

Australian Collaboration
Fetal Alcohol Spectrum Disorders
Project

Report on the Alcohol and Pregnancy
Community Conversations

Acknowledgements

The Australian Collaboration would like to thank the women who participated in the alcohol and pregnancy community conversations in Perth and Cairns. The willingness of these women to provide realistic, truthful and insightful responses has made a significant contribution to the Fetal Alcohol Spectrum Disorders (FASD) Project and future planning for prevention, education and advocacy in the fetal alcohol spectrum disorders field.

Thanks are also extended to the presenters and table facilitators who were an integral part of the community conversations.

Community participation process for the FASD Project

To ensure that consumers and the community could be actively engaged in this project outside the formal Delphi process, Community Conversations were held in Perth (December 2010) and Cairns (February 2011) using a 'World Café' Process. The world café is a method which makes use of an informal café style for participants to explore an issue by holding discussions in small table groups. These are held in multiple rounds of 20-30 minutes and conclude with a summary of the discussions.

Community Conversation purpose

The purpose of the alcohol and pregnancy community conversation was to provide input to the Steering Group for use when developing the screening and diagnostic instrument. The community voice aimed to engender information from consumers and the community who are not as well informed about FASD as the Steering Group consumer representatives and in a manner that would elicit the most truthful information from women. It was particularly important when the Steering Group was considering questions that maybe asked of women as part of the screening tool. The Community Conversation was an important foundation for meaningful and inclusive consumer and community participation.

Community Conversations Perth and Cairns

Presentations

These presentations provided an overview of recent and current alcohol and pregnancy research and information on fetal alcohol spectrum disorders and others were based on personal insight and experience, which provided compelling stories of raising children with a fetal alcohol spectrum disorder.

Agenda

The agenda was designed to allocate the majority of time to the small group discussions and whole group discussion, keeping presentations to a minimum.

Questions used in the world café process

The questions for the Perth community conversation were developed in consultation with the facilitator, two of the table facilitators, presenters and two health professional members of the FASD Collaboration. The questions were designed to:

- elicit responses on what information women expected their health professional to provide with respect to alcohol use in pregnancy;
- discuss the manner in which the health professional interacts with the woman; and
- elicit responses on the level of information a woman would provide to the health professional about their alcohol use in pregnancy.

Following a review of the evaluation forms from the Perth community conversation, the questions were revised for the Cairns community conversation as some questions appeared to be repetitive.

Statements from community conversation participants

Using the world café process participants were asked to write individual statements on sticky notes and place them onto the group sheet. All statements were transposed (no editing and in no particular order) into a spreadsheet and grouped into themes. The themes were:

- counselling/support
- family/community
- feelings
- general
- health professionals
- health professional training
- how to ask
- information to the public
- information to women
- language
- resources
- schools
- timing

Overwhelmingly women wanted health professionals to provide them with evidence based information that no alcohol during pregnancy is the safest option. Women wanted to know how alcohol could affect the fetus. Women were in agreement that any questions asked by a health

professional with respect to alcohol consumption during pregnancy should form part of a series of questions asked of all women, that is, questions about general health, smoking, diet, lifestyle etc.

There was also consensus for information to be provided to partners and families to help them understand the issues and provide support for the women.

There was unanimous support for a national campaign to raise awareness of the risks of drinking alcohol during pregnancy. Ideally the campaign would extend across all media – television, radio and social media such as YouTube and Twitter. It was important that the campaign include coasters and posters in hotels, bars, restaurants and liquor outlets, including placement behind toilet doors. There was also strong support for the inclusion of information on alcohol and pregnancy in high school health curricula.

Key issues from the community conversations

Key issues were identified from the community conversations held in Perth and Cairns.

- Prevention – national awareness campaign
- Messages in campaign and from health professionals must be consistent
- FASD is not curable – it's for life, but correct diagnosis can help with strategies to assist the child and family
- Instrument needs to provide a guide and referral pathways and must be appropriate for all Australian children and for different ages and throughout Australia (remote, regional, urban)
- Informed consent – parents/guardians/kinship carers should be asked if they want to proceed with screening
- Standard set of questions (diet, smoking, alcohol, lifestyle etc) that are asked by health professionals (GP, obstetrician, midwife, child health nurse) of all women, no individual singled out and reduce the opportunity for judgemental questions
- Education and training for health professionals – all health professionals (not just paediatricians) need education and training on FASD otherwise the instrument will not be used and children will not be screened or diagnosed
- Education for young people in schools

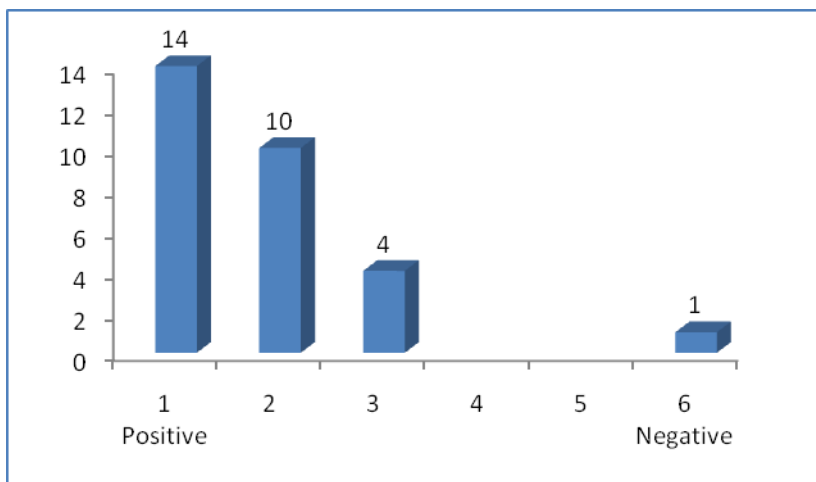
Evaluation

In line with good practice all participants were encouraged to complete an evaluation form. Women were asked to rank their opinion of their experience (one = positive through to 6 = negative)

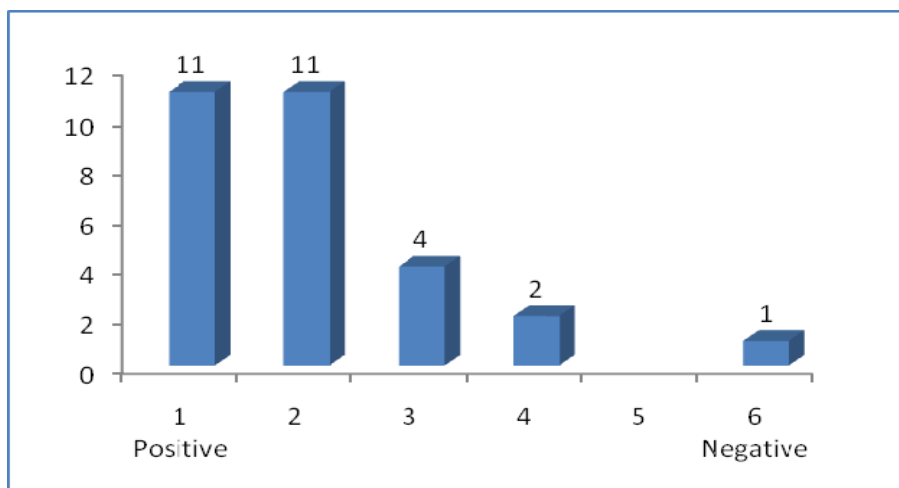
32 people attended the two alcohol & pregnancy community conversations

30 evaluation forms were returned but not all attendees completed all sections

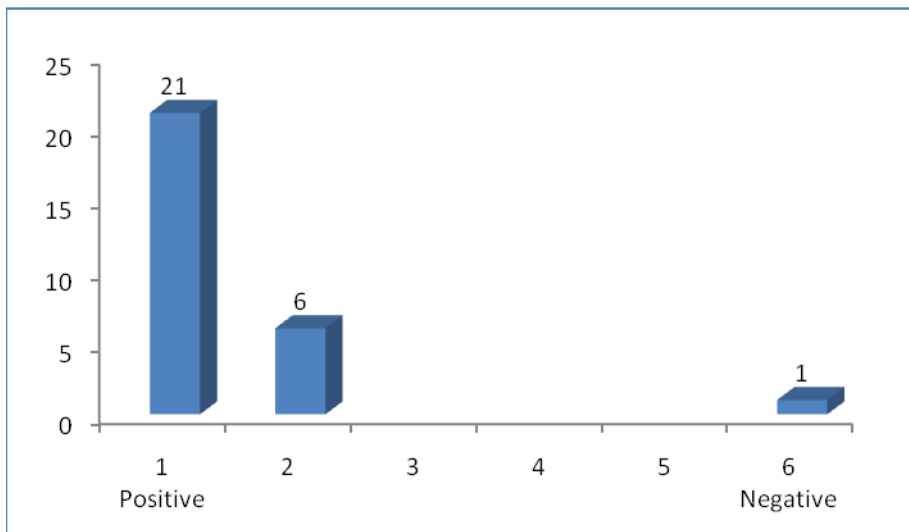
1.1 The 'community conversation' was informative: (N = 29)



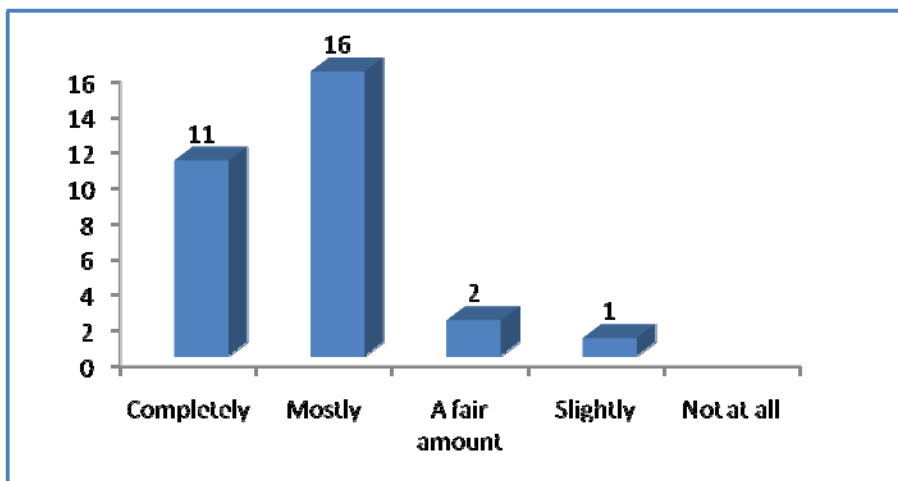
1.2 The 'community conversation' was useful: (N = 29)



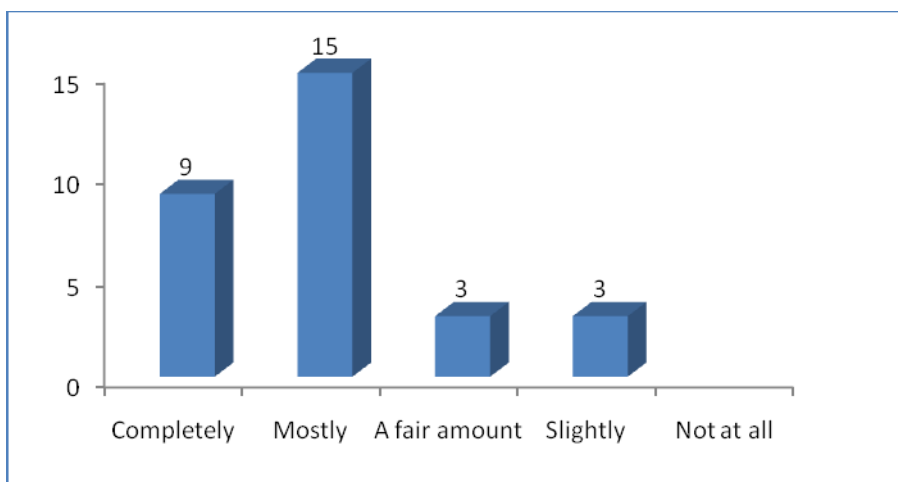
1.3 The 'community conversation' was participative: (N = 28)



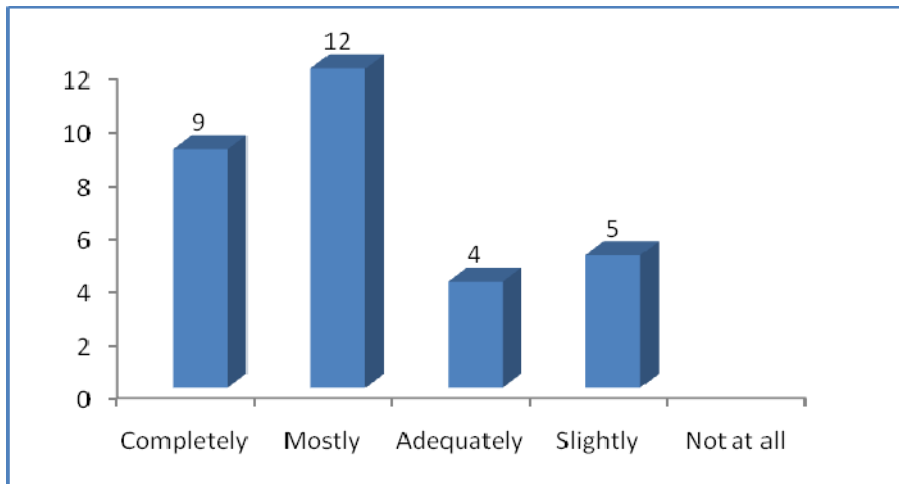
2. Did the 'community conversation' meet your expectations? (N = 30)



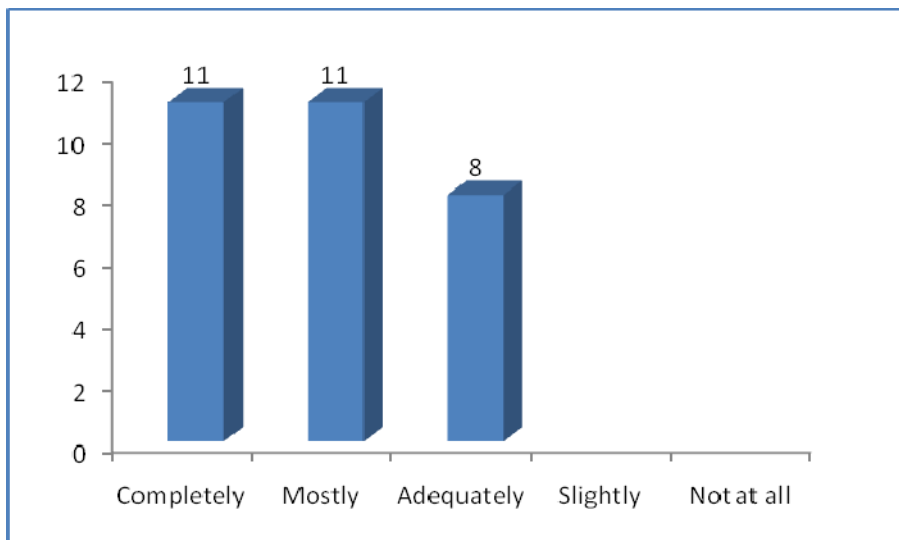
3. Did the 'community conversation' cover most areas that were important to you? (N = 30)



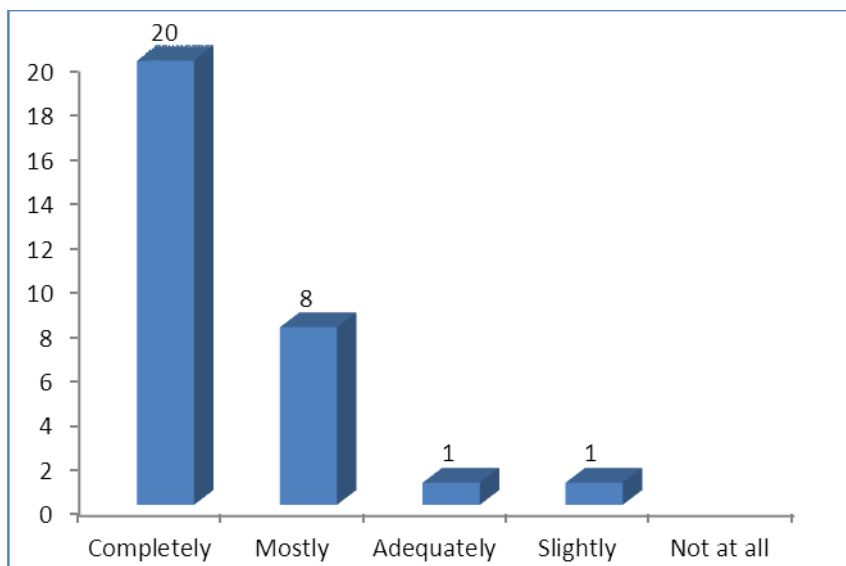
4. Did the presentation on current research projects provide enough information? (N =30)



5. How well were your questions answered? (N = 30)



6. Did you have an opportunity to put forward your ideas/priorities for research? (N = 30)



7. Is there anything else you would like to add?

- Because we can say/ask anything not on the specific global café process questions during lunch
- Thank you for the opportunity
- Felt a more age unified conversation group would have allowed everyone to express their different opinions
- Doctors need to give correct information 'no alcohol is safe' when pregnant
- Focus on developing screening when issue is bigger
- Get into schools
- Too many technical terms & too much information on slides
- As a health professional I would like to hear more about current research and recommendations
- Would have been beneficial to have more information about FASD & issues surrounding diagnosis
- More information about signs/symptoms of FAS as well as behaviours
- Health professionals have a different perspective from community members
- Questions repetitive about health professionals
- Internet networking of FASD would be great to access up to date sharing of information and resources
- A big thank you to Elizabeth Russell – an inspiring story

8. The best thing about the 'community conversation' was:

- Good opportunity to put forward views and was very informative
- Meeting people about FASD research and information sharing
- Opportunity to meet & interact with variety of different people, contribute to research & learn about the problem
- Meeting people who are concerned
- Different views
- Gaining information and opinions on a topic with which I was not familiar
- Learning other ideas
- Interactions with others
- Brainstorming
- Everyone getting their chance to have a say
- Having people interested in what we say

- Being in a group that gets to bounce ideas off each other
- Hearing different opinions
- Interaction, discussion and networking
- Information sharing
- I enjoyed the whole process
- All of it
- Our voices and points of view were heard
- The concept of the 'world café process'. It gave all participants the ability to put their ideas forward

9. The worst thing about the 'community conversation' was:

- Questions repetitive
- More distinct topics or different parts of the question @ different tables
- Too rushed
- Need more groups & more diverse questions
- Not enough people representative of 'pregnant people' or the ones who would have to answer the questions and young people who do drink
- Constantly moving tables
- No time for whole room discussion
- Not enough aboriginal groups or organisations participating
- Long time away from breast-fed baby. Maybe informal crèche – give honorarium towards cost of crèche
- Not interested in feedback summary
- Questions not deep enough
- I didn't see what the problem was – it wouldn't be a problem for me
- Not enough women from Cape York communities were present
- More people could have attended who could have benefited
- Nil
- There was no worst thing
- The lack of other community and health members
- Nothing – all good

10. Do you have any suggestions about how we might improve future 'community conversations'?

- Longer session x 3
- More time on the questions x 2
- More pre-information on the questions x 5
- Different process to the 'world café' 6
- Other (please specify):
 - ✓ Facilitators should move
 - ✓ Email answers so process not so long
 - ✓ Talk over questions before answering and specify what sort of response is wanted
 - ✓ More facilitators & mixed groups
 - ✓ Change nothing
 - ✓ Time for more questions to 'speakers'
 - ✓ Local statistics and concerns
 - ✓ Involvement of other organisations working in FASD people/issues
 - ✓ More advertising
 - ✓ Perhaps more specific groups. I realise a lot were targeted and didn't come
 - ✓ Can't think of a way to improve
 - ✓ Visit Cape communities during the 'off pay' week, in the evening

Conclusion

As set out in the NHMRC *Statement on Consumer and Community Participation in Health and Medical Research*¹ the collaboration of consumers and researchers to draw upon each other's knowledge will build on and strengthen the quality of health and medical research in Australia. As end users of health and medical research, consumers can provide valuable input to decisions about medical research and practices.

The outcomes from the two alcohol and pregnancy community conversations, together with current Australian research and Delphi process outcomes, will be used to inform the Australian Collaboration when developing the screening and diagnostic instrument and associated guidance notes for fetal alcohol spectrum disorders in Australia. This valuable community information supports and extends findings of Peadon² and France³.

Peadon et al⁴ found that women expected their health professional to ask and advise them about alcohol and pregnancy; however Payne et al⁵ concluded that only 45% of health professionals

routinely ask about alcohol use in pregnancy. The France et al survey indicated that some health professionals were making an assumption that women knew to minimise alcohol consumption during pregnancy. These findings are supported by the statements from the women participating in the two community conversations.

The FASD Project will use a Delphi process (questionnaire) to reach a consensus on what should be included in the screening and diagnostic instrument. To develop the statements and questions a systematic review of literature was conducted and a report provided to the Steering Group. The report of outcomes from the community conversations was also provided to the subgroup responsible for developing the Delphi instrument. An example of a statement in the Delphi instrument which arose from the community conversations and the ranking scale is listed below.

Statement from Prenatal Alcohol Exposure Section

4.24 Alcohol exposure should be assessed alongside other lifestyle factors including diet, physical exercise and smoking

Strongly agree	Agree	Neither	Disagree	Strongly disagree
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The Steering Group will hold a two-day workshop to finalise the screening and diagnostic instrument and the Community Conversation Report will be considered alongside the published evidence and outcomes from the Delphi process.

Issues arising from the community conversation specific to the instrument:

- Standard set of questions (diet, smoking, drugs, lifestyle etc) that are asked by health professionals (GP, obstetrician, midwife, maternal/child health nurse) of all women, no individuals or groups singled out
- Questions should be asked in private – not in front of partners or family
- Language should be culturally sensitive and questions should be easy to understand by all women – don't use medical terminology
- Informed consent – parents/guardians/kinship carers should be asked if they want to proceed with screening for FASD
- Instrument needs to provide a guide and referral pathways
- Appropriate for all Australian children (urban, rural and remote) and for different ages

Not all statements from the community conversations were specific to the development of the screening and diagnostic instrument. However these statements are relevant to the topic of alcohol and pregnancy and FASD.

Issues arising from the community conversations that are related to the introduction of the screening and diagnostic instrument and which require action on completion of the FASD Project:

- Health professionals need education and training on FASD and how to speak to women about alcohol and pregnancy
- Education and training not just for paediatricians – children in rural and remote areas will not have ready access to a paediatrician. Education and training important for GPs, maternal and child health nurses, health workers
- Health professionals should provide a clear and consistent message to women that researchers don't know what level of alcohol if any, is safe in pregnancy. Therefore the best advice is not to drink any alcohol while pregnant or breast feeding
- Resources for health professionals to be used in discussion with women should be visual (pictorial/DVD/models) and explain how alcohol reaches the baby and how it affects the baby

Women participating in the community conversations were concerned that health professionals were not providing them with information about alcohol and pregnancy and in some cases inconsistent messages were given to pregnant women. Women were of the view that without an education and training program for health professionals, information will not be provided and screening will not occur. As the screening of children will be undertaken by a range of health professionals, professional development in the area of FASD should be offered to health workers, maternal and child health nurses, general practitioners, paediatricians, psychologists and psychiatrists.

Issues arising from the community conversations that are related to alcohol and pregnancy and FASD that are important but outside the scope of the FASD Project:

- Prevention is the key – national awareness campaign with information in a range of media and venues – TV, radio, social media (YouTube, Twitter etc), buses, clubs, bars, restaurants, nightclubs, Centre Link, Medicare, doctors and clinic waiting rooms
- Education in schools (12 – 16 year olds)

The Steering Group will ensure that the Delphi statements reflect the community conversation information and, at the Steering Group Workshop, they will be considered as the screening and diagnostic instrument is finalised. Some may also be incorporated into recommendations arising from the FASD Project.

The final FASD Project Report will include a section on the Community Conversations and how the outcomes were incorporated into the final instrument and identified in the recommendations.

References

1. Statement on Consumer and Community Participation in Health and Medical Research (the Statement on Participation) National Health and Medical Research Council 2000-2001 and updated in 2004. Accessed on-line at <http://www.nhmrc.gov.au/publications/synopses/r22syn.htm>
2. *Women's knowledge and attitudes regarding alcohol consumption in pregnancy: a national survey*, by Peadon E, Payne J, Henley N, D'Antoine H, Bartu A, O'Leary C, Bower C, Elliott EJ in BMC Public Health, August 2010. (*Telephone interviews with 1103 Australian women 18 – 45 years and not pregnant*)
3. *Health Professionals Addressing Alcohol Use with Pregnant Women in Western Australia: Barriers and Strategies for Communication* by Kathryn France, Nadine Henley, Jan Payne, Heather D'Antoine, Anne Bartu, Colleen O'Leary, Elizabeth Elliott and Carol Bower in Substance Use and Misuse, 45: 1474 – 1490
4. *The role of the General Practitioner* by Peadon E, O'Leary C, Bower C, Elliott E. Impacts of alcohol use in pregnancy. in Aust Fam Physician. 2007; 36(11):935-939.
5. *Health professional's knowledge, practice and opinions about Fetal Alcohol Syndrome and alcohol consumption in pregnancy* by Payne J, Elliott E, D'Antoine H, O'Leary C, Mahony A, Haan E, et al. in Aust N Z J Public Health. 2005; 29(6):558-564.