

Online scan of FASD prevention and health promotion resources for Aboriginal and Torres Strait Islander communities

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Abstract

Issue addressed: Foetal Alcohol Spectrum Disorder (FASD) includes a range of life-long impairments caused by alcohol exposure in utero. Health professionals are vital to preventing FASD but many are hesitant to discuss FASD with clients due to their need for additional resources to aid the conversation. This scan sought to identify the scope and gaps in publicly available FASD prevention and health promotion resources, and assess their cultural appropriateness for use among five key groups of Indigenous Australian people including: (i) pregnant women, (ii) women of child-bearing age, (iii) grandmothers and aunts, (iv) men, and (v) health professionals.

Methods: Relevant resources published 1995-2017 were identified through the Australian Indigenous HealthInfoNet, FASD organisation websites, grey literature, Google searches, and field experts. Results were screened by inclusion and cultural appropriateness criteria developed and piloted by the research team, and further screened by health professionals attending FASD training workshops.

Results: 115 of the 2146 identified resources were eligible. Relevant resources were found for all five key groups; however, no resources were specifically designed for men, grandmothers or aunts.

Conclusions: A range of high-quality, culturally appropriate resources were identified, however, health professionals attending the training workshops were not aware of their availability. Further resource development is suggested for men, grandmothers and aunts.

So what? Prioritisation of active dissemination and implementation strategies is suggested to increase awareness and use of future resource developments. The inclusion of a resource trial among health professionals is a recommended strategy to increase awareness and use of newly developed resources.

KEYWORDS

Aboriginal and Torres Strait Islanders, alcohol consumption, capacity, health education, pregnancy

1 | INTRODUCTION

Foetal Alcohol Spectrum Disorder (FASD) includes a range of physical abnormalities and neurological impairments caused by foetal exposure to alcohol in utero.¹ Children affected by this disorder may have a range of complications including severe congenital anomalies, stunted growth, deficits in attention and memory, impaired social skills and a range of mental health disorders.² These life-long, incurable impairments may occur at any point in pregnancy; yet FASD is entirely preventable by eliminating a foetus' exposure to alcohol.

Many Australian women are unaware of the potential harm caused by drinking alcohol during pregnancy^{3,4} and the potential risk of FASD. In 2013, a national study found that one in four Australian women continued to drink after learning they were pregnant and only 53% abstained from alcohol during their entire pregnancy.⁵ National rates for Australian Aboriginal and Torres Strait Islander (hereafter respectfully referred to as Indigenous Australian) women are not available however a Western Australian report found that 23% of Indigenous Australian women consumed alcohol at some point during their pregnancy.⁶ While this proportion was significantly lower than the general population of Western Australia, Indigenous Australian women who consumed alcohol during their pregnancy did so at more hazardous levels.⁶ Recently the Liliwan project in the Fitzroy Valley conducted a study on a cohort of predominantly Indigenous Australian mothers and carers and found 55% consumed alcohol at some point during their pregnancy and 53% consumed alcohol during all three trimesters.⁷ Women have stated that they want to be provided with advice and information about the risks of FASD and would prefer to receive this information from a trusted health professional.^{3,8}

Health professionals therefore have a vital role in preventing alcohol exposed pregnancies and FASD in Indigenous Australian communities by providing health education and brief interventions to their clients. In a study of maternal health care delivery in Indigenous primary healthcare services, Rumbold et al (2011) found that only 34% of the 535 audited medical records had evidence of brief intervention or counselling advice for alcohol and other substance abuse during routine antenatal visits.⁹ In Western Australia, a survey of midwives showed that over a third did not provide information to their clients on the effects of alcohol on the foetus.¹⁰ Notwithstanding, 96% of these midwives¹⁰ and more than 96% of a separate cohort of Western Australian health professionals¹¹ agreed that all women of child bearing age should have access to clear information on alcohol use during pregnancy and the risks of FASD. Health professionals have attributed their hesitance to discuss alcohol consumption with pregnant clients to a lack of confidence in their ability to provide follow-up services and a need for more relevant resources for themselves and their clients.¹⁰⁻¹³

The FASD Prevention and Health Promotion Resources project (2015-2017), funded by the Australian Department of Health, aims to nationally replicate the success of an existing rural Indigenous Australian FASD prevention program¹⁴ and improve the capacity and

skills of child and maternal health professionals to provide health education and brief interventions on the risks of alcohol use during pregnancy and FASD in Indigenous Australian communities. This will be achieved by developing a set of discrete training modules and health promotion resources that are adaptable to the particular needs of individual health services and local Indigenous communities across Australia. Building on the holistic approach of the existing Indigenous Australian FASD prevention program,¹⁴ this package will assist health professionals working with five key groups: pregnant women; women of child bearing age; grandmothers and aunties (an Aboriginal term dignifying a female Elder); men; and other health professionals (inclusive of Indigenous Australian health workers/practitioners, midwives, nurses and general practitioners). Our experience and that of others highlights that health promotion resources are widely available,¹⁵ therefore we sought to gather existing resources through an online scan and, during the process, identify gaps in relation to the five key groups. In this article, we report on the results of the online scan of existing FASD prevention and health promotion resources. The specific aims of the scan were to:

1. Systematically identify and document publicly available FASD prevention and health promotion resources (including alcohol, tobacco and other drug consumption during pregnancy; and contraception/family planning options) targeting the five key groups.
2. Assess the quality, cultural appropriateness, and suitability of the identified resources for use by health professionals working with Indigenous Australians within the primary health care setting.
3. Identify the type of FASD prevention and health promotion resources currently available (i.e. printed materials, audio-visual aids etc.).
4. Identify resource gaps and opportunities for further development of FASD prevention and health promotion resources for the five key groups.

2 | METHODS

In line with the definition developed by McCalman et al (2014), resources were defined as step-by-step tools, guides, frameworks, applications, instruments or models¹⁵ designed to prevent FASD, alcohol use during pregnancy and related factors within Indigenous communities that experience poorer health outcomes as a consequence of colonisation, including: Australian Aboriginal and Torres Strait Islander peoples; Māori people; Native Americans; or Aboriginal Peoples of Canada. Online, publicly available FASD prevention and health promotion resources were identified using a search plan incorporating five sources. Overall search results were screened by quality inclusion (see Figure 1) and cultural appropriateness criteria developed by the lead author and circulated to the research team until consensus was reached on study design, definitions and methods. Eligible resources were trialled among health professionals attending the projects training workshops to further determine

1. The resource is publically available online
2. The resource content focuses on one of the following topics:
 - Fetal Alcohol Spectrum Disorder (FASD) prevention
 - Alcohol, tobacco or other drug use during pregnancy
 - Family planning and contraception options
3. The resource is targeted towards one of the following key groups:
 - Pregnant women
 - Women of childbearing age (15-45 years of age)
 - Grandmothers and aunts
 - Men
 - Health professionals
4. The resource aims to fulfil one of the following purposes:
 - Provide detailed information to educate or raise awareness of:
 - The risks of FASD, alcohol exposed pregnancies (AEP), and the current guidelines for alcohol consumption during pregnancy (outlined in criteria 6)
 - The risks of tobacco use during pregnancy and the current guidelines for tobacco use during pregnancy (outlined in criteria 7)
 - The risks of drug use during pregnancy
 - Family planning and contraception options
 - Provide health professions with information or tools for developing, implementing and evaluating prevention and health promotion programs.
 - Provide information and tools for individuals to use in discussing FASD or alcohol, tobacco, and other drug use during pregnancy to encourage positive behavioural changes within Indigenous Australian communities.
 - Outline solutions to potential barriers to preventing FASD or alcohol, tobacco, and other drug use during pregnancy.
5. The resource is culturally appropriate for use within Indigenous Australian communities as determined by: (i) the Australian Indigenous HealthInfoNet Knowledge Centre Reference Group; (ii) the Indigenous Australian members of the FASD Prevention and Health Promotion Resources projects Expert Advisory Group or Steering Group Committee; (iii) the Indigenous Australian members of the research team, and (IV) Indigenous Australian health professionals participating in the resource trial carried out through the projects training workshops.
6. If applicable, the resource adheres to the current 'Australian Guidelines to Reduce Health Risks from Drinking Alcohol' (National Health and Medical Research Council, 2009) by clearly stating that no alcohol consumption during pregnancy is the safest option.
7. If applicable, the resource adheres to the current 'Clinical Practice Guidelines: Antenatal Care – Module 1' (Commonwealth of Australia, 2012) by advising that it is best to stop or reduce smoking as early as possible in pregnancy.
8. If applicable, the resource complies with the diagnostic categories for FASD and terminology outlined in the 'Australian Guide to the diagnosis of FASD' (Bower & Elliott, 2016).

FIGURE 1 'FASD Prevention and Health Promotion Resource Package' inclusion criteria

relevance and suitability for use within the primary health care setting. Resulting resources were categorised according to their characteristics (see 'Categorisation of resources') to aid in the assembly of the resource package. These categories will inform search filters for the online platform that will house the package following its anticipated launch in late 2017.

2.1 | Search plan

The scan was conducted between June 2015 to July 2016 and updated in February 2017 following the launch of the 'Australian guide to the diagnosis of FASD' and the revised diagnostic categories for FASD.¹ Resources were not limited to Australia and the time period for resource publication was 1995 to Feb 2017 – two decades was considered sufficient to capture the extensive FASD prevention work occurring internationally and was feasible within the scope of the project. The five sources of the search plan included: (i) the Australian Indigenous HealthInfoNet including the FASD portal and health promotion resources page, (ii) relevant organisation websites, (iii) grey literature databases, (iv) Google search engines, and (v) consultation with experts in the field.

First, all resources on the Australian Indigenous HealthInfoNet FASD portal¹⁶ were included and the Australian Indigenous health promotion resources page¹⁷ was searched under: 'alcohol', 'births', 'disability', 'health promotion', 'health workers', 'illicit drugs', 'infants', 'maternal smoking', 'men', 'sexual health', 'tackling smoking', 'tobacco', 'volatile substances', and 'women' (n = 1902). Second, all organisation webpage links found through the first step were rigorously searched to determine additional resources published by the organisation (n = 192), this process is referred to as 'snowballing' here on out. Third, a manual hand search was conducted on references in key reports and grey literature identified during an early literature review for the project (n = 24). Fourth, a keyword search was conducted through Google using a combination of the terms: "FASD", "Fetal Alcohol Spectrum Disorders", or "alcohol exposed pregnancy" and "prevention", "health promotion", and "resources" (n = 16). Finally, the developing list of resources was circulated regularly to members of the FASD Health Promotion and Prevention Resources Project Expert Advisory Group and Steering Group Committee to identify resources that had not already been captured. Resources were excluded at this point if they were duplicates, broken web-links, or titles with obvious irrelevance (i.e. unrelated health topics such as ear health, diabetes or cancer).

2.2 | Screening process

2.2.1 | Quality inclusion criteria

The search results were assessed by two of the Aboriginal authors using the quality inclusion criteria outlined in Figure 1, with the remaining co-authors consulted if consensus was not reached. Resources were included if they met five quality criteria relating to content, availability, relevance to the key groups, and purpose.

Resources relating to tobacco and alcohol consumption required additional adherence to current best practice guidelines (see Figure 1). All resources relating to FASD or alcohol use during pregnancy were further screened for their compliance with the diagnostic categories and terminology outlined in the 'Australian Guide to the diagnosis of FASD'.¹

2.2.2 | Cultural appropriateness criteria

Resources obtained from the Australian Indigenous HealthInfoNet website were previously screened for relevance to Indigenous Australians by their Knowledge Centre Reference Group, as outlined on their website.¹⁸ All resources not sourced from the Australian Indigenous HealthInfoNet were screened for cultural appropriateness based on: (i) the use of plain English, (ii) the use of common Indigenous Australian terms (i.e. mob, Elder, Aunty, Uncle, community, country), (iii) the presence of cultural imagery, and (iv) its overall appeal to Indigenous Australian people. To ensure resources adhered to the four criteria on cultural appropriateness, we sought agreement from Indigenous Australian stakeholders engaged in the project, including members of: (i) the project Expert Advisory Group (n = 5) comprising of medical and research experts; (ii) the project Steering Group Committee (n = 5); (iii) the research team (n = 3), and (iv) health professionals participating in the resource trial carried out through the projects training workshops (n = 53). These individuals were selected for their extensive knowledge, experience and skills working with Indigenous Australian communities, knowledge and understanding of FASD and as valued members of their respective communities.

2.3 | Relevance and suitability

All eligible resources were trialled among health professionals attending the projects training workshops to further determine relevance and suitability for use within a primary healthcare setting. Five two-day training workshops were conducted across Australia (Darwin, Cairns, Sydney, Melbourne, and Perth) with 80 health professionals attending. Workshop attendees were experienced Indigenous Australian health workers/practitioners, midwives, child and family health nurses, clinic coordinators, health promotion officers, managers, and pregnancy support officers that had mostly held their current role for more than 2 years (62%). Group discussions were held among the health professionals to review all eligible resources on a range of questions including:

1. What purpose do you think this resource fulfils?
2. Which of the five key groups would benefit most from this resource?
3. How could this resource be used within your health service and community?
4. Do you have any strong feelings about the language, images or information portrayed in this resource?
5. Overall, do you think this resource would appeal to your community?

Resources were included based on the majority of opinion of the 80 participating health professionals as to suitability and relevance.

2.4 | Categorisation of resources

All eligible resources were categorised according to their characteristics to inform the development of search filters for an online platform where the package will sit following its anticipated launch in late 2017. These characteristics included: resource source (i.e. the Australian Indigenous HealthInfoNet FASD portal/health promotion resources page, snowballing, grey literature, Google search engines, expert recommendations); author; title; year of publication; material type (i.e. printed materials, audio-visual aids, kinaesthetic aids, social media campaigns, resource packages, training courses); adherence to the current guidelines if applicable (yes/no); primary purpose (see Figure 1. criteria four); relevance to the key groups (yes/no for each group); a brief summary of the resource; resource web link; costs associated with the resource (i.e. free online, download, order, or for purchase - cost and details specified); location of publication (country and state); and cultural appropriateness for Indigenous Australian communities (yes/no).

3 | RESULTS

3.1 | Availability of FASD prevention and health promotion resources

The scan identified 2146 separate resources, 115 of which were eligible for inclusion in the resource package (see Table 1). These resources include 68 print materials (i.e. booklets, brochures, fact

sheets, flipcharts, handbooks, guidelines, manuals, postcards, posters, story books, online resource development programs, and screening tools), 43 audio-visual aids (i.e. videos, radio segments, and web applications), two kinaesthetic aids (including a FASD doll and story cards), one social media campaign, and one contraception resource package. Ineligible resources were excluded due to duplication ($n = 684$), broken links ($n = 103$), and other reasons outlined in Figure 2 ($n = 1244$).

The resources were produced in Australia between 2006 and 2016 aside from a framework for evaluating interventions published in Canada in 2012. The Australian resources were largely produced within New South Wales ($n = 43$); followed by Western Australia ($n = 18$), Queensland ($n = 14$), the Northern Territory ($n = 11$), state unspecified ($n = 8$), Victoria ($n = 7$), the Australian Capital Territory ($n = 6$), South Australia ($n = 6$), and Tasmania ($n = 1$). The Australian resources were generalisable to all states and territories except five resources that used local terminology to describe marijuana as "yarndi" ($n = 1$) or "gunja" ($n = 4$).

The included resources were predominantly found through the Australian Indigenous HealthInfoNet FASD portal ($n = 41$) and health promotion resources page ($n = 48$); followed by the snowballing approach ($n = 22$), expert recommendations ($n = 3$), and Google engine searches ($n = 1$). The resources were largely accessible for free via download ($n = 55$), online viewing ($n = 53$), or online order ($n = 2$). The remaining five resources are available at a cost ranging from \$1.10 or \$33 per printed material, \$50 per DVD, \$160 per story card pack, and \$640 per FASD doll. Accessibility issues were experienced as a result of insufficient resource information or funding cuts for resource maintenance ($n = 34$); and difficulty navigating websites, including the Australian Indigenous

TABLE 1 Total and percentage of resources relevant to the five key groups, categorised by purpose^a

	Total ($n = 115$)	Pregnant women ($n = 74$)	Women of childbearing age ($n = 70$)	Grandmothers and aunts ($n = 40$)	Men ($n = 50$)	Health professionals ($n = 66$)
Educating or raising awareness of:						
FASD and alcohol consumption during pregnancy	60	42 (57%)	41 (59%)	31 (78%)	36 (72%)	34 (52%)
Tobacco use during pregnancy	36	30 (41%)	27 (39%)	9 (23%)	10 (20%)	12 (18%)
Drug use during pregnancy	8	6 (8%)	6 (9%)	5 (13%)	5 (10%)	6 (10%)
Family planning and contraception options	5	4 (5%)	4 (6%)	-	4 (8%)	4 (7%)
Planning evidence-based interventions:						
One-on-one sessions	3	-	-	-	-	3 (5%)
Health promotion programs	4	-	-	-	-	4 (7%)
Frameworks for evaluating interventions	1	-	-	-	-	1 (2%)
Encouraging behavioural change:						
Brief interventions or motivational interviewing	13	-	-	-	-	13 (20%)
How to support women	8	2 (3%)	2 (3%)	2 (5%)	4 (8%)	5 (8%)
Screening tools and guides	10	-	-	-	-	10 (15%)
Addressing barriers to FASD prevention	6	3 (4%)	3 (4%)	3 (8%)	3 (6%)	6 (10%)

FASD, Foetal Alcohol Spectrum Disorder.

^a'Purpose' as defined in inclusion criteria one. Some resources overlap in relevance to multiple key groups and purposes.

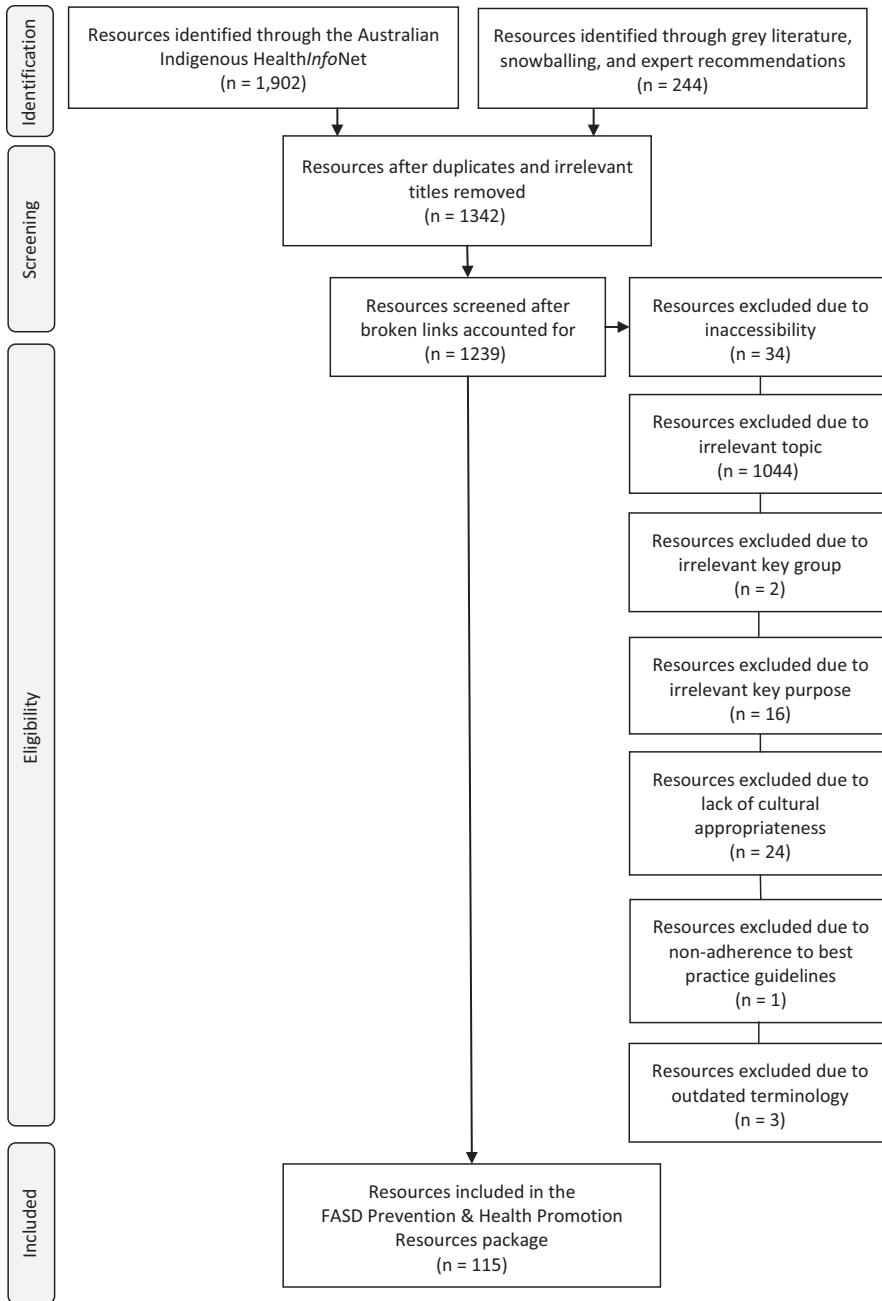


FIGURE 2 Flow chart depicting inclusion and exclusion rate of resources

HealthInfoNet. Furthermore, the majority of health professionals that participated in the training workshops indicated that they were unaware of the broad range of publicly available FASD prevention resources identified through this scan.

Table 1 provides an outline of the quantity of resources relevant to the five key groups. Many of the resources are applicable to all key groups (n = 22) or more than one key group (n = 70) and fulfil multiple purposes (n = 25). The majority of the resources are relevant to both pregnant women and women of childbearing age (n = 70); and are designed to educate or raise awareness (n = 89) (Table 1). No resources specifically designed to meet the needs of grandmothers and aunts were identified and only three were designed specifically for men. These

resources include a video, poster, and booklet that offer advice to men on how to support women to abstain from alcohol during pregnancy, and discuss their important role in influencing women's decisions.

Health professionals attending the Darwin training (n = 17) felt the self-reported nature of the AUDIT-C would inaccurately measure levels of alcohol consumption and therefore any resources featuring this screening tool should be excluded from the package. This concern was not shared by the health professionals attending the other training workshops. All resources featuring the AUDIT-C were therefore retained in the resources package to meet the needs of all health professionals and in keeping with the recommendations of the 'Australian guide to the diagnosis of FASD'.¹

4 | DISCUSSION

This online scan was carried out to identify and gather existing FASD prevention and health promotion resources for the development of a resource package that is adaptable to the particular needs of individual health services and local Indigenous communities across Australia. This scan also sought to identify any gaps to be prioritised for future resource development. This scan resulted in the identification of a broad range of high quality, culturally appropriate FASD prevention and health promotion resources for inclusion in the resource package ($n = 115$). Resources specifically designed to meet the needs of men, grandmothers and aunties were noticeably lacking. Accessibility issues were also noted with broken links, lost funding for resource maintenance, and difficulty navigating websites.

Despite the availability of FASD prevention and health promotion resources discovered in this scan, health professionals have continued to request additional resources for themselves and their clients.^{11-13,19} Health professionals attending our training workshops were unaware of many existing FASD prevention and health promotion resources, potentially resulting from poor accessibility and/or ineffective dissemination techniques. This is consistent with the findings of McCalman et al (2014) that the availability of health promotion resources in Indigenous Australian healthcare is sufficient in general; however, greater priority is needed for the development of effective dissemination and implementation strategies.¹⁵ This scan acknowledges the Australian Indigenous HealthInfoNet as a trusted and viable platform for culturally appropriate FASD prevention and health promotion resources ($n = 89$); however this website was not exempt from issues with broken links ($n = 87$) and inadequate information or loss of funding for resource maintenance ($n = 34$). These issues are potential barriers to health professionals' awareness and access to FASD prevention and health promotion resources and require further work in creating an easily accessible online platform that is well-advertised among health professionals working within the primary health care setting.

Furthermore, health professionals' ability to effectively prevent FASD in an all-of-community way may be hindered by gaps in resources designed specifically for men, grandmothers and aunties. Previous studies have highlighted the important role that men, grandmothers and aunties have in influencing Indigenous Australian women's decisions to consume alcohol during pregnancy.^{3,14,20-22} These social networks have the potential to become vital community advocates if they are effectively educated and supported in their role to prevent FASD.^{14,20,21} While this scan identified a range of resources that had relevance to these social groups, it is recommended that future resource development focuses on providing detailed information to these networks on how they can best support women to abstain from alcohol during pregnancy.

The resource trial among health professionals attending the projects training workshops was found to effectively increase health professional's awareness of the broad range of FASD prevention and health promotion resources currently available. This trial phase is recommended as a fundamental addition to future dissemination

strategies of newly developed resources or similarly assembled packages. Following this trial phase, the resource package was assembled in preparation for its anticipated online launch in late 2017 to further increase health professionals' awareness, access and use of the package.

To our knowledge, this appears to be the first systematic assessment of the availability of FASD prevention resources and their cultural appropriateness for use within Indigenous Australian communities. By adapting a systematic review process, we were able to apply quality inclusion criteria to screen for the most relevant resources for the key groups that had clear purposes and information consistent with current best practice guidelines. These methods determined resourcing gaps and indirectly uncovered accessibility issues that pose as potential barriers to health professionals' ability to effectively provide health education and brief interventions to reduce alcohol use during pregnancy and FASD within Indigenous Australian primary healthcare settings. These methods were not able to capture resources that are not publicly available online and therefore may have resulted in some key international or locally developed resources not being captured.

5 | CONCLUSION

The results of this scan extended our knowledge of the existence of a wide range of FASD prevention and health promotion resources. The systematic approach of this scan effectively identified the characteristics of publicly available FASD prevention and health promotion resources as well as their relevance and cultural appropriateness to the five key groups of Indigenous Australian people. This scan was further able to highlight the need for additional resources to specifically meet the needs of men, grandmothers and aunties. We suggest that future resource development focuses on providing information to men, grandmothers and aunties on the important role they can play in supporting pregnant women to make positive decisions around their alcohol, tobacco, and other drug use.

In addition to the initial aims, this scan also uncovered difficulties with resource accessibility and health professionals lack of awareness of resource. In an effort to address these issues, the eligible resources will be centrally available through an online platform that is anticipated to be launched to the general public in late 2017.

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AUTHOR CONTRIBUTIONS

HW led the study design, conduct, data acquisition and analysis, and the manuscript writing. NP contributed to the conception of the study, data interpretation and oversaw the conduct. RC and NH contributed to data interpretation. SS oversaw the conduct of all work produced under the FASD Prevention and Health Promotion Resources project. All authors contributed to the editing of the manuscript and approved the final version.

CONFLICT OF INTERESTS

None identified.

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