	Health professionals
58	Fetal Alcohol Spectrum Disorders Australian Collaboration	WA DoHA	2010	Newsletter	Fetal Alcohol Spectrum Disorders Australian Collaboration	Information	Various
59	Kulunga Research Network, at	WA	2010	Booklet	Start stronger, live longer: resource kit is	Information/education	Aboriginal health workers

TICHR	designed for use by Aboriginal Health Workers. The resource has a particular focus on Aboriginal child and maternal health, and it contains different sections on a range of health areas including: o Pregnancy and maternity o Aboriginal infants and children o Aboriginal adolescent and young people o Nutrition

					and being active o Mental health and wellbeing o Alcohol, tobacco and other drugs o Health promotion and research. The resource also contains lists of relevant resources, government legislation and related websites, and a services directory.		
60	RHEF	ACT	n.d.	Various	Link to FASD resources	Education	Various
61	Rural Health Education Foundation (RHEF)	ACT DoHA	2007	Educational documentary DVDs (one short and one	Drinking for Two? Asking the question: 'is it safe to	Education – Discussion of FASD within context of prevention, diagnosis, early intervention and long-term	Health professionals/ community educational services

				longer version)	drink when you're pregnant?' Reference to NHMRC 2001 Australian alcohol guidelines	management and support for sufferers and families	
62	SUPPS – Collaboration on Substance Use in Pregnancy and Parenting Service	NSW	n.d.	Presentation (narrative)	Family Support and Health – An Integrated Team. A True Government/ Non-Government Collaboration Targeting Pregnant Substance Using Women	Information/education	Other service providers
63	Child Health	NT	2009	Presentation	Fetal Alcohol Spectrum Disorder	Information/education	Health professionals
64	Apunipima Cape York Health Council	QLD	n.d.	Presentation	What is FASD?	Information/education	Various
65	Australian	QLD	n.d.	Paper	FASD position	Information/policy	Various

	Special Education Principals Association ASEPA				paper		
66	Indigenous Lead Centre	QLD	n.d.	Guide	Different cultures, common ground. Guide for engaging respectfully with Aboriginal and Torres Strait Islander people	Information/education	Service providers
67	NIAFASEN	QLD	n.d.	PowerPoint presentation – Lorian Hayes	FAS workshop – Indigenous focus	Information/education	Health professionals consumers academics
68	NIAFASEN	QLD	n.d.	PowerPoint presentation – Lorian Hayes	FAS workshop – Indigenous focus	Information/education	Health professionals consumers academics
69	NIAFASEN	QLD	n.d.	Web page	Services available from NIAFASEN	Advocacy/education/ training/support/ referrals/resources	Consumers
70	NIAFASEN	QLD	n.d.	Web page	Social health risk factors	Assessments	Consumers

71	NIAFASEN	QLD	n.d.	Web page	Overview of NIAFASEN – mission and services	Information	Consumers
72	RFFADA	QLD	n.d.	Web page	Links to FASD resources – training/ Aus websites	Information/education	Consumers
73	RFFADA	QLD	n.d.	Web page	What doctors can do	Information/education	Health professionals/ consumers
74	RFFADA	QLD	n.d.	Web page	Alcohol and pregnancy – interview with Elizabeth Russell – links to books by E Russell (mother of two FASD boys)	Information/education	Consumers
75	Women's Health Queensland Wide Inc	QLD	n.d.	Paper	Alcohol use during pregnancy	Information/education	Various
76	Aboriginal Drug and Alcohol Council (ADAC) SA Inc	SA Funded by Alcohol Rehab Found'n	n.d.	Leaflet	FASD questionnaire – shows images of a glass with a fetus in it, with	Advocacy/education	Aboriginal women – pregnant or childbearing age/general public

		Ltd			a skull and crossbones above; and of Aboriginal children being aggressive, unable to keep up at school, unable to participate in sport		
77	ADAC	SA	n.d.	Web-based information	2nd World FASD Conference – 21st May 2007	Information	General
78	NOFASARD	SA	n.d.	Pamphlet	Fetal Alcohol Spectrum Disorder (FASD) The preventable disability	Information/education	Women/pregnant women
79	NOFASARD (and teaming up with arbias)	SA	n.d.	Brochure	Alcohol & Pregnancy – be kind to me, stay alcohol free	Information/education	Women/pregnant women
80	ADAC	SA	2006	DVD	Alcohol and your body – the animated	Information/education	Various

					DVD		
81	DASSA	SA	2006	Guide	Fetal alcohol spectrum disorders – a guide for midwives	Guide/support	Midwives
82	Drug & Alcohol Services, SA (DASSA)	SA	2007	Clinical guidelines	Alcohol, Tobacco and Other Drugs	Clinical guidelines for nurses and midwives	Nurses and midwives
83	NOFASARD	SA	2007	Newsletter	NOFASARD Newsletter	Information/education	General
84	ADAC	SA	2008	Posters – various versions	None for Nine/Alcohol Gubbi Woman – its effects on me and my family/Fetal Alcohol Spectrum Disorder etc	Information/Education	General
85	NOFASARD/ SANDAS SA	SA	2008	Paper	The conundrum of FASD in Australia	Information/advocacy	Government/service providers
86	DASSA	SA	2010	Booklet	Women's Drinking Guide	Information/education/ support	Women
87	Drug Education	TAS	n.d.	Web-based resources	Various – educating and	All of the above	Various/General

	Network (DEN)				informing the community; training for service providers; building networks state wide, nationally and internationally; information and referral services for help on FASD		
88	NOFASARD	TAS	n.d.	Information package	Meeting with Chris Altis on behalf of Minister Roxon and Reps from NOFASARD	Information/education/ Policy	Health ministers
89	DEN	TAS	2007	Guidelines	Living with Foetal Alcohol Spectrum Disorder. A guide for parents and caregivers	Information/education/ Support	Parents and caregivers
90	Salvation Army	VIC	n.d.	Online resources	Various	A variety of sources for diagnosis, information,	Various

						support, etc	
91	VACCHO	VIC	n.d.	Leaflet	Alcohol … at what cost?	Information/support	Indigenous families
92	Peninsula Health	VIC	2006	Presentation	Core of Life – preparing Indigenous youth for a positive parenting future	Information about the program	Health professionals
93	VACCHO	VIC	2007	Presentation	Addressing alcohol use during pregnancy with Aboriginal women in Victoria: a holistic approach	Information/education	Various
94	Derbarl Yerrigan Health Service	WA	n.d.	Leaflet	Maternal and child health	Information/support contacts	Indigenous families
95	WA Dept of Health Inception strategies	WA	n.d.	Comic	Baby baby	Information	Indigenous families
96	Milliya Rumurra	WA	2010	Comic	Party Girl	Information/education/support for Indigenous	Indigenous women/pregnant

	Aboriginal Corporation					women to resist drugs and alcohol during pregnancy	women/service providers
97	OVAHS and MG OES	WA	2010	Presentation	A community takes control	Presentation on FASD and how its being addressed in Kununurra	Various

Appendix B: International resources

Resource #	From	Place/ Date	Type of resource	Description	Primary Purpose	Primary audience
1	Ministry for Children and Families British Columbia	Canada, 1999	Guide	Parenting children affected by FAS : a guide for daily living	Education/ information	Parents of FAS/D children
2	Health Canada	Canada, 2005	framework	FASD: a framework for action	Education/ information	Health workers
3	Ministry of Children and Family Development, British Columbia	Canada, n.d. > 2007	Paper	Strong, safe and supported, a commitment to BC's children and youth	Policy document	
4	Public Health Agency of Canada (PHAC)	Canada, 2008	Report	FASD Prevention: Canadian perspectives. Multiple approaches to FASD prevention	Education/ information/policy	Government policy makers service providers
5	Government of Canada	Canada, 2008	Guide	The sensible guide to a healthy	Education/ information	Pregnant women /women of

				pregnancy		childbearing age
6	Children with special health care needs program – public health – Seattle & King County	US, second ed. 2002	Manual	A training manual for trainers. Alcohol and the fetus	Education	Trainers
7	Florida Dept of Children & Families, Florida Dept of Health, Florida State University Center for Prevention & Early Intervention Policy	US, 2003, revised 2005	Guide	FASD : Florida resource guide	Information	Health professionals various
8	National Center on Birth	US, 2004	Guidelines	FAS: guidelines for referral and diagnosis	Education	Health professionals

	Defects & Developmental Disabilities					
9	SAMHSA	US DHHS, 2004/ 2007	Leaflet	How to help your family member or friend be an alcohol-free mother-to-be/ versions for Native men/women	Information	Women/men
10	SAMHSA	US DHHS, 2004	Leaflet	How to have a healthy baby: be an alcohol-free mother-to-be	Information	Women contemplating pregnancy/ pregnant women
11	Alaska Dept of Health and Social Services	US, 2005	Report	Honoring our past, shaping our future: enhancing and sustaining Alaska's FASD project	Information about prenatal exposure to alcohol and effects	Various
12	US DHHS	US, updated 2005	Guide	Helping patients who drink too much: a clinician's guide	Information/ education	Health professionals
13	Health Council of the Netherlands	Holland, 2005	Report	Risks of alcohol consumption related to pregnancy, conception and breastfeeding	Information/advice	Advice to government and the Parliament
14	SAMHSA	US DHHS,	Leaflet	FASD by the numbers	Information/ education	General public

		2006				
15	SAMHSA, Center for Substance Abuse Prevention	US Dept of Health & Human Services, 2007	Paper	Community health and unity: collaboration strategies	Education/ information	American Indian/Alaska Native/Native Hawaiian communities
16	SAMHSA	US DHHS, 2007	Paper	Make your community stronger: how you can promote alcohol-free pregnancy	Education/ information	American Indian/Alaska Native/Native Hawaiian communities
17	SAMHSA	US DHHS, 2007		Pregnancy is sacred: How to help yourself, your family member, or friend be an alcohol-free mother-to-be: tips for Native women	Information	Native American women
18	SAMHSA	US DHHS, 2007	Leaflet	FASD among Native Americans	Information/ education	Native Americans
19	SAMHSA	US DHHS, 2007	Leaflet	Effects of alcohol on women	Information/ education	Women
20	SAMHSA	US DHHS, 2007	Leaflet	The language of FASD	Information/ education	General public

21	SAMHSA	US DHHS, 2007	Leaflet	Effects of alcohol on a fetus	Information/ education	General public
22	SAMHSA	US DHHS, 2007	Leaflet	The physical effects of FASD	Information/ education	General public
23	SAMHSA	US DHHS, 2007	Leaflet	Preventing FASD: healthy women, healthy babies	Information/ education	Women/general public
24	US DHHS	US, 2009	Report	Building FASD state systems. Summary of general and affiliated meetings. FASD: reaching new heights together	Information/ education/policy	Policy makers various
25	US DHHS	US, 2009	Report	Reducing alcohol-exposed pregnancies. A report on the national taskforce on FAS and fetal alcohol effect	Information/ education/policy	Policy makers various
26	CDC	US, last updated 2010	Fact sheet	FASDs alcohol and pregnancy questions and answers	Information/ education	Consumers
27	NHS Lothian	Scotland, 2003	Resource pack	Substance misuse in pregnancy	Education/resources	Health professionals
28	Nova Scotia Health	Nova Scotia,	Workshop/forum	FASD. Stakeholder forum. Towards a	Information sharing/education	Stakeholders

		2008		coordinated approach to FASD in Nova Scotia		
29	National Institute of Public Health	Sweden, 2009	Report	Low dose exposure during pregnancy – does it harm?	Information/ education	Politicians/ administrators of preventive health care/ NGOs
30	HSE Drug Liaison Midwifery Service, Dublin	Ireland, 2009	Booklet	Effects of various drugs during pregnancy including alcohol	Information	Consumers/ pregnant women
31	New Zealand Governmen t	NZ, 2010	Guide	Alcohol and pregnancy. A practical guide for health professionals	Guide/information	Health professionals
32	Ministry of Health	NZ, 2010	Guide	Alcohol and pregnancy: a practical guide for health professionals	Education	Health professionals
33	Hawaii Dept of Health	US, n.d.	PowerPoint	FASD	Information	Various
34	SAMHSA	US DHHS, n.d.	Leaflet	I'm healthy. Thank you mother	Advice/advocacy	Pregnant women

35	Alcohol and Drug Services	Yukon Gov't Canada, n.d.	Leaflet	This is our baby – 5 versions	Education	Family/friends/partners of pregnant women
36	Manitoba government	Manitoba, Canada, n.d.	Brochure	Stop FAS	Information/ education	Pregnant women/ general public
37	ALAC	NZ ,n.d.	brochure	FAS – information for health professionals and community services	Information	Health professionals /community services
38	Alcohol Advisory Council of NZ (ALAC)	NZ, n.d.	Leaflet	Drinking and your baby. Shows pregnant woman with stubby and direct line from her mouth to fetus' brain	Advocacy/information	Pregnant women
39	WHO	n.d.	Paper	How to develop an action plan to implement the [WHO Western Pacific Regional Strategy to reduce alcohol-related harm] strategy	Policy/information	Governments/ policy
40	WHO	n.d.	Paper	Global strategy to reduce the harmful use of alcohol	Policy	Governments/ policy

41	University of British Columbia	Canada 2006, 2009, 2011	Conference	2nd international conference on FASD: Research, policy and practice around the world 3rd International Conference on FASD: Integrating research, policy & promising practice around the world. A catalyst for change 4th International Conference on FASD: the power of knowledge: integrating research, policy and promising practice around the world	Networking/ information/ education	Academics/ NGOs/ policy makers/ general public
42	BC Centre of Excellence for Women's Health	Canada, 2006	PowerPoint	Impairing agency: exploring the ethics of participatory health research with 'addicted' women	Information/ education	Academics/ policy makers/ healthcare professionals
43	BC Centre	Canada,	Review	Double exposure: a	Information/ education	Government/

	of Excellence in Women's Health & BC Women's Hospital and Health Care Centre	2008		better practices review on alcohol interventions during pregnancy		NGOs/service providers
44	BC Centre of Excellence for Women's Health	Canada, 2009 (part funded by Healthway)	PowerPoint conference presentation	Preventing FASD, promoting women's health	Information/ education	Academics/ policy makers/ healthcare professionals
45	University of Alberta	Canada, 2009	Report	FASD Awareness Campaign Project	Information	Government
46	Organization of Teratology Information Specialists (OTIS)	US, 2010	Fact sheet	Alcohol and pregnancy	Information	Consumers
47	Organization of Teratology Information Specialists (OTIS)	US, 2010	Fact sheet	Paternal exposures and pregnancy	Information	Consumers

48	HSAC	NZ, 2008	Review	A systematic review of the literature - FASD Systematic reviews of prevention, diagnosis and management	Information/ education	Academics/ policy makers health/ professionals
49	Medical Research Council, South Africa, University of Pretoria, University of Cape Town (emanating from the FASD Prevention Symposium, 2008)	South Africa, 2008	Policy brief	FASD in Cape Town, South Africa. A huge challenge requiring multi-faceted prevention strategies	Information/ education	Policy makers
50	Fetal Alcohol and Drug Unit, University of Washington	US, n.d.	List	On-line resources around the world (with links)	Information	Various

51	Pittsburgh University	US, n.d.	Paper	Fetal Alcohol Syndrome (Public Health and Genetics Information Series)	Information	Academics/ general public/policy makers
52	BC Center of Excellence in Women's Health	Canada, funded by First Nations and Inuit Health Branch, Health Canada, n.d.	Leaflet	Preventing FASD	Information	First Nations and Inuit peoples
53	BC Women's Hospital and Health Care Centre & BC Centre of Excellence for Women's Health	Canada, n.d.	Brochure	Working with women on substance use and related health issues pre-during and post pregnancy	Information/ education	Healthcare professionals
54	Ninezero.org (est. 2001)	Riverside County, USA	Program	FASTRAC – student version	Peer-to-peer education	Youth/students
55	NASADAD –	2005	Briefing paper	State issue brief no.	Policy	AOD agencies

	National Association of State Alcohol and Drug Abuse Directors Inc	supported by National Institute on Alcohol Abuse and Alcoh'lism (NIAAA)		2 Alcohol research on prenatal alcohol exposure, prevention, and implications for State AOD systems	paper/information	
56	ACOG – American College of Obstetricians and Gynecologists	US, 2006	Resource	Drinking and reproductive health: a FASD prevention toolkit	Information/ education	Healthcare providers
57	Utah Fetal Alcohol Coalition (est. 2008)	US, 2008	Resource list	List of books/websites/ support services/info sheets/NGOs	Information/ education	General public
58	Best start/ Motherisk (1985)/ FASworld (1999)/ others	Canada, 2002	Planning Guide	Training local physicians on alcohol use and pregnancy	Training	GPs

59	Best start: Ontario's maternal, newborn and early child developme nt resource centre (est. 1992)	Funded by Ontario Ministry of Health and Long-term Care 2003	Paper	Keys to a successful alcohol and pregnancy communication campaign	Information	Service providers/ interest groups
60	Mother craft /Breaking the cycle (Mother craft)	Canada, 2004	Paper	Nurturing change. Working effectively with high-risk women and affected children to prevent and reduce harms associated with FASD	Information/education	Health professionals NGOs
61	Ontario Federation of Indian Friendship Centres	Canada, Sept 2005 funded by Public Health Agency of Canada, n.d.	Tool Kit	FASD tool kit for Aboriginal families	'User-friendly' resource	Front line workers who work with children, youth, adults and families affected by FASD
62	Region 6	Edmonto	Strategies booklet	FASD: strategies not	Education	Caregivers/

	FASD child and youth sub-committee (est.2003?)	n, Canada, 2005		solutions		community
63	Best start/ motherisk and others	Canada, updated 2005	Paper	Supporting change: preventing and addressing alcohol use in pregnancy	Information/education	Policy makers/ health professionals
64	Motherisk	Canada, rev. 2005	Brochure	Drinking alcohol while breastfeeding	Information/education	Consumers
65	Best Start	Canada, 2005	Report	What we have learned: key Canadian FASD awareness campaigns	Information	Various
66	Best start/ Motherisk	Canada 2008, reprint	Leaflet	Screening for alcohol use/T-ACE questionnaire	Screening instrument/informatio n	Doctors/health professionals
67	Asante Centre for fetal alcohol syndrome (est. 2000)	Canada Oct 2009	List	FASD related resource list. Includes lists related to family support; prevention; diagnosis; policy & community development; adolescents and	Information	FAS/D children, families, carers

				adults with FASD; justice; education; language development; Aboriginal; other helpful topics; videos/DVDs; websites; links to other websites and documents/ resources		
68	Northern Family Health Society	Canada, 2009 Funded by PHAC	Toolkit	FASD Resource Toolkit, second edition	Education/information	health professionals/ Program and policy developers
69	Provincial Outreach Program for Fetal Alcohol Spectrum Disorder (POPFASD) established 2006	Funded by British Columbia Ministry of Education Updated Jan 2010	Print resource list	Includes guides to FASD; curriculum/resources;	information	Teachers/parents /caregivers/ people with FASD/service providers
70	FASD One : Ontario Network of	Canada, 2011	Symposium	FASD blueprint for action: towards a coordinated	Provide a background on complex issues related to diagnosis of	Researchers/ policy makers/ FASD specialists,

	Expertise			response	and responses to FASD	clinicians, counsellors/ Aboriginal communities, educators/ health/mental health professionals, administrators, service providers
71	Eurocare	Europe 2009	Policy	Eurocare recommendations for effective action to reduce the burden of alcohol problems		European Commission/DGs of Health
72	Eurocare	2009	Report	Eurocare shadow report on the implementation of the EU Alcohol Strategy September 2009		European Commission/DGs of Health
73	Eurocare	2009	Policy	Eurocare overview and recommendations for a sustainable EU alcohol strategy 2009		European Commission/DGs of Health
74	Eurocare	Sept 2009	Conference	Alcohol and Pregnancy	Inform/showcase research/build alliances	Academics/ policy makers/

				Conference		general public
75	Asante Centre for Fetal Alcohol Syndrome (est. 2000)	Canada n.d.	Book/DVD list	List of books/DVDs/ videos around FAS/D, availability and pricing – includes picture books, novels, care guides, auto biographical writings, drug and alcohol information	Support/information	FAS/D children, families, carers
76	Asante Centre for Fetal Alcohol Syndrome (est. 2000)	Canada n.d.	Website	Governed by the Fetal Alcohol Spectrum Disorder (FASD) Society for British Columbia. The Centre offers diagnostic, assessment and family support services, based on a multidisciplinary team approach, for children, youth and adults affected by FASD	Website is dedicated to providing up-to-date resources in the field of FASD	FAS/D families
77	FASD stake holders for Ontario –	Canada, funded by PHAC,	Leaflet	Details on the group and what services they provide	Information	General public

	formalised 2005	n.d.				
78	Best start	Canada, n.d.	Various – buttons/brochures/leaflets/ posters	Various – main messages are: There are serious, long-term consequences to alcohol use during pregnancy. There is no safe time to drink alcohol during pregnancy. There is no safe amount of alcohol during pregnancy. It is best to stop drinking before pregnancy. Help is available if you need it	Information	Consumers
79	Best start	Canada, n.d.	Paper	A sense of belonging: supporting healthy child development in Aboriginal families	Information/education	Various
80	Best start	Canada, n.d.	Brochure	Be safe: have an alcohol-free pregnancy	Information	Consumers
81	Best start/ Sieccan	Canada, n.d.	Report	Teen pregnancy prevention.	Review/information/ education	Policy makers/Education

	(Sex Info and Education Council) 1964			Exploring out-of-school approaches		professionals/ Healthcare professionals
82	Ninezero.org	US, n.d.	Workshop	FASTRAC – substance abuse program	Information/education	Women in recovery
83	Ninezero.org	US, n.d.	Program	Prenatal prevention materials and training	Information/education	Pregnant women
84	Ninezero.org	US, n.d.	Website	Social marketing campaigns – based around website. Features activities, information, free downloadable print materials, helpful links, inspirational videos, wristbands, an interactive blog that keeps health information seekers up-to-date on FASD issues	Information/education/ advocacy	General public
85	Ninezero.org	US, n.d.	Leaflets	Story leaflet, showing pregnant woman – and small child touching	Information/education	Pregnant women/partners/ general

				pregnant woman's stomach – tells story of villagers/ townspeople struggling to save drowning babies downstream. 5 questions, 1 answer; real questions, real answers. Leaflets variously show pictures of a fetus in the womb; a pregnant stomach; and a child hugging a pregnant stomach		
86	Family Resources Institute	US, n.d.	List	List of downloadable brochures	Information/advocacy	Various
87	Sunfield Research Institute charity – established 1930s	Worcest-ershire County Council, n.d.	Information sheets	10 information sheets	Information/support/ education	Health professionals
88	Sunfield Research Institute	Worcest-ershire County	Paper	Building bridges with understanding project: FASD focus	Information/education	Health/education professionals

		Council, n.d.		on strategies		
89	Sunfield Research Institute	Worcest-ershire County Council, n.d.	Resource pack	Practitioner resource pack	Information/education	Health professionals
90	BMA Board of Science	UK, n.d.	Guide	FASD: a guide for healthcare professionals	Information/education	Health professionals
91	The Cochrane Collab-oration (est. 1993)	Inter-national network, n.d.	Review	Psychological and/or educational interventions for reducing alcohol consumption in pregnant women and women planning pregnancy	Education/information / advocacy	Healthcare professionals/ policy makers
92	Eurocare	n.d.	Fact sheet	Alcohol and women	Education	Health care staff/ general public
93	Eurocare	n.d.	Fact sheet	Harm done by alcohol to children	Education	Health care staff/ general public
94	Fasstar	Canada, Septemb er 2003	Poster	FASD Awareness Day poster – I say 'No thanks!'	Advocacy/information	Pregnant women
95	Fasstar	Canada, updated 2005	Teaching tool	Lisa's baby: FASD Awareness skit/This is the baby that Lisa had	Advocacy/information	General public

96	Alcohol Health watch charitable trust (est. < 1999)	NZ, 2007	Briefing paper	FASD in NZ – Activating the awareness and intervention continuum	Information	Academics/ general public/ government
97	FANNZ & Alcohol Health watch	NZ, 2010	Promotional poster	Youth preventing fetal alcohol spectrum disorder – awareness day September 2010	Advocacy/information	Youth/ general public
98	Alcohol Health watch	NZ, 2010	Paper	Towards multidisciplinary diagnostic services for FASD	Education/advocacy/ information	Policy makers/general public
99	FASfacts	South Africa, n.d.	Brochure	Pregnant? Do not drink	Education/advocacy	Girls/adult women of childbearing age; Boys/male partners
100	FASfacts	South Africa n.d.	.wav files	FASRAPs – five downloadable rap songs about FAS (performed presumably by known youth rap performers in SA)	Education/advocacy	Young women/men
101	FASDSA (est. 2001)	South Africa n.d.	Web page	Summary of projects of the FASD Task Team	Information	General public

102	Fetal Alcohol Spectrum Disorders Ireland	Ireland, n.d.	Fact sheet	What is FASD? What happens?	Information	General public
103	FASD.IE (est. 2010?)	Ireland, n.d.	Leaflet	Zero alcohol in pregnancy is the best start for baby!! – image of newborn face	Advocacy/information	Pregnant women
104	Fasstar established c. 1999	Canada, n.d.	Brochures	Information on characteristics/symptoms of FAS; behaviour management; intervention strategies.	Education/advocacy	Parents/teachers/ students/ advocates/ professionals
105	Fasstar	Canada, n.d.	Handouts	Radio interviews/ information handouts on behaviours, characteristics, FASD facts, school advocacy information, zero alcohol recommendation document	Education/advocacy	Parents/teachers/ students/ advocates/ professionals
106	Fasstar	Canada,	Wallet cards	'No thanks' to	Education/advocacy	Parents/teachers/

		n.d.		alcohol		students/ advocates/ professionals
107	Fasstar	Canada, n.d.	Posters	101 reasons to abstain	Education/advocacy	Parents/teachers/ students/ advocates/ professionals
108	Fasstar	Canada, n.d.	Poster	Sometimes the biggest reason to abstain from alcohol is a little one – 101 reasons to abstain from alcohol during pregnancy	Advocacy/information	Pregnant women
109	Fasstar	Canada, n.d.	Poster	Whose baby is this? Shows photo of FAS-affected infant	Advocacy/information	Pregnant women
110	FASlink (est. early 1990s)	Canada, n.d.	Archives	Discussion forum/Archive of documents relating to FASD	Support/information	Individuals/ families/ professionals
111	FASlink	Canada, n.d.	Leaflet	FASDs are 100% preventable	Information/education	Pregnant women
112	NOFAS-UK (est. c 2007)	UK, n.d. registered charity	List	List of resources available from various websites – DVDs, leaflets, booklets	Information/education	Pregnant women/ general public
113	NOFAS-UK	UK, n.d.	Literature review	Facing the challenge	Information/education/	Education

				and shaping the future for primary and secondary aged students with FASD	policy	professionals
114	FAS-Aware	UK, n.d.	Leaflet	Alcohol can damage your baby's brain at any time during pregnancy – image of pregnant woman holding a glass of wine showing fetus in the womb	Advocacy/information	Pregnant women
115	FAS-Aware	UK, n.d.	Leaflet	If you drink when pregnant your baby drinks too – image of fetus in a bottle of tequila	Advocacy/information	Pregnant women
116	FAS-Aware	UK, n.d.	Leaflet	Who's out drinking with you tonight – ultrasound image of fetus in a martini glass	Advocacy/information	Pregnant women
117	FAS-Aware	UK, n.d.	Leaflet	If there's a chance you're pregnant don't chance a drink – image of pregnant stomach	Advocacy/information	Pregnant women
118	FAS-Aware	UK, n.d.	Leaflet	You'd be horrified if the person carrying	Advocacy/information	Pregnant women

				you home had been drinking tonight – text only		
119	FAS-Aware	UK, n.d.	Leaflet	Glass sizes with text – If you're pregnant cut this out – coupon to send for facts about FAS	Advocacy/information	Pregnant women
120	FAS-Aware	UK, n.d.	Leaflet	Smoking/drinking while pregnant – image of glass under pregnant stomach – sponsored by pre-natal supplement tablets	Advocacy/information	Pregnant women
121	FAS-Aware	UK, n.d.	Leaflet	A simple test to show you when to stop drinking – image of positive pregnancy test – sponsored by pre-natal supplement tabs	Advocacy/information	Pregnant women
122	FAS-Aware	UK, n.d.	Leaflet	If you drink when you're pregnant so does your baby – image of London Dry Gin bottle	Advocacy/information	Pregnant women
123	FAS-Aware	UK, n.d.	Leaflet	Image of fetus in	Advocacy/information	Pregnant women

				wine glass – for foetus sake, don't drink any alcohol when you're pregnant		
124	FAS-Aware	UK, n.d.	Leaflet	Fact sheet	Advocacy/information	Pregnant women
125	FANNZ	NZ, n.d.	Brochure	Drinking alcohol during pregnancy… is not a good idea – text and image of baby playing with a truck	Information/advocacy	Pregnant women
126	FANNZ	NZ, n.d.	Submission	To 2009 Law Commission's paper Alcohol in our lives	Description of FANNZ, expresses concern about alcohol use during pregnancy	Government
127	Alcohol Health watch	NZ, n.d.	Fact sheet	FASD: the effect of alcohol on early development	Information/education	General public
128	Alcohol Health watch	NZ, n.d.	Paper	Towards multidisciplinary diagnostic services for FASD	Advocacy/information	
129	Alcohol Health watch	NZ, n.d.	PowerPoint presentation	FASD: finding the fit	Information/education	
130	FAS Family Resource Institute	US, n.d.	List of brochures	Brochures of books to do with FAS/D	Advocacy/information /education	Teachers/parents/ caregivers/ people with FASD/service

						providers
131	The ARC/CDC	US, n.d.	Leaflet	You can hurt your unborn baby: think before you drink	Education/information	Pregnant women
132	Wawatay Online	Canada, n.d.	Dolls	Two dolls with different characteristics, indicating what to expect to see in a child affected by FAS	Education	General public

Appendix C: Terms of Reference

The FASD resources project

This project aims to develop templates that can be used in the development of culturally secure and appropriate resources to assist health professionals in Aboriginal and Torres Strait health care settings to address the issues of alcohol and pregnancy and Fetal Alcohol Spectrum Disorders (FASD).

Aims of the project

- To establish a National Aboriginal FASD Prevention Reference Group to oversee the project and the development of a comprehensive consultation process;
- To identify and critically review the existing FASD health promotion resources designed for Aboriginal and Torres Strait Islander health professionals and communities;
- To identify Aboriginal and Torres Strait Islander health professional and Aboriginal and Torres Strait Islander women's needs and issues in FASD health promotion through key informant and in-depth interviews to assist in developing a resource that resonates with target groups;
- To collaborate with WA DAO to adapt for use across Australia, where necessary and possible, the evidence-based FASD resources already developed for use by health professionals working with Aboriginal and Torres Strait Islander people in Western Australia;
- To identify Aboriginal and Torres Strait Islander communities requiring adaptation of the resources to address local culture and language and to tailor the resources for use in these communities;
- To develop templates based on existing resources and the adaptations identified in consultations with WA DAO, key informants, health professionals, and community and consumer groups;
- To develop a national train-the-trainer program for ensuring workforce development and dissemination and uptake of the FASD templates and resources; and
- To evaluate knowledge of national and targeted resources using a pre-post evaluation design.

Role of the project's Reference Group

The Reference Group will:

- Provide guidance and oversee the project;
- Assist in identifying processes required to develop templates for use in the creation of culturally secure and appropriate, evidence-based alcohol and pregnancy/FASD resources for use with Aboriginal and Torres Strait Islander people across Australia and for the development of targeted FASD resources for specific communities;
- Assist in development of a comprehensive consultation process:
    - Assist in identification and recruitment of key stakeholders – including Aboriginal and Torres Strait Islander community controlled organisations and other peak Aboriginal organisations, government

and non-Aboriginal non-government organisations, Aboriginal health workers and Aboriginal women – to carry out extensive consultations; and

- Assist in the development of pre- and post-evaluation strategies.

Project's Reference Group structure

The Reference Group will be chaired by the Project Leader, Professor Sherry Saggers, in consultation and partnership with Associate Investigator Dr Colleen O'Leary, both of the National Drug Research Institute, Curtin University.

The Reference Group will consist of approximately 12 people. Membership will include representatives from National Aboriginal Community Controlled Health Organisations (NAACHOs), the Department of Health and Ageing Drug Strategy Branch, Office of Aboriginal and Torres Strait Islander Health (OATSIH), Aboriginal and Torres Strait Islander Community Controlled service providers, Indigenous clinical service providers, the WA Drug and Alcohol Office and consultants with expertise in Aboriginal and Torres Strait Islander service delivery, research, and policy development. The selection of Reference Group representatives will be the joint decision of project staff.

Reference Group representatives will work in partnership with project staff from the National Drug Research Institute including the Research Fellows project managing the project, Dr Lynn Roarty and Dr Kate Frances.

Meetings

We expect to hold two consultations with the Reference Group over the course of the project; the first for one day in February-March 2011, and the second, for two days, towards the end of 2011. Reference Group members would need to be available to travel to Perth to attend both consultations. Travel costs will be covered by the project.

For further information, please contact:

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Email: k.frances@curtin.edu.au

Appendix D: Reference Group membership

Reference Group members as at December 2012		
Name	**State**	**Organisation**
Heather D'Antoine	NT	Menzies School of Health Research
Jennifer St Clair	NT	CAAC
Elizabeth Elliott	NSW	Sydney University
Kristie Harrison	NSW	AH&MRC
Simone Andy	VIC	VACCHO
Mary Buckskin	SA	AHCSA
Scott Wilson	SA	ADAC
Marnie Fraser	QLD	Apunipima Cape York Health Council
Oriel Murray	QLD	CCDEU
Lorian Hayes	QLD	UQ
Vicki Russell	TAS	CEO, NOFASARD
Wendy Casey	WA	DAO
Jan Payne	WA	TICHR
Violet Bacon	WA	UWA
Bill Kean	WA	DoHA DSB

Reference Group members (from project inception) now retired		
Name	**State**	**Organisation**
Priscilla Pyett	VIC	Melbourne University
Christine White	ACT	OATSIH
Leigh Westcott	ACT	DoHA DSB
Simon Doyle	WA	OATSIH
John Walker	ACT	OATSIH

Appendix E: Reference Group Workshop Summary

ALCOHOL AND PREGNANCY AND FETAL ALCOHOL SPECTRUM DISORDERS: RESOURCES FOR HEALTH PROFESSIONALS WORKING IN ABORIGINAL AND TORRES STRAIT ISLANDER HEALTH CARE SETTINGS

SUMMARY OF OUTCOMES FROM THE FIRST REFERENCE GROUP MEETING HELD AT THE NATIONAL DRUG RESEARCH INSTITUTE, SHENTON PARK, PERTH ON THURSDAY, 31 MARCH 2011

This project aims to develop templates that can be used to produce culturally secure and appropriate resources to assist health professionals in Aboriginal and Torres Strait Islander health care settings to address issues of alcohol and pregnancy and Fetal Alcohol Spectrum Disorders (FASD).

This brief paper reports a summary of the outcomes from the first meeting of the project Reference Group, held in Perth on Thursday, 31 March 2011. Sixteen of the 18 Reference Group members attended the meeting. Participants provided advice on the community consultation process to be undertaken in all states and territories (with the exception of Western Australia), and critically evaluated some existing FASD resources to assist the project team in gaining a better understanding of the kinds of resources that would be considered culturally secure and acceptable to Aboriginal and Torres Strait Islander women and communities.

Overall evaluations of the workshop
Fifteen (15) of the 16 non-NDRI attendees at the workshop completed a Workshop Evaluation at the end of the day. Responses to specific questions are detailed below.

Did you find the workshop increased your knowledge of the National FASD research project? All 15 responses indicated that the workshop had increased their knowledge of the project. Specific comments included that the workshop had provided new knowledge by:

- updating knowledge;
- identifying other resources in use generally;
- providing a clearer understanding of the project and the role of RG members;
- identifying resources in use in other communities;
- listening to others' critiques of sample resources and gaining insight into Indigenous members' perspectives on FASD materials;
- clarifying the concept of 'templates';
- clarifying that resources are to be targeted to both clinicians and consumers;
- introducing RG members to new networks; and
- providing an opportunity for RG members to meet with others with a common interest.

Did you find that your role in the Reference Group was clearly addressed at the workshop as outlined in the Terms of Reference originally sent to you?

(a) Provide guidance and oversee the project? Fourteen respondents to this question answered 'Yes' with one response left blank.

(b) Assist in the 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 for use with Aboriginal and Torres Strait Islander people across Australia and for the development of targeted FASD resources for specific communities? Eleven (11) respondents to this question answered 'Yes'. Two responses were left blank. One respondent indicated somewhere between 'Yes' and 'No', commenting that he/she had a better understanding that would improve as we go along; and one respondent answered 'No'.

(c) *Assist in the development of a comprehensive consultation process?* Twelve (12) respondents to this question answered 'Yes'. Two responses were left blank, one with a comment that the consultation process was still a 'work in progress'. One respondent answered 'No'.

(d) *Assist in the identification of key stakeholders to carry out extensive consultations?* Twelve (12) respondents answered 'Yes' to this question. One respondent wrote 'maybe', while another wrote that he/she was 'getting there but still need to clarify workers/communities'. One response was left blank.

(e) Assist in the recruitment of key stakeholders to carry out extensive consultations? Thirteen (13) respondents answered 'Yes' to this question; one respondent answered 'No'; and one response was left blank.

Is there anything you learned about your role in the National FASD research project that you may be unable to carry out? Thirteen (13) respondents to this question answered 'No'. One respondent indicated that presenting adequate feedback to the large group in Reference Group meetings was a concern; one response was left blank.

Do you have any suggestions for the next stage of the project, i.e., the community consultation process? Seven (7) respondents to this question indicated they had no suggestions for this process. One respondent noted that he/she would like to think some more about the process before offering any suggestions. Suggestions offered by others were:

- to consult Indigenous people to be their own experts in resources for them;
- to ensure that people with standing in the respective communities have involvement so that they bring some community engagement to the process;
- to work out the boundaries of the consultations and provide the communities consulted with feedback;
- to devise a national map of key contacts;
- to avoid overloading staff in communities;
- to work on developing strategies on how to work with Indigenous people in rural, urban and remote communities and what service providers need to be identified; and

- a clear delineation of the scale of the project is important. The consultation could sink if it uses all the resources.

Do you have any suggestions for the next National FASD Reference Group Workshop (date to be confirmed but will be held towards the end of 2011)? Nine (9) respondents to this question indicated they had no suggestions. Suggestions offered by others were:

- to have one Aboriginal person in each discussion group, and to ensure that anyone uncomfortable with presenting not be expected to do so; NDRI staff should present if necessary;
- have independent recorders of discussion points in small group sessions to avoid bias;
- workshop exercises need to be clear as groups can be sidetracked; one exercise (pm) in current workshop was a little unclear;
- provide an update on consultation process;
- provide draft templates for consideration; and
- continue with the small group format.

Do you have any other suggestions that you would like to make regarding the project and/or your role in it? Twelve (12) respondents indicated they had no suggestions. One respondent left this question blank. Suggestions offered by the remaining two respondents were:

- there will be a need for progress reports to the Reference Group. These can also be used as a vehicle for requests from the team to the RG; and
- to perhaps divide approaches to consultation process, i.e., community/ professionals – likewise with resources, as the approach and needs are very different.

Community consultation process

In general, Reference Group members advised that all states/territories should be invited to be involved in community consultations, that key services should be identified to ensure a diverse spread of consultations, and that existing consultation processes should be utilised. The consultation packs for participating communities should contain questions and guidelines for facilitators, should be consistent across jurisdictions, should emphasise principles of respect and duty of care, and contain assurances that the problem of FASD is not Indigenous-specific. Consultations should include knowledge of local resources wherever possible.

Critical review of resources

Several resources are in use in various jurisdictions and the group identified specific resources that are accepted in the communities in which they work. Acceptable resources are those that are non-judgmental, and use positive and simple language and culturally acceptable artwork. Reference Group members felt that some of the resources presented in the workshop could be adapted for use in other jurisdictions, and identified the range and types of resources that could be of use.

The advice provided by the Reference Group on all these matters has been used by the research team in its approach to communities in the states and territories seeking their assistance in the conduct of consultations. Outcomes from the meeting have been consulted to inform the development of the community consultation packs, which are currently being finalised.

Detailed responses from Reference Group members in small group discussions on the community consultation process and the critical review of resources are appended in table form.

Appendix F: Outcomes from discussions on the community consultation process

Worksheet for small group discussions
10.45am – 11.45am
Collated responses from all groups

Time	Program	Comments/suggestions
10.45am	**Issues to be addressed include:** **Jurisdictions** **Consultation process** **Stakeholder identification** **Stakeholder recruitment** **Consultation package**	**PLEASE TAKE NOTES INDIVIDUALLY ON THESE SHEETS** **A SPOKESPERSON FROM YOUR GROUP WILL BE ASKED TO REPORT TO THE WHOLE GROUP IN THE NEXT SESSION**
1)	**Is it necessary to include all states and territories in the consultation process, or should we focus on getting samples of participants from urban/rural/remote locations as per the emphasis in the Complementary Action Plan?**	• All states and territories must be invited/should be represented. • Not only ACCHOs – key service in different states/regions – a diverse spread is needed. • We need to identify how people access services. • Suggest consultation with RACGP, Aboriginal Medical Services and other professional groups. • Utilise existing consultation processes – but different consultation process/strategies needed in different localities. • Noted that in Qld, Qld Health and GPs are most often used in the urban centres; GPs are used in Bundaberg, Superclinic in Strathpine. Discover what is the local network. • A huge task, must have boundaries and consider what is already being done. • 'Buy in' from diverse groups will help implement, adopt and

		sustain. • Two respondents suggest NT, QLD, SA key states; suggest central consultation for NSW/Vic/Tas. • Target communities already proactive around/with high incidence of FASD. • Possibility of online consultations suggested by many respondents (possibly via NIDAC). • Different categories of people need to be consulted: communities; health workers; health promotion and education centres; clinicians/midwives; AOD workers; school educators. • Suggestion that each state affiliate could decide how they want consultation to occur in their state, and perhaps two levels of consultation – one face-to-face and a second level online. • A few people were concerned that the process not be WA-centric.
2)	**The consultation process has to be culturally safe and appropriate; in the context of this project, what particular steps need to be taken to ensure this?**	• Use processes of peak bodies/state ethics committees. • Local regional networks and health care services; Aboriginal health workers/forums. • Identify key people in communities – cultural issues come from this. • Feedback to the communities is very important. • Consistency in approach. • Both men's and women's groups. • Use NACCHO in development of cultural safety methods. • Go to community and meet with people doing focus groups. • Develop guidelines to inform consultation process – i.e., 'Do no harm', strengths-based. • Holistic/family-centred processes, non-judgmental, gender-sensitive. • Honouring women as individuals and ensuring their health and wellbeing is a focus.
3)	**What processes will be used for stakeholder identification?**	• Self-selecting participants – goodwill – and allow plenty of time to carry out the consultations. • Identify local regional networks. • Identify culturally appropriate stakeholders.

		• Identify those with FASD experience and knowledge. • NACCHO/NIDAC and other peak AOD organisations, state level. • Aboriginal health planning forums.
4)	**What processes will be used for stakeholder recruitment?**	• In SA, people on the ethics committees are also resources for recruitment within the communities. • Possibly use the National Association for Aboriginal Health Workers and the network of community registered training organisations. • Identify credibility and knowledge of FASD/issues around women and drinking. • Web-based; email; health professionals; women's groups. • Congress in Alice Springs. • Identify opportunities to link with conferences.
5)	**What should the consultation package – that is, the information provided to those carrying out the community consultations – include?**	• Information on how to gather demographic data. • Questions/guidelines for group facilitators. • Principles – overarching principle is respect; not setting unrealistic expectations; sharing evidence base and limitations; explaining the meaning of 'templates' very carefully; definitions; consistency; simple summary of project and information so people have something 'now'; duty of care process; gender and age-sensitive. • Background information provided should be consistent. • Great care needed here. Scare tactics/shame/blame/guilt out. • Debrief support. • People working in pairs. • Knowledge of local resources. • Provide resources on where to get help if needed. • Ensure resources can be included into existing programs (complementary), and request that consultation package be augmented by what may have been developed and used locally. • use the word 'baby' not 'fetus'; some people are not adverse to threat-based messages. • ensure message that problem is not Indigenous-specific. • use international resources also to show what is being done o/seas/for non-Indigenous communities.

Outcomes from the critical review of resources
Worksheet for small group discussions
1.15pm – 2.45pm
Collated responses from all groups

Time	Program	Comments/suggestions
1.15pm	**Issues to be addressed include:** **Resources in use in various jurisdictions** **Evidence-base for usefulness or otherwise of resources**	**PLEASE TAKE NOTES INDIVIDUALLY ON THESE SHEETS.** **A SPOKESPERSON FROM YOUR GROUP WILL BE ASKED TO REPORT TO THE WHOLE GROUP IN THE NEXT SESSION**
1)	**How acceptable, and to whom (Aboriginal communities, health professionals) are the resources currently in use in various jurisdictions?**	Smokey Sue works well. Largely those in use at Apunipima are well accepted. The FASD dolls Vodka and egg is accepted. Resources such as these could be complemented by templates that cover steps family can take to address alcohol use in community or in the home. None for Nine Alcohol in pregnancy calendar Comic – 'Party girl' 'CARPA' and 'the grog story' 'Strong spirit strong mind' Most resources are not evidence based – some are heavily influenced by overseas resources, although more and more communities are developing their own messages. No consistency in the messages. Too often very wordy. There are some good key messages out there but some go over the top. Acceptable resources are those that are non-judgmental, use

		positive and simple language, and artwork. Calendar with seasons for different areas with message – for health professionals. Alcohol flip chart for AHWs Drinking and pregnancy life scripts by HDWA – life style prescription. The Grog Story/Grog book Competition to design a FASD poster Most looked at as examples not 100% appropriate but information in them would assist in developing new resources.

2)	**Can any of these resources be modified for other jurisdictions?**	Alcohol in pregnancy – also having national content. Yes, with some changes to language, artwork and with short, concise messages. Yes, once the evidence and framework is established. Need to address: strategies for lowering or stopping alcohol consumption; nutrition; culturally appropriateness; local art work. Community support needs to be identified. Some of the examples used at the reference group meeting could be adapted to use local language/people. Resources must be visual. Can take print ready and modify with logos etc. Focus on alcohol and health, not just FASD – women's health as important as baby's health. Ensure suitability for Torres Strait Islanders. Focus on child-rearing as a broader strategy – 'the trouble drinking is making for you'. Very sensitive issues around consent, conception, concerns about birth. Language needs to be simplified. Maori pamphlet easy to read but picture not appropriate.
3)	**What type of resources (e.g. brochures, DVDs,**	DVDs

	flipcharts etc) are appropriate in various jurisdictions?	Fridge magnets Flipcharts Playing cards with messages Life scripts Use things such as calendars Brochures Posters T-shirts, Arm bands Resources developed by community Key rings Towels for new baby Touch screens Case scenarios Comic style resources that include the whole family Plays visiting communities Strong spirit strong minds Mobile phones, internet, telecentres, learning centres, online. Need diverse range of options – takeaway freebies, wide range of resources. Urban communities need images of urban Aboriginal people. Content of template should be adaptable for future use. Harm minimisation approach important – strengths based.
4)	**What range of resources (e.g. how many different types) are appropriate in various jurisdictions?**	Need a range of resources. Things that people are going to be using regularly and that others can see – practical, useful things. Things that suit different age groups, professions – i.e., pens for doctors, towels for babies. Things that are family-oriented. Some states are better than others at developing Aboriginal-specific

		resources, particularly in relation to AOD. Posters are an important source of information. Consistent message for all - important Age, gender and group specific Up to the communities to decide what resources they need. 'Moving stories' More clinical focus for health workers Moving pictures for remote areas Risks of alcohol, and risks of alcohol and FASD for pregnant women. Alcohol drinking and FASD, what you can do to help your partner for men. Bigger focus on partner – support Images important – need to be state-specific Continuity of care – honesty and trust – key thing is knowledgeable health professional with relationship with women. Touch screens in health centres TV ads Individual stories
5)	**Please take a look at our sample pack/s of resources and let us know what you think are their strengths and weaknesses.**	**Resource**: **How dads can help: growing strong** Strengths? *By enabling Dad to have responsibility for child.* Weaknesses? *More info on how Dad can help.* **Resource**: **Who's out drinking with you tonight?** – *no comments on this resource were received* **Resource**: **Strong spirit strong mind** Strengths? *Visuals/ pictures.* Weaknesses? *Too much writing.*

		Resource: **Drinking and your baby …** Strengths? *Plain positive message.* Weaknesses? *If in language consider difference in language spoken.* **Resource**: **None for Nine** Strengths? *Catchy slogan* *Images important but need to be appropriate, not scare tactics.* *Simple, non-judgmental, catchy message* Weaknesses? *Skull & cross-bones; type-cast images.* *Too busy; pictures with baby in glass and skull and cross-bones not appropriate. Not strengths focused. Can't read easily – particularly for women with low level literacy. Misinformation and not evidence based.* *Shame. Not evidence based.* *Dangerous message - does not encompass breastfeeding and not drinking. Negative images. Too much writing, no cultural content.* *Worry about '100% preventable' message. Stereotypes women – male doctors/white coats. Busy graphics.* **Resource**: **London Dry Gin** Strengths? *Straightforward message* *As mainstream ad quite useful. Gets to the point about effects on baby. Not aimed at Indigenous women, but shows not just an Indigenous problem.* Weaknesses? *Not culturally apt.* *Not aimed at Indigenous women. Lots of hidden messages.*

		Resource: **The preventable disability** Strengths? *Great info and support.* *Lovely picture – humanises. Good for health professionals to go through with clients. Good information – useful contacts for support.* Weaknesses? *Not culturally apt. Too much info. Leaves a feeling of blame and hopelessness.* **Resource**: **The power of our youth** Strengths? *Gives a positive message that things can improve.* *Pregnancy is sacred message is okay – power to inspire? Good simple message. Good logical flow of information. Stays positive – FASD children can develop. Doesn't leave with sense of hopelessness. Sharing information. Importance of focus on next baby. Ideas about how to raise issue with people.* Weaknesses? *Non-Indigenous specific* *Aimed at US.* **Resource**: **The diary** Strengths? *Helps women to document what they are drinking plus financial cost. Some relevant information.* Weaknesses? *Too detailed.* *Not suitable for all Aboriginal people. Too much information – more western focused.* *Looks like a Women's Weekly insert. Not likely to attract Indigenous women.* **Resource**: **You can hurt your unborn baby**

		Strengths? *Factual.* Weaknesses? *Focus only on FAS and not spectrum. Too detailed.* *Too much information – nothing about breast feeding. Need to be more specific pertaining to Aboriginal people.* *Some inappropriate language. FAS is too specialised. Should focus on FASD instead.* **Resource**: **Tequila** Strengths? *None (repeated by more than one respondent).* *It's dramatic.* Weaknesses? *Everything.* *Scare tactic.* *Shame. Indistinct.* *Disgusting and disempowering. Victim blaming and not culturally safe.* **Resource**: **Healthy pregnancies, healthy babies for Koori communities** Strengths? *In context and used for purpose strong messages for Koori communities.* Weaknesses? *Too long, complex messages.* **Resource**: **Be kind to me …** Strengths? *Good, but perhaps needs simpler message.* Weaknesses? *Too wordy – too much info.* **Resource**: **For foetus sake …**

		Strengths? *Simple message. Gets message across clearly.* Weaknesses? *Cultural significance of image* **Resource**: **If you are pregnant …** Strengths? *Perhaps an important source of information.* *Clear concise message, not too wordy.* Weaknesses? *Provide detail of how to get local help.* *Needs the wording 'If you are thinking of getting pregnant'.* **Resource**: **No alcohol in pregnancy is the safest choice** Strengths? *Would work well with younger demographic, i.e., uni students.* Weaknesses? *Too much in one thing. Images are all wrong. Language. Picture better than words. Can't stand alone. Westernised images.* **Resource**: **No shame no blame** Strengths? *One liners are good. Pictorial images. Respect. Useful advice and range of options. Easily adaptable – integrate FASD story into it.* Weaknesses? *None – except p4 should have link to info on legal obligations re child protection.* **Resource**: **Who are you out drinking with tonight?** Strengths? *Message is fine re drinking with baby but needs to be particular audience. Could be adapted. Baby should look unwell.* Weaknesses? *Connection between baby and alcohol needs to be clearer, and*

		significance given to the text. **Resource**: **Pregnancy and breastfeeding** Strengths? *Used in Apunipima – language is mixed – simple/not so simple.* Weaknesses? *Too many negatives. Needs more visuals. Other people need to be around the image of the woman.*

6)	**In the development of new templates, what content is culturally appropriate and secure?**	Include community context – take focus off the mother. More images/use comparative messages. Focus on the positives of not drinking during pregnancy. No blame, no scare tactics – non-judgmental. Family focus – not just Mum Image focused Evidence-based information Pregnancy planning information Pictures are more appropriate for some areas Basic reading level Cultural systems of care Gender sensitive/specific Ability to amend reference to be group-specific e.g., Nyoongar, Yamatji etc. Sense of hope Contacts information Not just Indigenous – about alcohol and pregnancy for everyone, include all stats. Two-way messages – drinking not part of the culture.
7)	**What style should new templates follow (e.g. language, artwork, cultural symbols etc)**	Template must contain an evaluation aspect (for the future). Interactive/adult-learning

		Flipcharts Visual Messages need to be simple – strong but short. Templates need to be clear in their advice, be clear on message, and guided by evidence of impact. Plenty of positive artwork – shouldn't be just text. Artwork that can be used generically in Aboriginal communities. Generic message and room for adaptation, with specific cultural factors addressed locally . CARPA manuals very good – simple message – could be good starting point. Pitch depends on audience Urban/rural/remote more than jurisdictions Include young people and mobile phones Cultural symbols, theatre/dance Extended family unit with healthy pictures of children, pregnant women, supportive men etc. Educational. Use Aboriginal languages where necessary. Use cultural paradigms Recognise available services/resources in each context. Provide aftercare and broad support information – follow-up for women. Recognise broader social context – family, violence, drug abuse, alcohol abuse, welfare issues.

Appendix G: Examples of evidence-based text available for selection from iPad app/web-based platform database

What is FASD? Fetal Alcohol Spectrum Disorders (FASD) is the name used to describe all the problems – physical, emotional, and intellectual – that may affect people whose mothers drank alcohol during their pregnancy

No alcohol is the best and safest choice for having a healthy baby

Alcohol and pregnancy don't mix

It's never too late to stop drinking

No one knows for sure how much alcohol causes FASD

There is no safe time to drink during pregnancy

It can be difficult to stop drinking. If you need help, talk to your doctor or local health worker

Help is available if you need it. Talk to your doctor or local health worker

There's no type of alcohol that's 'safer' to drink while pregnant.

FASD is preventable

There's no cure for FASD

It's not always easy to tell if a baby has FASD

Drinking alcohol may cause permanent harm to your baby

Stay healthy throughout your pregnancy

The safest choice is to not drink if you're planning on having a baby

The safest choice is to not drink if you're pregnant

Preventing FASD is everyone's responsibility

If you need help with your drinking talk to your doctor or local health worker

If you drink while breastfeeding, the alcohol goes through your milk into your baby. It's safest to not drink while breastfeeding

Talk to your doctor or health worker about your drinking. They can help you cut down or stop drinking in safe ways

You can help your baby grow up strong by staying healthy throughout your pregnancy

Dads have a part to play too – support your partner's healthy choices during pregnancy

Healthy mums and dads = healthy kids

Strong women, strong babies

If someone says 'no' to drinking, respect their choice

Thinking of becoming pregnant? Ask your doctor or health worker about staying healthy during pregnancy

Thinking of becoming pregnant? No alcohol is safest

Planning to have a baby? No alcohol is safest

Any chance you could be pregnant? No alcohol is safest for your baby. Talk to your doctor or local health worker

Australia's National Health & Medical Research Council advises that if you are trying to become pregnant, or if you are pregnant, no alcohol is safest for you and your baby

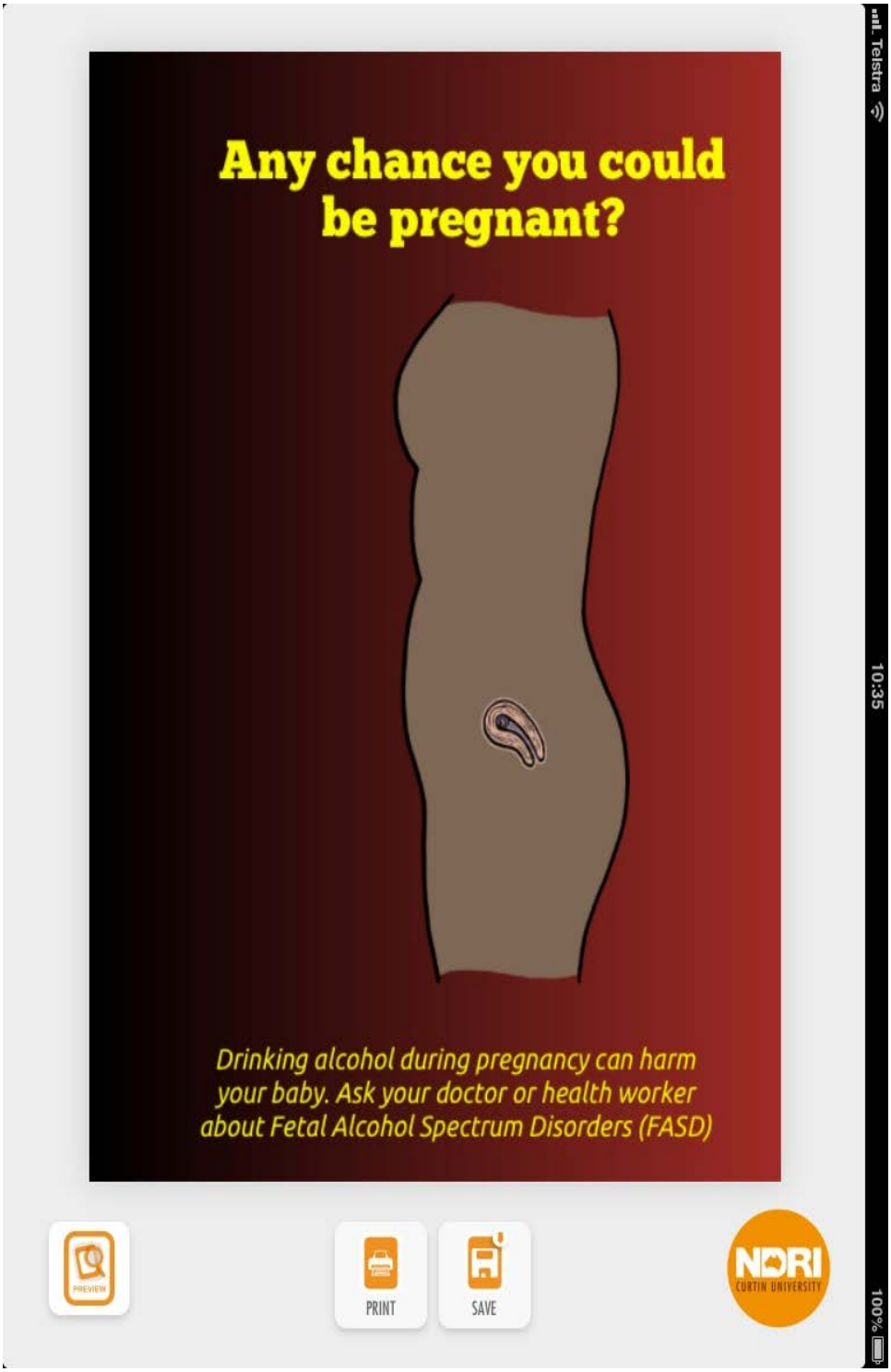
Maternal drinking can have serious and lifelong effects on the unborn child. Talk to your clients about the risks of drinking in pregnancy

Fetal Alcohol Spectrum Disorders (FASD) is caused by maternal drinking. We don't know the safe level of consumption, so the NH&MRC advises 'no alcohol is safest'

Prenatal exposure to alcohol can cause a range of lifelong problems, from relatively minor behavioural symptoms through to serious and debilitating conditions. Talk to your clients about the risks of drinking in pregnancy

Make messages about not drinking part of your approach to a healthy pregnancy.

Appendix H: Screenshots of a sample of poster templates included in the PosterMaker app



Talk with your clients about FASD

- **Ask about alcohol use**
- **Make use of screening tools**
- **Advise not drinking is safest**
- **Help them to stop drinking**
- **Make sure they have ongoing support**

PREVIEW PRINT SAVE

NDRI CURTIN UNIVERSITY

Alcohol and pregnancy don't mix

Talk to young people in your community about the risks of drinking while pregnant, so that they know the risks well before they become pregnant

PREVIEW PRINT SAVE

NDRI CURTIN UNIVERSITY


No alcohol is the best and safest choice for having a healthy baby
FASD
Talk to your clients about the risks of drinking in pregnancy
If your client is alcohol dependent, she may need specialist help.
PREVIEW
PRINT
SAVE
NDRI
CURTIN UNIVERSITY
Telstra
10:35
100%


Every child is precious
You can help your baby grow up strong by staying healthy throughout your pregnancy
Alcohol and pregnancy don't mix
Help is available if you need it. Talk to your doctor or local health worker
PRINT
SAVE
NDRI
CURTIN UNIVERSITY
Telstra
10:36
100%

Dads have a part to play too

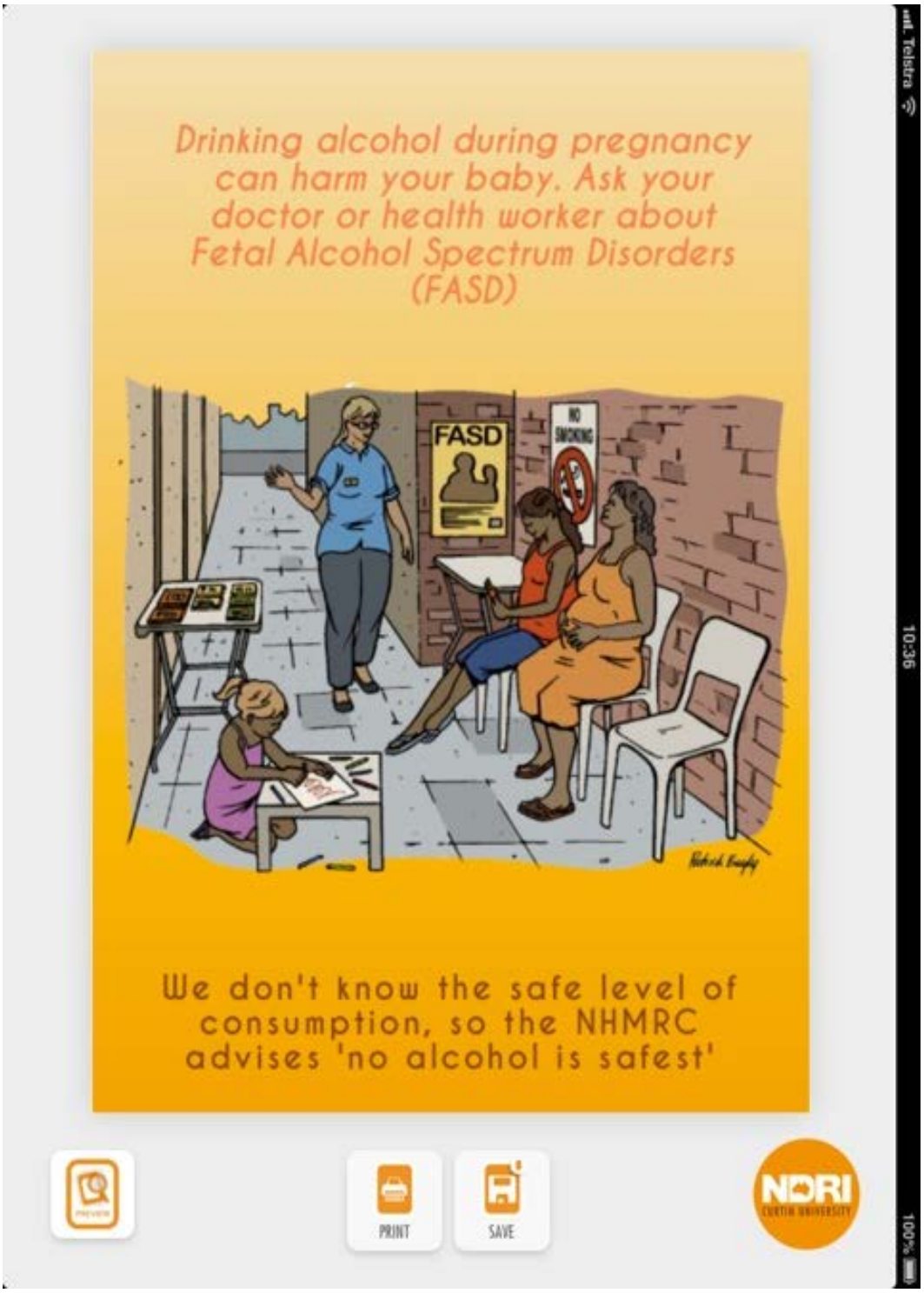
Talk to your doctor or health worker about your drinking

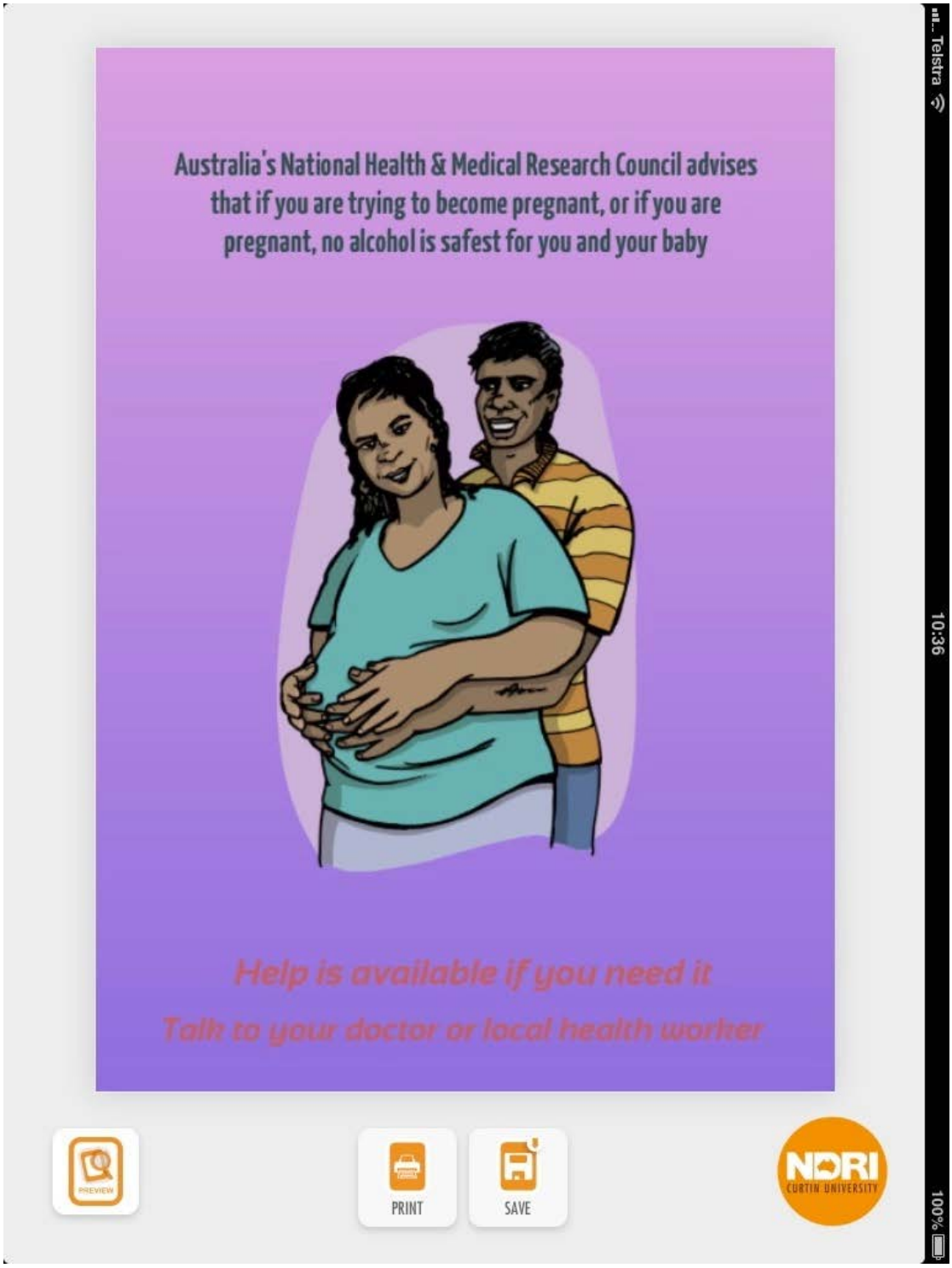
If you are drinking in a risky way, they can help you cut down or stop drinking safely.

Preventing FASD is everyone's responsibility

Place service logo and contact details here

PRINT SAVE


Drinking alcohol during pregnancy can harm your baby. Ask your doctor or health worker about Fetal Alcohol Spectrum Disorders (FASD)
FASD
NO SMOKING
We don't know the safe level of consumption, so the NHMRC advises 'no alcohol is safest'
PRINT
SAVE
NDRI
CURTIN UNIVERSITY


Australia's National Health & Medical Research Council advises that if you are trying to become pregnant, or if you are pregnant, no alcohol is safest for you and your baby
Help is available if you need it
Talk to your doctor or local health worker
PREVIEW
PRINT
SAVE
NDRI
CURTIN UNIVERSITY
Telstra
10:36
100%

ndri.curtin.edu.au

NDRI

national drug research institute

Curtin University