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## The Development and Implementation of a Culturally Safe Survey for Measuring Knowledge, Attitudes and Values around FASD and Alcohol Use During Pregnancy in a Remote Australian Aboriginal Community Setting

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## Abbreviations

ACR: Aboriginal Community Researcher  
FASD: Fetal Alcohol Spectrum Disorder  
NHMRC: National Health and Medical Research Council

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## **Introduction**

Fetal Alcohol Spectrum Disorder (FASD) is characterised by a range of lifelong disabilities caused by alcohol exposure during pregnancy (Mattson, Crocker, & Nguyen, 2011; Streissguth, Barr, Kogan, & Bookstein, 1996). Worldwide the estimated prevalence of FASD is 22.77 (0–176.77) cases per 1000 live births (Roozen et al., 2016). The average additional yearly cost associated with being born with FASD in four western countries has been estimated at USD \$20,000 per year (Greenmyer, Klug, Kambeitz, Popova, & Burd, 2018). Furthermore, without appropriate support the social and emotional difficulties faced by children born with FASD and their families can seriously impact the whole family and community (Jonsson, 2019). While there are therapeutic approaches aimed at reducing the impact of FASD on children and families, these are difficult and costly to implement with variable efficacy (Reid et al., 2015). FASD is however preventable, and preventative measures are likely to yield the most positive outcomes for affected communities.

## **Context of the Fitzroy Valley**

Over 2,500 kilometres from the State capital of Perth, the Fitzroy Valley is an incredibly remote area. It is comprised mostly of Aboriginal and/or Torres Strait Islander people (Australian Bureau of Statistics, 2016), speaking more than eight languages including Bunuba, Jaru, Kija, Kimberley Kriol, Gooniyandi, Nykina, Wangkatjungka and Walmajarri. For many residents, English is not a first language with around 33% of households speaking a non-English language at home (Australian Bureau of Statistics, 2016). Additionally, many local languages have no written form. Approximately 3500 Aboriginal residents live in more than 40 communities spread over hundreds of kilometres (Morphy, 2010). The community-led Lililwan active case-ascertainment survey found 52% of women reported alcohol use in pregnancy, of whom 93% reported drinking at high-risk levels indicated by Alcohol Use Disorder Identification Test – Consumption (AUDIT–C) scores of five or over (Fitzpatrick et al., 2015). A cohort study conducted in the Fitzroy Valley found a relatively high proportion (~20%) of children were born with FASD in 2002–2003 (Fitzpatrick, Latimer, et al., 2017).

With the understanding that FASD can impair memory, and the ability to learn and retain information, Chief Executive Officer (CEO) of the Marninwarntikura Women's Resource Centre (MWRC) and Fitzroy Crossing community Elder June Oscar AO, led a campaign in 2007 against Fetal Alcohol

Spectrum Disorder (FASD) towards improving the lives of Aboriginal people in remote communities. Oscar considered FASD to be a serious threat to preserving Aboriginal cultural traditions in the Valley, which are passed down by elders and not recorded in writing. Aboriginal cultural knowledge is taught to new generations through song, dance and storytelling, and Oscar was concerned that kids in the Valley may have speech delays and difficulty remembering. She observed that memory is critical to ‘our’ whole heritage because Aboriginal culture and language is passed down orally (Roberts, 2013). Aboriginal leaders in the Fitzroy Valley too saw that many children and families were suffering permanent physical and mental effects from alcohol use during pregnancy. Many young mothers were not aware of the harm they were causing their unborn children. Therefore, a concerted campaign was implemented to reduce alcohol use during pregnancy and thus prevent – or reduce the rate of – children being born with FASD. The FASD prevention activities fell under the broader Marulu Strategy, which is a community initiative to overcome FASD and Early Life Trauma and means “Worth nurturing” in the local Bunuba language (Fitzpatrick, Oscar, et al., 2017).

### **Alcohol Use and Prevention in Indigenous Communities**

The background of colonisation has led to different patterns of alcohol use amongst Aboriginal and non-Aboriginal Australians (Gray et al., 2017). While the normative nature of drinking crosses many social and economic boundaries in Australia, some groups are at a higher risk than others, including people living in remote and rural locations, Aboriginal and Torres Strait Islander peoples (Australian Institute of Health and Welfare, 2020) and increasingly, young women (Slade et al., 2016). A systematic review of prevention interventions for prenatal alcohol exposure and FASD in Indigenous communities found ten studies (Symons, Pedruzzi, Bruce, & Milne, 2018). Approaches ranged from public health education of the whole population down to individual brief interventions with women at high-risk of an alcohol exposed pregnancy. Some approaches had potential; however, the risk of potential bias present led the methodological quality of all studies to be rated as poor as assessed by consensus between multiple reviewers using the systematic review tools developed by The National Heart, Lung and Blood Institute in the US (Symons et al., 2018).

Although many prevention activities are carried out, they are not often evaluated, with researchers in Canada and Australia finding hundreds of resources and interventions, but less than 10 evaluations published in peer-

reviewed literature (Salmon & Clarren, 2011; H. M. Williams, Percival, Hewlett, Cassady, & Silburn, 2018). Prevention interventions utilised in Indigenous populations are not routinely designed specifically with or for their communities, but are typically designed for the broader population and then modified to be culturally appropriate. For example, the Screening, Brief Intervention and Referral for Treatment (SBIRT) and Changing High-risk alcohol use and Increasing Contraception Effectiveness Study (CHOICES) are mainstream drug and alcohol prevention programs adapted for American Indian populations in the United States (Gorman et al., 2013; Hanson et al., 2017). Modifications are often minor, including language adaptation, use of local images, and ensuring information is provided in a way that is understood by the target community. The effectiveness of these modifications is unclear and has not been thoroughly assessed.

### **Specific Aims and Approach of the Marulu Prevention Strategy**

The overarching aim of the Marulu Strategy in the Fitzroy Valley was to support the development of local FASD prevention interventions, and to evaluate the effectiveness of these interventions in reducing alcohol use during pregnancy (Fitzpatrick, Oscar, et al., 2017). There was a concurrent reduction in alcohol use during pregnancy recorded by midwives during the strategy from 2010–2015 (Symons et al., 2020). The main goals of the prevention activities relevant to this study were to increase community awareness and knowledge about FASD and its impacts; and increase community knowledge of the supports available to assist women to abstain from alcohol during pregnancy. Given the remote, and sparse distribution of the communities in Fitzroy Valley a range of dissemination approaches were used in September 2015 around the time researchers implemented the Knowledge, Attitude and Practices (KAP) surveys for which the development and implementation details are described in this study. These activities centred around International FASD Awareness Day (9<sup>th</sup> of September) and included: Mass media television advertisements and posters from the Strong Spirit Strong Future – Healthy Women and Pregnancies Project; a FASD Awareness Day community march; Local radio advertisements delivered in local language (Kimberley Kriol); Pamphlets and posters promoting no alcohol in pregnancy; and information provided to research participants by community researchers after collecting KAP survey data. To both inform the future development of the prevention strategy, and measure the efficacy of the approach used, it was important to understand the knowledge, attitudes, and practices of Fitzroy Valley residents with respect to alcohol use during pregnancy and FASD.

### **Knowledge, Attitudes and Practices (KAP) Surveys**

KAP surveys are commonly used to assess health behaviours, and identify factors that might influence behaviours, reasons for held attitudes and how and why people engage in health behaviours (World Health Organization, 2008). While qualitative measures gather rich deep information about individual attitudes and behaviours, the survey method allows for a larger representative sample of the population to be reached, which can assist with benchmarking and pre-post evaluation of program efficacy. KAPs around alcohol-use during pregnancy and FASD have been assessed globally including among Native American Indians (Robinson, Armstrong, Moczuk, & Loock, 1992), rural communities in the US (Logan, Walker, Nagle, Lewis, & Wiesenbahn, 2003) and women across Australia (Peadon et al., 2010).

### **Measuring the Effectiveness of a Prevention Campaign**

Alcohol use during pregnancy in the Fitzroy Valley collected by midwives showed a significant decrease from 61% to 32% from 2010–2015 (Symons et al., 2020). However, measuring use does not provide insights into factors which may influence or explain use during pregnancy, preventative measures in place in the community or the best methods of targeting or disseminating health promotion messages. The use of a KAP survey at multiple time-points can measure changes over time and major trends. The responses can be further used to identify targets for prevention; both in terms of the target populations (older/younger women, specific geographical areas) and the messaging and communication channels that might be most appropriate for those targets. A more thorough description of these activities is available elsewhere (Fitzpatrick, Oscar, et al., 2017; Symons et al., 2020).

### **Importance of Indigenous Involvement in Survey Development**

Aboriginal Australians have been researched and investigated by outsiders, since the arrival of the British; with skulls and bones of deceased Aboriginal peoples being sent to Britain for the display in museums in the interest of science (Delamothe, 1991). Centuries later some of these are yet to be returned. Even more recently, research has had very little benefit for the individuals and communities involved (Guillemin et al., 2016). Research practice is changing with calls for Aboriginal people to be involved in all aspects of research involving them (D'Antoine et al., 2020). Advice and guidance is provided for researchers within the National Health and Medical Research Council (NHMRC) Human Research Ethics Committee guidelines and the Australian

Institute of Aboriginal and Torres Strait Islander (AIATSIS) Principles for research with First Nations Australian communities. Responsibility 3.1 of the AIATSIS Code of Ethics for Aboriginal and Torres Strait Islander Research states “Indigenous people involved in research, or who may be affected by research, should benefit from, and not be disadvantaged by, the research project” (Australian Institute of Aboriginal and Torres Strait Islander Studies (AIATSIS), 2020).

### **Contextual Considerations for Survey Adjustments**

There are contextual cultural factors to consider when designing survey research in remote Aboriginal communities such as the Fitzroy Valley. The number of languages and the lack of written form precludes the translation and use of written surveys. Therefore, face-to-face surveys delivered in interview style are appropriate. Some recommendations on the type of language to use include a focus on contextual meaning, not using jargon, and to be both flexible and culturally sensitive (Eades, 1992). For example, the questionnaire designed to assist in the Lililwan prevalence study in the Fitzroy Valley was developed in conjunction with local Aboriginal community members with adaptations to ensure the language and cultural components were appropriate, the use and creation of local visual aids, and implementation with Aboriginal community navigators (Fitzpatrick et al., 2013). Surveys developed for use in this region must account for these potential language barriers and following best practice should be designed to be culturally safe.

### **Cultural Safety in Administering Surveys**

Cultural safety has many definitions, with one suggesting it goes beyond a simple awareness of cultural differences to take appropriate actions to make people of a culture to feel safer (Coffin, 2007). In the area of alcohol use in pregnancy, recommendations are available for working with Indigenous communities in Canada included using flip-charts to help understanding, using culturally appropriate materials and a collectivist approach (Montag et al., 2017). In Australia suggestions made for more effectively working with Aboriginal people in a culturally safe way include employment of Indigenous staff, incorporation of local Indigenous ways of knowing and being, and learning together (Dudgeon et al., 2014; Munns, 2010). Further, differences in philosophical perspectives are postulated as relevant to health and related outcomes that could also inform survey design. Aboriginal people prefer concrete knowledge that is related directly to the context of their lives to abstract concepts that are omnipresent in Western health including associating incidents

with their specific context (at the BBQ at a friend's house) rather than an abstract time and date such as at 2pm on March 3rd (Morgan, Slade, & Morgan, 1997). Shame is also a broader concept that may include being separated from their peers or singled out (Morgan et al., 1997), which may lead to a preference for participating in surveys in a group setting. Gender issues are also important and where possible many issues should be discussed with someone of the same gender (Morgan et al., 1997).

### **Gaps Addressed**

A review of the literature found no comprehensive, self-described culturally appropriate surveys developed to measure knowledge, attitudes and practices around FASD and alcohol use during pregnancy for use in rural, Aboriginal settings in Australia.

### **Study Aims**

Describe the development of a culturally safe quantitative survey to identify knowledge, attitudes and practices associated with prenatal alcohol use and FASD in remote Australian Aboriginal communities.

Describe the implementation of the survey in the communities including challenges and limitations.

### **Methods**

#### **Survey Development**

##### **Initial Survey Development**

An initial set of candidate questions was developed by referencing KAP surveys from other fields as well as KAP surveys developed related specifically to FASD. The general KAP layout was informed by the World Health Organization document "A Guide to Developing Knowledge, Attitude and Practice Surveys" (World Health Organization, 2008). Similar surveys developed for FASD and alcohol use during pregnancy were used as inspiration for developing question frameworks as outlined in the Source column of Table 2. Three of these initial surveys were developed for use in Indigenous populations and five were more general.

## **Consultation**

Aligned with the NHMRC guidelines and a culturally secure approach, the initial draft was refined after lengthy consultation with two senior Aboriginal local health workers residing in the Fitzroy Valley (The Aboriginal Therapy Assistant and the Coordinator for Environmental Health at Nindilingarri Cultural Health Services). Based upon their feedback, specific local response options were incorporated, and question wording adapted to support understanding with local participants. Following this, suggestions were sought from international experts working in the FASD and/or Indigenous research fields (See Acknowledgements).

After the initial drafts were completed, a working group formed from survey development experts within Telethon Kids Institute met four times to refine the survey. The final draft was produced and discussed with international collaborators and Aboriginal community advisors in Fitzroy Crossing. The face validity of the final survey items was verified through testing and feedback with local health workers. Finally, it was piloted with an Aboriginal community member from the Fitzroy Valley, and the male and female Aboriginal Community Researchers (ACRs). Their recommendations were incorporated into the final live survey including removing questions about trauma they identified as being confronting and not useful as nearly all people would be expected to answer yes for most items.

A subset of the fifteen questions considered most important for evaluating the goals of the prevention campaign, primarily about FASD knowledge, were translated into Kimberley Kriol by a qualified translator who also worked as the Aboriginal Therapy Assistant at Nindilingarri.

## **The Survey**

The final survey used in October 2015 is included in Supplementary Material Appendix A and took on average 35 minutes to complete. It was also available as a Qualtrics survey that was completed online and is compatible with the offline version of Qualtrics. The Qualtrics survey can be made available by request to the corresponding author.

The initial questions established previous survey completion for before and after comparisons and assessed age requirements (>15 years old) or need for parental consent (<18 years old).

The survey consisted of mixed methods questions organised into sections: 1. Administrative and Demographic, 2. Sources of Health Information, 3. Alcohol Use and Use During Pregnancy, 4. FASD/PAE Knowledge and Awareness, 5. FASD/PAE Attitudes, 6. Practices and Care Seeking Behaviour for Alcohol Use During Pregnancy, 9. Media Recall, Attitudes and Practices (Inserted for October), 7. Further Demographics, 8. Sources of FASD Information. Additional questions included: demographics (11), alcohol use during pregnancy (29), FASD (22), media exposure (18), and where participants obtained health information (4). Additional sub-categorisation of questions, the goals of the prevention campaign they were most related to, the questions identified as most important, and the theoretical constructs in psychology questions were related to are in Table 2.

The survey conducted in October of 2015, after the mass media campaign, included additional questions to measure exposure to the campaign and local community FASD messages including print, radio, and community events/seminars/information sessions and how that exposure may have changed participant attitudes and potential future actions.

## **Implementation**

### **Participant Information Forms**

Participant information forms were developed in consultation with ACRs and designed to be easy to understand. The contents of the Participant Information Form were explained to participants by ACRs beforehand as literacy in English was not assumed using a mixture of Kimberley Kriol, English, or their local language, depending on need and shared language with the ACR. Participant questions were addressed by both the researcher and the ACR to ensure clarity. These procedures were followed to ensure that informed consent (Dreise, 2018) was obtained as set out in the National Health and Medical Research Council's Document, "Values and Ethics: Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Health Research" (National Health and Medical Research Council, 2003). The concept of confidentiality was repeated, and a translation of this section was available in Kimberley Kriol within the survey.

### **Sampling**

Random sampling is considered the survey gold standard. However, random sampling requires definitive knowledge of all members of the population to be sampled, and the statistical probability of any individual being chosen randomly

to participate. The fluid nature of the population in the Fitzroy Valley (Morphy, 2010) and absence of a central register for dwelling occupants made a true random sample impractical. For these reasons, a sample of convenience was used.

Sample margin of error was calculated based on a population estimate of 3500 Fitzroy Valley residents, of whom approximately 2540 were 15 or over and eligible to participate (calculated from graphs in (Morphy, 2010), with the aim of achieving a confidence level of 95%. A sample of 200 participants would give a margin of error of 6.65% and with 400 participants a margin of error of 4.5% (<http://www.raosoft.com/samplesize.html>, accessed 14/08/2015).

### **Local Aboriginal Community Researchers (ACRs)**

Following the advice of Eades (1992) and stakeholders, local ACRs were employed to assist with the implementation of the survey. Where possible an ACR of each gender was present. The ACRs first completed the survey as participants to get an understanding of the instrument, its structure and how it felt to be a participant in the study. ACRs were then trained in data collection, including confidentiality and informed consent, typical survey methodologies such as not priming the respondent, and provided with additional knowledge about FASD. These researchers were invaluable for explaining the value of the research to the community and recruiting people to undertake the survey, for explaining the consent process, and helping to clarify questions and responses. The ACRs also provided translation and interpretation of the research and consent process, and the survey tool for participants. Also, as members of the local community, the ACRs had an in-depth knowledge of their communities and best methods for approaching participant recruitment in each location.

### **Recruitment**

Researchers and ACRs wore the bright orange shirts used by workers at Nindilingarri Cultural Health Services. Permission was given to wear these shirts as it let potential participants know that the research was supported by the local Aboriginal Medical Service. Typically, ACRs would approach a house or potential respondent(s) alone. After making contact they would establish rapport before briefly outlining the research without mentioning FASD, harms caused by alcohol use during pregnancy or related concepts to avoid priming. At this point they would ask if the interviewers could approach the potential participants. The survey was explained in further detail and the potential

respondent asked if they would like to participate. If they gave their verbal assent, then the full consent process would take place.

Most surveys were initiated via door-knocking and approaching participants at their homes in their communities by the ACRs. Data was also collected by setting up at the local supermarket and approaching workers at local organisations such as Marra Worra Worra (the oldest and largest regional Aboriginal Resource Agency) and Marninwarntikura Fitzroy Women's Resource Centre. Where possible recruitment was integrated with other local events, such as the football and school sports carnival, or co-ordinated with visits by other community workers such as working with the Men's Sexual Health Advisor from WA Health in two communities during the October collection period.

### **Data Collection**

Data was typically recorded electronically on iPads using the Qualtrics software package. Due to poor internet access in the remote locations Qualtrics was used offline and surveys saved and uploaded when internet access was available. Where electronic recording was not possible hardcopy questionnaires were used and entered via Qualtrics online. A randomly selected sample of ten percent of the hardcopy records from both collection periods were independently checked for accuracy with acceptable error rate ( $\leq 2\%$ ).

### **Educational Component**

To provide value to the community, an educational component was incorporated within the survey and feedback of results provided to stakeholders and the community. After all knowledge-based questions were answered, on-the-spot feedback was given to respondents about any questions they could not answer. This was done informally during the August 2015 survey period, and later formalised in the October 2015 survey with suggested wording (See Figure 1). The relevant sections were read out while checking for understanding. At survey completion, locally developed pamphlets explaining FASD in Kimberley Kriol, Kimberley Drug and Alcohol Service information, and an English FASD pamphlet were provided. During the October collection period the mass-media campaign advertisements and radio advertisements were played on the iPad for the participants to reinforce prevention messaging. Additionally, based on local advice fishing reels or FASD branded camping mugs were offered to thank participants for their time.

After data analysis was completed for each data collection period, the results were reported to key stakeholders in both written form and oral presentations to staff members at local services. In addition, where possible researchers attended community events (camps, community council meetings) to provide oral feedback to the community. All participants were mailed a summary of the results which used visual aids when describing proportions of respondents for each question.

FASD stands for Fetal Alcohol Spectrum Disorder. Fetal Alcohol means that the baby can be affected by alcohol if the mother drinks when she is pregnant. Spectrum means that the baby can be born with a wide range of problems. Some of them have small problems and some of them have big problems. Disorders just means problems. So the doctors name for the problems those kids can have is FASD.

When the kid is born their brains and bodies might not be ok. They could have difficulties with learning, they might not remember things well, they might have trouble with speaking or listening, some of them have problems with walking or throwing, some of them can be a bit wild. For some of them they may not really understand what is right or wrong so they might do anything that people tell them. They can have trouble concentrating and might have trouble at school or get into trouble with the police. They might be born small and grow up more slowly.

Some of the kids with FASD have FAS, Fetal Alcohol Syndrome. The kids born with FAS might look a bit different. They can have a small upper lip, the part between their lip and nose can be smooth and they can have smaller eyes. The problems caused by FASD last a lifetime but it is preventable if mothers don't drink while pregnant. (**Adapt based on their previous knowledge**)

**Figure 1:** Suggested wording for FASD Education Provided in October 2015 Campaign

### **Survey Changes: Development and From Pre- (August) to Post-Mass Media Campaign (October)**

Iterative improvements were made to the survey before the post-campaign collection period based on a debriefing between the ACR and researchers including rearranging demographic questions and adding a “not-applicable” option when asking about pregnancy action intentions. Additional questions included post-media campaign exposure to measure FASD knowledge (Q4.13–

4.14) and exposure to FASD prevention activities (Q6.20–Q9.8) are indicated by superscripts f and g (Table 2). The exposure questions matched similar questions asked by the WA Drug and Alcohol Office (now part of the WA Mental Health Commission) when conducting surveys to determine the impact of the Strong Spirit Strong Future (SSSF) mass-media campaign advertisement used (Government of Western Australia Mental Health Commission, 2020). A more comprehensive measure of employment/study/income/living situation (Q7.6) was included and one question reworded to ask if people would like to help in passing on FASD information in their community rather than helping with the Marulu FASD Strategy specifically (Q8.5).

### **Responses to the survey**

The final question of the survey was open-ended and asked: “Q8.10 Were there any problems with this interview? How do you think we could make it better?” Responses were recorded by researchers in as much detail as possible but were not recorded and transcribed. Qualitative content analysis was undertaken by two researchers (MS, DT) independently with any disagreements resolved through discussion and consensus. Responses could be assigned multiple categories.

### **Ethics**

Ethical approval for this research was provided by the Western Australian Aboriginal Health Ethics Committee (HREC Reference number: 575), with reciprocal approval granted by the UWA Human Research Ethics Committee (RA/4/1/6947).

## **Results**

### **Consultation and Ensuring Cultural Safety**

#### **Survey Changes**

After consultation with Aboriginal community members and ACRs, the expert working group and international FASD collaborators, the language and content of the questions were simplified and condensed. Suggestions made by community members and ACRs were incorporated into the final survey including, but not limited to: removing questions about alcohol use during pregnancy; adding local options to responses; suggestions on how to approach finding out if people knew about FASD without prompting; and adding a question about where people would like to get more FASD information. Prompts

before each section outlined the topic area. Participants were reminded at the start of each section of their rights to skip any questions, and to withdraw participation at any time.

It was initially planned to record detailed alcohol use for each respondent. Based on discussion with Aboriginal advisors and evidence provided by experienced members of the Telethon Kids working group, it was concluded that these questions were invasive and could make participants retrospectively feel uncomfortable about participation. A single question was kept, “Q7.7 Do you drink alcohol?” This question was at the end of the survey so rapport was established and it would not affect other responses. It was asked non-judgementally and participants were reassured that alcohol use is a common everyday activity and nothing to be ashamed about if they displayed nervousness.

Two new questions were added in October to further assess objective knowledge including whether only Aboriginal children could get FASD (Q4.13), and if all kids with FASD have different facial features (Q4.14). Additional language group, cultural background and residence options were included in the post-campaign survey after appearing regularly pre-campaign. Similar additions were made to the flip-charts and their associated questions including adding the Hospital and Clinics as separate entities.

### **Flip Charts**

Questions with a large pool of common potential answers were identified during piloting with Aboriginal Medical Service (AMS) health workers and the translator. Local ACRs suggested visual feedback options would be more appropriate. Therefore, flip-charts which displayed both the English response options with associated clear, colourful icons developed by a graphic designer. Question responses were grouped by colour and location in “friends and family”, “medical and treatment”, and “mass media” sections. Nine flip-charts were developed for the post-campaign survey (Q2.2, Q2.4, Q2.5, Q4.7, Q6.10, Q9.6 (two, one displaying resources), Q9.7, Q8.9). Example flip-charts are available in Supplementary Material Appendix B.

### **Survey Implementation**

The survey was completed a total of 403 times in the Fitzroy Valley during the months of August (n=200) and October (n=203) in 2015. Fifty participants

completed the survey during both time periods. The trimmed mean for completion time was 34 minutes.

### **Weather and Timing**

Weather and timing issues were important considerations as interviews were typically conducted outdoors. The second data collection period was in October after the mass media campaign was aired in September. The timing could not be later due to hot weather, the wet season potentially cutting off community access, and the start of traditional law and culture time during which many people travel and have additional responsibilities potentially reducing the pool of participants. Data collection was hindered in October with temperatures over 40 degrees Celsius reducing willingness to complete the survey during afternoons. Therefore, during October data collection began earlier. Typically, data collection started around 08:00–08:30 after children left for school and generally ceased from 12:00–13:00 as community members preferred not to be disturbed while eating lunch. Collection finished around 16:00 as workers and children returned home and dinner preparation began and to return from outlying communities before dark (~18:00) as cows and kangaroos made driving dangerous at night and insurance unavailable. Given these times it was less likely full-time workers could participate.

### **Gender/Kinship Issues**

In Fitzroy Valley Aboriginal communities, many topics are considered gendered with a delineation between what is considered “women’s business” and “men’s business”. Typically, it was most appropriate for the survey to be completed with an interviewer of the same gender. When an interviewer of the same gender was not available, participants were offered the opportunity to complete it with the interviewer of the same sex later or with the opposite gender. Men did not always answer the question about where they got information or advice about pregnancy or giving birth (Q2.5). The ACRs encouraged men to participate as issues around pregnancy and birth are “women’s business” and not typically discussed by men. Without foreshadowing survey content, the male ACRs explained how pregnancy could be considered as “men’s business.” emphasising the role of men in having happy healthy babies by understanding more about pregnancy. At times the ACRs could not participate in the survey either for the entire process, or after informed consent had been explained and confirmed, due to kinship considerations with the respondent where communication was either entirely taboo (e.g. mother-in-law for men) or restricted (e.g. particular female relatives for men).

### **Group vs Individual Responses**

Responding to requests by participants, and to maintain cultural safety, the survey was sometimes conducted in groups particularly when participants were uncomfortable alone or preferred to do it with their partner or family/friends. Paper surveys were used in conjunction with the iPad. Each group member was prompted to answer questions individually. When it appeared participants were answering as a group, the ACRs would make it clear that honest individual responses were preferred, using phrases such as “Just tell us what *you* think”. Some participants preferred to complete the survey alone to retain privacy.

### **Declining Participation**

Consultation with local Aboriginal staff and service providers indicated that potential participants may not always feel comfortable directly refusing to take part. Therefore, we took care to emphasise that they did not have to do the survey multiple times. On the other hand, other reasons for refusal might be given that on face value would seem to indicate a willingness to do the survey at a later point (e.g. “Just doing some cleaning now, maybe later.”). However, this was not the intention and they would prefer not to do the survey but did not feel comfortable directly refusing.

### **Problematic Questions, Concrete Thinking and Lists**

Post-survey debriefing among researchers and ACRs found the following questions may not have achieved their intended goals and were not appropriately worded or attempted to measure constructs not relevant to participants. Some issues with questions may have arisen in relation to a preference for more concrete questions. Participants appeared uncertain when we asked them about FASD with the wording “Can you tell me what you think it is?” so Q4.6 was altered to read, “Can you tell me anything else about FASD?” When we asked, “Is it possible to prevent or stop FASD?” in Q4.11, some participants interpreted this as meaning is it possibly to cure a child was born with a FASD. It was altered to “Is it possible to prevent or stop babies from being born with FASD?” To help further potential issues, participants were given an opportunity to express their concerns with the survey or methods and give suggestions about improvements (Q8.10).

The wording for Q4.14, “Do all kids who have FASD look different to other kids?” was not precise enough. This question intended to ask if participants thought all children with FASD had the three sentinel facial features.

However, it was sometimes interpreted as meaning behaving differently as well. Participants occasionally had difficulty expressing the kinds of problems FASD caused for their community (Q5.4), even after stating FASD was a problem. Finally, a question asking participants to rate the effect that exposure to information about FASD or alcohol use had on them (Q9.6), following the SSSF methodology, may have been too abstract and difficult to explain in a way that responding was natural. These questions will not be analysed for publication. Some open-ended questions asked participants to provide examples or lists of responses. It is possible that participants provided their first thought and considered the question answered even though there might be additional responses available to them. This meant further culturally sensitive probing was required for open ended items.

### **Exclusion Criteria**

Potential participants who appeared intoxicated or under the effects of other substances and those in common drinking areas were avoided. This may have resulted in excluding those who were most likely high-risk drinkers and possibly using alcohol during pregnancy.

### **Responses to the Survey Itself**

A total of 120 participants gave no response to the final question about the survey itself (76 in August and 44 in October). Answers were coded into 340 items (Table 1) with comments targeted towards the prevention campaign at the bottom. The most common response (47.4%) was comparatively neutral saying the survey was ok or fine or they had no problems. Some comments were positive or appreciative of the researchers (13%).

**Table 1:** Count of Responses by Assigned Category to Q8.10 (n = 340)

<b>Response Category</b>	<b>n</b>	<b>Percent</b>
Neutral about survey	161	47.4
Positive about survey	29	8.5
Appreciative or thankful to researchers	12	3.5
The survey was too complex	12	3.5
Target young women and mothers	10	2.9
Need to tailor survey e.g. for men, older participants, language etc.	9	2.6
Have food etc. as incentive	7	2.1
Give more advance notice to communities before you come	7	2.1
Use less words and more visual aids	4	1.2
Survey took too long to complete	2	0.6
Should have more information about FASD	1	.03
<b>Suggestions About Prevention Campaigns</b>		
Comment about prevention activities	47	13.8
Asking for more community visits and/or group discussions	31	9.1
Gave feedback about the associated advertising campaign	8	2.4

There were also negative responses and suggestions for improvement. The topic of gender came up with suggestions that young women and mothers needed to be targeted, and that some questions were not suitable for men or should be adapted. Some suggested that the survey was too complex and that more visual aids, speaking in Kriol, and further simplifying language and/or concepts, such as how much effect seeing advertisements had, would all be of value. Interestingly, the Kimberley Kriol pamphlet was identified as difficult to read as Kriol mostly spoken rather than written. Potential improvements in implementation included providing more notice prior to visiting communities, explaining more about the survey before starting, providing food and drinks, putting up posters or flyers, and/or visiting in the afternoon when it is cooler.

In total, 86 comments were grouped together as being about prevention activities generally rather than the survey (Base of Table 1). Thirty-one specifically requested more community visits by experts or health workers or group discussions about the subject. Eight comments made suggestions for the

advertising campaign, such as providing the campaign in each of the local languages.

## **Discussion**

We worked alongside key community members and stakeholders to design a survey with culturally relevant questions implemented in a culturally safe way. This approach was considered critical to collect accurate information while also providing community benefit. When working with Indigenous peoples as researchers from a different culture, there are many important issues to consider which can be identified and addressed by consultation and working closely with local people. We believe that by considering cultural awareness lessons shared with us by the local community we were able to develop and implement a survey, covering areas with considerably associated stigma, alcohol use in pregnancy and FASD, in a culturally safe way. This was supported by the fact that almost all participants completed the survey despite it typically taking an hour and a half, the generally positive comments received, and the approval of the CEO of the local Aboriginal Medical Service that supported this research (MC).

Following recommendations from previous research (Montag et al., 2017), visual flip-charts were developed and used for collecting data, questions were altered to be culturally and locally relevant, and a collectivist approach was used when collecting data by allowing participants to complete the survey in groups where they chose which also reduced potential shame (Morgan et al., 1997). Local Aboriginal ways of knowing and being were incorporated by getting advice from locals about which questions to include, how to ask the questions, obtaining translations of key questions into the local Kimberley Kriol and most importantly by working with locals employed as community researchers who guided us, dramatically improved recruitment, and provided constant assistance during data collection (Dudgeon et al., 2014; Munns, 2010). Other important factors identified for cultural safety in survey implementation for this study were identified. Gender was an important factor in two ways. Pregnancy is regarded as a women's issue that men would not ordinarily engage in, but our male community researchers helped overcome this reticence often by framing it as an issue about the health of children. Secondly, by having male and female researchers and community researchers, surveys could be completed with the same gender where possible although in a few cases where this was not possible women chose to do the survey with the male researcher.

Additionally, surveys can be used as an opportunity for education about the potential health risks to the child associated with prenatal alcohol exposure including FASD, with the survey itself acting as an intervention when paired with information sharing by the interviewers.

A limitation of the study was the use of convenience sampling over simple random sampling. Whilst the gold standard of sampling measures simple random sampling, in a population that is highly transient and often with no records on population numbers, addresses or fixed phone lines, it is not possible. Data collection outside normal working hours was difficult, and therefore the sample of convenience was also limited to those not working during the day. Together these issues may have led to the possibility of selection bias. Working in the Fitzroy Valley region created additional limitations. The intense heat in the afternoons, long distances to some communities, and inability to travel after dark due to free roaming cattle and kangaroos reduced the amount of time available for conducting surveys. Statistical methods could also be used in future to test the construct and concurrent validity, reliability including test-retest reliability and inter-rater reliability, and examining issues such as collinearity and the factor structure of the items (Carpenter, 2017). Finally, when our ACRs were not available recruitment was slow and difficult. This occurred on a number of days due to 'sorry business' (time associated with cultural mourning practices), health issues, and cultural and family obligations. Providing the basic research training to a pool of ACRs to cover availability and build capacity would be recommended.

The results for both the pre- and post-campaign survey periods in the Fitzroy Valley will be submitted to peer reviewed journals for publication. Slightly modified versions of the survey have also been used in the adjoining Pilbara region. Although close geographically, there may be important differences, including different sets of cultural and language groups, and a comparison between the two areas may be enlightening. In the future, it is likely to be used in further sites in Australia. A goal of this paper was to make the survey available for other researchers to use and/or adapt to facilitate further use. It would also be of interest to determine if the survey would be appropriate for metropolitan areas.

Overall, most participants indicated that they had no issue with the survey and for those that participated it was generally well received. However, further improvements could be made. Cultural security can be defined as directly linking understanding of culture to actions implemented as part of

procedure and/or policy (Coffin, 2007). To ensure cultural security into the future more detailed protocols around the issues discussed could be included into the survey itself to ensure correct procedures are followed no matter who is using it. Further yarning with the community about the survey and results may identify further elements to improve cultural security. A question about beliefs around alcohol use by men potentially affecting the child such as used in (R. J. Williams & Gloster, 1999) may be interesting as well as additional questions about the use of other drugs and smoking.

**Table 2:** Questions from Original Survey with Source, Area of Information Gathered, FASD Prevention Goal Addressed and Key Questions

Num.	Question Text	Source	Area	KAP Type <sup>a</sup>	Sub-area	Goal Num. <sup>b</sup>	Key Q's <sup>c</sup>
<b>1. Administrative and Demographic</b>							
1.1	Hi, my name is _____ and this is _____ (community researcher name).		Administrative				
1.2	Have you done this survey before?		Administrative				
1.3	How long ago did you do it? We have to make sure that you haven't done it in the last month.		Administrative				
1.4	We have some information sheets that explain everything in more detail. Do you agree to do the survey?		Administrative				
1.5	Before we start we have to fill out a few details.		Administrative				
1.6	ID number		Administrative		Anonymisation		
1.7	What is today's date?		Administrative				
1.8	Where is this survey being conducted?	(Fitzpatrick et al., 2013)	Administrative				
1.9	Who is conducting this survey?	(Fitzpatrick et al., 2013)	Administrative				
1.10	Is the respondent male or female?		Demographics		Gender		
1.11	These first questions are to find out a bit about you.	(Fitzpatrick et al., 2013)	Administrative				
1.12	How old are you?		Demographics		Age		
1.13	What languages do you speak at home?		Demographics		Languages		
1.14	Are you an Aboriginal or Torres Strait Islander?	(Fitzpatrick et al., 2013)	Demographics		Aboriginality		
1.15	From the cultural side, what is your main language group?	(Fitzpatrick et al., 2013)	Demographics		Cultural background		
1.16	Where do you usually live?	(Fitzpatrick et al., 2013)	Demographics		Residence		

Num.	Question Text	Source	Area	KAP Type <sup>a</sup>	Sub-area	Goal Num. <sup>b</sup>	Key Q's <sup>c</sup>
<b>2. Sources of Health Information</b>							
2.1	Now we want to ask you some questions about how often you like to watch TV, listen to the radio, use the internet and where you usually get your health information from.		Administrative				
2.2	How often do you do the following? (Frequency of media use by type)		Media Exposure				
2.3	Where do you use the internet?		Media Exposure				
2.4	Where do you get information about your health?		Health information	Knowledge	Source		
2.5	Where do you get information or advice about pregnancy or giving birth?		Health Information	Knowledge	Source	2	
<b>3. Alcohol Use and Use During Pregnancy</b>							
3.1	Now we would like to ask you some questions about drinking alcohol and drinking alcohol during pregnancy.		Administrative				
3.2	Do you think that drinking alcohol is a problem in your community?		Alcohol use <sup>e</sup>	Attitudes	Community		
3.3	What problems has it caused in your community?		Alcohol use <sup>e</sup>	Attitudes	Community		
3.4	If a pregnant woman drinks alcohol, what effect can it have on the baby?		Alcohol use <sup>e</sup>	Knowledge	Effects	1	
3.5	If a pregnant woman drinks alcohol, how much is safe for the baby?	(R. J. Williams & Gloster, 1999)	Alcohol use <sup>e</sup>	Knowledge	Effects	1	
3.6	If a pregnant woman drinks alcohol, is there a time when it is safe for the baby?		Alcohol use <sup>e</sup>	Knowledge	Effects	1	

3.7	What are some things that you think influence a woman to drink alcohol when pregnant?		Alcohol use <sup>e</sup>	Attitudes	Causes	3
3.8	What things might help a woman to not drink alcohol when she is pregnant?		Alcohol use <sup>e</sup>	Attitudes	Causes	3
3.9	Do you think it is ok for a woman to drink while she is pregnant?		Alcohol use <sup>e</sup>	Attitudes	Personal	3

Num.	Question Text	Source	Area	KAP Type <sup>a</sup>	Sub-area	Goal Num. <sup>b</sup>	Key Q's <sup>c</sup>
<b>4. FASD/PAE Knowledge and Awareness</b>							
4.2	If a pregnant woman drinks alcohol, can it harm her baby?	(Robinson et al., 1992), (Logan et al., 2003)	Alcohol use <sup>e</sup>	Knowledge	Effects	1	*
4.3	Do you know the name for that harm?		FASD	Knowledge	Name	1	
4.4	What kinds of problems do you think it can cause?		Alcohol use <sup>e</sup>	Knowledge	Effects	1	
4.5	Had you ever heard of any of the following: Fetal Alcohol Syndrome, also called FAS. or Fetal Alcohol Spectrum Disorders which is also called FASD?	(Mutch, Watkins, Jones, & Bower, 2013)	FASD	Knowledge	Name	1	*
4.6	Can you tell me anything else about FASD?	(Mutch et al., 2013)	FASD	Knowledge	Effects	1	
4.7	Where did you hear about FASD?		FASD	Knowledge	Source	1	
4.8	How much do you know about FASD?	(Mutch et al., 2013)	FASD	Knowledge	Self-assessed	1	
4.9	How can a person get FASD?		FASD	Knowledge	Causes	1	*
4.10	How long do FASD problems last?		FASD	Knowledge	Effects	1	
4.11	Is it possible to prevent or stop babies from being born with FASD?	(Elliott, Payne, Haan, & Bower, 2006)	FASD	Knowledge	Prevention	3	*
4.12	How can it be prevented or stopped?		FASD	Knowledge	Prevention	3	
4.13	Do you think only Aboriginal children can get FASD? <sup>f</sup>						

4.14 Do all kids who have FASD look different to other kids?<sup>f</sup>

Num.	Question Text	Source	Area	KAP Type	Sub-area	Goal Num. <sup>b</sup>	Key Q's <sup>c</sup>
<b>5. FASD/PAE Attitudes</b>							
5.1	Thanks for answering those questions about what you know about FASD. Now we would like to ask you some questions about how you feel about FASD.		Administrative				
5.2	Is FASD a problem in Fitzroy Valley?		FASD	Attitudes	Community	1	*
5.3	How big a problem is FASD in Fitzroy Valley		FASD	Attitudes	Community	1	
5.4	What kinds of problems does FASD cause for your community?		FASD	Attitudes	Community	1	
5.5	Is FASD something that you are worried about?		FASD	Attitudes	Personal	1	
5.6	Description of FASD (see Figure 1) <sup>f</sup>		Administrative/ Educational				

Num.	Question Text	Source	Area	KAP Type <sup>a</sup>	Sub-area	Goal Num. <sup>b</sup>	Key Q's <sup>c</sup>
<b>6. Practices and Care Seeking Behaviour for Alcohol Use During Pregnancy</b>							
6.1	We are more than half way through. Thank you! This section has questions about advice and help around alcohol and pregnancy.		Administrative				
6.2	Have you heard any health workers talk about alcohol and pregnancy? For example, a doctor, midwife, or AMS workers.		Alcohol use <sup>e</sup>	Knowledge	Sources	2	*
6.3	If so, who?		Alcohol use <sup>e</sup>	Knowledge	Sources	2	*

6.4	The Western Australians Drug and Alcohol Office says “No alcohol in pregnancy is the safest choice”; Have you been told anything different by anyone?		Alcohol use <sup>e</sup>	Knowledge	Sources	4	*
6.5	Who could someone talk to for help or advice if they wanted to reduce their drinking during pregnancy?		Alcohol use <sup>e</sup>	Knowledge	Community Help	2	
6.6	If you (or your partner) became pregnant, do you think you would drink alcohol during the pregnancy?	(Fitzpatrick et al., 2013)	Alcohol use <sup>e</sup>	Practices	Support	3	*
6.7	If someone close to you became pregnant would you help them to not drink alcohol?		Alcohol use <sup>e</sup>	Practices	Support	3	*
6.8	If someone close to you became pregnant would you help them by not drinking alcohol around them?		Alcohol use <sup>e</sup>	Practices	Support	3	
6.9	If you (or your partner) were pregnant, would you ask someone for help or advice about alcohol and pregnancy?		Alcohol use <sup>e</sup>	Practices	Help Seeking	3	
6.10	If you wanted help or advice about alcohol and pregnancy, who would you feel comfortable talking to?		Alcohol use <sup>e</sup>	Practices	Help Seeking	2	
6.11	If you wouldn't get help or advice about alcohol and pregnancy, can you tell me why?	(Logan et al., 2003)	Alcohol use <sup>e</sup>	Practices	Help Seeking	2	
6.12	If you saw a woman drinking during pregnancy would you do or say anything?		Alcohol use <sup>e</sup>	Practices	Support	3	
6.13	What would you do or say?		Alcohol use <sup>e</sup>	Practices	Support	3	
6.14	If not, what would stop you from doing or saying something?		Alcohol use <sup>e</sup>	Practices	Support	3	
6.15	Have you tried to help someone to not drink alcohol during pregnancy?	Similar to (Logan et al., 2003)	Alcohol use <sup>e</sup>	Practices	Support	3	
6.16	If you have, what did you do?		Alcohol use <sup>e</sup>	Practices	Support	3	

6.17	Did it have any effect?		Alcohol use <sup>e</sup>	Practices	Support	3	
6.18	Why do you think it didn't work?		Alcohol use <sup>e</sup>	Attitudes	Support	3	
6.19	What other things might help women not to drink when pregnant?		Alcohol use <sup>e</sup>	Attitudes	Support	2	*
6.20	Have you heard anyone talking about not drinking alcohol during pregnancy or FASD? <sup>g</sup>		Health information	Practices	Others sharing knowledge		
6.21	Who did you hear talking about it? <sup>g</sup>		Health information	Practices	Others sharing knowledge		
6.22	And have you heard of any women asking men or their partners to stop or cut down their drinking while she is pregnant <sup>g</sup>		Alcohol use <sup>e</sup>	Practices	Support		

Num.	Question Text	Source	Area	KAP Type <sup>a</sup>	Sub-area	Goal Num. <sup>b</sup>	Key Q's <sup>c</sup>
<b>9. Media Recall, Attitudes and Practices</b>							
9.1	Have you recent seen or heard anything about FASD or women drinking alcohol when they are pregnant? <sup>g</sup>	SSSF Evaluation <sup>d</sup>	Media Exposure				
9.2	What can you tell me about what you have seen or heard? <sup>g</sup>		Media Exposure				
9.3	Next, I will play you a TV ad. How many times have you seen this TV ad before? <sup>g</sup>	SSSF Evaluation <sup>d</sup>	Media Exposure				
9.4	What do you think they are trying to say in this ad? <sup>g</sup>	SSSF Evaluation <sup>d</sup>	Media Exposure				
9.5	Next, I will play you some radio ads. How many time have you heard these radio ads before? <sup>g</sup>	SSSF Evaluation <sup>d</sup>	Media Exposure				
9.6	We would like to know what you recently saw or heard about FASD or drinking alcohol during pregnancy and if it had an	SSSF Evaluation <sup>d</sup>	Administrative				

	effect it had on you. Did it change your thinking, feelings, or what you do? <sup>g</sup>				
9.7	The next four questions are all similar. For each one we want to know if anything that you saw or heard recently about FASD or drinking alcohol during pregnancy made you think about the following: <sup>g</sup>	SSSF Evaluation <sup>d</sup>	Administrative		
	a. Men or a partner should support their women not to drink alcohol while pregnant <sup>g</sup>		Alcohol use <sup>e</sup>	Practices	Support
	b. Men or a partner should support pregnant women by not drinking alcohol around them <sup>g</sup>		Alcohol use <sup>e</sup>	Practices	Support
	c. Everyone should help pregnant women to not drink alcohol <sup>g</sup>		Alcohol use <sup>e</sup>	Practices	Support
	d. Women who are wanting to get pregnant shouldn't drink alcohol before they are pregnant <sup>g</sup>		Alcohol use <sup>e</sup>	Attitudes	Personal
9.8	The next six questions are all similar. After seeing or hearing anything recently about FASD or drinking alcohol during pregnancy, we want to know if you will do these things more often, less often or about the same as before: <sup>g</sup>	SSSF Evaluation <sup>d</sup>	Administrative		
	a. Tell your friends or family who are pregnant that they shouldn't drink alcohol <sup>g</sup>		Alcohol use <sup>e</sup>	Practices	Support
	b. Get some advice from the doctor or other health worker about drinking alcohol <sup>g</sup>		Alcohol use <sup>e</sup>	Knowledge	Seeking
	c. Not drink alcohol if you (or your partner) get pregnant <sup>g</sup>		Alcohol use <sup>e</sup>	Practices	Personal

- |    |  |                          |           |          |
|----|--|--------------------------|-----------|----------|
| d. | (Only for women) Ask your partner not to drink alcohol and support me while I am pregnant <sup>g</sup> | Alcohol use <sup>e</sup> | Practices | Support  |
| e. | (Only for women) Not drink alcohol if you are trying to get pregnant <sup>g</sup>                      | Alcohol use <sup>e</sup> | Practices | Personal |
| f. | Talk to your partner about how much alcohol the two of you drink generally <sup>g</sup>                | Alcohol use <sup>e</sup> | Practices | Support  |

Num.	Question Text	Source	Area	KAP Type <sup>a</sup>	Sub-area	Goal Num. <sup>b</sup>	Key Q's <sup>c</sup>
<b>7. Further Demographics</b>							
7.1	Thanks for answering those questions. We have a few more questions that we would like to ask you about yourself before we get to the last section of the survey. These questions are all optional and you don't have to answer any that you don't like.		Administrative				
7.2	How many children do you have?		Demographics	Experience with pregnancy			
7.3	How old is your youngest child?		Demographics	How recently pregnant			
7.4	What is the highest level of education you have finished?		Demographics	Education			
7.6	How would you describe your current living situation? <sup>g</sup>	Aboriginal Researcher	Community	Demographics	Employment, income or Study		
7.7	Do you drink alcohol?		Demographics	Alcohol Use			

Num.	Question Text	Source	Area	KAP Type <sup>a</sup>	Sub-area	Goal Num. <sup>b</sup>	Key Q's <sup>c</sup>
<b>8. Sources of FASD Information</b>							
8.1	Thanks for being so patient. This is the last section and we would like to find out how we can help people learn more about FASD.		Administrative				
8.2	Have you heard about the Lililwan Project?		FASD	Knowledge	Local Projects	1	
8.3	What do you know about the Lililwan Project?		FASD	Knowledge	Local Projects	1	
8.4	Have you heard about the Marulu FASD Strategy?		FASD	Knowledge	Local Projects	1	
8.5	Would you like to help with passing on FASD messages in your community? <sup>g</sup>		FASD	Practices	Support	3	
8.6	Do you feel like you know enough about FASD?		FASD	Knowledge	Self-assessed	1	*
8.7	Would you like more information about FASD?	(Mutch et al., 2013)	FASD	Knowledge	Wants	1	*
8.9	Where would you like to get more information about FASD?	Aboriginal Community Researcher	FASD	Knowledge	Wants	1	*
8.10	Were there any problems with this interview? How do you think we could make it better?	(Fitzpatrick et al., 2013)	Survey	Attitudes			
a	KAP Type	Refers to whether the question was about Knowledge, Attitudes or Practices,					
b	Goal Num.	Refers to the goal number of the prevention campaign.					
c	Key Q's:	Key Questions are indicated by an asterisk.					
d	SSSF Evaluation	Refers to the Strong Spirit Strong Future Evaluation (TNS (now Kantar Public Division), 2014),					
e	Alcohol Use.	Refers to Alcohol use during pregnancy					
f	Post-media campaign exposure to measure FASD knowledge						
g	Post-media campaign exposure to FASD prevention activities						

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## Supplementary Appendix A: Final October KAP Survey

### FASD KAP October 2015

Q1.1 Hi, my name is \_\_\_\_\_ and this is \_\_\_\_\_ (community researcher name). We are doing a survey in Fitzroy Valley about alcohol and pregnancy. We want to know how women can be helped to have a healthy pregnancy. Do you have some time now to talk about it? Can I confirm that you are at least 18 years old?

Q1.2 Have you done this survey before?

- Yes
- No

**Answer If Have you done this survey before? Yes Is Selected**

Q1.3 How long ago did you do it? We have to make sure that you haven't done it in the last month.

**(Read out the following information).**

Many of the questions will be the same as last time so thank you for being patient. We want to ask these questions to find out if you engaged in any of the FASD activities in September and to see if there any changes in answers that people give over time.

- I did it in the last few weeks (In October)
- I did it more than a month ago (In August)

**If I did it in the last few weeks Is Selected, Then Skip To End of Survey**

Q1.4 We have some information sheets that explain everything in more detail.

**(Hand out the Participant Information Sheet)**

CONFIDENTIALITY: I just want to repeat that the information you give us will be kept private. Your name will not be recorded on the survey and the answers you give will only be reported after being combined with all of the other peoples' answers. Your answers will be stored on a computer and won't be shared with anyone outside of the research team.

Ie wundu telim yoo det Ola information yoobin gibim melu, usmob guddu keepim en karn telim or givem peebool eneechien storee liegu yors naim, usmob karn poodim lungu det survey. En ola answers dai guddu poodim lungu det report liegu wen dai poodim orlud toogethu guddu nuthulot peebool blu answers Yor answers dai guddu poodim en keepim lungu computer en dai karn telim or gibem peebool eneechien storee lungu eneebodee outsiedwai brom detlod research mob. Meebulu kin blogim eneetiëm blungu yoo liegu blu yoo to nebu to answer orla questions det yoo don liegim or don habim aneemor answer for. Yoo riet to doowim dis survey?

We can stop at any time if you feel uncomfortable and you don't have to answer any questions that you don't like or don't have an answer for. There are no right or wrong answers.

Do you agree to do this survey?

- Yes
- No

**If No Is Selected, Then Skip To End of Survey**

Q1.5 Before we start we have to fill out a few details.

**(This first section is for collection of administrative information and does not need to be read aloud.)**

Q1.6 ID number **(Must be filled to continue)**

Q1.7 What is today's date?

Q1.8 Where is this survey being conducted?

Q1.9 Who is conducting this survey?

- Martyn
- Kaashifah
- Community Researcher 1 (record name) \_\_\_\_\_
- Community Researcher 2 (record name) \_\_\_\_\_

Q1.10 Is the respondent male or female?

- Male
- Female

Q1.11 These first questions are to find out a bit about you. The community researcher is here to help out if you have any questions. You don't have to answer any questions that make you feel uncomfortable.

Q1.12 How old are you? **(If under 18 get consent from parents. No surveys for people under 15)**

Q1.13 What languages do you speak at home?

- Kriol
- English
- Bunuba
- Jaru
- Gooniyandi
- Nyikina
- Wangkatjunka
- Walmajarri
- Other \_\_\_\_\_
- Don't want to say

Q1.14 Are you an Aboriginal or Torres Strait Islander?

- Yes
- No
- Don't want to say

Answer If Are you an Aboriginal or Torres Strait Islander? **Yes, Is Selected**

Q1.15 From the cultural side, what is your main language group?

- Bunuba
- Gooniyandi
- Kija
- Jaru
- Nyikina
- Walmajarri
- Wangkatjunka
- Other \_\_\_\_\_
- Don't want to say

Q1.16 Where do you usually live?

- Fitzroy Town
- Bayulu
- Noonkanbah
- Muludja
- Wangkatjunka
- Yakanarra
- Bungardie
- Darlgunaya
- Djugerari
- Gillaroong
- Joy Springs (8 Mile)
- Junjuwa
- Kurnangki
- Loanbung
- Mindi Rardi
- Ngalingkadji
- Ngurtuwarta
- Yiyili
- Other \_\_\_\_\_
- Don't want to say

**Skip to Section 3 if they did the survey before**

Q2.1 Now we want to ask you some questions about how often you like to watch TV, listen to the radio, use the internet and where you usually get your health information from.

Q2.2 How often do you do the following? (**Show flip card and ask for each individual media type**)

	I don't	One or two days a week	3 to 6 days a week	Every day	Don't want to say
Watch TV	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Listen to the radio	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Make mobile phone calls	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Send text messages on your mobile	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Use bluetooth on your mobile	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Use the internet	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Answer If How often do you do the following? **Use the internet - I don't Is Not Selected Or Don't want to say Is Not Selected**

Q2.3 Where do you use the internet?

- At home
- At work
- At school
- On my phone
- Other \_\_\_\_\_
- Don't want to say

Q2.4 Where do you get information about your health?

**(Record unprompted replies first, then show flip chart, may choose multiple options. This is the first time with the flip chart so read out all of the options and explain how they are grouped)**

	Unprompted	Prompted
Female relatives (Mother, grandmother, aunts or sisters)	<input type="checkbox"/>	<input type="checkbox"/>
Male relatives (Father, grandfather, uncles or brothers)	<input type="checkbox"/>	<input type="checkbox"/>
Partner	<input type="checkbox"/>	<input type="checkbox"/>
Other Family	<input type="checkbox"/>	<input type="checkbox"/>
Elders	<input type="checkbox"/>	<input type="checkbox"/>
Friend	<input type="checkbox"/>	<input type="checkbox"/>
Workmate	<input type="checkbox"/>	<input type="checkbox"/>
Doctor	<input type="checkbox"/>	<input type="checkbox"/>
Nurse	<input type="checkbox"/>	<input type="checkbox"/>
Midwife	<input type="checkbox"/>	<input type="checkbox"/>
Hospital	<input type="checkbox"/>	<input type="checkbox"/>
Clinic	<input type="checkbox"/>	<input type="checkbox"/>
Nindilingarri	<input type="checkbox"/>	<input type="checkbox"/>
Marninwarntikura	<input type="checkbox"/>	<input type="checkbox"/>
Baya Gawiy	<input type="checkbox"/>	<input type="checkbox"/>
Other Aboriginal Medical Service	<input type="checkbox"/>	<input type="checkbox"/>
Alcohol and Drug Services	<input type="checkbox"/>	<input type="checkbox"/>
Other health services	<input type="checkbox"/>	<input type="checkbox"/>
Baby group/class	<input type="checkbox"/>	<input type="checkbox"/>
School	<input type="checkbox"/>	<input type="checkbox"/>
Church	<input type="checkbox"/>	<input type="checkbox"/>
Television	<input type="checkbox"/>	<input type="checkbox"/>
Radio	<input type="checkbox"/>	<input type="checkbox"/>
Internet	<input type="checkbox"/>	<input type="checkbox"/>
Email	<input type="checkbox"/>	<input type="checkbox"/>
Social Media (Facebook etc.)	<input type="checkbox"/>	<input type="checkbox"/>
Written (Poster, Pamphlet, Newspaper, Book)	<input type="checkbox"/>	<input type="checkbox"/>
Mobile Phone	<input type="checkbox"/>	<input type="checkbox"/>
Community Events/Festivals/Seminars	<input type="checkbox"/>	<input type="checkbox"/>
Other	<input type="checkbox"/>	<input type="checkbox"/>
Don't want to say	<input type="checkbox"/>	<input type="checkbox"/>

Q2.5 Where do you get information or advice about pregnancy or giving birth?

**(Record unprompted replies first, then show flip chart, may choose multiple options)**

	Unprompted	Prompted
Female relatives (Mother, grandmother, aunts or sisters)	<input type="checkbox"/>	<input type="checkbox"/>
Male relatives (Father, grandfather, uncles or brothers)	<input type="checkbox"/>	<input type="checkbox"/>
Partner	<input type="checkbox"/>	<input type="checkbox"/>
Other family	<input type="checkbox"/>	<input type="checkbox"/>
Elders	<input type="checkbox"/>	<input type="checkbox"/>
Friend	<input type="checkbox"/>	<input type="checkbox"/>
Workmate	<input type="checkbox"/>	<input type="checkbox"/>
Other Family (Who?)	<input type="checkbox"/>	<input type="checkbox"/>
Doctor	<input type="checkbox"/>	<input type="checkbox"/>
Nurse	<input type="checkbox"/>	<input type="checkbox"/>
Midwife	<input type="checkbox"/>	<input type="checkbox"/>
Hospital	<input type="checkbox"/>	<input type="checkbox"/>
Clinic	<input type="checkbox"/>	<input type="checkbox"/>
Nindilingarri	<input type="checkbox"/>	<input type="checkbox"/>
Marninwarntikura	<input type="checkbox"/>	<input type="checkbox"/>
Baya Gawiy	<input type="checkbox"/>	<input type="checkbox"/>
Other Aboriginal Medical Service	<input type="checkbox"/>	<input type="checkbox"/>
Alcohol and Drug services	<input type="checkbox"/>	<input type="checkbox"/>
Other health services	<input type="checkbox"/>	<input type="checkbox"/>
Baby group/class	<input type="checkbox"/>	<input type="checkbox"/>
School	<input type="checkbox"/>	<input type="checkbox"/>
Church	<input type="checkbox"/>	<input type="checkbox"/>
Television	<input type="checkbox"/>	<input type="checkbox"/>
Radio	<input type="checkbox"/>	<input type="checkbox"/>
Internet	<input type="checkbox"/>	<input type="checkbox"/>
Email	<input type="checkbox"/>	<input type="checkbox"/>
Social Media (Facebook etc.)	<input type="checkbox"/>	<input type="checkbox"/>
Written (Poster, Pamphlet, Newspaper, Book)	<input type="checkbox"/>	<input type="checkbox"/>
Mobile Phone	<input type="checkbox"/>	<input type="checkbox"/>
Warning labels on alcohol bottles or glasses	<input type="checkbox"/>	<input type="checkbox"/>
Community events/festivals/seminars	<input type="checkbox"/>	<input type="checkbox"/>
Other (Please record)	<input type="checkbox"/>	<input type="checkbox"/>
Don't want to say	<input type="checkbox"/>	<input type="checkbox"/>

Q3.1 Now we would like to ask you some questions about alcohol drinking in your community and drinking alcohol during pregnancy. Remember, if you don't want to answer some questions you don't have to and we can stop at any time.

Q3.2 Do you think that drinking alcohol is a problem in your community?

- Yes
- Maybe
- No
- Don't know / Not sure
- Don't want to say

Answer If Do you think that drinking alcohol is a problem in your community? **Yes** or **Maybe** Is Selected

Q3.3 What problems has it caused in your community?

Q3.4 If a pregnant woman drinks alcohol, what effect can it have on the baby?  
**(Prompted)**

Liegu wen woman hoo habimbud baibee, en dringgimbud grog, yoo regin ee kin doowim sumding lu baibee?

- It can harm the baby (Liegu ee kin harm det baibee)
- It doesn't harm the baby (Mudee ee karn harm det baibee)
- Don't know (Or ie don noa)
- Don't want to say

Q3.5 If a pregnant woman drinks alcohol, how much is safe for the baby?  
(Prompted)

Liegu wen woman hoo habimbud baibee en dai dringgimbud grog, houmutj yoo  
regin ee riet en goodwun blu baibee?

- Once a month (Wun month oanlee liegu wun dring)
- Once a week (Wunbulu tiem lu week)
- 1 drink every day (Oanlee wun dring ebre dai)
- 2 drinks every day (Oanlee toobulu dring ebre dai)
- Any amount is safe (Aneekien orlud eriet)
- No alcohol in pregnancy is the safest choice (Noa grog lu wen habimbud  
baibee ee goodwun)
- It depends on how healthy the mother is (Eriet for mumeewun det im  
healthywun)
- Don't know (Ie don noa)
- Don't want to say

Q3.6 If a pregnant woman drinks alcohol, is there a time when it is safe for the  
baby? (Prompted)

Wen woman hoo habimbud baibee en dringgimbud grog yoo regin dai noa wen  
ee goodwun blu baibee?

- Any time is ok (Liegu eneeti em ee riet)
- First three months of pregnancy (Liegu blu firs thuddeebulu month's wen  
dai guddum baibee lu dai guds)
- Middle three months of pregnancy (Liegu blu lu middle thuddeebulu  
month's wen dai guddum baibee lu dai guds)
- Last three months of pregnancy (En dijan blu thuddeebulu month's wen dai  
guddum baibee lu dai guds)
- There is no safe time to drink (Ther is noa saif tiem blu dringging)
- Don't know (Ie don noa)
- Don't want to say

Q3.7 What are some things that you think cause a woman to drink alcohol when  
pregnant?

Q3.8 What things might help a woman to not drink alcohol when she is  
pregnant?

Q3.9 Do you think it is ok for a woman to drink while she is pregnant? (**Want to get opinion**)

- Yes
- A bit
- No
- I don't have an opinion
- Don't know
- Don't want to say

Q4.2 If a pregnant woman drinks alcohol, can it harm her baby?

Liegu wen woman hoo habimbud baibee dringgimbud grog, yoo regin ee kin maigim baibee sikwun?

- Yes
- Maybe
- No
- Don't know
- Don't want to say

Answer If a pregnant woman drinks alcohol, can it harm her baby? **Yes** or **Maybe** Is Selected

Q4.3 Do you know the name for that harm?

(**Record NR for No Response, if they say FAS or FASD ask them if they know what that stands for**) Yoo noa det naim blungu det harm?

Answer If a pregnant woman drinks alcohol, can it harm her baby? **Yes** or **Maybe** Is Selected

Q4.4 What kind of problems do you think it can cause?

(**Record NR for No Response**) Wod sumbulu problems yoo regin eegin korsim?

Q4.5 Had you ever heard of any of the following: Fetal Alcohol Syndrome, also called FAS. or Fetal Alcohol Spectrum Disorders which is also called FASD?

(**Important branching question, the “Don’t want to say” option has been left out**)

Yoo bin hirimbud eneekien blungu det Fetal Alcohol Syndrome, en dai korlim FAS or Fetal Alcohol Spectrum Disorders en det is wod dai korlim?

- Yes
- No

If **No** Is Selected, Then Skip To **Q5.6** and explain what FASD is!

Q4.6 Can you tell me anything else about FASD?

**(Record NR for No Response)** Yoo kin telim mee wod yoo regin blunga diswun?

Q4.7 Where did you hear about FASD? **(Record unprompted replies first, then show flip chart, may choose multiple options)** Yoo bin hirimbud or noa blungu dis FASD?

	Unprompted	Prompted
Female relatives (Mother, grandmother, aunts or sisters)	<input type="checkbox"/>	<input type="checkbox"/>
Male relatives (Father, grandfather, uncles or brothers)	<input type="checkbox"/>	<input type="checkbox"/>
Partner	<input type="checkbox"/>	<input type="checkbox"/>
Other family	<input type="checkbox"/>	<input type="checkbox"/>
Elders	<input type="checkbox"/>	<input type="checkbox"/>
Friend	<input type="checkbox"/>	<input type="checkbox"/>
Workmate	<input type="checkbox"/>	<input type="checkbox"/>
Doctor	<input type="checkbox"/>	<input type="checkbox"/>
Nurse	<input type="checkbox"/>	<input type="checkbox"/>
Midwife	<input type="checkbox"/>	<input type="checkbox"/>
Hospital	<input type="checkbox"/>	<input type="checkbox"/>
Clinic	<input type="checkbox"/>	<input type="checkbox"/>
Nindilingarri	<input type="checkbox"/>	<input type="checkbox"/>
Marninwarntikura	<input type="checkbox"/>	<input type="checkbox"/>
Baya Gawiy	<input type="checkbox"/>	<input type="checkbox"/>
Other Aboriginal Medical Service	<input type="checkbox"/>	<input type="checkbox"/>
Alcohol and Drug services	<input type="checkbox"/>	<input type="checkbox"/>
Other health services	<input type="checkbox"/>	<input type="checkbox"/>
Baby group/class	<input type="checkbox"/>	<input type="checkbox"/>
School	<input type="checkbox"/>	<input type="checkbox"/>
Church	<input type="checkbox"/>	<input type="checkbox"/>
Television	<input type="checkbox"/>	<input type="checkbox"/>
Radio	<input type="checkbox"/>	<input type="checkbox"/>
Internet	<input type="checkbox"/>	<input type="checkbox"/>
Email	<input type="checkbox"/>	<input type="checkbox"/>
Social Media (Facebook etc.)	<input type="checkbox"/>	<input type="checkbox"/>
Written (Poster, Pamphlet, Newspaper, Book)	<input type="checkbox"/>	<input type="checkbox"/>
Mobile phone	<input type="checkbox"/>	<input type="checkbox"/>
Warning labels on alcohol bottles or glasses	<input type="checkbox"/>	<input type="checkbox"/>
Community events/festivals/seminars	<input type="checkbox"/>	<input type="checkbox"/>
Other	<input type="checkbox"/>	<input type="checkbox"/>
Don't want to say	<input type="checkbox"/>	<input type="checkbox"/>

Q4.8 How much do you know about FASD?

**(Prompted)** Houmutj yoo noa blungu det FASD?

- I have only heard about it (Ie bin oanlee hirimbud blu thuddun)
- I know a bit about it (Ie noa a bit blu im)
- I know a lot about it (Ie noa mor blu im)
- Don't want to say

Q4.9 How can a person get FASD? **(Record NR for No Response)** Hou yoo regin wunbulu perjin kin gedim det FASD?

Q4.10 How long do FASD problems last?

**(Prompted, changed the treatment option)** Houmutj yoo regin det FASD stop for?

- Only when they are children (Oanlee wen dai kid)
- Until they start school (Oanlee wen dai stard skool)
- All their life (Blungu dai lief)
- Until they get treatment (Oanlee wen dokdu loogim dem) **(Include what type of treatment)** \_\_\_\_\_
- Don't know
- Don't want to say

Q4.11 Is it possible to prevent or stop babies from being born with FASD?

Wud yoo regin blu diswun FASD weelod kin blogim?

- Yes
- Maybe
- No
- Don't know
- Don't want to say

Answer If Is it possible to prevent or stop babies from being born with FASD? **Yes or Maybe** Is Selected

Q4.12 How can it be prevented or stopped?

**(Record NR for No Response)** Houmutj weelod kin blogim?

Q4.13 Do you think only Aboriginal children can get FASD?

- Yes
- No
- Not sure
- Don't want to say

Q4.14 Do all kids who have FASD look different to other kids?

- Yes
- No
- Not sure
- Don't want to say

Q5.1 Thanks for answering those questions about what you know about FASD. Now we would like to ask you some questions about how you feel about FASD.

Q5.2 Is FASD a problem in Fitzroy Valley?

- Yes
- Maybe
- No
- Don't know
- I don't want to say

Answer If Is FASD a problem in Fitzroy Valley? Yes or Maybe Is Selected

Q5.3 How big a problem is FASD in Fitzroy Valley? (**Prompted**)

- A little problem
- A bit of a problem
- A big problem
- I don't want to say

Answer If Is FASD a problem in Fitzroy Valley? Yes or Maybe Is Selected

Q5.4 What kinds of problems does FASD cause for your community? (**Record NR for No Response**)

Q5.5 Is FASD something that you are worried about?

- Yes
- Maybe
- No
- Don't want to say

**SKIP TO HERE if they hadn't heard about FASD before**

Q5.6 FASD stands for Fetal Alcohol Spectrum Disorders. Fetal Alcohol means that the baby can be affected by alcohol if the mother drinks when she is pregnant. Spectrum means that the baby can be born with a wide range of problems. Some of them have small problems and some of them have big problems. Disorders just means problems. So the doctors name for the problems those kids can have is FASD.

When the kid is born their brains and bodies might not be ok. They could have difficulties with learning, they might not remember things well, they might have trouble with speaking or listening, some of them have problems with walking or throwing, some of them can be a bit wild. For some of them they may not really understand what is right or wrong so they might do anything that people tell them. They can have trouble concentrating and might have trouble at school or get into trouble with the police. They might be born small and grow up more slowly.

Some of the kids with FASD have FAS, Fetal Alcohol Syndrome. The kids born with FAS might look a bit different. They can have a small upper lip, the part between their lip and nose can be smooth and they can have smaller eyes. The problems caused by FASD last a lifetime but it is 100% preventable if mothers don't drink while pregnant. **(Adapt based on their previous knowledge)**

Q6.1 We are more than half way through. Thank you! This section has questions about advice and help around alcohol and pregnancy.

Q6.2 Have you heard any health workers talk about alcohol and pregnancy? For example, a doctor, midwife, or AMS workers.

- Yes
- No
- Don't want to say

Answer If Have you heard any health workers talk about alcohol and pregnancy? **Yes** Is Selected

Q6.3 If so, who? (**Prompted**)

- Doctor
- Midwife
- Nurse
- AMS Worker
- Alcohol and Other Drugs Counsellor
- Other (please record) \_\_\_\_\_
- Don't want to say

Q6.4 The Western Australians Drug and Alcohol Office says “No alcohol in pregnancy is the safest choice”; Have you been told anything different by anyone? (**Record who if yes**)

- Yes \_\_\_\_\_
- No
- Don't want to say

Q6.5 Who could someone talk to for help or advice if they wanted to reduce their drinking during pregnancy? (**Unprompted**)

	Unprompted
Female relatives (Mother, grandmother, aunts or sisters)	<input type="checkbox"/>
Male relatives (Father, grandfather, uncles or brothers)	<input type="checkbox"/>
Partner	<input type="checkbox"/>
Other family	<input type="checkbox"/>
Elders	<input type="checkbox"/>
Friend	<input type="checkbox"/>
Workmate	<input type="checkbox"/>
Doctor	<input type="checkbox"/>
Nurse	<input type="checkbox"/>
Midwife	<input type="checkbox"/>
Hospital	<input type="checkbox"/>
Clinic	<input type="checkbox"/>
Nindilingarri	<input type="checkbox"/>
Marninwarntikura	<input type="checkbox"/>
Baya Gawiy	<input type="checkbox"/>
Other Aboriginal Medical Service	<input type="checkbox"/>
Alcohol and drug services	<input type="checkbox"/>
Other health services	<input type="checkbox"/>
Baby group/class	<input type="checkbox"/>
School	<input type="checkbox"/>
Church	<input type="checkbox"/>
Other	<input type="checkbox"/>
Not sure	<input type="checkbox"/>
Don't want to say	<input type="checkbox"/>

Q6.6 If you (or your partner) became pregnant, do you think you would drink alcohol during the pregnancy?

**(If maybe record any additional response, Not applicable option available)**

- Yes
- Maybe \_\_\_\_\_
- No
- Don't know
- Not applicable
- Don't want to say

Q6.7 If someone close to you became pregnant would you help them to not drink alcohol?

- Yes
- Maybe \_\_\_\_\_
- No
- Don't know
- Don't want to say

Q6.8 If someone close to you became pregnant would you help them by not drinking alcohol around them? (**Not applicable option added for people who don't drink**)

- Yes
- Maybe \_\_\_\_\_
- No
- Don't know
- Not applicable
- Don't want to say

Q6.9 If you (or your partner) were pregnant, would you ask someone for help or advice about alcohol and pregnancy? (**Not applicable option available**)

- Yes
- Maybe \_\_\_\_\_
- No
- Don't know
- Not applicable
- Don't want to say

Q6.10 If you wanted help or advice about alcohol and pregnancy, who would you feel comfortable talking to? (**Prompted, show flip chart**)

	Prompted
Female relatives (Mother, grandmother, aunts or sisters)	<input type="checkbox"/>
Male relatives (Father, grandfather, uncles or brothers)	<input type="checkbox"/>
Partner	<input type="checkbox"/>
Other family	<input type="checkbox"/>
Elders	<input type="checkbox"/>
Friend	<input type="checkbox"/>
Workmate	<input type="checkbox"/>
Doctor	<input type="checkbox"/>
Nurse	<input type="checkbox"/>
Midwife	<input type="checkbox"/>
Hospital	<input type="checkbox"/>
Clinic	<input type="checkbox"/>
Nindilingarri	<input type="checkbox"/>
Marninwarntikura	<input type="checkbox"/>
Baya Gawiy	<input type="checkbox"/>
Other Aboriginal Medical Service	<input type="checkbox"/>
Alcohol and Drug services	<input type="checkbox"/>
Other health services	<input type="checkbox"/>
Baby group/class	<input type="checkbox"/>
School	<input type="checkbox"/>
Church	<input type="checkbox"/>
Other	<input type="checkbox"/>
Nobody	<input type="checkbox"/>
Not applicable?	<input type="checkbox"/>
Don't want to say	<input type="checkbox"/>

Answer If you (or your partner) were pregnant, would you ask someone for help or advice about alcohol **No or Don't want to say or Maybe Is Selected**

Q6.11 If you wouldn't get help or advice about alcohol and pregnancy, can you tell me why?

**(Record NR for No Response)**

Q6.12 If you saw a woman drinking during pregnancy would you do or say anything?

- Yes
- Maybe
- No
- Don't know
- Don't want to say

Answer If you saw a woman drinking during pregnancy would you do or say anything? **Yes or Maybe** is selected

Q6.13 What would you do or say? (Record NR for No Response)

Answer If you saw a woman drinking during pregnancy would you do or say anything? **Yes Is Not Selected**

Q6.14 If not, what would stop you from doing or saying something? (**Record NR for No Response**)

Q6.15 Have you tried to help someone to not drink alcohol during pregnancy?

- Yes
- No
- Don't want to say

Answer If Have you tried to help someone to not drink alcohol during pregnancy? **Yes Is Selected**

Q6.16 If you have, what did you do? (**Record NR for No Response**)

Answer If Have you tried to help someone to not drink alcohol during pregnancy? **Yes Is Selected**

Q6.17 Did it have any effect? (**Prompted, read out all options**)

- They kept drinking the same or more
- They cut down their drinking
- They stopped drinking
- Don't want to say

Answer If Did it have any effect? **They kept drinking the same or more Is Selected**

Q6.18 Why do you think it didn't work? (**Record NR for No Response**)

Q6.19 What other things might help women not to drink when pregnant?  
(**Record NR for No Response**)

Q6.20 Have you heard anyone talking about not drinking alcohol during pregnancy or FASD?

- Yes
- Maybe
- No
- Don't want to say

Answer If Have you heard anyone talking about not drinking alcohol during pregnancy or FASD? **Yes or Maybe** Is Selected

Q6.21 Who did you hear talking about it?

- Women talking with women
- Men talking with men
- Women and men talking together
- Other \_\_\_\_\_
- Don't want to say

Q6.22 And have you heard of any women asking men or their partners to stop or cut down their drinking while she is pregnant?

- Yes
- Maybe
- No
- Don't want to say

Q9.1 Have you recently seen or heard anything about FASD or women drinking alcohol when they are pregnant?

- Yes
- Maybe
- No
- Don't want to say

Have you seen or heard anything about women drinking alcohol when they are pregnant or FASD recently? **Yes or Maybe** is Selected

Q9.2 What can you tell me about what you have seen or heard?

Q9.3 Next, I will play you a TV ad. How many times have you seen this TV ad before?

**(Play TV ad in Movies, choose 0 if they haven't seen it before. Record and then prompt them to guess number)**

Q9.4 What do you think they are trying to say in this ad?

Q9.5 Next, I will play you some radio ad's. How many times have you heard these radio ad's before?

**(Play radio ads in Music, choose 0 if they haven't seen it before. Record and then prompt them to guess number)**

Q9.6 We would like to know what you recently saw or heard about FASD or drinking alcohol during pregnancy and if it had an effect it had on you. Did it change your thinking, feelings, or what you do?

**(Show both flip charts. If other community event please record)**

	Didn't see/hear it	A big effect	A bit of an effect	No effect	Don't want to say
Television ad	<input type="radio"/>				
Radio ad	<input type="radio"/>				
Doing this survey before and talking with researchers	<input type="radio"/>				
Brochure/pamphlet/flyer	<input type="radio"/>				
"Alcohol Think Again" poster	<input type="radio"/>				
FASD Awareness Day/Walk	<input type="radio"/>				
Marulu T-shirt	<input type="radio"/>				
Social Media (Facebook etc.)	<input type="radio"/>				
Other community event:	<input type="radio"/>				

Q9.7 The next four questions are all similar. For each one we want to know if anything that you saw or heard recently about FASD or drinking alcohol during pregnancy made you think about the following:

**(Repeat feeder question before each option if necessary)**

	Yes	A bit	No	Don't want to say
Men or a partner should support their women not to drink alcohol while pregnant	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Men or a partner should support pregnant women by not drinking alcohol around them	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Everyone should help pregnant women to not drink alcohol	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Women who are wanting to get pregnant shouldn't drink alcohol before they are pregnant	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Q9.8 The next six questions are all similar. After seeing or hearing anything recently about FASD or drinking alcohol during pregnancy, we want to know if you will do these things more often, less often or about the same as before:

**(Not applicable options are available for questions only for women, or for people who don't drink alcohol. Repeat feeder question where necessary)**

	More often	About the same	Less often	Don't want to say	Not applicable
Tell your friends or family who are pregnant that they shouldn't drink alcohol	<input type="radio"/>				
Get some advice from the doctor or other health worker about drinking alcohol	<input type="radio"/>				
Not drink alcohol if you (or your partner) get pregnant	<input type="radio"/>				
(Only for women) Ask your partner not to drink alcohol and support me while I am pregnant	<input type="radio"/>				
(Only for women) Not drink alcohol if you are trying to get pregnant	<input type="radio"/>				
Talk to your partner about how much alcohol the two of you drink generally	<input type="radio"/>				

Q7.1 Thanks for answering those questions. We have a few more questions that we would like to ask you about yourself before we get to the last section of the survey. These questions are all optional and you don't have to answer any that you don't like.

Q7.2 How many children do you have? **(Record NR for No Response)**

Q7.3 How old is your youngest child? **(Record NR for No Response)**

Q7.4 What is the highest level of education you have finished? (**Select one only**)

- Left before completing Year 10
- Year 10
- Year 11 or Year 12
- Diploma/TAFE
- Other training/Karrayili
- Degree
- Postgraduate
- Don't want to say

Q7.6 How would you describe your current living situation? (**Prompted**)

- Work part-time or casual
- Work full-time
- RJCP (Work for the dole)
- Have my own business
- Studying
- Disability Pension
- Home-maker
- Carer
- Other \_\_\_\_\_
- Don't want to say

Q7.7 Do you drink alcohol?

- Yes, I drink alcohol
- I used to drink but I don't now
- No, I never drink
- Don't want to say

Q8.1 Thanks for being so patient. This is the last section and we would like to find out how we can help people learn more about FASD.

Q8.2 Have you heard about the Lililwan Project?

- Yes
- Maybe
- No
- Don't want to say

Answer If Have you heard about the Lililwan Project? **Yes** Is Selected

Q8.3 What do you know about the Lililwan Project? (**Prompted**)

- I only heard about it
- I know the results
- My child was part of the project
- Don't want to say

Q8.4 Have you heard about the Marulu FASD Strategy?

**(If they haven't heard about either tell them about it:**

**The Liliwan Project: About 5 years ago Dr James and a team of health workers checked all of the kids in Fitzroy Valley for FASD. At that time about 1 in 5 kids had some problems because of FASD, but it looks like that drinking in pregnancy has been going down since then)**

**The Marulu FASD Strategy is what we are working on with the goal of making FASD history in the Fitzroy Valley and helping everyone to have happy, healthy kids. That is why we asked all of these questions, to find out what people know and the best ways that we can support women not to drink during pregnancy)**

- Yes
- Maybe
- No
- I don't want to say

Q8.5 Would you like to help with passing on FASD messages in your community?

**(If yes, give contact details for Marninwarntikura and the Marulu FASD Unit)**

- Yes
- No
- Don't want to say

Q8.6 Do you feel like you know enough about FASD?

- Yes
- No
- Maybe
- Don't want to say

Q8.7 Would you like more information about FASD?

- Yes
- No
- Don't want to say

Only ask if they haven't done the survey before

Q8.9 Where would you like to get more information about FASD? (**Show flip chart, may choose multiple options**)

	Prompted
Doctor	<input type="checkbox"/>
Nurse	<input type="checkbox"/>
Midwife	<input type="checkbox"/>
Hospital	<input type="checkbox"/>
Clinic	<input type="checkbox"/>
Nindilingarri	<input type="checkbox"/>
Marninwarntikura	<input type="checkbox"/>
Baya Gawiy	<input type="checkbox"/>
Other Aboriginal Medical Services	<input type="checkbox"/>
Alcohol and Drug services	<input type="checkbox"/>
Other health services	<input type="checkbox"/>
Baby group/class	<input type="checkbox"/>
School	<input type="checkbox"/>
Church	<input type="checkbox"/>
Television	<input type="checkbox"/>
Radio	<input type="checkbox"/>
Internet	<input type="checkbox"/>
Email	<input type="checkbox"/>
Social Media (Facebook etc.)	<input type="checkbox"/>
Written (Poster, Pamphlet, Newspaper, Book)	<input type="checkbox"/>
Mobile Phone	<input type="checkbox"/>
Warning labels on alcohol bottles or glasses	<input type="checkbox"/>
Community Events/Festivals/Seminars	<input type="checkbox"/>
Other	<input type="checkbox"/>
Don't want to say	<input type="checkbox"/>

Q8.10 Were there any problems with this interview? How do you think we could make it better

## Supplementary Appendix: Flip Charts

### Question 2.2

How often do you do the following?

Watch T.V		<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Listen to the radio		<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Make mobile phone calls		<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Send messages on your mobile		<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Use bluetooth on your mobile		<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Use the internet		<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
		I don't	One or two days a week	3 to 6 days a week	Every day

### Question 2.4

## Where do you get information about your health?

The infographic displays 28 icons representing different sources of health information, arranged in four rows. Each icon is accompanied by a label and, where applicable, a brief description.

- Family and Social:** Female family (Mother, grandmother, aunts or sisters), Male family (Father, grandfather, uncles or brothers), Partner (Husband, wife), Other family, Workmate, Elders, Baby group/class, School, Church.
- Health Professionals:** Doctor, Nurse, Midwife, Nindilingarri (Indigenous Health Workers logo), Baya Gawiy (Indigenous Health Workers logo), Marninwarntikura (Indigenous Health Workers logo), Other Aboriginal Medical Service, Alcohol and Drug Services, Other health services.
- Media and Technology:** Television, Radio, Internet, Email, Social Media (Facebook etc.), Written (Poster, Pamphlet, Newspaper, Book, Sign), Mobile Phone.
- Community:** Community events/festivals/seminars, Other.

Question 2.5

## Where do you get information or advice about pregnancy or giving birth?



### Question 4.7

## Where did you hear about FASD?



Female family  
(Mother, grandmother,  
aunties or sisters)



Male family  
(Father, grandfather,  
uncles or brothers)



Partner  
(Husband, wife)



Other family



Workmate



Elders



Baby group/  
class



School



Church



Doctor



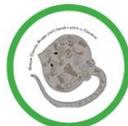
Nurse



Midwife



Nindilingarri



Baya Gawiy



Marninwarntikura



Other  
Aboriginal  
Medical Service



Alcohol and  
Drug Services



Other health  
services



Television



Radio



Internet



Email



Social Media  
(Facebook etc.)



Written  
(Poster, Pamphlet,  
Newspaper, Book)



Mobile Phone



Warning labels on alcohol  
bottles or glasses



Community events/festivals/  
seminars



Other

### Question 6.5

Where could someone go if they wanted to reduce their drinking during pregnancy?



Other

Question 6.10

If you wanted advice about alcohol and pregnancy, who would you feel comfortable talking to?

The image shows a survey question with two rows of icons. The first row contains nine icons: a female silhouette, a male silhouette, a couple, three people, two people in work clothes, two elderly people, a person with a baby, a bus, and a church. The second row contains nine icons: a doctor, a nurse, a midwife, a circular logo with a hand, a circular logo with a hand, a rectangular logo with a landscape, a green leaf, a crossed-out alcohol bottle, and a first aid kit. Below these are two more options: a 'No' symbol and four dots.

Female family  
(Mother, grandmother, aunts or sisters)

Male family  
(Father, grandfather, uncles or brothers)

Partner  
(Husband, wife)

Other family

Workmate

Elders

Baby group/  
class

School

Church

Doctor

Nurse

Midwife

Nindilingarri

Baya Gawiy

Marninwarntikura

Other  
Aboriginal  
Medical Service

Alcohol and  
Drug Services

Other health  
services

Nobody

Other

### Question 8.9

## Where would you like to get more information about FASD?



Doctor



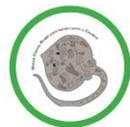
Nurse



Midwife



Nindilingarri



Baya Gawiy

Marninwarntikura



Other  
Aboriginal  
Medical Service



Alcohol and  
Drug Services



Other health  
services



Television



Radio



Internet



Email



Social Media  
(Facebook etc.)



Written  
(Poster, Pamphlet,  
Newspaper, Book)



Mobile Phone



Warning labels on alcohol  
bottles or glasses



Community events/festivals/  
seminars



Other