



# Fetal Alcohol Spectrum Disorder Priority Setting Partnership Report

**FASD Research Australia**  
Centre of Research Excellence



**Consumer and Community  
Health Research Network**

## Acknowledgements



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*The Fetal Alcohol Spectrum Disorder (FASD) Community Priority Setting Partnership for Research Project Team sincerely thank all of the people who contributed to this project: the people who took the time to complete the survey and ranking survey; attended the workshop and shared valuable experiences and insights; and the FASD Consumer Reference Group members who willingly provided their perspectives and experiences to the development and implementation of the project. Your contributions have really made a difference to the project.*

## Ethics approval

RA/4/1/9240 Approved Ethics Application

Approval to conduct this project was provided by The University of Western Australia, in accordance with its ethics review and approval procedures.

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This report will be available on [www.involvingpeopleinresearch.org.au](http://www.involvingpeopleinresearch.org.au)



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# 1 EXECUTIVE SUMMARY

This report describes the Fetal Alcohol Spectrum Disorder (FASD) Community Priority Setting Partnership for Research Project (the Project) and processes for establishing a list of priorities for future research in the FASD Research Australia Centre for Research Excellence.

The aim of the Project was to help focus future research on the questions that matter to people who are interested in alcohol consumption during pregnancy, people with lived experience of FASD and service providers.

The process used in the Project is based on the James Lind Alliance in the UK, an organisation established and funded by the National Institute of Health Research to provide an infrastructure and process to help people agree on the most important research questions, or uncertainties, in their area of interest.

The Project Team was established in March 2017 and consisted of representatives from the FASD Research Australia Centre for Research Excellence and its Consumer Reference Group; Crowe Associates (UK); the Western Australian Consumer and Community Health Research Network; and importantly, community members from around Australia who have lived experience of FASD or an interest about alcohol consumption during pregnancy.

The Western Australian Consumer and Community Health Research Network (the Network) has a key aim of bringing together researchers and the community to make decisions about research priorities, practice and policy. The Network has long associations with similar organisations in the UK who have established priority setting partnerships. The Project Team accessed support and guidance from independent UK based consultant, Sally Crowe from Crowe Associates (UK), who has priority setting expertise. Sally previously collaborated with the Network on a priority setting project in family and domestic violence in 2016.



*The best part was meeting everyone, coming together. Great group of subject matter experts*

**- Consensus Workshop Participant**



## Project objectives

1. Conduct a survey to identify themes and topics of interest for future research considered important by community members who have lived experience of FASD or are interested in alcohol consumption during pregnancy
2. Use information from the survey to develop an initial list of potential research themes
3. Conduct a follow-up survey with community members to rank the themes in order of importance
4. Review the ranked themes and develop a list of research themes for discussion at a consensus workshop
5. Hold a one-day consensus workshop, informed by the above-mentioned list to develop ten community priorities that will be used to inform future research
6. Publicise the results of the Project and its process
7. Take the results to researchers in the FASD Research Australia Centre for Research Excellence to be considered for funding



*FASD is not isolated just to the low socioeconomic drunk or disadvantaged, those with low literacy, the stereotypical alcoholic, or women who suffer abuse*



**- Community Survey Participant**



*All the mixed messages out there about drinking alcohol during pregnancy*



**- Community Survey Participant**

## Top ten research priorities

Although a key objective of the project was to establish a list of top ten FASD research priorities, it was clear as the consensus workshop progressed that the Aboriginal community participants had significantly different context and concerns to consider. The Project Team decided that a list of priorities for the Aboriginal community needed to be captured separately to ensure their priorities were given the appropriate consideration.

## Top ten priorities

1. Changing society views and beliefs about alcohol use during pregnancy
2. Doctors' and/or other health professionals' knowledge about alcohol in pregnancy
3. National public health campaign/education
4. Education about the risks of drinking alcohol during pregnancy in high school
5. More training in the diagnosis of FASD is required
6. Is the workforce appropriately trained to support people with FASD?
7. Understanding why women drink
8. What is the best/most effective support for those with FASD?
9. Non-judgemental pregnancy support
10. What support is there for parents and families living with FASD?

## Top ten priorities - Aboriginal community members

1. National public health campaign/education
2. Education about the risks of drinking alcohol during pregnancy in high school
3. Mums staying healthy during pregnancy
4. Role of immediate, extended family and/or community and being good role models to support women
5. Non-judgemental pregnancy support
6. Intergenerational trauma
7. Understanding why women drink
8. Changing society views and beliefs about alcohol use during pregnancy
9. Doctors' and/or other health professionals' knowledge about alcohol in pregnancy
10. What is the best/most effective support for those with FASD?

The next stage in the process is to seek answers and actions for these top ten priorities and use the results to shape policy and practice. The FASD Research Australia Centre of Research Excellence will review their research strategy and continue to advocate for a national strategic approach to FASD research that includes the views and perspectives of the community.

# PRIORITY SETTING PARTNERSHIP PROJECT TIMELINE





## 2 FASD OVERVIEW

Fetal Alcohol Spectrum Disorder (FASD) is a term for severe impairments of the growth and development of the brain (this may include difficulties with physical activities, language, memory, learning and behaviour) that result from brain damage caused by alcohol exposure before birth<sup>1</sup>. In countries where alcohol is consumed, FASD is a disability that can be prevented and unfortunately results in secondary disabilities including issues with learning, misuse of alcohol or drugs, mental illness, and contact with the justice system.

FASD is an issue that is not confined to a particular community or social group; it is a disorder that crosses financial, racial and education boundaries. Few accurate data on the proportion of people with FASD in Australia are available but it is estimated that FASD affects roughly between 2% and 5% of the population in the United States<sup>2</sup>. As reflected in the international data, Australian studies have also found higher rates of FASD among some Indigenous communities. The potential harm of consuming alcohol during pregnancy to the developing child is a major public health concern in Australia. Approximately 50% of pregnancies in Australia are unplanned which can result in a lack of awareness that the fetus is being exposed to alcohol. Recent studies have shown that up to 59% of women drank alcohol during pregnancy and it is one of the reasons why the prevention of FASD was considered in the scope of research topics for this project<sup>3, 4</sup>. In the past, government responses to the issue of FASD include the Commonwealth Department of Health FASD Action Plan<sup>5</sup>, which comprised five key action areas for 2013-17. In 2017, the Commonwealth Department of Health commissioned a Strategic Review of FASD in Australia, which involved wide consultation with a range of stakeholders in every State and Territory. The resulting National FASD Strategic Action Plan 2018 - 2022 is due for release in early 2018.

Community involvement in FASD research in Australia to date has been to advise or collaborate on specific projects, usually following the funding award. Community and consumer representatives have collaborated on a range of issues including understanding attitudes towards drinking during pregnancy, health professionals' knowledge of the issues and developing a guide for the diagnosis for FASD<sup>6,7</sup>. In 2017, FASD community workshops were held in Darwin and Brisbane seeking input into identifying stakeholders for the research centre and to communicate outcomes from the FASD Australia Research Centre of Research Excellence. The insights provided by community members have been extremely valuable for specific projects and committees, however, to date the broader FASD research agenda in Australia has been heavily influenced by funders, researchers and clinicians. Internationally, Canada has been the most active in seeking community input into research priorities. The activities in Canada have involved parents of children living with FASD, not members of the general population concerned about alcohol use during pregnancy and FASD. In 2016 and 2017, various Canadian organisations consulted with stakeholders, including parents, to identify needs across several brain disorders, from which they established priorities for future research.



# 3

## PROJECT TEAM



**Professor Carol Bower** is the Director for the FASD Research Australia Centre of Research Excellence and a senior epidemiologist and public health physician. This priority setting project is a great opportunity to ensure that the Centre of Research Excellence (which Carol co-leads) undertakes research on topics that the community values highly in the field of alcohol use in pregnancy and Fetal Alcohol Spectrum Disorder.



**Elizabeth Elliot AM** is Professor in Paediatrics and Child Health at the University of Sydney and Consultant Paediatrician at the Children's Hospital at Westmead. She is dedicated to improving health and quality of life for children in Australia and beyond, through education, research, clinical care and advocacy. During 30 years she has established an international reputation for high quality laboratory, clinical and public health research and holds a prestigious senior National Health and Medical Research Council (NHMRC) Practitioner Fellowship.



**Anne McKenzie AM** has worked as a Consumer Advocate at The University of Western Australia's School of Population and Global Health and Telethon Kids Institute since 2004. Anne is now the Head of the WA Health Translation Network's Consumer and Community Health Research Network. In January 2015, Anne was appointed to the Order of Australia for 20 years of service in the area of health consumer advocacy.



**Bridgette Birda** is a community member, providing a community perspective to the development, facilitation and delivery of the project. Bridgette lives in Rockhampton and has 4 biological children who are healthy. She cares for three nieces - 16, 8 & 7. The younger two have FASD and every single day is a challenge. Bridgette advocates for better access to diagnostic facilities.



**Helen Donnelly** works as a registered Psychologist and has over 15 years in the mental health and community services industry in Australia and the UK. Currently working for government and also has experience working with the not for profit and community sector, correctional services, Department of Child Protection and Headspace. Helen brings to the table both clinical expertise and also consumer experience.



**Amy Finlay-Jones** is a clinical and academic psychologist focusing primarily on translational research, child and adolescent mental health, and e-health. She is currently a postdoctoral researcher at Telethon Kids Institute (FASD Research Australia) and has an adjunct academic position at Curtin University (compassion research and paediatric e-health)



**Diane Mayers** is a community member, providing a community perspective to the development, facilitation and delivery of the project. Diane is an Indigenous Alcohol and Other Drugs worker in the Elliott Community in NT. She has seen FASD within her community, but finds it very difficult to help because there is no diagnosis of FASD in the region. Diane does a lot of work in the prevention of FASD and awareness of the effects of using alcohol and drugs.



**Narelle Mullan** is a Program Manager for the FASD Research Australia Centre of Research Excellence.



**Rebecca Nguyen** is a Research Officer for the Consumer and Community Health Research Network. She assists the implementation of consumer and community involvement to support the aims of the Consumer and Community Health Research Network across the WA Health Translation Network's partner organisations.



**Neil Reynolds** is a father to nine children (five biological and four long term foster children) his youngest three foster children ten, nine and six, all have some complex needs. His nine and six year olds are siblings who have FASD. He and his wife have been involved in fostering children with special needs for sixteen years. They have been on the FASD journey for six years now and he volunteers some of his spare time as a FASD Educator with Telethon Kids Institute and NOFASD Australia.



**Paula Sargent** is concerned that the government fails to make sure there is adequate labelling on alcohol bottles about the risks of FASD to the unborn child. She is also concerned that the only advertising over the years was from WA and it aimed towards educating indigenous woman. All women should be aware of FASD regardless of ethnicity. Paula is raising her brother's three children.

## Project contributors



**Belinda Frank** is a Research Officer for the Consumer and Community Health Research Network. She assists the implementation of consumer and community involvement to support the aims of the Consumer and Community Health Research Network. Belinda works with researchers to help support their involvement activities.



**Hayley Harrison** is the Senior Project Officer for the Consumer and Community Health Research Network. She is responsible for developing and implementing resources, systems and processes to support the aims of the Consumer and Community Health Research Network. In this capacity she has been integral to the development of the database and a dedicated website.



**Kim Hudson** is a Consumer Advocate for the Consumer and Community Health Research Network.



**Heather Jones** has a background in education and event management. She has worked in different roles in the non-government health sector and commenced as the Program Manager with the Alcohol Pregnancy & FASD Research Team at Telethon Kids Institute in 2010. Heather is focussed on research translation and developing effective partnerships.



**Tanya Jones** is a Consumer Advocate for the Consumer and Community Health Research Network. She works with the Telethon Kids Institute and Princess Margaret Hospital to develop and expand consumer and community involvement initiatives.



**Ngaire McNeil** is the former Communications Officer for the Consumer and Community Health Research Network. She was responsible for the communications functions including designing publications and building a social media presence.



**Briony Williams** is a Consumer Advocate for the Consumer and Community Health Research Network. She works with the University of Western Australia and Harry Perkins Institute of Medical Research to develop and expand consumer and community involvement initiatives.



# 4

## PROCESS FOR SETTING PRIORITIES

FASD Research Australia Centre for Research Excellence initially contacted the Network to discuss potential collaborations for a priority setting project to understand the views of the community in the areas of prevention, diagnosis and treatment of FASD. A business proposal was drafted by the Network which included the timeline, budget and scope of the priority setting project and was accepted by the FASD Research Australia Centre for Research Excellence.

The Project included four phases to establish the list of top ten priorities and are described in detail below:

1. Community survey
2. Theming
3. Ranking survey
4. The consensus workshop

### Community survey

An online survey was developed by the project team that consisted of four open-ended questions about concerns or information gaps relating to alcohol consumption during pregnancy and the diagnosis and treatment of FASD (questions listed below). This was followed by a short demographic section (Appendix A).

The survey asked participants to suggest questions that they would like to see answered by research:

1. What questions or concerns do you have about the consumption of alcohol during pregnancy?  
E.g. How can we encourage a pregnant woman's family and friends to be more supportive? What can we do to raise awareness about young women binge drinking/unplanned pregnancy?
2. What questions do you have about the diagnosis of FASD?  
E.g. How can we get more doctors trained in diagnosing FASD?
3. What questions do you have about the treatment for FASD?  
E.g. Why don't teachers in Australia know more about FASD?
4. Do you have any other comments (about anything else regarding FASD)?

The survey was distributed online to:

- Professional support networks of the FASD Research Australia Centre for Research Excellence
- The Consumer and Community Health Research Network's Involvement Network
- Professional and community contacts of the FASD Research Australia Centre for Research Excellence's Community Reference Group
- Professional and community contacts of the Project Team
- FASD service providers

## Theming

Two staff members from the FASD Research Australia Centre for Research Excellence, who specialise in FASD research, worked together to analyse and group the participant survey responses from the open-ended questions into themes. Results from the survey (the participants' responses) were quoted and included as supporting sentences (or questions) with each theme. These are listed as dot points beneath each theme. The Network staff then reviewed these themes and provided modifications. The list of themes was then circulated for review to the entire Project Team with no further changes being made.

## Ranking survey

The list of themes were developed into a follow-up online ranking survey (Appendix B). Participants were asked to read the themes developed from the online survey and rank them in order of importance. The ranking survey was emailed to all community members who took part in the initial survey, as well as redistributing to the initial groups who took part in the 'Community Survey' phase (listed above). Community members who were invited to take part were not required to have completed the initial survey. The ranking survey also allowed community members who were unable to attend the consensus workshop have say about their priorities for research.

## Consensus workshop

The Project used an abridged version of the James Lind Alliance priority setting partnership consensus workshop.

An essential step in preparation for the consensus workshop was to arrange a pre-workshop briefing with all project team members to discuss the roles of table facilitators, researchers and support staff. A Facilitation Pack (Appendix C) was developed to support facilitators and included important information about how to assist with facilitating each phase of the consensus workshop.

Participants who completed either the initial community or ranking survey were invited to register their interest in taking part in the consensus workshop. They were followed up via email after the ranking survey, with an invitation to register their attendance to the consensus workshop. The consensus workshop invitation was also circulated to the wider community and those interested were not required to complete either of the surveys.

The aim was to have approximately 30 community members who:

- had an interest in alcohol consumption during pregnancy;
- have lived experience of FASD, support someone who has FASD;
- were staff members of a service provider.

The ranked themes were presented at the consensus workshop for participants to discuss and prioritise into the top ten themes most important to inform future research.

The consensus workshop was conducted in four phases aligned with an abridged version of the James Lind Alliance workshop process, where literature suggests that a nominal group meeting should be structured as sequential steps of consensus building . These phases are described in detail below, with results from each phase detailed in 'The Consensus Workshop Results' section of the report.

A facilitation technique called 'Parking Post-Its', commonly used by the Network, was applied throughout the workshop to address any topics raised and discussed by workshop participants that were not directly related to the FASD themes. These topics were written on a Post-It note by the table facilitator and put up on an A3-sized poster, labelled 'Parking', and allowed facilitators to redirect discussion back to the themes. The 'Parking' topics are listed in the 'Out of scope comments' section of this report.

### **Workshop phase 1 - Small group discussion: Review and discussion of themes**

Participants were encouraged to discuss all 22 themes and contribute the views they felt most and least strongly about. Table facilitators made a positive (+) or negative (-) note next to each theme in order to later determine an order in which to list the small group's priority of themes. Each facilitator used various facilitation skills for their group to establish rapport with members and to effectively manage interactions within the group discussions. Any themes discussed, that did not fit into any of the 22 themes were noted by the table facilitator and discussed with the entire group in Phase 2.

### **Workshop phase 2 – Whole group discussion: Sharing feedback from small groups**

Table facilitators summarised key points discussed and reviewed by their table members and shared this back to the whole group. Much of the discussions from each table were based around whether specific themes should be combined, or whether a new theme(s) should be established. Members who felt strongly about combining or establishing a new theme were invited to discuss and provide their reasoning to the whole group. This was then followed by a whole group vote to decide the outcome.

### **Workshop phase 3 – Small group discussion: Priority Setting**

In this phase, table facilitators were tasked to achieve a prioritised list of themes from their tables. In each facilitator pack, themes were pre-printed on an A4 card (one theme for each card) with spare cards used for the new/combined themes resulting from the previous phase. Once tables could establish their prioritised list of themes, table facilitators would use the Score Sheet (Appendix C) to write down the ranked order of the themes. This was

then handed to the lead facilitator to combine all tables and produce a further list to be prioritised one last time in Phase 4.

### **Workshop phase 4 – Whole group discussion: Prioritising and agreeing on final list**

Three of the four group rankings were combined to achieve an overall rank order for the final list themes to be discussed by the whole group. As the Aboriginal participants had significantly different issues, it was decided the this group's ranking needed to be captured separately to ensure their priorities were given the appropriate consideration. The theme cards were then displayed on the floor (with the Aboriginal priorities displayed alongside) in rank order and the whole group were invited to reflect on these shared priorities.

- The ranking was discussed by the entire group, with the aim of agreeing on the top ten by the end of the discussion session
- The workshop facilitator chaired the discussion to ensure no individual participant dominated the decision-making. If consensus could not be reached by discussion, decisions were put to a vote.

There was a lot of open discussion where participants were actively engaged and each person was given the opportunity to contribute. There was a voting process on some of the themes as some participants felt there was an overlap that could be included within a priority that had already been captured.



*I am concerned of the lack of education for young women regarding the risks of FASD*

**- Community Survey Participant**



*[This] was the first time I had been involved with one of these workshops. An interesting experience!*

**- Consensus Workshop Participant**





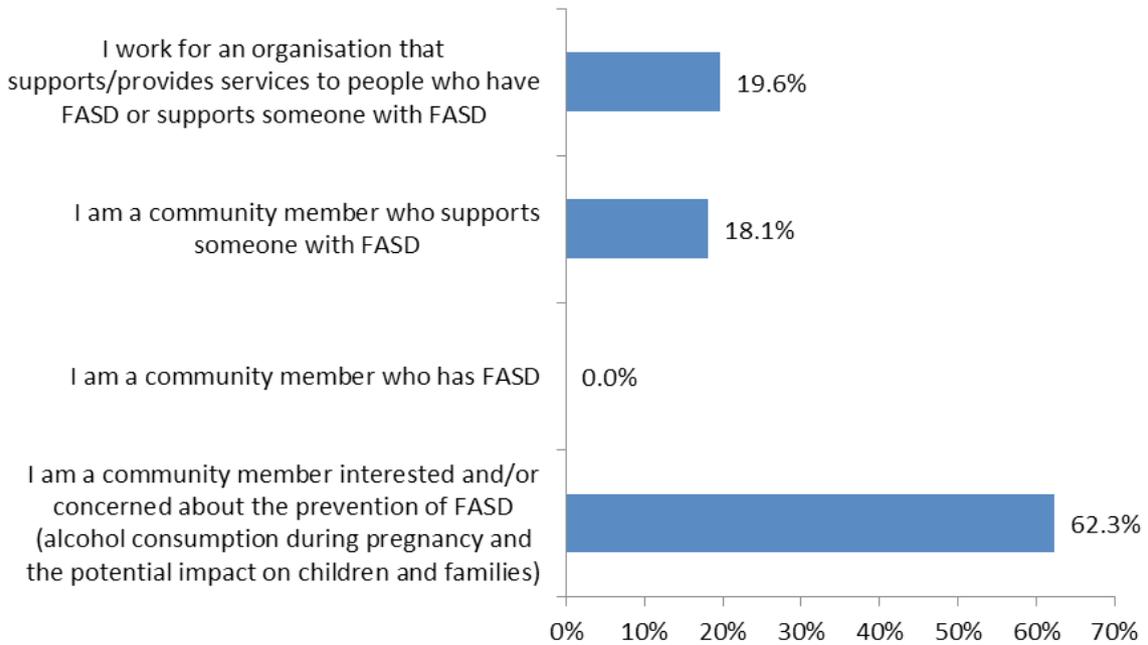
# 5

## RESULTS

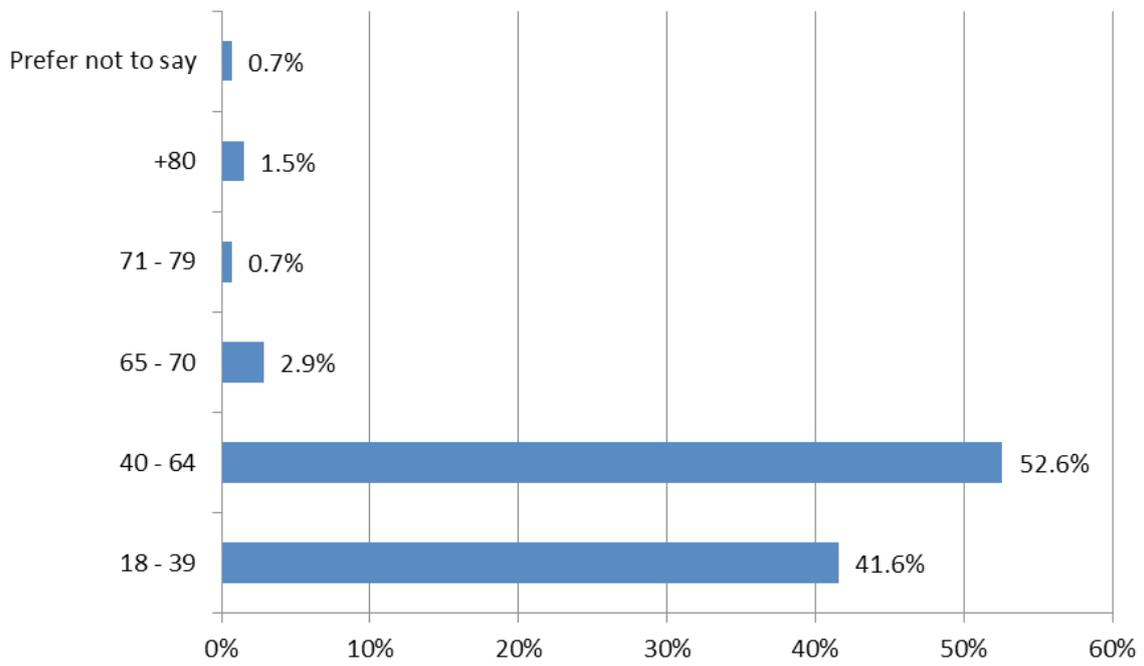
### Community survey

The survey was circulated for approximately four weeks in October 2017 and a total of 146 responses were received. The demographic characteristics of survey respondents are displayed in the following figures:

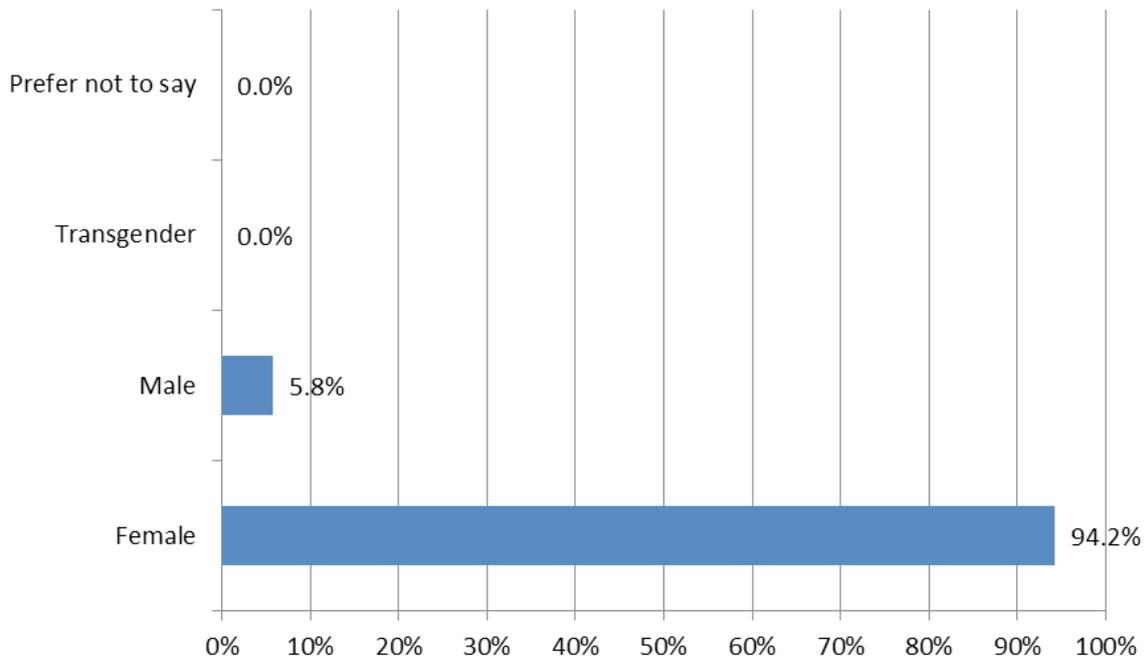
**Figure 1: Type of respondents**



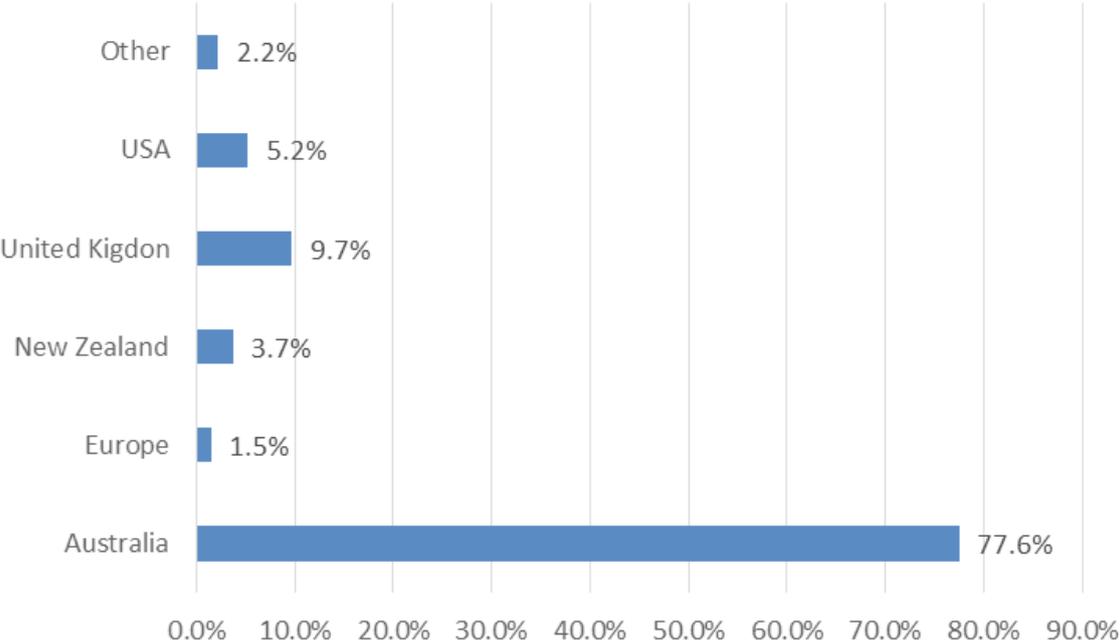
**Figure 2: Age of respondents**



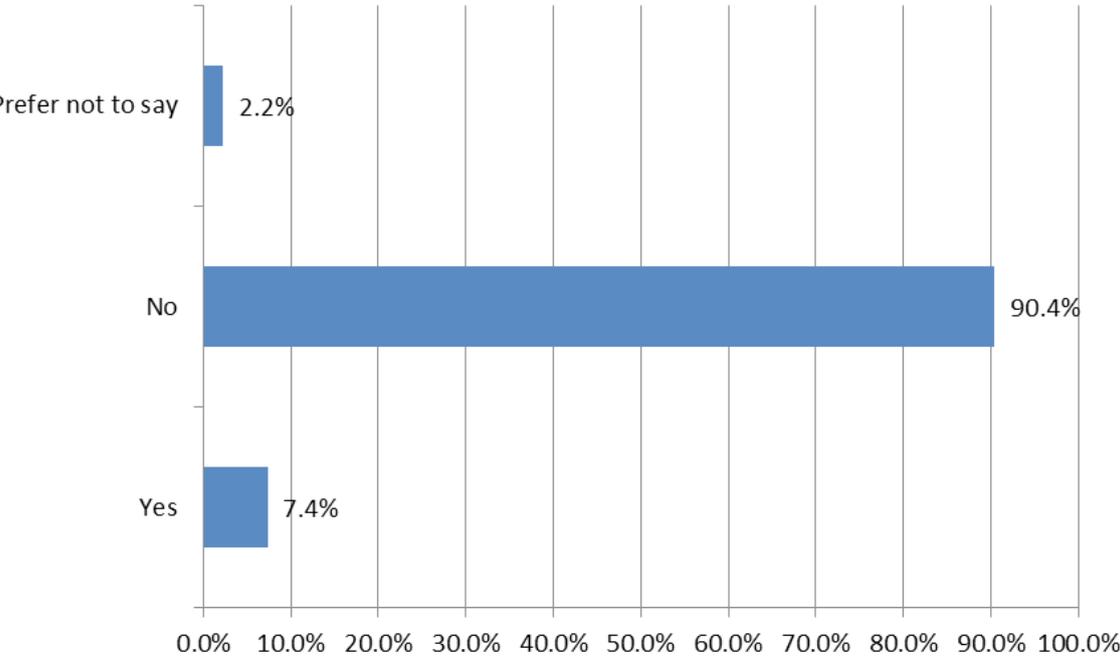
**Figure 3: Gender of respondents**



**Figure 4: Country of birth**



**Figure 5: Aboriginal and Torres Strait Islander**



## **Themes from survey responses (in alphabetical order)**

The 146 responses were summarised into 29 themes. Each theme had a leading question/ statement followed by one or more dot points (listed underneath) taken directly from survey responses to further explain the issue.

There were 128 responses to the first question about Prevention, 123 responses to the second question about Diagnosis and Treatment and 103 responses to the final question asking 'Any other comments about FASD?'

### **Are there certain periods within pregnancy that drinking alcohol causes higher risk of FASD?**

- At what stage does damage from consuming alcohol in pregnancy begin? How much is enough to do damage?

### **Are there any drug therapies for FASD?**

- Are pharmacological interventions possible?

### **Are there any tests to screen for FASD?**

- Assessment tools, screening, biomarkers, tests
- Can anything be done in schools to test for or identify FASD?
- Can FASD be diagnosed by using a brain scan?

### **Changing society views and beliefs about alcohol use during pregnancy:**

- Some people believe that drinking alcohol during pregnancy is ok.
- Why do women continue to drink?
- There needs to be more community awareness and prevention messaging; how can clear messages be sent to the community?

### **Comparison of FASD to other conditions such as Attention Deficit Hyperactivity Disorder:**

- Has there been a comparison and use of treatments from other disorders?

### **Doctors and/or other health professional's knowledge about alcohol in pregnancy:**

- Risks of alcohol consumption not promoted enough in health professionals
- Why is there no consensus by the medical field, despite the numbers of people affected by FASD?

### **Education about the risks of drinking alcohol during pregnancy in high school:**

- Some high school teachers do not take alcohol consumption amongst teens seriously
- Is there a program that can be introduced into schools so all students get the information?

### **How can men support women not to drink alcohol during pregnancy?**

- How relevant is men's alcohol use? More focus should also be put on spousal support

### **How is FASD diagnosed and who can diagnose FASD?**

- Who has the knowledge to diagnose FASD?

### **Impact of other factors such as genetics on the diagnosis of FASD?**

- Are there underlying factors with the alcohol use that lead to a higher proportion of children with FASD?

### **Improving access to and financial support for services for FASD:**

- How to improve access to services?
- Diagnosis is complex, do we need more clinics?

### **Is it possible to treat unborn babies for FASD?**

- What treatments are appropriate for what ages?

### **Is the workforce appropriately trained to support people with FASD?**

- FASD may be a contributing factor in the behaviour of kids and not understood by schools, service providers and the community

### **Is there a link between diagnosis & support services for FASD in Australia?**

- Is there a referral pathway to support services? Have we got enough support services to pick up diagnostic referrals?

### **Is there a safe level of alcohol use during pregnancy?**

- Is there a safe amount to drink during pregnancy?
- Can you drink different amounts at different times during the pregnancy?

### **Is there a treatment or cure for FASD?**

- What is the treatment? Can it be cured?

### **More training in the diagnosis of FASD is required:**

- Doctors and other health professional's knowledge, understanding, lack of understanding of diagnosis nationally is an issue

### **Non-judgemental pregnancy support:**

- More support and awareness campaigns targeting pregnant women is required
- How to help women at risk without stigmatising?

### **Pregnancy planning and drinking prior to pregnancy recognition:**

- Unplanned pregnancies are a problem; consumption in the early stages when you do not know you are pregnant is an issue
- What can be done about the risk of drinking prior to pregnancy recognition?

### **Schools need to support students with FASD:**

- Teachers and schools need to support children with FASD
- Is there evidence for which teaching methods work best for kids with FASD?

### **What are signs and symptoms of FASD?**

- How different is it to Attention Deficit Hyperactivity Disorder and Autism Spectrum Disorder?

### **What are the harms caused by drinking alcohol while pregnant?**

- What is the harm to the children? Why can some women drink and not others?

### **What is known about FASD statistics in Australia?**

- How many kids in Australia have FASD? Is there a difference between locations and over time?

### **What is the best/most effective support for those with FASD?**

- Which treatments work best?

### **What is the optimal age for diagnosing FASD?**

- What age should a child be diagnosed?

### **What is the optimal age for intervention & support for FASD?**

- What is the optimal age to start treatment for FASD?
- What is available for young adults?

### **What support is there for parents and families?**

- Is there treatment/support for parents and families of children who have FASD?

### **Why are some medical doctors reluctant to diagnosis FASD?**

- What are the benefits of a diagnosis?
- Is there an issue with parental acceptance of the diagnosis?

## **Ranking survey**

The ranking survey allowed the project team to evaluate what was considered a priority to the community. The aim was to reduce the number of themes from 29 to 20. Overall, 45 community responses were received.

Participants were asked to rank 29 themes in order of preference with one being the most important theme and 29 being the least important theme. The ranked responses from participants were combined to achieve an overall rank order for the themes. As themes 20, 21 and 22 were very close in score, the Project team agreed to present 22 themes to the workshop.

Below is the list of themes in ranked order; the themes ranked the least (highlighted in blue at the bottom of the list) were removed from the list.

- Are there certain periods within pregnancy that drinking alcohol causes higher risk of FASD?
- Changing society views and beliefs about alcohol use during pregnancy

- Doctors and/or other health professional's knowledge about alcohol in pregnancy
- Education about the risks of drinking alcohol during pregnancy in high school
- How can men support women not to drink alcohol during pregnancy?
- Is there a safe level of alcohol use during pregnancy?
- Non-judgemental pregnancy support
- Pregnancy planning and drinking prior to pregnancy recognition
- What are the harms caused by drinking alcohol while pregnant?
- What effects does the father's alcohol consumption have on the pregnancy?
- Are there any tests to screen for FASD?
- How is FASD diagnosed and who can diagnose FASD?
- Impact of other factors such as genetics on the diagnosis of FASD?
- Improving access to and financial support for services for FASD
- Is the workforce appropriately trained to support people with FASD?
- Is there a link between diagnosis and support services for FASD in Australia?
- What is the optimal age for diagnosing FASD?
- More training in the diagnosis of FASD is required
- Schools need to support students with FASD
- What are signs and symptoms of FASD?
- What is the best/most effective support for those with FASD?
- What support is there for parents and families?
- Is it possible to treat unborn babies for FASD?
- What is the optimal age for intervention & support for FASD? What is the optimal age to start treatment for FASD?
- Comparison of FASD to other conditions such as Attention Deficit Hyperactivity Disorder
- Why are some medical doctors reluctant to diagnosis FASD?
- What is known about FASD Statistics in Australia?
- Are there any drug therapies for FASD?
- Is there a treatment or cure for FASD?

## Consensus workshop

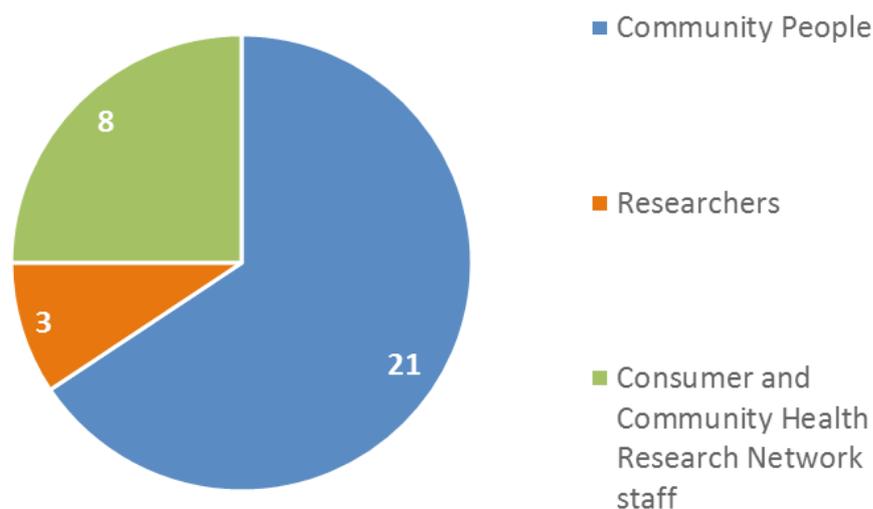
The consensus workshop's primary aim was to discuss the 22 themes produced from the online survey to determine the top ten priorities of community members. This would inform future research undertaken by the FASD Australia Centre for Research Excellence on alcohol prevention during pregnancy and FASD.

The consensus workshop was held on Thursday 19th November 2017 at Mantra on Murray Hotel in Perth, Western Australia.

A total of eleven staff and researchers attended the consensus workshop. This included eight staff from the Network and three researchers, whose role was to support the facilitator and provide any relevant insight into FASD research.

Twenty one community members registered and attended the workshop. To allow an even mix of community members with an interest in alcohol consumption during pregnancy or having lived experience of FASD attendees were designated a table.

**Figure 6: Breakdown of workshop attendees**



A full description of the results from each phase of the consensus workshop is described in the following section. Following an introduction and overview of the survey results, the program for the day included four phases outlined below:

- Phase 1: small group discussion of initial reactions and discussion to themes;
- Phase 2: whole group reflection;
- Phase 3: small group ranking of the themes and then combination of small group ranks to achieve an overall ranking of themes;
- Phase 4: whole group discussion and voting on final ranking including the top ten themes; next steps for the outcomes of the workshop and workshop close.

## Results from each phase

### Workshop phase 1 - Small group discussion: Review and discussion of themes

#### Blue table

The table facilitator opened the discussion by asking if group members had the opportunity to read the presented themes and if there were any points requiring discussion. Some of the participants had not been able to review the themes prior to the workshop. The facilitator prompted discussions and reviews of each theme allowing the participants the opportunity to share their experiences and perspectives. As the discussion progressed, the facilitator allocated positive (+) or negative (–) symbols with key discussion points to each theme to indicate the strength of support shown by group members. Discussion of some themes raised differing opinions from the participants and prompted vigorous dialogue whilst other themes were not even considered. No new themes were suggested; however the group did suggest that two themes (B & E) be merged.

- B. Changing society views and beliefs about alcohol use during pregnancy*
- E. How can men support women not to drink alcohol during pregnancy?*

#### Green table

The table facilitator opened the discussion by asking participants if they had reviewed the themed results prior to the Workshop. As most were not familiar with the themes, the facilitator read them out and invited each participant to comment on any themes which stood out to them. The group discussed each theme as it was raised and some participants shared personal experiences to illustrate the importance of a particular theme. The table facilitator noted when themes were discussed and if a comment was made that seemed to relate to another theme, the table facilitator directed the group's attention to that specific theme. By the end of the discussion, most themes had been discussed and many were considered of equal importance by the group members. However, it was apparent that two themes stood out as being highly important for all members '*B.Changing society views and beliefs about alcohol use during pregnancy*' and '*E.Doctors and/or other health professional's knowledge about alcohol in pregnancy*'. During the discussion, a participant also raised '*alcohol use while breastfeeding*' as being a significant issue that was not



covered by the existing themes. The group agreed that this should be put forward to the wider group for consideration as a potential new theme.

### **Yellow table**

The table facilitator opened the discussion by asking participants if they had read the themed results of the survey. All participants were familiar with the themes and so the facilitator asked each participant, in turn, to discuss the themes that they felt strongly about, either positively or negatively. After each participant shared their thoughts, group discussion followed. Each participant's own experience of the issues being discussed influenced what they felt were the most important themes, however it was clear that one theme, *'E. Changing society views and beliefs about alcohol during pregnancy'*, was highly valued by all participants. This theme was discussed in more detail and the group then agreed that a particular component of this theme, *'a national public health campaign/ education'*, needed to be a theme in its own right.

### **Pink table**

The group on this table consisted of women who identified with being Aboriginal or Torres Strait Islander. Some had not had a chance to take part in the survey or to read the themes. The table facilitator gave the group an opportunity to review the themes and make comments asking those who had read the themes if they had any comments. The discussion quickly highlighted that the issue of FASD was very important to their community, their young women – *"our girls and community"*. The group felt that the themes they read did not cover all areas that were important to them and identified new themes including; *'intergenerational trauma'* and *'understanding the reasons behind why women may drink alcohol'*. Education and the importance of a national health message or campaign was a key priority for them. There were other 'parking' issues raised that are listed in the section under 'Out of Scope Comments'. Other interesting differences raised by this group included discussion about young women in the community not visiting health practitioners whilst pregnant, not giving birth in hospitals or registering the birth of a child. These comments led to a discussion about priorities for this particular table being kept separate from the combined theming of other tables.



## **Workshop phase 2 – Whole group discussion: Sharing feedback from small groups**

From the small group discussions, there were six points raised, suggesting five new themes and amending the wording of one theme.

Table facilitators raised their suggestions to the whole group and stated their case as to why they felt the new theme was important and should be included. The potential new themes discussed included:

- *'Mums staying healthy during pregnancy'*
- *'Alcohol use during breast feeding'*
- *'National public health campaign/education'*
- *'Intergenerational trauma'*
- *'Understanding why women drink'*

A discussion was also held about amending theme ‘E. How can men support women not to drink alcohol during pregnancy?’ by replacing the word, ‘men’, with ‘immediate and extended family’. The lead facilitator then invited other participants to raise any questions or comment on the suggestions. During this phase, it was evident that the Aboriginal community participants had a different perspective of the suggested new themes. The unique differences in knowledge and cultural experiences of the Aboriginal community compared to non-Aboriginal participants was acknowledged and it was agreed there would be a separate list of priorities for Aboriginal participants. For the remaining themes where there was limited difference between the Aboriginal and non-Aboriginal perspectives, it was agreed that a group vote would take place to decide the outcomes. Similarly, a vote would also take place to determine whether the wording for theme E should be amended.

The outcomes were as follows:

- ‘Mums staying healthy during pregnancy’ – whole-group consensus to accept this as a new theme. This theme now became theme ‘W’
- ‘Alcohol use during breast feeding’ – consensus, with one objection. This theme now become theme ‘X’
- ‘National public health campaign/education’ – whole-group consensus. This theme now became theme ‘Y’
- There was an agreement from the whole group that the two potential new themes ‘Intergenerational trauma’ and ‘Understanding why women drink’ should definitely be added. However there was a discussion as to whether they should be combined as one new theme or two separate themes. It was agreed with a vote of 18 in favour of keeping them separate, and so theme ‘Intergenerational trauma became theme ‘Z’ and ‘Understanding why women drink’ became theme ‘AA’
- Theme ‘E’ was renamed to ‘How can immediate and extended family support women not to drink alcohol during pregnancy?’ – whole-group consensus

At the completion of Phase 2, there were now a total of 27 themes to be discussed and prioritised in individual groups for the next phase.

### Workshop phase 3 – Small group discussion: Priority setting

#### Blue table

The table facilitator placed all themes in survey ranked order from 1-27 around the table and led the group into discussion, moving from least to the most supported themes. In the first stage, the group quickly found consensus on the least supported themes and these were removed from further discussion. The middle section saw some themes moved into higher rankings and some lower. The themes the group could not reach consensus on were placed in an approximate ranked position and were left and returned to later for final deliberation. The top fifteen themes had the most discussion with the group taking care to ensure each theme was ordered in a way that they felt would make the biggest overall impact. ‘Prevention of FASD’, ‘supporting



*those currently living with FASD* and *'B. Changing society views and beliefs of alcohol use during pregnancy'* were the top themes that received the strongest support from the table. Final consensus was reached with all group members supporting the top ten themes. There were some opposing views on the order of the top ten but the group was comfortable this was not crucial, as the order would change when all the group's results were combined.

### **Green table**

The table facilitator placed the themes around the table with two themes identified as most important at the top – *'B. Changing society views and beliefs about alcohol use during pregnancy'* and *'C. Doctors and/or other health professional's knowledge about alcohol in pregnancy'*. This was followed by new themes and themes of equal ranking in the middle, and less important themes and those that hadn't been discussed at the bottom. The table facilitator asked the group to discuss and decide whether each theme belonged in the top ten, in the middle or towards the bottom of the priority list, and in what order. Participants felt that some of the themes were related so these themes remained grouped together at this stage.

The participants then discussed the themes that were still grouped according to the key issues of education, diagnosis, workforce training and support. Everyone agreed that these four key issues needed to be represented in the top ten, so the discussion focused on which themes within these four categories would have the greatest impact on the community, if researched. Themes within each broader category that were deemed less important for creating change were moved outside of the top ten. The group also sought clarification from the research support person about which themes had already been the focus of research. These themes were moved to the bottom of the list. As it was still proving difficult to settle on the top ten themes, each participant was invited to explain their reasoning for which themes should be included in the top ten. In doing so, the group arrived at a final top ten that everyone was comfortable with. The participants then reviewed the ranking of the remaining themes, and after making a few changes, all agreed they were satisfied with the final list of priorities for their table.

### **Yellow table**

During the first discussion, most themes were considered and equally weighted in importance. However, one theme was clearly the most popular - *'Y. A national public health campaign/education'*, and a handful of other themes were not discussed at all. As such, the table facilitator placed the cards on the table in order of most important, equally weighted and not discussed; this formed a starting point for ranking the themes.

Participants quickly agreed that the theme, *'Y. A national public health campaign/education'*, should be ranked first. Discussion followed and the top three themes began to form:

1. *'A national public health campaign/education'*
2. *'Changing society views and beliefs about alcohol use during pregnancy'*
3. *'Is there a safe level of alcohol during pregnancy?'*



Participants then started to group themes into 'education', 'diagnosis' and 'support'. Most of the group agreed that this was the correct order in which to rank the themes, however one participant was not happy for 'support' to be ranked at the bottom. The table facilitator suggested using a voting system to decide the rank of the themes. All participants agreed and were given five Post-Its. One Post-It represented one vote and participants were allowed to give only one vote per theme. For themes with tied votes, discussion followed and the group achieved consensus on the order before moving on. The top ten themes were agreed upon. This process was continued a second time, and the next thirteen themes were ranked. The final four themes were discussed amongst the group and a consensus of the order was achieved. Lastly, the facilitator asked participants to review the ranking of the themes and ensure they were happy with it, which all participants were.

### **Pink table**

The theme cards were ordered with the most the discussed themes at the top and the least discussed themes towards the bottom. At this stage, two members of the group had left the workshop, however they had provided their suggestions and priorities to the table facilitator before leaving so their opinions were taken into account. At first the group wanted to order their theme cards in a manner that progressed through the life stages of FASD, for example; prevention, education, pregnant mother, the child, care and treatment of child, services, education and workforce for child. This was logical to the group as it followed a specific order. The table facilitator reminded the group that the top ten theme cards would be the priority and ordering it this way would mean all their priorities would be focused on community awareness and health promotion themes. The group then looked at each life stage grouping they had created and considered what theme was the most important to them. The group selected the themes they felt covered enough of the life stage grouping. The key message from this group was that education was important to the wider community.



### **Workshop phase 4 – Whole group discussion: Prioritising and agreeing on final list**

Three of the four group rankings were combined to achieve an overall rank order for the final list themes to be discussed as a whole group. As the Aboriginal participants had significantly different issues, it was decided the fourth group's ranking needed to be captured separately to ensure their priorities were given the appropriate consideration. The theme cards were then displayed on the floor with the Aboriginal priorities displayed alongside in rank order and the whole group were invited to reflect on these shared priorities.

- The ranking was discussed by the entire group, with the aim of agreeing on the top ten by the end of the discussion session
- The workshop facilitator chaired the discussion to ensure no individual participant dominated the decision-making. If consensus could not be reached by discussion, decisions were put to a vote.

There was a lot of open discussion where participants were actively engaged and each person was given the opportunity to contribute. There was a voting process on certain themes as some participants felt there was an overlap with a theme that had already been captured.

Discussion was held around four themes currently listed in the top ten being very similar, all relating to 'support of FASD':

- O - Is the workforce appropriately trained to support people with FASD?*
- S - Schools need to support students with FASD*
- U - What is the best/most effective support for those with FASD?*
- V - What support is there for parents and families?*

It was suggested that one of the four themes be replaced by theme 'AA – Understanding why women drink' which was currently ranked outside of the top ten. In order to reach consensus, a group vote was held to see if everyone agreed that theme AA should be listed in the top ten. As Aboriginal members had their own prioritised list, they decided that it would not be fair to be counted in the group vote. This meant that 15 members were now able to vote and resulted in 8 votes in favour of adding theme AA to the top ten. The next step was to decide which of the four themes (O, S, U or V) was to be replaced by theme AA. It was agreed via 9 votes in favour, that theme S would be captured in theme 'V – what support is there for parents' and so theme S dropped out of the top ten and was replaced with theme 'AA – Understanding why women drink'.



## Top ten priorities (detailed)

Below is a list of the top ten priorities for future research into FASD, including themed responses from the online survey (the dot points beneath each theme are quotes from the online survey included as supporting sentences (or questions)).

1. Changing society views and beliefs about alcohol use during pregnancy
  - *'Some people believe that drinking alcohol during pregnancy is ok'*
  - *'I'm concerned that 'middle class' Australians are not fully aware of the risks of consuming alcohol during pregnancy and whilst breastfeeding'*
  - *'How do we change the culture of alcohol use in Australian society?'*
  - *'FASD is perceived as an Aboriginal and 'lower class' issue, affecting only the uneducated, what's the prevalence in other communities?'*
  - *'Some pregnant women from high to medium socioeconomic status would drink alcohol even though they know alcohol may harm their unborn child'*
  - *'FASD is not isolated just to the low socioeconomic drunk or disadvantaged, those with low literacy, the stereotypical alcoholic, or women who suffer abuse'*
  - *'The blasé "it's my body" attitude of middle class women'*
2. Doctors' and/or other health professionals' knowledge about alcohol in pregnancy
  - *'Risks of alcohol consumption not promoted enough by health professionals'*
  - *'Why is there no consensus by the medical field, despite the numbers of people affected by FASD?'*
  - *'All the mixed messages out there about drinking alcohol during pregnancy'*
  - *'Doctors give differing advice'*
  - *'Inconsistent advice given. Not enough spoken about the dangers of consuming alcohol whilst pregnant'*
  - *'The generalised confusion over safe levels of consumption during pregnancy and the hesitance of health professionals to speak to pregnant women about abstaining from alcohol during pregnancy'*
  - *'My OB told me that up to seven standard drinks a week would be safe (not all consumed together!) - is that not the case?'*
3. National public health campaign/education
  - New theme
4. Education about the risks of drinking alcohol during pregnancy in high school
  - *'Is there a program that can be introduced into schools so all students get the information?'*
  - *'Is there enough education where it is needed the most and do we even know which groups to target?'*
  - *'I am concerned of the lack of education for young women regarding the risks of FASD'*

- *'I'm concerned that some high school teachers do not take alcohol consumption amongst teens seriously and are not serious about presenting it in health education'*
- *'It would be very helpful to give resources to schools to raise awareness'*

**5.** More training in the diagnosis of FASD is required

- *'Doctors and other health professional's knowledge, understanding, lack of understanding of diagnosis nationally is an issue'*
- *'Can doctors etc. be trained in diagnosing FASD it's not that hard to see'*
- *'All of the paediatricians and doctors I contact with regard to a diagnosis of a child in their location are not familiar with the fact that we have diagnostic guidelines in Australia'*
- *'It is such a complex diagnosis that it is hardly worth the doctor's time to conduct and refer'*

**6.** Is the workforce appropriately trained to support people with FASD?

- *'FASD may be a contributing factor in the behaviour of kids and not understood by schools, service providers and the community'*
- *'Need support and treatment in community and human services settings - child protection, justice, drug and alcohol, mental health where there is likely to be high prevalence of FASD'*
- *'Given the high numbers of people incarcerated with FASD what can be done to educate prison officers and promote proper treatment to further successful rehabilitation of people affected by FASD and linking them and their families to supports on release?'*

**7.** Understanding why women drink

New theme

**8.** What is the best/most effective support for those with FASD?

- *'Which treatments work best?'*
- *'Where can families and professionals go to find high quality evidence on the treatment of FASD?'*
- *'Who is monitoring the children already diagnosed to see what is working and what does not?'*
- *'What is the most effective early intervention?'*
- *'The treatment should involve the whole family and should be done in a supportive environment'*

**9.** Non-judgemental pregnancy support

- *'More support and awareness campaigns targeting pregnant women are required'*
- *'How to help women at risk without stigmatising?'*
- *'How do we avoid stigmatising women and people with FASD in our prevention messaging?'*

- *'More support for women (and men) is needed during this period'*
- *'I am concerned that pregnant women and their partners believe drinking alcohol during pregnancy is ok and cannot cause any harm'*
- *'Many women feel guilty if they drink or deprived if they don't'*

**10.** What support is there for parents and families?

- *'Which treatments work best?'*
- *'Where can families and professionals go to find high quality evidence on the treatment of FASD?'*
- *'Who is monitoring the children already diagnosed to see what is working and what does not?'*
- *'What is the most effective early intervention?'*
- *'The treatment should involve the whole family and should be done in a supportive environment'*

## Top ten priorities - Aboriginal community members

Below is a list of the top ten priorities for future research in FASD for the Aboriginal community, including themed responses from the online survey. It is important to note that seven of the themes prioritised by the Aboriginal community members were also in the above list of community priorities, although prioritised in a different order.

- 1.** National public health campaign/education\*
- 2.** Education about the risks of drinking alcohol during pregnancy in high school\*
- 3.** Mums staying healthy during pregnancy  
New theme
- 4.** Role of immediate, extended family and/or community and being good role models to support women  
New theme
- 5.** Non-judgemental pregnancy support \*
- 6.** Intergenerational trauma  
New theme
- 7.** Understanding why women drink\*
- 8.** Changing society views and beliefs about alcohol use during pregnancy\*

\*Detailed explanation included on pages 28 to 30

- 9. Doctors' and/or other health professionals' knowledge about alcohol in pregnancy\*
- 10. What is the best/most effective support for those with FASD?\*

## Out of scope comments

Due to the nature of the workshop allowing a free discussion about themes for alcohol consumption during pregnancy or FASD, there were many topics and comments that were raised by participants that did not fall under the predetermined themes. These comments were 'parked' (written on Post-Its) for post-workshop consideration.

Why is the message 'no alcohol during pregnancy' 'watered down'? – What would it take to ensure the message is stronger?

Focus of research should move from the Kimberley/Pilbarra to other parts of the state

Dry Communities: - White workers bringing in - drinking over the border

Aboriginal researchers on Aboriginal research projects!

Culture is important – applied to everything

Accountability – want feedback and to know the outcomes

Is the alcohol use during pregnancy from recent trauma? I.e. is the baby a result of rape or domestic violent due to unwanted pregnancy?

## Consensus workshop wrap-up

At the conclusion of the workshop, participants were thanked and informed of 'what next'; how their contribution at the workshop would be collated and used to inform research partners and organisations of future research priorities for alcohol consumption during pregnancy and Fetal Alcohol Spectrum Disorder. Participants were also invited to sign up to keep informed about the progress and outcomes of the Project (Appendix D).

Participants were also asked to complete an evaluation form for the consensus workshop (Appendix E). An evaluation summary from workshop participants can be found in Appendix F.

\*Detailed explanation included on pages 28 to 30



## 6 PROJECT CHALLENGES

The Project Team faced a number of challenges in different stages of the project.

The first challenge was acquiring the target number of participants to complete the survey. The Project Team anticipated at least 100 respondents to complete the survey, but realised that including “FASD” in the title of the project may have indicated that the project’s focus was only on those who had a lived experience of FASD. As the Project was also very interested in prevention, the Project Team also wanted to hear from community members who were interested in alcohol consumption during pregnancy. The online survey and consensus workshop title was then re-named to ‘Alcohol & Pregnancy and FASD Priority Setting’ survey and consensus workshop, respectively. The Project Team also decided to spend additional amounts to promote the Facebook post by ‘boosting’ – this allowed the post to be scheduled at certain times and to target a specific demographic .

Another challenge of running the online survey was the number of respondents who indicated their interest in attending the consensus workshop who resided outside of Western Australia. The project team had to clearly state that those expressing their interest in attending the consensus workshop had to support their own travel and associated costs. The project team acknowledged it would be difficult for other respondents to travel to Western Australia for the workshop and therefore provided an opportunity to rank the survey online. Members of the FASD Research Australia Centre of Research Excellence Community Reference Group living Interstate were invited to attend the workshop and five were able to do so.

Bringing together twenty one community members with unique needs, motivations and priorities to reach a consensus on ten themes to inform future research in FASD was a major challenge of the Project. The Network’s skills and experiences of facilitating projects and workshops, coupled with the knowledge and support of the FASD Research Australia Centre for Research Excellence’s team and their Consumer Advisory Group, was a testament to the success of the Project.



*At the beginning we all had different experiences and opinions, I didn’t think it would ever come together, but it did!*

**- Consensus Workshop Participant**





# 7

## CONCLUSION

The FASD Community Priority Setting Partnership for Research Project provided an opportunity for the Australian community to share their experiences, issues and concerns about FASD and the prevention of alcohol consumption during pregnancy. The consensus priority setting workshop that followed also gave the opportunity for the community to then prioritise the themes to inform future research undertaken by the FASD Research Australia Centre for Research Excellence.

Adapting the James Lind Alliance priority setting process was instrumental in producing two lists of top ten themes from the original 146 survey results. The process enabled collaboration within the Project Team and community members to have a voice in establishing the research priorities, ensuring the research is relevant, focused and informed by the community voice. The community perspective and priorities had not previously been captured in FASD research in Australia, and will result in research that will directly address the communities' needs.

This report will be available to the public, and distributed to research partners and relevant research organisations to ensure that the communities' priorities inform future research into the prevention of alcohol consumption during pregnancy and FASD.



*The generalised confusion over safe levels of consumption during pregnancy and the hesitance of health professionals to speak to pregnant women about abstaining from alcohol during pregnancy*

**- Community Survey Participant**



*The best thing about the workshop was getting more insight into different cultures, priorities & thoughts*

**- Consensus Workshop Participant**





# 8

## APPENDICES

- Appendix A: Survey
- Appendix B: Ranking survey
- Appendix C: Facilitator pack
- Appendix D: Sign-up sheet
- Appendix E: Workshop evaluation
- Appendix F: Workshop evaluation summary

### Fetal Alcohol Spectrum Disorder Priority Setting Partnership Project

#### Online Survey

##### INTRODUCTION

The Fetal Alcohol Spectrum Disorder Research Australia Centre for Research Excellence is a national research program that aims to reduce the effects of alcohol use during pregnancy by: supporting families to reduce or stop alcohol use in pregnancy, increasing awareness of Fetal Alcohol Spectrum Disorder (FASD), finding effective treatment and improving access to services for children with Fetal Alcohol Spectrum Disorder and their families.

When completing this survey you may find it difficult to describe or express your ideas - there is no 'right way' to do this and the project team members will work with whatever you manage to tell us about.

You may also feel potential distress when confronted with memories or stories. If you feel you need to speak with someone please contact:

**Beyond Blue**

Website: <https://www.beyondblue.org.au/>

Phone: 1300 22 4636

Chat: <https://online.beyondblue.org.au/WebModules/General/OutOfHours.aspx>

**NOFASD AUSTRALIA**

Website: <http://www.nofasd.org.au/>

Phone: 1300 306 238

##### PART ONE – ABOUT YOU

We would appreciate it if you could give us some non-identifying information about yourself by answering the questions in the box below. However, if you would prefer not to, then just leave this section blank. Please note that these details will NOT be published in association with your response.

1. Please select from options a, b, c or d that best describe you:
  - a. I am a community member interested and/or concerned about the prevention of FASD (alcohol consumption during pregnancy and the potential impact on children and families)
  - b. I am a community member who has FASD
  - c. I am a community member who supports someone with FASD
  - d. I work for an organisation that supports/provides services to people who have FASD or supports someone with FASD
  
2. What is your age? (Please select the appropriate option)
  - 18-39

## Appendix A: Survey

- 40-64
- 65-70
- 71-79
- 80+
- Prefer not to say

3. What is your gender? (Please select the appropriate option)

- Female
- Male
- Transgender
- Prefer not to say

4. What is your country of birth?

5. Do you identify as Aboriginal or Torres Strait Islander?

- a. Yes
- b. No

6. Do you currently access any organisations that support or provide services for FASD, or have you accessed them in the past? For example this may be a doctor, counsellor etc

- a. Yes
  - i. If yes please list the services that you have accessed:
- b. No
  - i. If you haven't accessed any services can you please tell us why:

7. Have you ever looked up information online or contacted a support service to enquire about alcohol consumption during pregnancy? For example this may be a doctor, counsellor etc

- a. Yes
  - i. If yes please list the services that you have accessed:
- b. No
  - i. If you haven't accessed any services can you please tell us why:

### **PART TWO – QUESTIONS YOU WOULD LIKE TO SEE ANSWERED BY RESEARCH**

It is important that we understand what is important to you, and that our future research is driven by questions and issues that are important to: people living with FASD, people who support others living with FASD; FASD service providers; people who are interested and/or concerned about the prevention of FASD (alcohol consumption during pregnancy).

Please tell us what areas you would like to see researched, or would like an answer to. Please write these in the box below. Your questions or ideas can be in any order of importance.

To help you, here are some examples of questions/issues that people have asked in other surveys **not related to FASD**:

- Loneliness is an issue for older people

## Appendix A: Survey

- Does a drinking lot of water help with losing weight?
- I am worried about my children's education
- It's not easy to access dental services without a healthcare card

### 1. Prevention

What questions or concerns do you have about the consumption of alcohol during pregnancy?

E.g. How can we encourage a pregnant woman's family and friends to be more supportive?

What can we do to raise awareness about young women binge drinking/unplanned pregnancy?

### 2. Diagnosis and Treatment of FASD

a. What questions do you have about the diagnosis of FASD?

E.g. How can we get more doctors trained in diagnosing FASD?

b. What questions do you have about the treatment for FASD?

E.g. Why don't teachers in Australia know more about FASD?

3. Do you have any other comments (about anything else regarding FASD)?

Thank you for completing this survey – we appreciate your support!

### Fetal Alcohol Spectrum Disorder Priority Setting Partnership Project

#### Online Ranking Survey

##### INTRODUCTION

The Fetal Alcohol Spectrum Disorder Research Australia Centre for Research Excellence is a national research program that aims to reduce the effects of alcohol use during pregnancy by: supporting families to reduce or stop alcohol use in pregnancy, increasing awareness of Fetal Alcohol Spectrum Disorder (FASD), finding effective treatment and improving access to services for children with Fetal Alcohol Spectrum Disorder and their families.

Recently we distributed an online survey (which you may have participated in) asking the community about important questions to be researched around the prevention, diagnosis and treatment of FASD.

From the responses we received from this survey, project investigators have themed them into the following topics.

We would like you to order the following list from MOST important to LEAST important (from top to bottom). We will be analysing your top ten topics from all ranking survey responses and will select the top 30 ranked topics to be discussed and prioritised at the consensus workshop.

When completing this survey you may feel potential distress when confronted with memories or stories. If you feel you need to speak with someone please contact:

##### **Beyond Blue**

Website: <https://www.beyondblue.org.au/>

Phone: 1300 22 4636

Chat: <https://online.beyondblue.org.au/WebModules/General/OutOfHours.aspx>

##### **NOFASD AUSTRALIA**

Website: <http://www.nofasd.org.au/>

Phone: 1300 306 238

##### **PART ONE – ABOUT YOU**

We would appreciate it if you could give us some non-identifying information about yourself by answering the questions in the box below. You may have completed this section if you participated in the initial survey, however we would still appreciate if you could please complete this again. If you would prefer not to, then just leave this section blank. Please note that these details will NOT be published in association with your response.

1. Please select from options a, b, c or d that best describe you:

## Appendix B: Ranking survey

- a. I am a community member interested and/or concerned about the prevention of FASD (alcohol consumption during pregnancy and the potential impact on children and families)
- b. I am a community member who has FASD
- c. I am a community member who supports someone with FASD
- d. I work for an organisation that supports/provides services to people who have FASD or supports someone with FASD

2. What is your age? (Please select the appropriate option)

- 18-39
- 40-64
- 65-70
- 71-79
- 80+
- Prefer not to say

3. What is your gender? (Please select the appropriate option)

- Female
- Male
- Transgender
- Prefer not to say

4. What is your country of birth?

5. Do you identify as Aboriginal or Torres Strait Islander?

- a. Yes
- b. No

6. Do you currently access any organisations that support or provide services for FASD, or have you accessed them in the past? For example this may be a doctor, counsellor etc

- a. Yes
  - i. If yes please list the services that you have accessed:
- b. No
  - i. If you haven't accessed any services can you please tell us why:

7. Have you ever looked up information online or contacted a support service to enquire about alcohol consumption during pregnancy? For example this may be a doctor, counsellor etc

- a. Yes
  - i. If yes please list the services that you have accessed:
- b. No
  - i. If you haven't accessed any services can you please tell us why:

## Appendix B: Ranking survey

**Please click and drag the topics so that are listed from top (most important) to bottom (least important).**

**Are there certain periods within pregnancy that drinking alcohol causes higher risk of FASD?**

- At what stage does damage from consuming alcohol in pregnancy begin? How much is enough to do damage?

**Are there any tests to screen for FASD?**

- Assessment tools, screening, biomarkers, tests
- Can anything be done in schools to test for or identify FASD?
- Can FASD be diagnosed by using a brain scan?

**Changing society views and beliefs about alcohol use during pregnancy:**

- Some people believe that drinking alcohol during pregnancy is ok.
- Why do women continue to drink?
- There needs to be more community awareness and prevention messaging; how can clear messages be sent to the community?

**Doctors and/or other health professional's knowledge about alcohol in pregnancy:**

- Risks of alcohol consumption not promoted enough in health professionals
- Why is there no consensus by the medical field, despite the numbers of people affected by FASD?

**Education about the risks of drinking alcohol during pregnancy in high school:**

- Some high school teachers do not take alcohol consumption amongst teens seriously
- Is there a program that can be introduced into schools so all students get the information?

**How can men support women not to drink alcohol during pregnancy?**

- How relevant is men's alcohol use? More focus should also be put on spousal support

**How is FASD diagnosed and who can diagnose FASD?**

- Who has the knowledge to diagnose FASD?

**Impact of other factors such as genetics on the diagnosis of FASD?**

- Are there underlying factors with the alcohol use that lead to a higher proportion of children with FASD?

**Improving access to and financial support for services for FASD:**

- How to improve access to services?
- Diagnosis is complex, do we need more clinics?

**Is the workforce appropriately trained to support people with FASD?**

- FASD may be a contributing factor in the behaviour of kids and not understood by schools, service providers and the community

## Appendix B: Ranking survey

### **Is there a link between diagnosis & support services for FASD in Australia?**

- Is there a referral pathway to support services? Have we got enough support services to pick up diagnostic referrals?

### **Is there a safe level of alcohol use during pregnancy?**

- Is there a safe amount to drink during pregnancy?
- Can you drink different amounts at different times during the pregnancy?

### **More training in the diagnosis of FASD is required:**

- Doctors and other health professional's knowledge, understanding, lack of understanding of diagnosis nationally is an issue

### **Non-judgemental pregnancy support:**

- More support and awareness campaigns targeting pregnant women is required
- How to help women at risk without stigmatising?

### **Pregnancy planning and drinking prior to pregnancy recognition:**

- Unplanned pregnancies are a problem; consumption in the early stages when you do not know you are pregnant is an issue
- What can be done about the risk of drinking prior to pregnancy recognition?

### **Schools need to support students with FASD:**

- Teachers and schools need to support children with FASD
- Is there evidence for which teaching methods work best for kids with FASD?

### **What are signs and symptoms of FASD?**

- How different is it to Attention Deficit Hyperactivity Disorder and Autism Spectrum Disorder?

### **What are the harms caused by drinking alcohol while pregnant?**

- What is the harm to the children? Why can some women drink and not others?

### **What is the best/most effective support for those with FASD?**

- Which treatments work best?

### **What is the optimal age for diagnosing FASD?**

- What age should a child be diagnosed?

### **What support is there for parents and families?**

- Is there treatment/support for parents and families of children who have FASD?

**Thank you for completing this survey – we appreciate your support!**



**FASD Research Australia**  
Centre of Research Excellence

### **Fetal Alcohol Spectrum Disorder (FASD) Community Priority Setting Partnership for Research Workshop**

**Wednesday 8<sup>th</sup> November 2017 at Mantra on Murray  
305 Murray St, Perth**

#### **Facilitator pack**

1	Workshop purpose	Page 2
2	Consensus workshop program	Page 2
3	Facilitator roles and teams	Page 3
4	Process diagram	Page 4
5	Details of process	Page 4
6	Support for members	Page 8
7	Tips for facilitators	Page 8
8	Facilitator skills	Page 9

## Appendix C: Facilitator Pack

### 1. Workshop purpose

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Participants are going to discuss, explore and identify concerns or issues regarding alcohol consumption during pregnancy and fetal alcohol spectrum disorder that are important for future research. We will use the results of a recent survey to help shape the discussion. We will be aiming for 10 - 14 research priorities.

### 2. Consensus workshop program

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09.30	<b>Refreshments, registration</b>
10.00	<b>Welcome – Anne McKenzie</b> <ul style="list-style-type: none"><li>• Acknowledgement of Country</li><li>• Welcome to the workshop</li><li>• Introductions</li></ul>
10.15	<b>Workshop overview and getting to know each other – Anne McKenzie</b>
10.35	<b>FASD presentation – Carol Bower</b> <ul style="list-style-type: none"><li>• Overview of FASD and Alcohol and Pregnancy research</li><li>• Why research priorities matter</li><li>• Survey methods and results</li></ul>
10.45	<b>Small group discussion #1: Review and discussion of themes</b> <ul style="list-style-type: none"><li>• Consider the survey results so far</li><li>• Are there other items to include?</li></ul>
11.45	<b>Refreshment break</b>
12.10	<b>Whole group discussion #1: Sharing feedback from small groups</b> <ul style="list-style-type: none"><li>• General impressions of survey results</li><li>• Agreeing on additional theme(s)</li></ul>
13.00	<b>Lunch break</b>
13.45	<b>Small group discussion #2: Priority setting</b>
14.45	<b>Refreshments</b>
15.15	<b>Whole group discussion #2: Prioritising and agreeing on final list</b>
16.00	<b>Next steps for the project – Carol Bower</b>
16.15	<b>Workshop concludes - thanks from Anne McKenzie</b>

## Appendix C: Facilitator Pack

### 3. Facilitator roles and teams

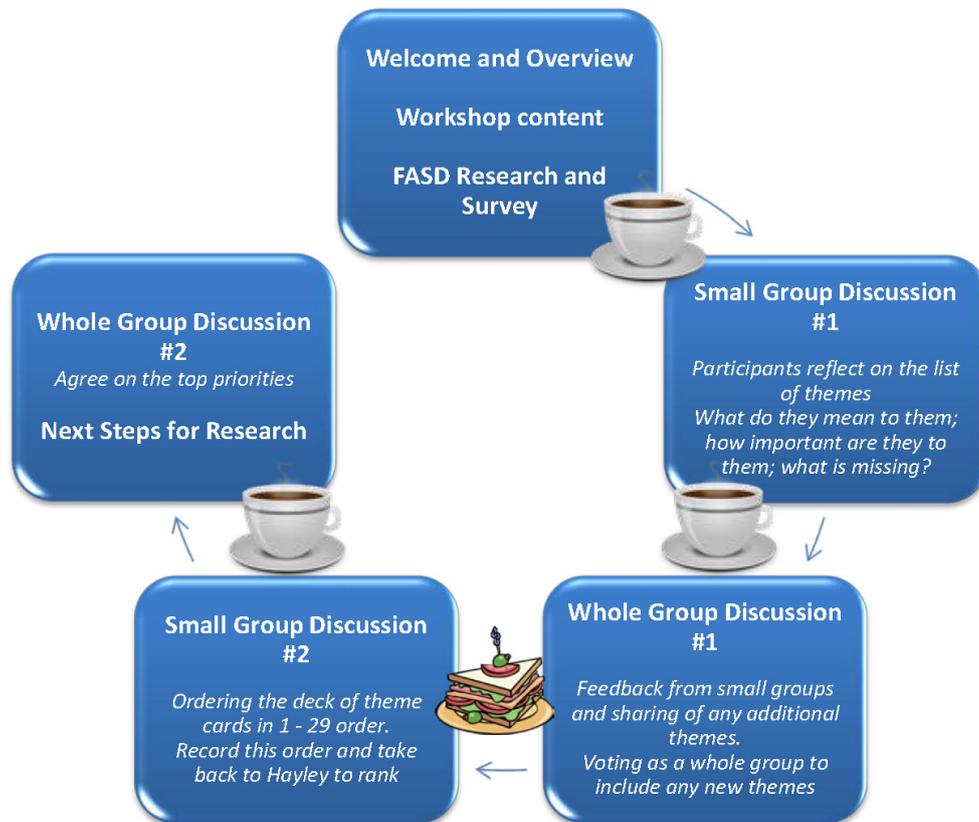
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#### Facilitator roles

Position	Names	Roles and responsibilities
<b>Facilitator</b>	Anne	<ul style="list-style-type: none"> <li>• 'Holding the day' together, large group discussion, prioritization process and small group if needed</li> </ul>
<b>Facilitator Support</b>	Hayley, Bec	<ul style="list-style-type: none"> <li>• Providing support and assistance to the Facilitator and table facilitators</li> <li>• Completing the table rankings (FASD workshop excel master.xls)</li> <li>• Collect catering</li> <li>• Photos</li> </ul>
<b>Small Group Facilitators</b>	Ngaire, Belinda, Ben, Tanya, Briony	<ul style="list-style-type: none"> <li>• Small group discussions</li> <li>• Keeping the group on task (whether it is discussion or ranking the theme cards)</li> <li>• Ensuring maximum participation by the group members</li> <li>• Ensuring a fair and equitable discussion</li> </ul>
<b>Research supporters</b>	Carol, Narelle, Heather  Hayley, Bec and Kim to support	<ul style="list-style-type: none"> <li>• Ensuring that signals of distress from participants are acted on quickly and quietly</li> <li>• Helping to manage discussions when they focus on aspects of research - not allowing the debate to get too technical, clarifying and explaining where needed</li> </ul>
<b>Support roles</b>	Carol Bower	<ul style="list-style-type: none"> <li>• Care and support of participants</li> </ul>

## Appendix C: Facilitator Pack

### 4. Process diagram



### 5. Details of process

#### The facilitator's role is to:

- Ensure that everyone in your group is present (there will be colour coded group lists)
- Ensure that everyone understands the discussion and tasks
- Ensure that the environment is conducive to open dialogue (ensuring that people don't talk over each other, using prompts to encourage further discussion etc.)
- Manage the more dominant group participants (asking them to wait to make their point, purposefully asking group members to contribute in turn etc.)
- Keep the discussion and debate focussed on the research themes or new ideas being proposed
- Clarify and reflect back important statements, concepts and ideas to the group and make a note of these on blank theme cards

People have sometimes been reluctant to openly discuss issues relating to alcohol consumption in pregnancy and FASD because of:

## Appendix C: Facilitator Pack

- A sense of shame or guilt felt about disclosing
- Fear of judgement
- Fear of not being understood
- Lack of perceived support structures or awareness of these

Please be aware of these issues and accommodate speakers as much as you can. Previous focus group work suggests the following guidance might be helpful:

- No right or wrong answers
- Permission to disagree
- We want to hear from all
- We might have to interrupt due to time constraints

### Detailed process

The plan is the same for each group. Groups to be mixed and pre selected beforehand.

#### 10.45 Small group discussion #1

- Ask group members in turn to discuss the themes that they feel strongly about, or they recognise as part of their own experience as a starting point, either positively or negatively
- Please ensure that everyone has said something about the list from their point of view
- Make a note of themes that are **coming up frequently in discussion either negatively or positively**, suggest that you put either a tick/plus or a cross/negative next to themes on your 'Pre-Workshop Themes Information' coloured sheet
- Ask the group to **reflect on any gaps, themes/issues that they think are missing** - try and get as clear a picture as possible and record this on the bottom of your 'Pre-Workshop Themes Information' coloured sheet. Read back the theme/comment to be very sure you have captured these correctly, use the skills of your research partner to help with this – if this new suggestion actually fits with one of the existing themes make a note of the theme letter - keep to one side
- We need to 'keep a lid' on new ideas due to time constraints so suggest that we limit these to 5
- **Table facilitators to take any new themes to Hayley during the refreshment break at 11:45**

## Appendix C: Facilitator Pack

### 12:10 Whole Group Discussion #1: Sharing feedback from small groups

- Feedback from small groups and sharing of any additional themes.
- Voting as a whole group to include any new themes

### 13.45 Small Group Discussion #2: Priority setting

- **During lunch, position the cards on your table to reflect the ranking as decided in the previous group discussion**
- This session focuses on creating a ranked order of themes by group (table) - the most important at the top and least important at the bottom of the list.



- Introduce the new themes, if they exist (Hayley will have written these for each group on coloured card)
- Ensure that all the other theme cards are visible on the table – it will probably look similar to the photo above
- Encourage group members to indicate when they want to talk about a theme by placing their hand on a card. Facilitators will then invite people to speak so discussions are kept on topic. Theme cards cannot be reordered by anyone other than the facilitator and only when the group is in agreement
- When you feel you have consensus on a card placement in the order - tell the group this, and move on
- Your research support staff can help explain any particular issues on the themes that may be directly related to the research - **REMEMBER** we are not asking participants to assess how researchable these themes are but **HOW IMPORTANT THEY ARE**
- Keep track of time, and make sure that you allow enough discussion for each theme (except where there is overwhelming consensus in which case swiftly move on)
- Sometimes groups get stuck on one theme – if this happens, put the card to the side and come back to it later
- If you end up with equal places like the below image, ask the group to vote

## Appendix C: Facilitator Pack



- You are aiming for a long line of cards in rank order, that the group are content with
- **Before you finish this session, write down the order of themes onto the 'FASD Facilitator Score Sheet' and take this to Hayley**



### 15.15 Whole group discussion #2: Prioritising and agreeing on final list

- After ranked themes from each group are collated and re-ranked by Hayley, the theme cards will be placed **on the floor** in the new rank order
- Members are asked to make a circle and sit around the themes on the floor. Anne will facilitate and open the floor to anyone who would like to debate the ordering of any themes
- This process is repeated until there is consensus from all members and a decision is made on the top 10 priorities for research

#### “Parking”

- You may find that members make comments or suggestions about topics that have little or no connection to alcohol consumption during pregnancy or FASD
- Let them know that you will (or they are welcome to) write their comments on a Post-It to be ‘parked’ (a large butchers paper that will be pinned up), which will ensure that this input is recorded and not dismissed.

### 6. Support for Members

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Professor Carol Bower will be available on the day to provide support to any attendee that may appear to be distressed when confronted with memories or stories. If an attendee needs support, then have the research support person on your table advise Anne, Hayley or Bec.

Attendees can also be offered the “Support Services” information flyer to access professional services via telephone or online should they require additional support after the workshop.

### 7. Tips for facilitators

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- If people are struggling to articulate their views - ask them how they feel about themes, if any of them are familiar
- Try and keep the momentum going, and use time constraints to focus people's minds, *“we need to have agreed on our list before the break”*.
- Remind them of the bigger picture. All these themes are important, but taking a pragmatic view, we need to prioritise them. None of them are off the table; it is just about the order....
- If participants want to tell their story – try and respectfully make links to this and the themes – if there is no connection then it is important that you move them on – **use the PARKING paper** provided to record important but not relevant issues
- As you build your order list – remind people what you have achieved e.g. *“so we have now agreed on the top 6 – that is great – let’s move on to the next 6”*
- Good phrases to use in the ranking session are –  
*“From your perspective which research theme would make the biggest change around alcohol consumption during pregnancy/FASD?”*  
*“Which is the more important of these two themes in your opinion?”*  
*“We seem to have stalled on this theme – let’s put it to one side and come back to it in a bit.”*  
*“We have a theme that is thought to be very important by some and not very important by others so the best place for this is in the middle.”*
- Look out for non-verbal disengagement in group members – check in with them at the break to see if there are any issues that can be addressed in the workshop
- We have been advised that some participants will be disassociated from their experience – so that they can talk about their experiences without obvious emotion, others may get emotional...everyone will be different
- You may find that people get very attached to their priorities – remind them that their rank order will be combined with the other three groups results.... so things will change in the final session, but that they have another chance in the final session.

## Appendix C: Facilitator Pack

### 8. Facilitator skills

The skills of a good facilitator ...	The downfalls of a Poor facilitator ...
Being <b>prepared</b> – know the materials and participants	Being unfamiliar with the materials and participants
Being <b>aware</b> of the needs of participants: – Before: e.g. appropriate materials and timetable – During: need to be flexible	Being unable to recognise the needs of participants either before or during the session  Unable to adapt accordingly
Understanding the <b>limits</b> and <b>boundaries</b> of what the group can give	Not knowing when to say ‘no’ in order to stay in control of a situation
<b>Bringing people and ideas together</b> Acknowledging where good ideas are coming from	Being judgmental  Concentrating on those who speak most
<b>Enabling</b> people	Trying to control discussions
<b>Recognising</b> effort and struggle to participate <b>Encouraging</b> input, creating space for discussion and thinking	Being unenthusiastic or dismissive of people’s views  Not allowing time for people to respond to questions or think through issues
Being aware of and using appropriate <b>body language</b>	Using inappropriate body language (e.g. no eye-contact)
Establishing <b>relationships</b> quickly e.g. making an effort to remember participants names	Being unable to establish relationships
<b>Recognising “baggage”</b> and knowing when to deal with it	Diving straight into a program before people are ready to do it
Managing time	Poor time management
Being <b>comfortable</b> and confident with themselves and their role	Being unclear about their role
Being <b>skilled listeners</b>	Not listening and responding to people
<b>Synthesising</b> ideas and dialogue <b>summarising</b> and <b>paraphrasing</b>	Being unable to summarise discussions and pull out main issues

# Appendix D: Sign-up sheet



**FASD Research Australia**  
Centre of Research Excellence

## Would you like to be involved in future research about Fetal Alcohol Spectrum Disorder?

Please add your details below and we will ensure that you are contacted when research is being developed.

Name	Phone Number	Email	Do you have a particular area of interest?



## Appendix E: Workshop Evaluation

8. *Is there anything else you would like to add?*

9. *The best thing about the workshop was:*

10. *The worst thing about the workshop was:*

11. *Do you have any suggestions about how we might improve future workshops?*

- Longer session*
- More time on themes or discussions*
- More pre-information*
- Other (please specify):*

*Thank you for attending and for your valuable feedback.  
Please give your completed evaluation form to your facilitator.*

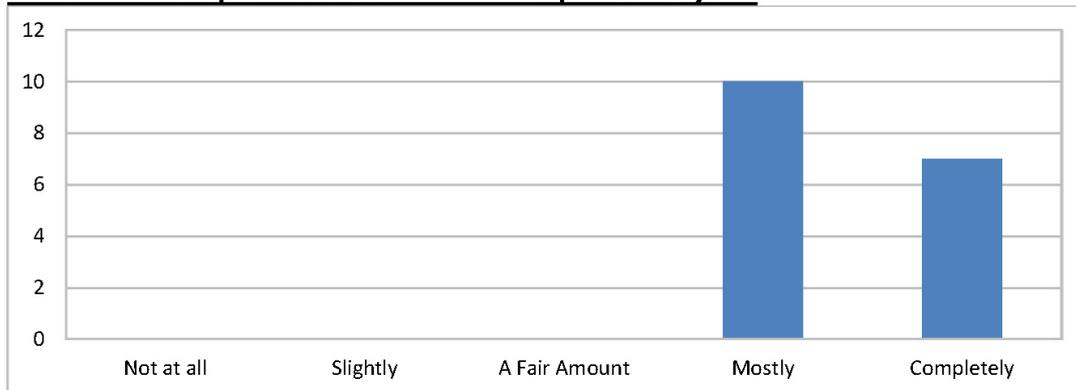


## Appendix E: Workshop Evaluation Summary

### 2. Did the workshop meet your expectations?



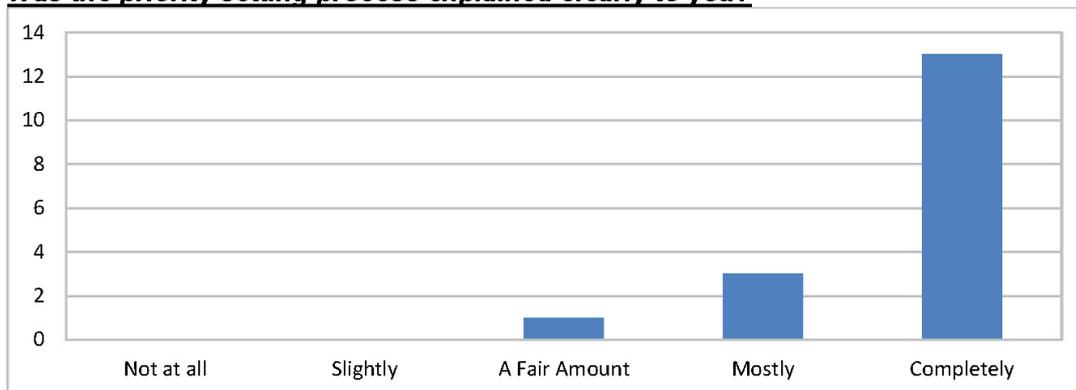
### 3. Did the workshop cover areas that were important to you?



***If "not at all" please specify what additional information could have been included:***

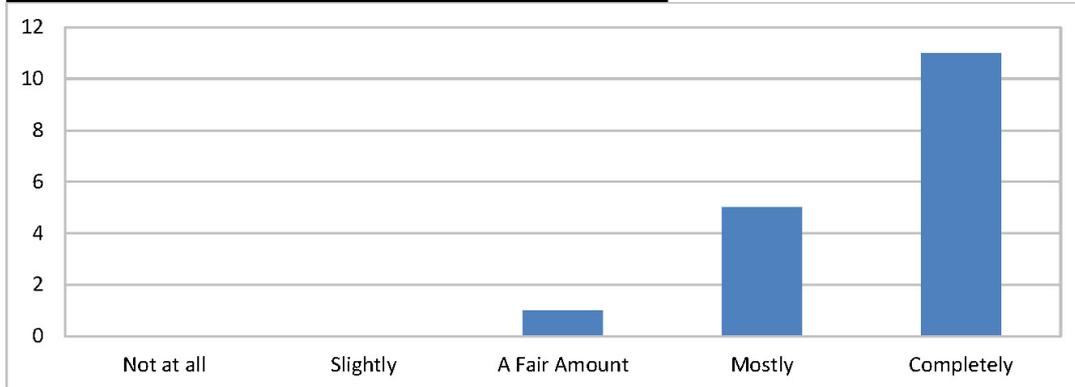
- My perspective was prevention, support for families, support for people living with FASD and research on mainstream prevalence

### 4. Was the priority setting process explained clearly to you?

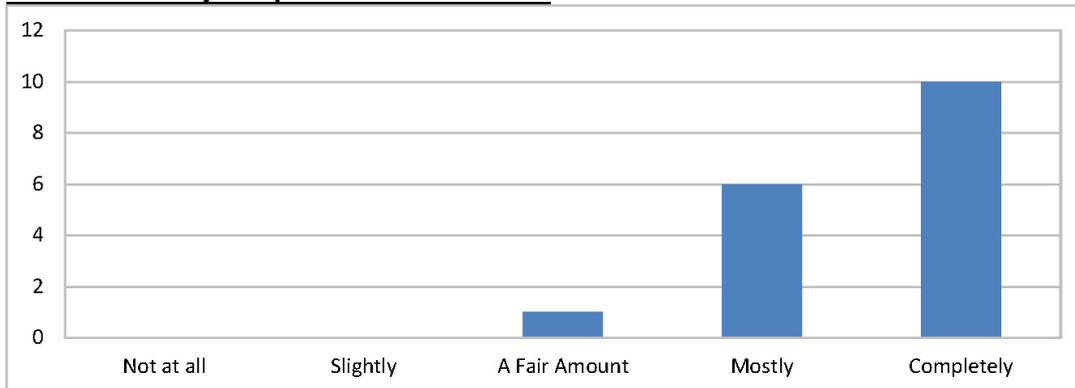


## Appendix E: Workshop Evaluation Summary

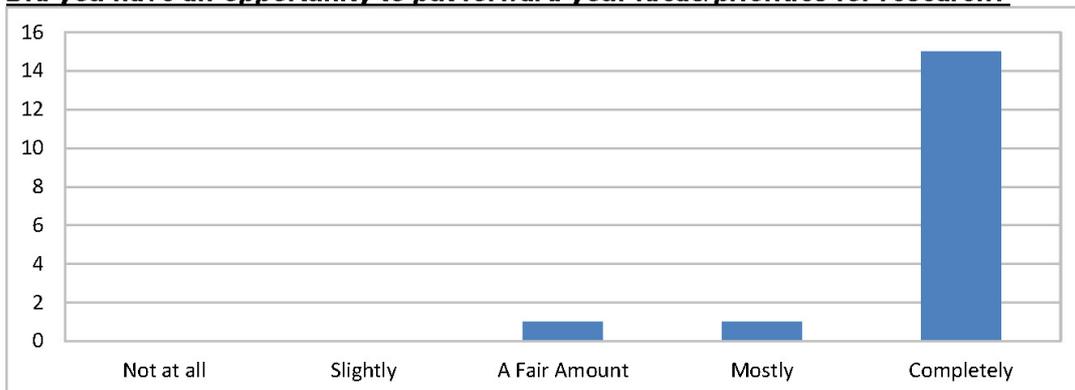
### 5. Did the presentations provide enough information?



### 6. How well were your questions answered?



### 7. Did you have an opportunity to put forward your ideas/priorities for research?



### 8. Is there anything you would like to add?

- Maybe emphasize at what stage things will be included. If I knew something would be included regardless – it didn't require further discussion
- Was the first time I had been involved with one of these workshops. An interesting experience!
- Would like to see an Aboriginal part of the team
- Aboriginal component by Aboriginal woman in the workshop. History of where are people have come from. Parts acts & policies

## Appendix E: Workshop Evaluation Summary

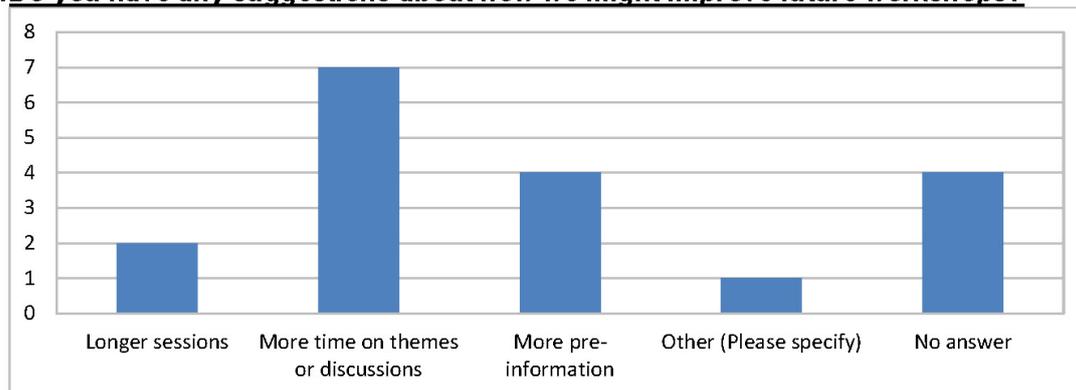
### 9. The **best thing about the workshop was:**

- Learning more about the importance of having a wide range of knowledge in the community about FASD
- Hearing other perspectives
- Getting more insight into different cultures, priorities & thoughts
- Instructions were explained clearly and table facilitators did a great job of organising
- Meeting everyone
- Participating
- Well organised & run to schedule
- Having my voice heard, thank you
- Meeting everyone, coming together. Great group of SME
- Well organised
- Listening to ideas, points of view and discussions
- Everything
- Lots of staff and a very well held group
- Coming together at the end. We were able to compromise

### 10. The **worst thing about the workshop was:**

- Bit too small an area to work
- Lack of time for table discussions
- Too far from home
- Coming to an agreement on the top 10!
- Not enough financial appreciation. Token \$50 for full day is a joke
- Suggestions many themes would have been grouped prior to the workshop as many themes were duplicated – clean explanation of headings/sub points
- All good, loved hearing the different perspectives
- Trying to integrate some of the points into research when the research has already been overseas
- Justifying the Aboriginal component

### 11. **Do you have any suggestions about how we might improve future workshops?**



#### **Comments:**

- **'More pre-information':** Maybe a summary of relevant evidence already published
- **'Longer session':** 2 day, or 1 week long
- **'Other, please specify':** Perhaps people with similar interests, then algorithm probably cost prohibitive



## 9

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