



ALCOHOL PREGNANCY & FASD RESEARCH PROGRAM

ANNUAL REPORT 2015

Alcohol Pregnancy & FASD Research Program

Telethon Kids Institute

Office Address: 100 Roberts Road Subiaco WA 6008

Postal Address: PO Box 855 West Perth WA 6872

Telephone: 08 9489 7724

Email: fasd@telethonkids.org.au

Website: <http://alcoholpregnancy.telethonkids.org.au/>

This report provides a review of the Alcohol Pregnancy & FASD Research Program activities for the year 2015.

Acknowledgements

We would like to acknowledge the support, assistance and advice of Telethon Kids Institute professional teams to our research program. We also acknowledge the leadership and guidance provided by Glenn Pearson Head Aboriginal Research Development.

Administration Officer – Claire Fowler

Communications & Development – Liz Chester, Tammy Gibbs, Jasmine Raisbeck, Caroline Wise, Tim McInnis, Megan Keep

Consumer & Community Participation Program – Anne McKenzie, Hayley Haines, Ngaire McNeil

Data Services – Chris Ellis

Facilities – Tihan Radanovich, Adrien Venaille

Finance – Nick Wood, Kathleen Lim, Anita Giuffre, Gina Jagoe, Ariel Jin, Kavuyi Nanyangwe

IT – Adam Moretta, Arrol Khoo, Joseph Bartlett, Cidalia Vaz

KARDU Unit – Isabelle Adams, Mara West

People & Culture – Jade Orazi, Sharifa Burah, Young Chae, Louise Richardson

Research & Development – Nicky Lewis, Regis Williams, Tobias Schoep, Ashley Schoof

Scientific Services – Gerard Good

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About the Alcohol Pregnancy & FASD Research Program

It is important that everyone is aware of the harm that can be caused by alcohol on the developing baby. To achieve this we will work with children and young people, their families and communities, and build on partnerships with government and non-government organisations, policy makers, service providers, politicians, educators, researchers and international organisations.

Fetal Alcohol Spectrum Disorders (FASD) are a range of conditions caused by prenatal exposure to alcohol. Although the use of 'fetal' may imply these conditions only relate to babies; the effects of fetal alcohol exposure are life-long and may not be seen at birth.

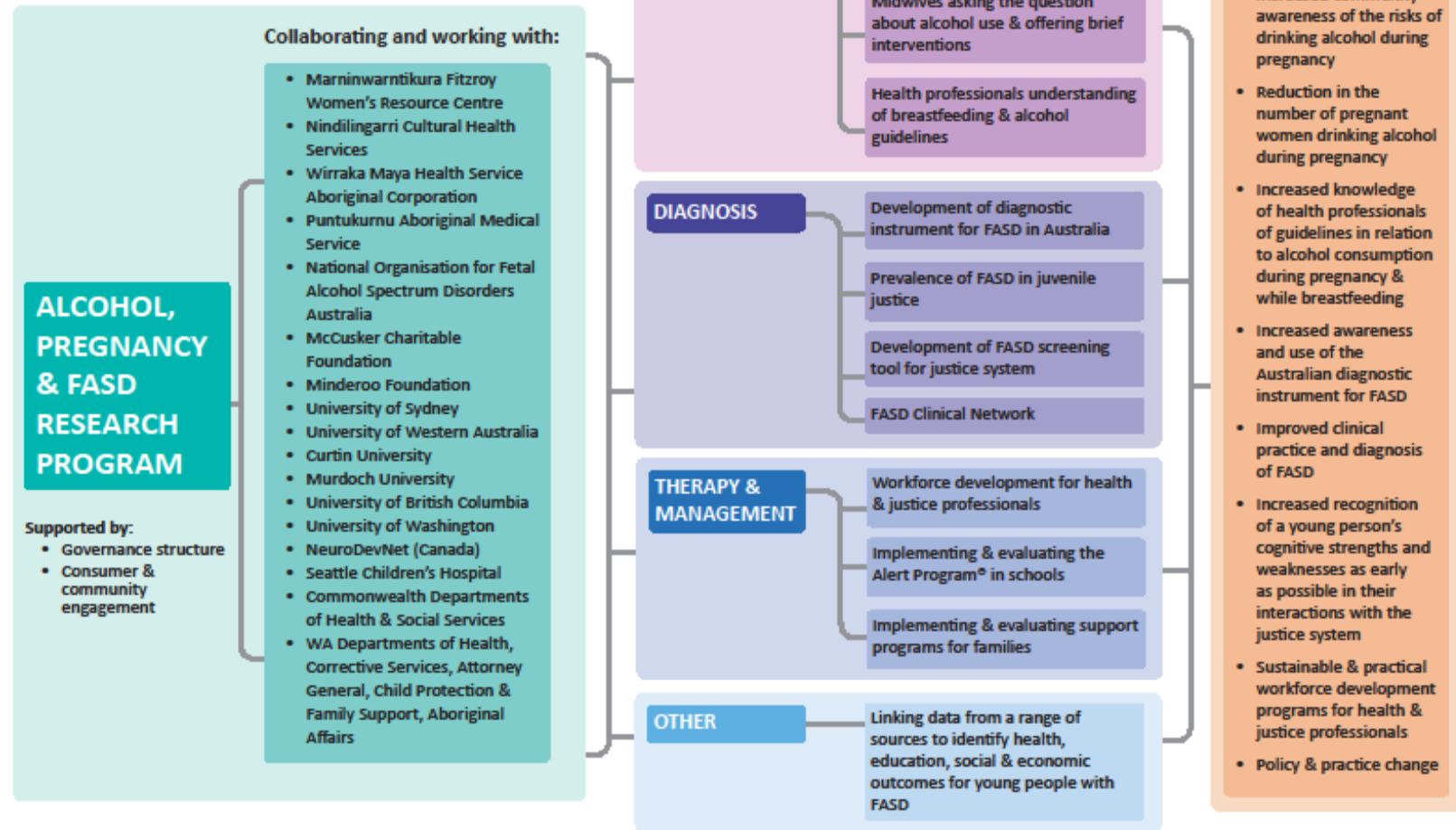
The Alcohol Pregnancy & FASD Research Program brings together the strengths of all members of the team and a range of projects into a comprehensive program of research to achieve our goals of developing prevention strategies; building the capacity of health, justice and other professionals; and implementing and evaluating programs for children and young people with FASD and their families. An outline of our program can be found on page 2 of this report.

Detailed information on our program, individual projects, publications and resources can be found on our [website](#).



Not drinking alcohol in pregnancy and while breastfeeding is the safest option

ALCOHOL, PREGNANCY & FASD RESEARCH PROGRAM



Overview 2015

Collaboration with communities and stakeholders is at the forefront of research in the Alcohol Pregnancy & FASD Research Program. In April we had the opportunity to work with Dr Dan Goldowitz from NeuroDevNet in Canada and this has led to new partnerships with the organisation including new project grants and Centre for Research Excellence. We also had the occasion to meet with Dr Julianne Conry an international leader in work on youth with FASD and involvement in the justice system.

Working with Aboriginal communities in the Kimberley, we have seen a reduction in the proportion of pregnant women drinking alcohol during pregnancy from approximately 65% in 2010 to 20% in 2015. The collaboration with communities has also seen an increase in people's awareness to more than 95%, that alcohol can harm the developing baby and it's not OK to drink while pregnant. Building on our model of community-led research, we were successful in receiving a National Health and Medical Research Council (NHMRC) grant to undertake work in prevention, diagnosis and support and therapy interventions in the Pilbara region.

The Alert Program® was conducted at the Muludja School, with the school staff, parents and children providing positive feedback. The program was also successful in receiving funding from the 100 Women Foundation for a capacity building program for community researchers on the Alert Program® Study over the next two years.

Partnership was key to the success of the FASD resources for justice professionals' project. The expertise, wisdom and personal experiences of the Steering Group ensured the resources were relevant to the target audience. Also working closely with stakeholders is the Banksia Hill FASD project team. The Banksia Hill FASD project commenced work assessing sentenced youth in Banksia Hill Juvenile Detention Centre and working with staff on workforce development. Another aspect of our work in the justice system was the release of FASD resources for justice professionals.

In late 2015 a collaboration of Australian researchers, including members of the Alcohol Pregnancy & FASD Research Program, were successful in gaining a NHMRC Centre of Research Excellence Grant 'Reducing the Effects of Antenatal Alcohol on Child Health'. This centre will commence in 2016.



Dan Goldowitz visit April 2015



Julianne Conry visit August 2015

Alcohol Pregnancy & FASD Research 2015

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Alcohol Pregnancy & FASD Research Program Team 2015

- **Professor Carol Bower** – Director Alcohol Pregnancy & FASD Research Program (Trial & Implementation Australian Diagnostic Instrument for FASD, Banksia Hill FASD Project, 3M Project, Audit C midwives workforce development, Development of FASD resources for justice professionals)
- **Dr James Fitzpatrick** – Deputy Director Alcohol Pregnancy & FASD Research Program/McCusker Clinical Research Fellow in Aboriginal Child Health (Marulu FASD Prevention Strategy, Alert Program® Study, 3M Project, Hedland, Making FASD History in the Pilbara, True Blue Dreaming)
- **Dr Roslyn Giglia** – Deputy Director Alcohol Pregnancy & FASD Research Program/NHMRC Translational Research Fellow (Evaluating the uptake of breastfeeding and alcohol guidelines)
- **Kaashifah Bruce** – Senior Research Officer (Marulu FASD Prevention Strategy)
- **Sue Cherel** – Community Researcher (Alert Program® Study)
- **Carmen Condon** – Research Officer (Banksia Hill FASD Project)
- **Juanita Doorey** – Senior Research Officer (Trial & Implementation Australian Diagnostic Instrument for FASD)
- **Angela Dudley** – Research Officer (NDIA submission, FASD Clinical Network Coordinator)
- **Jacinta Freeman** – Research Officer (Banksia Hill FASD Project)
- **Sharynne Hamilton** – Research Officer (Banksia Hill FASD Project)
- **Heather Jones** – Program Manager Alcohol Pregnancy & FASD Research (Development of FASD resources for justice professionals)
- **Natalie Kippin** – Speech Pathologist (Banksia Hill FASD Project)
- **Sylvia Lockyer** – FASD Coordinator (Hedland & Pilbara FASD projects)
- **Dr Philippa May** – Senior Research Officer (Derby FASD Strategy)
- **Associate Clinical Professor Raewyn Mutch** – Clinical Research Fellow (Banksia Hill FASD Project)
- **Joanna Nicholas** – Senior Research Officer (True Blue Dreaming)
- **Hayley Passmore** – Research Assistant & PhD candidate (Banksia Hill FASD Project)
- **Candice Rainsford** – Research Officer (Banksia Hill FASD Project)
- **Dr Tracy Reibel** – Senior Research Officer (3M Project, Audit C midwives workforce development)
- **Bernadette Safe** – Occupational Therapist (Banksia Hill FASD Project)
- **Dr Martyn Symons** – Senior Research Officer (Marulu FASD Prevention Strategy)
- **Avinna Trzeninski** – Research Assistant (Alert Program® Study)
- **David Tucker** – Research Officer (Hedland FASD Project)
- **Bree Wagner** – Alert Program® Study Coordinator
- **Noni Walker** – Senior Research Officer (Banksia Hill FASD Project)
- **Associate Professor Roz Walker** – Research Fellow (Pilbara FASD Project, Pilbara FASD Project)
- **Dr Rochelle Watkins** – Senior Research Fellow (Trial & Implementation Australian Diagnostic Instrument for FASD, Banksia Hill FASD Project, FASD Data Linkage)
- **Kristen White** – Senior Research Officer (Hedland FASD Project)

Casual Community Researchers

- Isabelle Palmer – Alert Program® Study
- Tamika Shaw – Alert Program® Study
- Katrina Shaw – Alert Program® Study
- Harlen Bedford – Marulu FASD Prevention Strategy
- Paul Bin Busu – Marulu FASD Prevention Strategy
- Hozaus Claire – Marulu FASD Prevention Strategy
- Beryl Dickens – Marulu FASD Prevention Strategy

- Jayedene Green – Marulu FASD Prevention Strategy
- Sherina Malo – Marulu FASD Prevention Strategy
- Leo Thirkall – Marulu FASD Prevention Strategy
- Yvette Councillor – Hedland FASD Project
- Adva Daniel – Hedland FASD Project
- Douglas Pungana – Hedland FASD Project
- Michaela Ramirez – Hedland FASD Project

Students

- Hayley Passmore – University of Western Australia, PhD candidate
- Bernadette Safe – University of Western Australia, Masters of Child Health Research
- Bree Wagner – University of Western Australia, Masters of Child Health Research
- Julia Hensel – Curtin University Professional Practice Placement
- Kerry Anne Menenzes – Curtin University Professional Practice Placement
- Eliza Offerins – Curtin University Professional Practice Placement
- Kelly Shaw – Curtin University Professional Practice Placement
- Libby Tearne – Curtin University Master of Dietetics Research Placement

Honorary Positions

- Maureen Carter – CEO Nindilingarri Cultural Health Services Fitzroy Crossing Western Australia
- June Oscar – CEO Marninwarntikura Women’s Resource Centre Fitzroy Crossing Western Australia
- Dr Jan Payne – Honorary Research Fellow
- Associate Professor Carmela Pestell – Clinical Psychologist & Neuropsychologist and Director Robin Winkler Clinic (University of Western Australia)
- Dr Amanda Wilkins – Paediatrician Child Development Service, WA Department of Health

Research Projects

The Alert Program® Study: an evidence based program to improve self-regulation and executive functioning in primary school aged children with and without FASD in the Fitzroy Valley

Investigators

- Dr James Fitzpatrick¹
- Professor Karen Edmond²
- Professor Jane Latimer³
- Professor Branko Celler⁴
- Dr Trevor Mazzucchelli⁵
- Mr Glenn Pearson¹
- Dr Heather Carmichael Olsen⁶
- Dr Rochelle Watkins¹
- Professor John Boulton^{7,8}
- Ms Maureen Carter⁹

¹Telethon Kids Institute, The University of Western Australia, Perth, Australia

²Western Australian Government Department of Health

³George Institute for Global Health, Sydney Australia

⁴University of New South Wales Electrical Engineering and Telecommunications, Biomedical Systems Laboratory, Sydney Australia

⁵Department of Psychology, Curtin University Perth, Australia

⁶Department of Psychiatry and Behavioural Sciences, University of Washington School of Medicine, Seattle Childrens Hospital, Washington USA

⁷Kimberley Regional Health, Broome Australia

⁸University of Notre Dame, Broome, Australia

⁹Nindilingarri Cultural Health Services, Fitzroy Crossing, Australia

Project staff

Bree Wagner

Project summary

While lots of children going to school in the Fitzroy Valley do well, some kids find school hard. They may have problems controlling their actions and mood which can affect their ability to learn in the classroom. This can be a big problem for children who have FASD. Primary schools in the Fitzroy Valley are going to teach the Alert Program® in the classroom so students can learn to control their actions and mood. We call these skills “self-regulation”.

We want to find out if teaching them the Alert Program® will help improve their learning and behaviour skills. This might help them to get better at remembering things, solving problems, paying attention, planning and organising themselves. These “executive functioning” skills are important for children to engage with the demands of school life.

The Alert Program® teaches kids that their body is like a car engine. It can go into high speed, it can go into low speed and it can go into just right speed. The program teaches kids different ways they can change their engine speeds (level of alertness) by using ‘tools’ for their mouth, body, ear, eyes and hands to help them self-regulate and therefore learn more easily in the classroom. For example, a student could be feeling hyped up when they enter the classroom after recess (high gear). The teacher or Aboriginal and Islander Education Officer might teach the student to do some chair push-ups (heavy work) to shift their engine (level of alertness) into just right gear so they can concentrate on their spelling task when sitting at their desk.

Project aims

The goal of this research is to develop, implement and evaluate a school curriculum version of the Alert Program® to improve impairments in self-regulation and executive functioning of children attending grades 1-6 in the Fitzroy Valley.



What happened in 2015

In 2015, the first year of this project, a comprehensive formative process was undertaken in partnership with various health, education and community stakeholder from the Fitzroy Valley. The formative process involved seven visits to the Fitzroy Valley and included working with the Kimberley Education Regional Office (KERO), the Marulu FASD Leadership Team, schools and the Kimberley Population Health Unit occupational therapists.

Relationships were also formed between researchers, families and community representatives through a series of school visits, by running community barbecues and breakfast events, presenting information about the study at school conferences, community and service provider meeting, joining community networks and being visibly present on a regular basis within the community. This has also meant getting to know people outside of more formal situations by embracing the chance to be involved in activities like camping, fishing and cultural events with local community members. Regular communication and input into project design has also been facilitated by convening consumer reference group meetings, publishing regular study

newsletters and keeping in touch with key stakeholders by email and telephone.

Conducting a pilot study at a small remote community school enabled the team to trial all aspects of the Alert Program® project and to gain valuable feedback from teachers, school support staff and families before finalising plans for the full study phase in 2016 and 2017. This included piloting research procedures, information and consent forms, the Alert Program® curriculum guide, resources and equipment, assessment tools and staffing processes. Investing time in community and consumer participation, as well as running a pilot study during the formative stage, has ensured the research design is not only rigorous but appropriate to the Fitzroy Valley context.



The employment of Aboriginal community members as community researchers on this project has been fundamental to researchers and community members developing shared understanding and expectations for culturally and contextually sensitive research practices and processes. Locally employed community researchers have provided language and cultural support to both families participating in the research and to non-Aboriginal research staff. This two way research partnership has been central to the project being accepted by the community and to maximising participation from schools and families. Additional funding has been received to enable locally based Aboriginal research staff to complete a Certificate II in Community Health Research between 2016 and 2017. By doing so, community researchers working on

this project will develop the research skills to complement their existing expertise and knowledge which will enable them to seek employment across other research projects taking place in the Fitzroy Valley. This has already occurred in 2015 whereby Alert Program® Community Researchers were able to be employed on the Fitzroy Valley FASD Prevention research project that is also taking place through the Telethon Kids Institute.



Where to Next?

Analysis of findings in 2018 will contribute to the basis for recommendations and preparation of guidelines for the use of the Alert Program® with children who have impairments in self-regulation and executive functioning in similar settings. The team also hopes to report on the importance of the formative process undertaken to inform and enhance the project and by doing so, hopefully influence similar projects to recognise the benefits of including community and consumer participation in program design, service delivery and research.

Project funder



External collaborators

- Nindilingarri Cultural Health Service, Western Australia
- Fitzroy Valley primary schools, Western Australia
- Kimberley Education Regional Office, Western Australia
- Department of Health, Western Australia
- University of Washington, USA
- Therapy Works Inc., USA

Acknowledgments

We are grateful for the assistance provided by other organisations for data collection

- Joanna Fox – Kimberley Education Region (Lead School Psychologist)
- Phillipa Whyte – Kimberley Education Region (School Psychologist)

Thanks also to Julie Munro who assisted with the writing of the curriculum guide and delivered parent workshops and to Martyn Symons for his assistance with data management and statistics.

3M FASD Prevention Strategy: Marulu, Mass Media, Midwives

Investigators

- James Fitzpatrick¹
- Maureen Carter²
- June Oscar³
- Rochelle Watkins¹
- Carol Bower¹
- Glenn Pearson¹
- Jonathan Carapetis¹
- Mike Daube⁴
- Kaashifah Bruce¹

¹Telethon Kids Institute, The University of Western Australia, Perth, Australia

²Nindilingarri Cultural Health Services, Fitzroy Crossing, Australia

³Marninwarntikura Fitzroy Women's Resource Centre, Fitzroy Crossing, Australia

⁴McCusker Centre for Action on Alcohol and Youth, Curtin University, Australia

Project Staff

Kaashifah Bruce, Martyn Symons, Tracy Reibel

Project Summary

This program has three initiatives responding to high FASD prevalence rates in the Fitzroy Valley through a whole of community prevention strategy:

Marulu: An exemplar high-impact FASD prevention strategy in the communities of the Fitzroy Valley, where high FASD prevalence has been documented;

Midwives: A workforce intervention up-skilling midwives in the documentation and brief intervention around alcohol use in pregnancy, to reinforce the community-wide interventions; and

Mass Media: A mass media strategy targeting regional and remote communities throughout the Kimberley and Pilbara, with a further aim

of ensuring state-wide impact for the program and its messages.

Project aims

The objective of the *FASD Prevention Strategy* is to implement and evaluate a community designed FASD prevention strategy for the Fitzroy Valley and surrounding communities that, if effective, can be translated to other settings in Western Australia.



What happened in 2015

This overarching evidence-based and woman-centred Strategy was developed using a 'Four Part Model of Prevention' framework (see page 12 of this report) and comprises three distinct but interrelated initiatives: the *Marulu FASD Prevention Strategy* in the Fitzroy Valley; a midwife screening/brief intervention strategy (*Workforce Development Strategy*); and a community-wide *media strategy*, with an initial focus on both Aboriginal and non-Aboriginal people in the Kimberley and Pilbara, as well as a health promotion strategy more broadly throughout Western Australia. The annual schedule of activities for the Strategy incorporating the intervention components is outlined in the figure on page 13 of this report.



Project funders



Government of **Western Australia**
Department of **Health**



Government of **Western Australia**
Department of **Aboriginal Affairs**

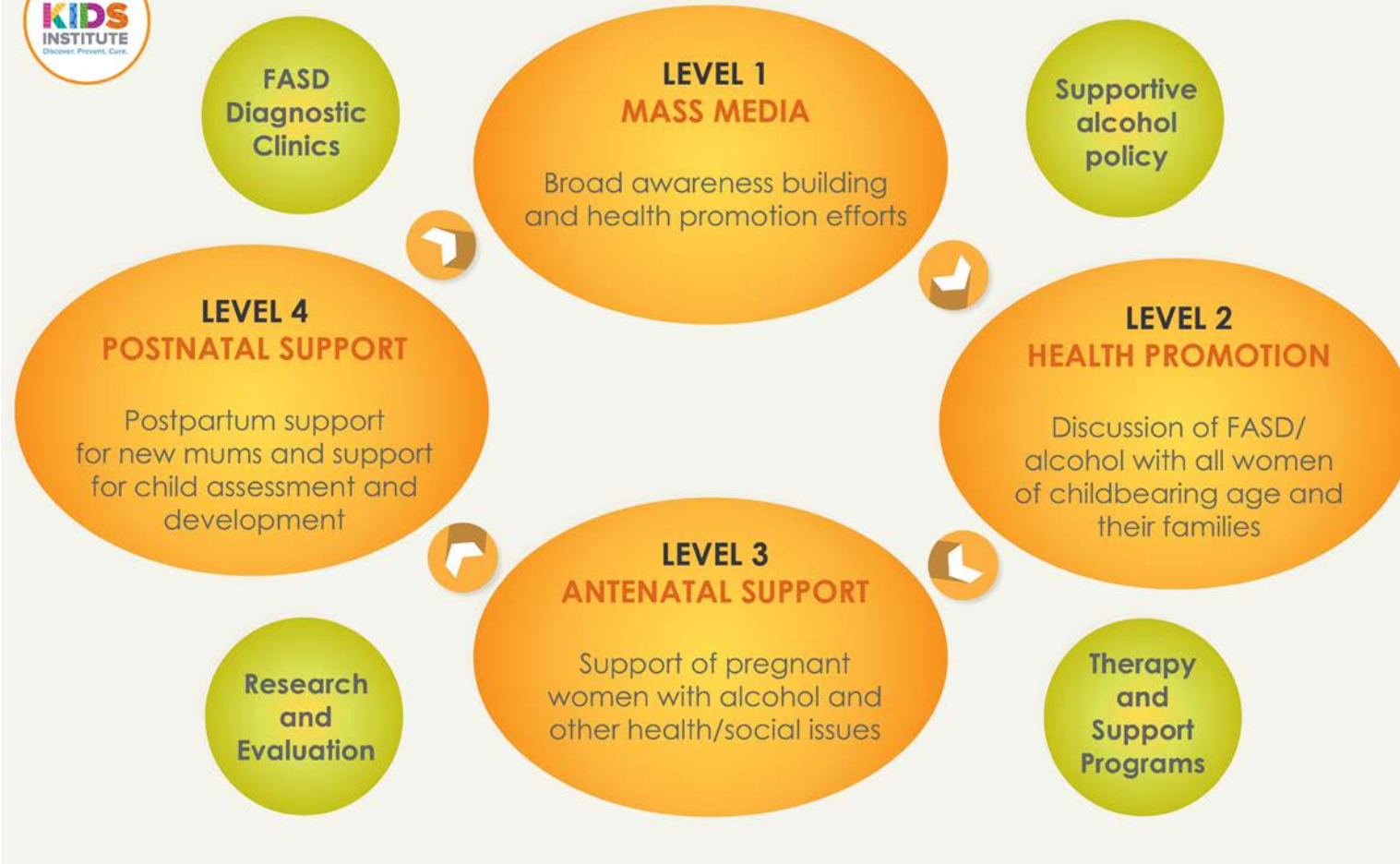
External collaborators

- Mike Daube, McCusker Centre for Action on Alcohol and Youth, Curtin University, Australia
- Maureen Carter, Nindilingarri Cultural Health Services, Fitzroy Crossing, Australia
- June Oscar, Marninwarntikura Fitzroy Women's Resource Centre, Fitzroy Crossing, Australia
- Gary Kirby, Michelle Gray, WA Mental Health Commission, Australia

Acknowledgements

- Kristy Newett, Community Midwife, WA Country Health Service
- Annette Kogolo, Aboriginal Therapist
- Nindilingarri Cultural Health Service
- Patrick Davies, Environmental Health Team Coordinator, Nindilingarri Cultural Health Services





Adapted from Canadian FASD Prevention Researcher Nancy Poole's Four Part Model



Annual FASD Prevention Strategy Activities

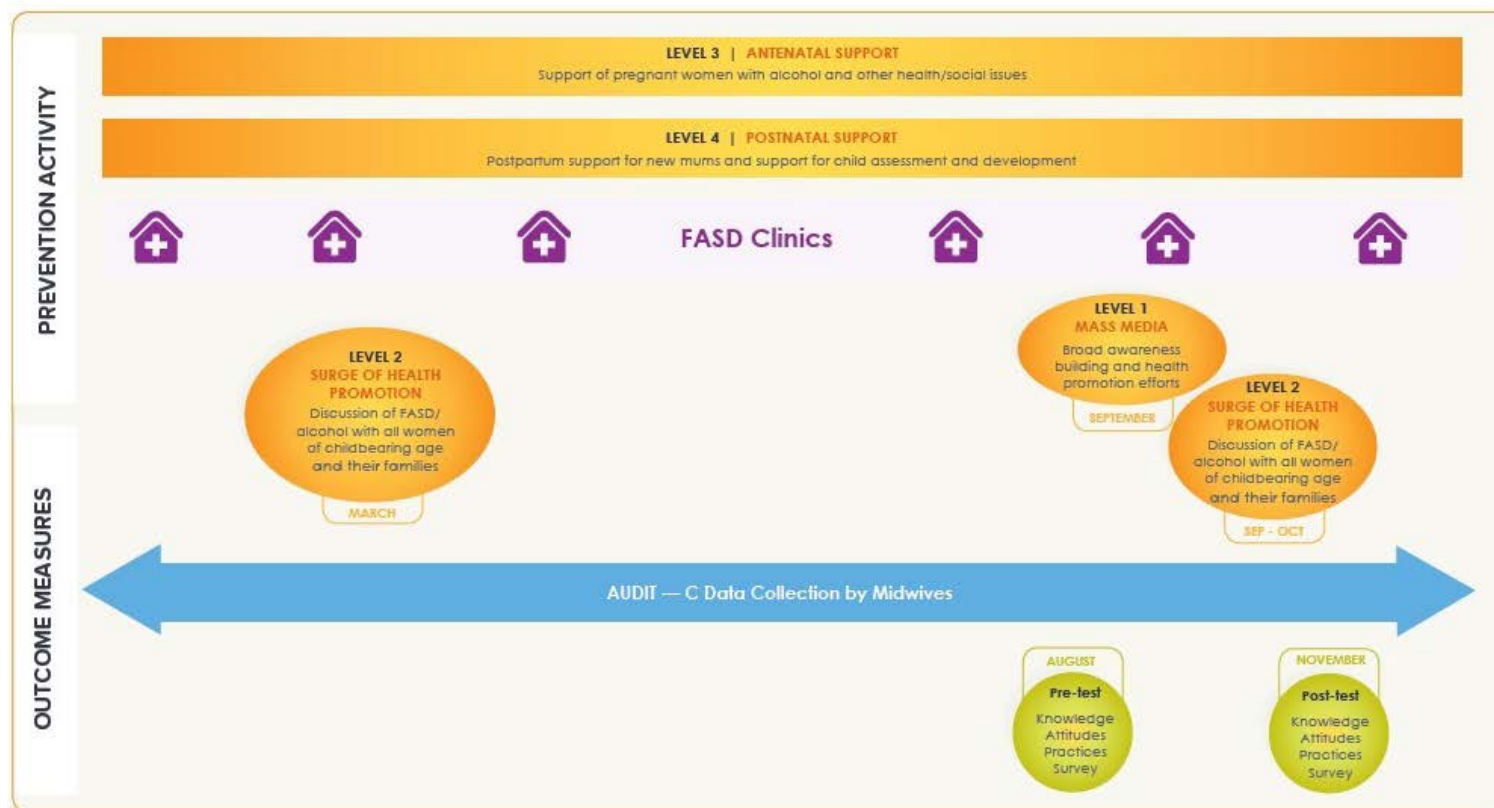
TARGETS



Percentage of women drinking while pregnant



Community Knowledge, Attitudes and Practices of alcohol use in pregnancy



Midwives and Women Audit C Intervention project (part of 3M)

Investigators

- Tracy Reibel¹
- Carol Bower¹

¹Telethon Kids Institute, The University of Western Australia, Perth, Australia

Project Staff

Tracy Reibel

Project summary

It is important that pregnant women are consistently informed by midwives that 'no alcohol in pregnancy is the safest option' as a public health preventive measure. This project will develop a guide for midwives to assist them in providing consistent advice about alcohol use to women during pregnancy care visits.

Project background and aims

This project is in direct response to previous research conducted by the Alcohol, Pregnancy and FASD program which identified that health professionals in general, but midwives specifically, are not always confident when discussing alcohol use with pregnant women. Since 2009, the NHMRC Guideline 4 has recommended that all health professionals advise pregnant women that 'no alcohol in pregnancy is the safest option'. While it is generally understood that this prevention message has likely penetrated the broader community, there is evidence that midwives do not always address the issue of alcohol use by pregnant women. Where the question regarding alcohol use is posed in the antenatal setting, education of the potential for negative impacts on the developing baby is often not provided. Therefore, the research clearly indicates a need for education which promotes the use of a screening tool by midwives to establish the risk exposure for individual women and the application of a brief intervention. Brief intervention

conducted by midwives in the antenatal setting act as an education intervention, reinforcing the public health message regarding alcohol use in pregnancy. Workforce development is an integral component of improving prevention measures. The project will develop a readily accessible resource guide for midwives to use in the antenatal setting when taking personal histories with women during pregnancy. It will also provide guidance on where to access professional education and resources to use with women.

What was achieved in 2015

During 2015 ethics approval was sought and approved and trial site governance processes were put in place. An Expert Reference Group was formed, with midwifery academic, senior management and clinical management representatives and a consumer representative. A systematic literature search was performed, which contributed to a critical review of the current evidence relevant to the use of screening and brief intervention by midwives in the antenatal setting. Focus groups were held in the broader community with women who had recent experience of maternity care and interviews conducted at the trial site with women currently receiving maternity care. Group discussions and interviews focused on women's experiences of being asked about alcohol use in pregnancy, their knowledge about alcohol use in pregnancy and the acceptability of screening tool questions.

Project funder



Government of **Western Australia**
Department of **Health**

External collaborators

- Armadale Health Service as the trial site.

Hedland FASD Project

Investigators

- Glenn Pearson¹
- James Fitzpatrick¹
- Roz Walker¹

¹Telethon Kids Institute, The University of Western Australia, Perth, Australia

Project Staff

Kaashifah Bruce, Sylvia Lockyer, David Tucker, Kristen White

Project summary

This 5-year project is the first of a twenty year research program aimed at reducing the prevalence and impact of FASD in the Pilbara taking a regional approach but focusing in particular on Port Hedland, Warralong and Yandeyarra. The work will be structured to intentionally foster genuine community leadership (particularly women's leadership) and ownership of issues related to alcohol and substance use in pregnancy and increase the resilience and empowerment of local families.

Following on from Telethon Kids Institute's previous work and recognising ongoing local action, the Hedland FASD Project will work with Wirraka Maya and the Hedland FASD Network and others to support local efforts in prevention, diagnosis, treatment, family support, capacity building and policy advocacy through identifying needs, evidence-based practices, and evaluating specific strategies, programs and activities.

Critical focus will also be on supporting and measuring the effectiveness of programs that build the knowledge and capacity of families with children with FASD, and increasing their confidence in engaging with services and establishing/determining their own initiatives.

Project aims

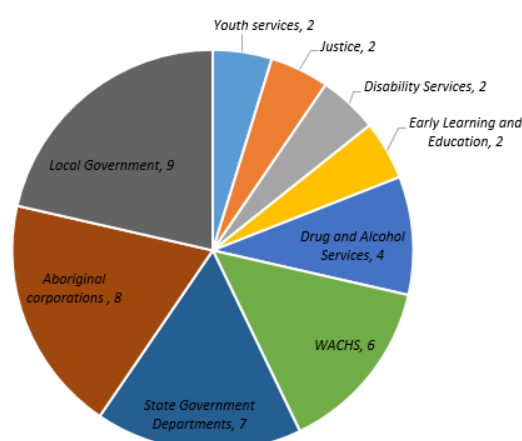
Working with existing Hedland services, networks and communities, the project aims

to build an evidence base on what works in preventing FASD and assists in supporting children and families affected by FASD. The project specifically aims to:

- Identify rates of alcohol use in pregnancy using AUDIT-C data routinely collected by midwives during antenatal care:
- Reduce the rates of alcohol use in pregnancy among local Aboriginal women; and
- Increase the capacity of the local community and services to care for and support individuals and families affected by FASD.

What happened in 2015

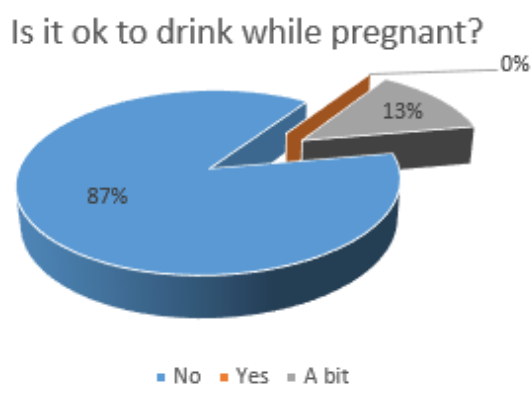
Building on past consultations the project used a model of Community Participatory Action Research (CPAR) to conduct consultations and interviews with women leaders and stakeholders.



Number of interviews by participant category

3 new project staff and 10 casual community researchers were employed to work on the project.

261 surveys were conducted by project staff and community researchers with people in shopping centres and community events to find out if people thought it was OK to drink alcohol during pregnancy, what they knew about the risks of drinking alcohol during pregnancy and FASD. (Survey results from the first 123 surveys completed)



Project funder

The current project has been funded through community investment from BHP Billiton, and as a requirement of this funding is focused specifically on the Town of Port Hedland and surrounding communities (Warralong and Yandeyarra).



External collaborators

- Wirraka Maya Health Service Aboriginal Corporation, South Hedland, Australia
- Hedland FASD Network, South Hedland, Australia

Acknowledgements

We acknowledge the research assistance provided to us from other organisations for data collection:

- WA Country Health Service – Alie Scott, Brendan Shaw and Leigh Clifton
- Wirraka Maya Health Service Aboriginal Corporation – Angela Geddes (Community midwife)

Banksia Hill FASD Project

Investigators

- Professor Carol Bower¹
- Clinical Associate Professor Raewyn Mutch¹
- Professor Rhonda Marriot²
- Dr Rochelle Watkins¹
- Professor Steve Zubrick¹
- Associate Professor Carmella Pestell³
- Dr James Fitzpatrick¹
- Peter Collins⁴
- Dr Jonathan Carapetis¹

¹Telethon Kids Institute, The University of Western Australia, Perth, Australia

²School of Psychology and Exercise Science, Murdoch University, Perth Western Australia

³Robin Winkler Clinic, The University of Western Australia, Perth, Australia

⁴Legal Aid Western Australia

Project staff

Vicole Bothma, Carmen Condon, Candy Cheung, Jacinta Freeman, Roslyn Giglia, Sharynne Hamilton, Natalie Kippin, Raewyn Mutch, Hayley Passmore, Candice Rainsford, Bernadette Safe, Helen Shield, Noni Walker

Background and aims of the project

The Alcohol and Pregnancy and FASD Research Group is working on a project that aims to determine how common Fetal Alcohol Spectrum Disorders are in young people in detention, develop appropriate management strategies for all young people assessed in the project and develop a FASD screening tool appropriate for young people entering the juvenile justice system. Partnerships are vitally important as the project connects with the Department of Corrective Services, the Department of Child Protection and Family Services, young people in detention, their families and communities.

What happened in 2015

The project, based at the Banksia Hill Detention Centre in Canning Vale (the only centre in WA for detainees aged between 10 and 17 years), began recruitment in May 2015 among young people who have been sentenced.

Young people are interviewed by the project research assistant and are assessed by a paediatrician, neuropsychologist, occupational therapist and speech pathologist to provide information that may identify FASD or other conditions or impairments.

A report for each young person includes the findings from the assessment, a provisional diagnosis if one has been identified, their individual strengths and difficulties, recommendations for managing any difficulties the young person has, and referrals for further investigation or treatment if needed.

The findings are discussed with the young person and their parent/guardian/carers. Greater awareness of the impairments experienced by young people, including those identified with FASD, will assist staff at Banksia Hill to support them during detention and community youth justice services staff following their release.

We are also finding out from staff at Banksia Hill how the recommendations match with how staff currently communicate and manage young people, so that we can develop useful, appropriate and effective training and support for staff.

Project funder

Targeted Call for FASD Funding



External collaborators

- WA Government Department of Corrective Services
- WA Government Department for Child Protection and Family Services

Acknowledgements

We acknowledge the assistance provided to us by the Department of Corrective Services and staff at Banksia Hill Juvenile Detention Centre.

Understanding FASD: a guide for justice professionals

Investigators

- Heather Jones¹
- Associate Professor Raewyn Mutch¹
- Professor Carol Bower¹
- Dr Rochelle Watkins¹

¹Telethon Kids Institute, The University of Western Australia, Perth, Australia

Project staff

Heather Jones

Project summary

Our previous research identified what justice professionals knew about FASD, how this impacted on their work, what information they required and how this information should be delivered. The next phase of our work was to translate this research, together with health and legal concepts and knowledge into practical educational resources for justice professionals

Project aims

To develop FASD resources for justice professionals so they can:

- recognise cognitive impairments and possible FASD in young people engaging with the criminal justice system whether as an offender, witness or victim, and children and young people in protection and care matters
- identify legal implications
- consider referral for assessment if cognitive impairments and/or disability is suspected
- consider decision making with respect to orders, sentencing and management to accommodate cognitive impairments and disability

What happened in 2015

We developed and implemented educational resources to build the capacity of justice professionals to use best practice

interventions for young people suspected of having FASD. We developed:

- FASD and justice website
<http://alcoholpregnancy.telethonkids.org.au/fasd-justice/>
- 6 videos
<http://alcoholpregnancy.telethonkids.org.au/fasd-justice/professional-development/>
- on-line continuing professional development module for lawyers

We also presented at many seminars, workshops and conferences



Project funders



Government of **Western Australia**
Department of the **Attorney General**



External collaborators

- Magistrate Catherine Crawford: Perth Children's Court
- Trish Heath: Office of the Commissioner for Children & Young People
- Julie Waud: Aboriginal Legal Service WA
- Claire Rossi and Anna O'Connor: Legal Aid WA
- Robyn Williams: Community representative and PhD candidate

Feasibility of the Easy Diet Diary smartphone app for estimating dietary intake

Investigators

- Dr Roslyn Giglia¹
- Associate Professor Gina Ambrosini²

¹Telethon Kids Institute, The University of Western Australia, Perth, Australia

²School of Population Health, The University of Western Australia, Perth, Australia, Honorary Research Fellow, Telethon Kids Institute

Project summary

Traditional methods of recording what people eat for research is time consuming and labour intensive for the person recording what they eat. Often they will need to weigh and write down all the foods eaten over a three day period. This information then needs to be returned to the researcher for review and dietary analysis. This research will explore the possibility of research participants recording their food intake using a mobile phone app which contains an electronic diary and a complete list of Australian foods which can be searched to match what the participant is eating. Foods can then easily be entered and dietary records can be emailed back to the researcher for analysis and feedback to participants.

Assessing usual dietary intake in research settings is a major challenge due to the complexity of the human diet and limited availability of evaluated tools, each having varying degrees of accuracy and acceptability. Furthermore, respondent burden often results in poor response rates (especially paper based tools), dietary under-reporting and potentially biased observed diet-disease associations. Recently however, technological advances in smart phones, smart phone apps, and mobile internet access has opened up

new opportunities to improve dietary assessment methods.

The advantages of using a mobile phone application to record dietary intake are manifold. Firstly, the portability of a mobile phone enables real time dietary recording, avoiding the need for respondents to recall their food intake using a questionnaire, which can reduce data quality. Collecting real time data at each eating occasion provides an unparalleled opportunity to measure eating contexts e.g. where food is eaten, who the consumer is with, and what the consumer is doing; factors increasingly recognised as having the potential to influence diet quality. Finally, respondents can be automatically reminded to record their dietary intake via text message, which also maintains data quality.

Many smartphone apps are freely available to consumers to monitor their calorie intake and assist with weight loss, yet very few have been designed or tested as a dietary assessment tool suitable for application in research (none in Australia to our knowledge). Obesity researchers in the UK have shown that use of an app (My Meal Mate) developed to record and monitor dietary intake is acceptable to users and compared to a written (paper) diet diary, results in greater participant retention (93% vs 53%) and greater adherence. Development of an Australian app for assessing dietary intake in research is essential to record local brands of foods and to utilise Australian food composition data.

Project aims

This pilot study aims to test the feasibility of a smartphone application to assess usual dietary intake in a population health research setting, specifically:

1. the acceptability of the app using qualitative data from respondents
2. a comparison of levels of dietary under-reporting in the app vs a traditional diet diary

What happened in 2015

In 2015 a project officer was employed part time to help recruit participants into the study. Collaboration with Curtin University Nutrition and Dietetics Department has enabled the dietary recalls to be collected by student dietitians in the final year of their degree. At the end of 2015 advertising for participants and recruitment had commenced.

Project funder

WA Department of Health Merit Award



(NHMRC near-miss funding RA/1/85/265): \$75,000; 2016 (Ambrosini GL, Scott J, Trapp G, Bull F, Oddy WH. Determining modifiable lifecourse influences that lead to poor diets in young adults: a prospective analysis in the Raine Study).

External collaborators

- Associate Professor Gina Ambrosini, School of Population Health, UWA. Honorary Research Fellow, Telethon Kids Institute

Parental Infant Feeding Intervention (PIFI)

Investigators

- Dr Roslyn Giglia¹
- Bruce Maycock²
- Jane A Scott²
- Yvonne L Hauck²
- Sharyn K Burns²
- Suzanne Robinson²
- Satvinder Dhaliwal²
- Peter A Howat²
- Colin W Binns²

¹Telethon Kids Institute, The University of Western Australia, Perth, Australia

² School of Public Health, Curtin University, Perth, Australia

Project summary

The choice to breastfeed and how long a woman breastfeeds her baby most often depends on the father's attitude and preference for breastfeeding. This study will investigate if supporting fathers during the period of breastfeeding can prolong breastfeeding in the mother. Three different ways of supporting the fathers will be trialled in three different groups of fathers including the use of a mobile phone app specific to fathers.

Project aims

Very few Australian infants are exclusively breastfed to 6 months as recommended by the World Health Organization. There is strong empirical evidence that fathers have a major impact on their partner's decision to breastfeed and continuation of breastfeeding. Fathers want to participate in the breastfeeding decision making process and to know how they can support their partner to achieve their breastfeeding goals. The aim of the Parent Infant Feeding Initiative (PIFI) is to evaluate the effect on duration of any and exclusive breastfeeding of three breastfeeding promotion interventions of differing intensity

and duration, targeted at couples but channelled through the male partner. The study will also undertake a cost-effectiveness evaluation of the interventions.

The PIFI study is a factorial randomised controlled trial. Participants will be mothers and their male partners attending antenatal classes at selected public and private hospitals with maternity departments in Perth, Western Australia. Fathers will be randomly allocated to either the usual care control group (CG), one of two medium intensity (MI1 and MI2) interventions, or a high intensity (HI) intervention. MI1 will include a specialised antenatal breastfeeding education session for fathers with supporting print materials. MI2 will involve the delivery of an antenatal and postnatal social support intervention delivered via a smartphone application and HI will include both the specialised antenatal class and the social support intervention. Outcome data will be collected from couples at baseline and at six and 26 weeks postnatal. A total of 1600 couples will be recruited.

The PIFI study will be the first Australian study to provide Level II evidence of the impact on breastfeeding duration of a comprehensive, multi-level, male-partner-focused breastfeeding intervention. Unique features of the intervention include its large sample size, delivery of two of the interventions by mobile device technology, a rigorous assessment of intervention fidelity and a cost-effectiveness evaluation.

What happened in 2015

The Milk Man app was finalised for use as part of the MI2 and HI intervention. By the end of 2015 344 couples had been recruited to the study and recruitment questionnaire response rates were maintained at ~70% for mothers and fathers.

There has been an overwhelmingly positive response to the app and fathers have been using it widely and regularly. The protocol paper published in 2015 (Maycock et al. BMC Pregnancy and Childbirth (2015) 15:159 DOI 10.1186/s12884-015-0601-5) was highly cited.

Project funder

Healthway Health Promotion Research Grant
(No: 24023)



External collaborators

- * Curtin University – Bruce Maycock, Jane A Scott, Yvonne L Hauck, Sharyn K Burns, Suzanne Robinson, Satvinder Dhaliwal, Peter A Howat, Colin W Binns

Australian FASD Diagnostic Instrument: Feasibility Trial and Implementation

Investigators

- Professor Carol Bower¹
- Professor Elizabeth Elliott²
- Dr Rochelle Watkins¹

¹Telethon Kids Institute, The University of Western Australia, Perth, Australia

²University of Sydney, Sydney Children's Hospital Network (Westmead)

Project staff

Juanita Doorey

Project summary

The Australian FASD Diagnostic Instrument and a draft Guide for its use were completed in 2012. In 2014-2015 the Telethon Kids Institute, in collaboration with the University of Sydney, was contracted by the Commonwealth Department of Health to conduct a feasibility trial of the Instrument and Guide prior to national implementation.

Project aims

The associated aims of the project are that implementation of the Diagnostic Instrument and Guide will promote timeliness and consistency in diagnosis and will help estimate the prevalence of FASD in Australia. This in turn will improve the evidence base for prevention, diagnosis, management and advocacy for improved services and supports.

What happened in 2015

Sixteen paediatricians from across Australia took part in the feasibility trial. They worked in metropolitan, regional and remote locations and clinical settings that included specialised FASD clinics, child development services and general and developmental paediatric practices. Based on clinicians' evaluation from the trial, changes were made to the Instrument and Guide.

Parents/guardians of children being assessed during the feasibility trial were invited to

provide feedback on the diagnostic assessment process, with a small number electing to do so.

A Guide and five on-line training modules were developed to assist doctors in using the Instrument. The Instrument, Guide and training modules will be freely accessible on the Telethon Kids Institute website.

Information and an electronic link to the website will be sent to professional colleges and a wide range of other organisations in Australia.

A draft final report, with the Guide, Instrument and on-line training modules, was submitted to the Commonwealth Department of Health in December 2015. After consideration of the new Canadian FASD Guidelines (which were published in December 2015), and changes if needed, the Australian resources will be widely disseminated in mid-2016.

Project funder



The
Department
of Health

External collaborators

- The University of Sydney; Sydney Children's Hospital Network (Westmead) – Professor Elizabeth Elliott, Dr Marcel Zimmet
- NOFASD Australia – Vicki Russell
- Expert Review Panel & Steering Group: Professor Carol Bower, Professor Elizabeth Elliott, Mr Scott Avery, Dr Felicity Collins, Dr Jennifer Delima, Dr James Fitzpatrick, Ms Andrea Lammel, Ms Vicki Russell, Dr Doug Shelton, Dr Lydia So, Dr David Thomas, Dr Amanda Wilkins, Dr Marcel Zimmet

Evaluating the evidence-practice gap between the NHMRC alcohol and breastfeeding guideline (2009), clinician application and maternal uptake

Investigator

- Dr Roslyn Giglia¹

¹Telethon Kids Institute, The University of Western Australia, Perth, Australia

Project summary

Despite wanting to breastfeed many Australian women also want to return to drinking alcohol after the birth of their baby. Drinking alcohol is the cultural norm in Australia but alcohol in breastmilk can disrupt the hormones needed to successfully breastfeed. This results in the baby receiving less breastmilk and being hungry and cranky and can often lead the mother to introduce infant formula to help settle her baby. This project will look at what doctors and nurses tell new mothers about drinking alcohol while they are breastfeeding so that they can provide supportive messages which allow a mother to drink and still safely breastfeed.

Background and aims of the project

In 2009 the National Health and Medical Research Council (NHMRC) released the revised 'Australian Guidelines to Reduce Health Risks from Drinking Alcohol'. A national first was the inclusion of an alcohol guideline exclusively for breastfeeding women (4B), and not merely as an add-on to the pregnancy guideline. The guideline recommended 'not drinking as the safest option' however practical advice for safe drinking was included in an effort to acknowledge that lactating women may cease breastfeeding in order to start drinking alcohol. Previous public health campaigns aimed at pregnant women have shown a marked effect on the reduction of alcohol consumption during pregnancy however

there has been no associated campaign for the period of breastfeeding despite continued alcohol consumption during this time.

With limited promotion of this guideline it is not known whether practitioners use this guideline in their daily practice and if a resulting decrease in maternal drinking and extended duration of breastfeeding has occurred in Australian women.

This project will use both qualitative and quantitative methods to investigate the awareness and utilisation of the alcohol guideline for breastfeeding women amongst maternal health practitioners and maternal consumers. Obstetricians, general practitioners, midwives, child health nurses and paediatricians will be the primary target group of maternal health practitioners as they most often answer questions relating to breastfeeding in the early days following the birth of a child.

An educational campaign for the maternal health practitioners will be evaluated to see if any changes in their knowledge and behaviour (i.e. utilisation) of guideline 4B resulted from the education campaign. A secondary target group is breastfeeding women. Their knowledge and awareness of guideline 4B and use of educational resources relating to this guideline will be assessed following an education campaign tailored to their level of knowledge, awareness and behaviour regarding alcohol consumption during lactation.

What happened in 2015

Key stakeholders from all stakeholder groups were engaged to develop an on-line survey to investigate practice around the alcohol and breastfeeding guideline. Focus groups were conducted with mothers to gain insight into their understanding of the guideline and their practice of drinking alcohol and breastfeeding.

Project funder

NHMRC Translating Research into Practice
Fellowship



Critical Review of FASD Literature and Report to the National Disability Insurance Agency

Investigators

- Angela Dudley¹
- Tracy Reibel¹
- Carol Bower¹
- James Fitzpatrick¹

¹Telethon Kids Institute, The University of Western Australia, Perth, Australia

Project summary

The NDIA identified FASD as an important category of disability for consideration within the National Disability Insurance Scheme (NDIS).

The report considered:

- Assessment, diagnosis and planning interventions for FASD
- Map of FASD impairments and indicative assessments across the lifecourse
- Types of disability supports, services and interventions required across the lifecourse
- *Best practice programs* that met criteria regarding research design quality, impacts, specificity and replicability.
- *Emerging programs* that have some evidence to support effectiveness in terms of content or delivery.

Peer reviewed and grey literature, organisational networks and websites were reviewed and disability services were consulted.

A FASD Expert review panel provided their feedback and comments on all aspects of the project.

What happened in 2015

A critical review of the literature was conducted to identify the domains of impairment and how these impact on daily functioning, and, the services and supports

required to ensure those with FASD are afforded opportunities to participate in education, employment and social activities.

Literature was evaluated using a valid evaluation framework – both quantitative and qualitative studies were included.

The evaluation demonstrates effectiveness for people with FASD for an outcome related to living independently and/or participation in daily life.

The evaluation was assessed to be of sufficient quality, using a validated assessment checklist.

As with other disabilities, outcomes for people with FASD can be improved through early diagnosis, early intervention, and a life course approach to improving function and participation (See Figure on page 28 of this report).

The report was submitted to NDIA in September 2015 and it will be published on the NDIA website.

Project funder



Acknowledgements

The authors wish to acknowledge the following members of the Expert Review Panel who contributed to this work:

Lynne Adamson, Heather Carmichael Olson, Elizabeth Elliott, Denise Luscombe, Raewyn Mutch, Carmela Pestell, Vicki Russell, Doug Shelton, Sven Silburn, Rachel Skoss, Claire Townsend, Robyn Williams, Amanda Wilkins, and Marcel Zimmet

MAP OF FASD IMPAIRMENTS & INDICATIVE ASSESSMENTS ACROSS THE LIFE COURSE

Emerging impairments affect ability to participate in activities - activity limitations lead to participation restriction (WHO - ICF)

Each individual affected by FASD has a **unique neurocognitive profile** determining their degree of executive and adaptive functioning impairment; requiring assessment to determine the types of interventions required to improve activity participation



Australian FASD Clinical Network

The Network was established by Dr James Fitzpatrick in 2015 and has 18 members:

- 15 lead clinicians/directors of clinical services
- 2 national community/stakeholder representatives
- 1 Honorary international representative

Purpose

The purpose of the Network is to coordinate, expand capacity and standardise our approach to FASD referral, diagnosis, management and support in Australia.

Terms of Reference (TOR)

Members developed TOR for the Network:

- To provide collegiate support in establishing and expanding FASD diagnostic services.
- To standardise our approach to assessment, diagnosis, data management, therapy and ongoing support.
- To provide opportunity for national and international collaboration in clinical research.
- To standardise the definitions of training related to FASD education and continuing professional development.
- To provide support for the development of continuing professional education tools for use by health professionals in Australia.
- To support the national accreditation of continuing professional development in FASD.
- To support workforce development in FASD assessment, diagnosis and therapy.
- To contribute to research in FASD assessment, diagnosis and therapy.
- To contribute to the development and maintenance of regional and national FASD databases.

Criteria for membership of the Australian FASD Clinical Network

Members agreed to 3 membership categories:

1. Lead clinicians/directors of an established clinic/service who are actively involved in FASD diagnosis. These clinics/services will also be:
 - a) multidisciplinary in nature
 - b) providers of training in FASD diagnosis, management and support
 - c) Involved in the collection of FASD diagnostic data that can contribute to a national FASD database.
2. Researchers who are actively involved in FASD research activity in diagnosis, management and support in collaboration with an established FASD clinic/service.
3. Consumer/community/policy members who represent and advocate in the interest of individuals, carers and families of those with FASD.

What happened in 2015

The Network held 3 meetings in 2015 and submitted an application for a NHMRC Project Grant to evaluate the effectiveness of evidence-based FASD interventions, compared with standard care, to improve self-regulation and executive functioning in children with FASD aged 5-15 years and to improve caregiver wellbeing and reduce caregiver stress. This trial will be within a network of four established Australian FASD diagnostic clinics.

Project funder

There is no funding attached to the Network.

Australian FASD Clinicians Forum

The Clinicians Forums commenced in 2014 and currently has over 150 people who have attended one or more forums.

Purpose

To provide an opportunity for health professionals to discuss current issues related to FASD diagnosis and therapy interventions

The forum is open to any health professionals interested in FASD assessment – paediatricians, geneticists, psychiatrists, psychologists, occupational therapists, speech pathologists and physiotherapists.

There has also been interest from people working with children and young people and their families such as social workers, child protection and corrections staff, disability sector workers and some non-government organisations.

What happened in 2015

In 2015 there was only 1 forum, however there was significant interest in training for health professionals and many workshops were held across WA in 2015 (see pages 32-36 of this report) .

Project funder

There is no funding attached to the clinical forums.

2015 Success

Theses passed

| Name | Theses |
|-------------------|--|
| James Fitzpatrick | PhD University of Sydney The Lililwan Project: Prevalence of FASD among school aged children in the Fitzroy Valley |
| Ester Elisaria | PhD Curtin University. A Cohort Study of Feeding Patterns and Health Outcomes of Infants in the Rufiji District of Tanzania (Supervisor Roslyn Giglia) |

Awards and Prizes

| Name | Award/Prize |
|-------------------|--|
| Carol Bower | Distinguished Service Award, International Clearinghouse for Birth Defects Surveillance and Research |
| James Fitzpatrick | Royal Australian College of Physicians (RACP) Wiley New Investigator Award |
| James Fitzpatrick | Asia Pacific Society Alcohol and Addiction Research best oral presentation |
| Heather Jones | Consumer and Community Participation Award |

External Committees

International

| Name | Committee |
|-------------------|--|
| James Fitzpatrick | International FASD Conference Scientific Committee 2015 |
| Carol Bower | International Clearinghouse for Birth Defects Surveillance and Research Nominating Committee |

National

| Name | Committee |
|---------------------------|--|
| Carol Bower, Raewyn Mutch | National FASD Technical Network 2014-2015 |
| Carol Bower | National Perinatal Epidemiology Statistics Unit Steering Committee for Congenital Anomalies. 2012 - 2015 |

| | |
|-------------------|--|
| Carol Bower | Australian Paediatric Surveillance Unit Scientific Review Panel. 2012 - 2015 |
| Carol Bower | Reference Group, Australian Indigenous Alcohol and Other Drugs Knowledge Centre 2014 – 2015 |
| James Fitzpatrick | Australian National Advisory Council on Alcohol and Drugs (expert member) 2014-2015 |
| Roslyn Giglia | Dietitians Association of Australia. Scientific and Social Planning Committee, Perth National Conference 2014 - 2015 |
| Roslyn Giglia | NHMRC Postgraduate Scholarships Review Panel 2015 |
| Roslyn Giglia | Department of Health Western Australia – Breastfeeding Key Stakeholders Group 2014 - 2015 |

Local

| Name | Committee |
|-----------------|--|
| Carol Bower | Alcohol Advertising Review Board. Panel member for the Review Board. 2012 - 2015 |
| Jan Payne | Alcohol Advertising Review Board. Panel member for the Review Board. 2012 – 2015 |
| Kaashifah Bruce | Public Health Association of Australia WA Branch 2015 Committee member |

Invited Presentations

International (abstracts submitted and subject to review)

| Names (Presenter/s) | Conference |
|---|---|
| Heather Jones, Raewyn Mutch | Developing FASD educational interventions for justice professionals. FASD & The law: Continuing the conversation about current research, best practices & ethical considerations. Vancouver March 2015. |
| Heather Jones, Raewyn Mutch, Rochelle Watkins, Carol Bower | What did the community and justice professionals want in FASD educational resources. 6 th International Conference on FASD Research: Results and Relevance 2015, Vancouver March 2015 |
| Jan Payne, Heather Jones, Rochelle Watkins, Tracy Reibel, Raewyn Mutch, Amanda Wilkins, Julie Whitlock, Carol Bower | Midwives' knowledge, attitudes and practice. 6 th International Conference on FASD Research: Results and Relevance 2015, Vancouver March 2015 |
| James Fitzpatrick, Heather Carmichael Olsen | The Lililwan project: Neurodevelopmental outcomes and FASD in remote Australia. 6 th International Conference on FASD Research: Results and Relevance 2015, Vancouver March 2015 |

| | |
|---|---|
| <i>James Fitzpatrick, Maureen Carter</i> | "It's like herding cats" Patches Paediatrics – establishing FASD diagnostic and management capacity in remote Australian communities. 6 th International Conference on FASD Research: Results and Relevance 2015, Vancouver March 2015 |
| <i>James Fitzpatrick, Maureen Carter, June Oscar, Kaashifah Bruce, Bree Wagner, Carolyn Hartness, Elizabeth Elliott</i> | The Marulu Strategy: 'Making FASD History' in Remote Aboriginal Communities. 6 th International Conference on FASD Research: Results and Relevance 2015, Vancouver March 2015 |

National (invited)

| Name/s | Conference |
|---------------------|---|
| <i>Carol Bower</i> | Primary prevention of birth defects. Maternal, Child and Family Health Nurses Conference. Perth, Australia, 2015. |
| <i>Raewyn Mutch</i> | Correctional Services Healthcare Summit. Melbourne, Australia, September 2015 |

National (abstracts submitted and subject to review)

| Name | Conference |
|--------------------------|--|
| <i>Carol Bower</i> | Addressing Fetal Alcohol Spectrum Disorders in Western Australia. 4 th APSAAR/5 th IDARS Conference. Sydney, Australia, August 2015 |
| <i>James Fitzpatrick</i> | The Lililwan Project: neurodevelopmental outcomes and FASD in remote Aboriginal Australian children. 4 th APSAAR/5 th IDARS Conference. Sydney, Australia, August 2015 |
| <i>Heather Jones</i> | Developing FASD resources for justice professionals. 4 th APSAAR/5 th IDARS Conference. Sydney, Australia, August 2015 |
| <i>James Fitzpatrick</i> | The Lililwan Project: neurodevelopmental outcomes and FASD in remote Aboriginal Australian children. APSAD Annual Scientific Alcohol and Drug Conference, Perth, Australia, November 2015 |
| <i>James Fitzpatrick</i> | The Marulu Strategy: Making FASD History in Remote Fitzroy Valley Communities. APSAD Annual Scientific Alcohol and Drug Conference, Perth, Australia, November 2015 |
| <i>James Fitzpatrick</i> | The Marulu Strategy: Making FASD History in Remote Fitzroy Valley Communities. APSAD Annual Scientific Alcohol and Drug Conference, Perth, Australia, November 2015 |
| <i>Heather Jones</i> | Developing FASD resources for justice professionals. APSAD Annual Scientific Alcohol and Drug Conference, Perth, Australia, November 2015 |
| <i>Carol Bower</i> | Research in a Corrective Setting: A lesson in protocol development and procedures to conduct a prevalence study of FASD in a juvenile detention centre. APSAD Annual Scientific Alcohol and Drug Conference, Perth, Australia, November 2015 |

Jacinta Freeman Have you talked to ... about your FASD project. APSAD Annual Scientific Alcohol and Drug Conference, Perth, Australia, November 2015

Local (invited)

| | |
|--------------------------|--|
| Name/s | Conference |
| <i>James Fitzpatrick</i> | Keynote Address. Making FASD History in the Fitzroy Valley. The Marulu Strategy 2013-2018. <i>Western Australian Aboriginal Maternal and Child Health Conference</i> , Perth, Western Australia. 13 May 2015 |
| <i>Carol Bower</i> | Alcohol & Pregnancy & FASD Research at the Telethon Kids Institute. Western Australian Aboriginal Maternal and Child Health Conference, Perth, Western Australia. 13-14 May, 2015 |
| <i>Raewyn Mutch</i> | <u>M.E.R.C.Y@Justice</u> Fetal Alcohol Spectrum Disorder: Sharing Solutions. Institute of Advanced Studies, UWA. Perth, Australia. August, 2015 |
| <i>Natalie Kippin</i> | Curtin University Speech Pathology Ideas Night 19 August 2015 |

Workshops and training

| | |
|---|--|
| Name | Event |
| <i>Heather Jones</i> | 3 rd year nurses Notre Dame University. 16 March 2015 |
| <i>Heather Jones</i> | UWA Law Students FASD and implications for law - part of the Birth Life & Death & the Law lectures. 26 March 2015 |
| <i>Roslyn Giglia</i> | Telethon Kids Institute. Public lecture series. Growing healthy kids through good food. 22 April 2015 |
| <i>Raewyn Mutch, Heather Jones</i> | Juvenile & Family Fire Awareness (JAFFA) Program. Fire and Emergency Services. Perth. June 2015 |
| <i>Raewyn Mutch, Heather Jones</i> | WA Branch Australian Psychological Society Seminar on FASD. Perth. June 2015 |
| <i>Raewyn Mutch, Heather Jones, Jacinta Freeman</i> | Boronia Pre-Release Centre. Women's Education Program. Perth. June 2015. |
| <i>Carol Bower</i> | Maternal and early childhood health. Healthy Futures Forum. Great Southern Science Council. Albany, Western Australia, July, 2015. |

| | |
|---------------------------------------|--|
| <i>Carol Bower, Desiree Silva</i> | Supportive environment for a health start to life. Wheat Belt Early Years Conference. Kellerberrin, Western Australia, August, 2015. |
| <i>Heather Jones, Hayley Passmore</i> | FASD Presentation. Women's Council Training Day. Perth. September 2015 |
| <i>Tracy Reibel, Heather Jones</i> | Outcomes midwives survey and AUDIT-C project and FASD. WACHS Esperance. September 2015. |
| <i>Heather Jones, Hayley Passmore</i> | Understanding FASD. Ability Centre. Perth, Western Australia. October 2015. |

Research Impact

ACTIVE research collaborations

| Name | Organisation |
|------------------------------|---|
| Elizabeth Elliott | University of Sydney |
| Nancy Poole | British Columbia Center of Excellence for Women's Health and CANFASD, Canada (Kimberley and Pilbara FASD prevention projects) |
| Dan Goldowitz | Chair of the Research Management Committee. NeuroDevNet, a Canadian Network of Centres of Excellence |
| Claire Collins | University of Newcastle, Newcastle, NSW Australia; Roslyn Giglia Associate Investigator 2015 |
| Helen Skouteris | Deakin University, Melbourne, Victoria, Australia; Roslyn Giglia Associate Investigator 2015 |
| Deb Costello | Injury Control Council of WA. Alcohol and Pregnancy Peer Education Program Jan Payne and Heather Jones 2012- 2015 |
| Gary Kirby and Michelle Gray | WA Government Drug and Alcohol Office |
| Mike Daube | McCusker Centre for Action on Alcohol and Youth |

ACTIVE involvement in research networks

| Name | Network |
|---------------------------|---|
| Heather Jones (Member) | National Organisation for Fetal Alcohol Spectrum Disorders Australia. Australian & New Zealand FASD Practice Consortium 2013-2015 |
| James Fitzpatrick (Chair) | Australian FASD Clinical Network |

ACTIVE involvement with the community (eg. committees, boards, councils)

| Name | Organisation |
|-------------------|---|
| Heather Jones | Consumer and Community Advisory Council |
| James Fitzpatrick | Marulu Leadership Team |
| | All AAP&FASD projects have involvement with consumers and members of the community through Steering Groups and Reference Groups |
| Kaashifah Bruce | Public Health Association of Australia (WA Branch) Committee |

Reports provided for government

| Name | Organisation |
|---|--|
| Angela Dudley, Tracy Reibel, Carol Bower, James Fitzpatrick | Report to the National Disability Insurance Agency Critical Review of the Literature: Fetal Alcohol Spectrum Disorders |
| Telethon Kids Institute | Submission to the House of Representatives Standing Committee on Indigenous Affairs Inquiry into harmful use of alcohol in Aboriginal and Torres Strait Islander Communities + appearance at the hearing in Perth http://www.aph.gov.au/Parliamentary_Business/Committees/House/Indigenous_Affairs/Alcohol/Submissions |

Translation

Marulu Strategy

The Marulu FASD Strategy conducted in the Fitzroy Valley includes prevention, diagnosis, and therapy/support interventions to address FASD. The broader aim of this Strategy is to develop a sustainable model for the Pilbara, Derby, and other Western Australian communities as well as offering support to additional communities/regions expressing a need for establishing a similar model. Encouragingly, translation of this research has commenced in the Pilbara and Kimberley with stakeholder engagement underway in Derby, as well as the initiation of two programs: the Hedland FASD Project and the Pilbara FASD Prevention Strategy.

A health promotion DVD and training package is being developed which will be used to disseminate research findings and provide a template for implementing FASD strategies in other communities. Application of the FASD Strategy to the metropolitan/non-Aboriginal community context will also be progressed and the outcomes of these research initiatives will contribute to influencing national health policy, namely inclusion of the model in the National FASD Action Plan.

FASD Resources for justice professionals

Our previous research with justice professionals identified what they knew about FASD, how this impacted on their work, what information they required and how this information should be delivered. The next phase of our work translated this research into practical educational resources for justice professionals

Changes to clinical practice

Australian FASD Diagnostic Instrument

In 2015 the Australian FASD Diagnostic Instrument, Guide and on-line training modules for health professionals were developed in consultation with Australian clinicians. The availability of the Diagnostic Instrument, the Guide and the on-line training modules (in 2016) to support clinicians to make a FASD diagnosis using the national standardised diagnostic criteria and instrument will provide the foundation to improve rates of diagnoses of FASD in Australia. The resources will promote timeliness and consistency in diagnosis and will help estimate the prevalence of FASD in Australia. This in turn will improve the evidence base for prevention, diagnosis, management and advocacy for improved services and supports.

AUDIT-C

The AUDIT-C alcohol use in pregnancy screening tool is a robust three item questionnaire used to identify people drinking at hazardous levels or with alcohol use disorders and was chosen as the most appropriate measure of alcohol consumption drinking during pregnancy in the Fitzroy Valley. In collaboration with senior Kimberley Population Health Unit/WA Country Health Service staff including the Director (Kimberley Population Health Unit), the KPHU Maternal and Child Health Coordinator, the Director of Nursing Fitzroy Valley Hospital and the Operations Manager Derby/Fitzroy Valley Health Service it was agreed that the AUDIT-C would be added as a test available in the Communicare medical record system that is widely used across the Kimberley (Fitzroy Valley, Derby Hospital, Halls Creek). The AUDIT-C appears as an alert in the Communicare system for midwives to complete at the first meeting with pregnant women. AUDIT-C data is collected relating to the 3 months before the recognition of pregnancy, and then subsequently once during each trimester.



Prevention



Diagnosis



Therapy & Management

