

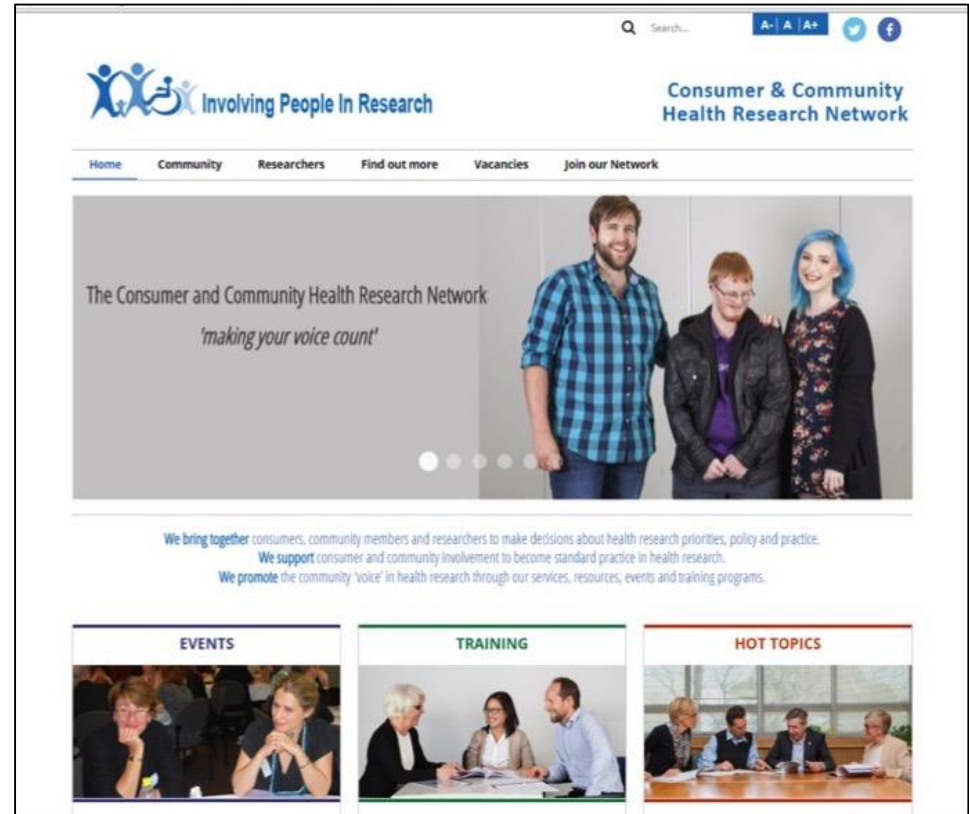
Fetal Alcohol Spectrum Disorder (FASD) Community Priority Setting Partnership for Research

Presenters: Anne McKenzie & Narelle Mullan


The Consumer and Community Health Research Network

Services provided

- Advocacy and support
- An evidence base
- Community links & networks
- Methods for involvement
- Resources
- Teaching and training



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 Involving People In Research

Consumer & Community Health Research Network

Home Community Researchers Find out more Vacancies Join our Network

The Consumer and Community Health Research Network
'making your voice count'

We bring together consumers, community members and researchers to make decisions about health research priorities, policy and practice.
We support consumer and community involvement to become standard practice in health research.
We promote the community 'voice' in health research through our services, resources, events and training programs.

EVENTS TRAINING HOT TOPICS

www.involvingpeopleinresearch.org.au

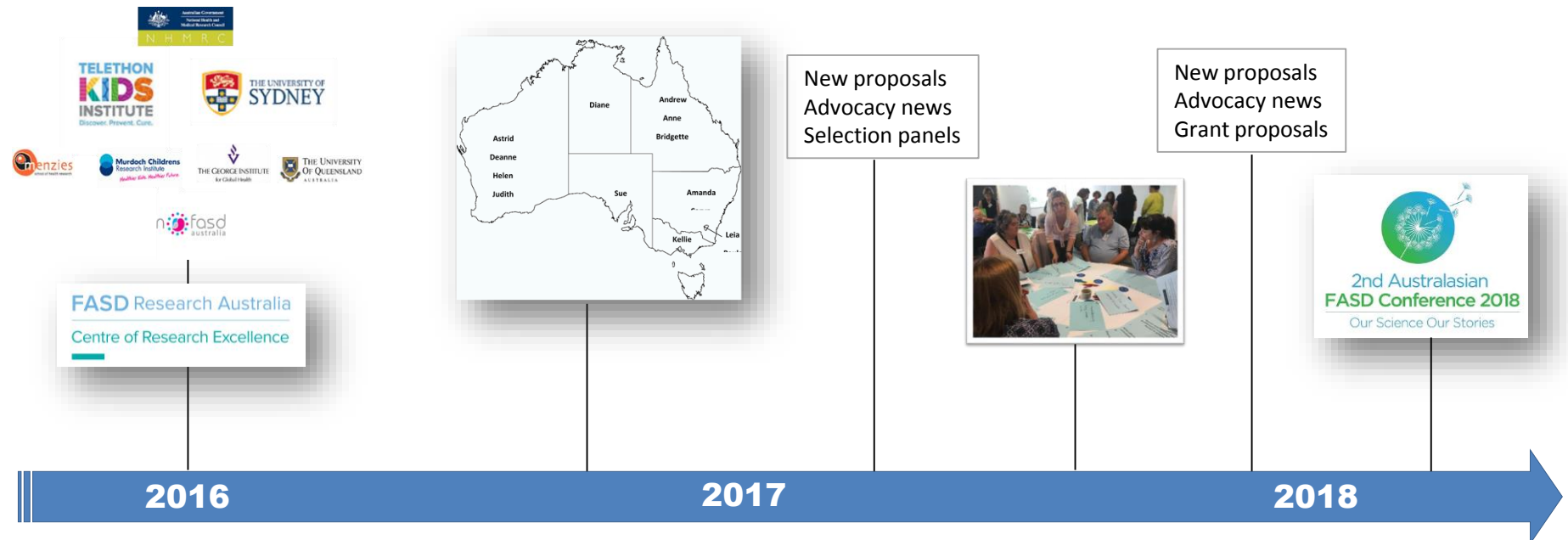
- 2450+ members registered
- 460+ community members on committees

FASD Research Australia 2016 – 2020

NHMRC Centre of Research Excellence that aims to

- Prevent alcohol use in pregnancy
- Decrease the incidence of FASD
- Improve FASD diagnostic & management capabilities

FASD Research Australia CRE has established a Community Reference Group consisting of 15 people across Australia



Problems in research



- To reduce mismatches in what gets researched, and what is useful to research
- To avoid waste in research



James
Lind
Alliance

Priority Setting Partnerships

The process we used



Results

Survey of priorities for research:

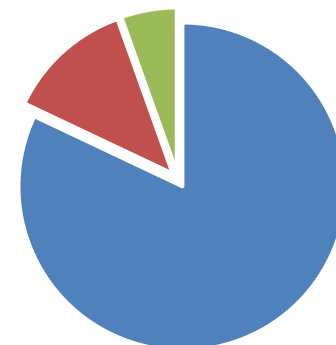
- 138 responses
- 29 themes identified

Ranking Survey to prioritise and condense themes:

- 45 responses
- 22 themes

Attendees included:

- **21 community members**
- **8 CCHR staff**
- **3 researchers**



Purpose of the consensus workshop

- To discuss, explore and identify issues for research about alcohol consumption during pregnancy and Fetal Alcohol Spectrum Disorder
- The themes from of the survey responses were used to shape the discussion
- Reach a consensus of top 10 priorities for future research



Consensus workshop process

Morning:

- Small group discussion – review and discussion of themes
- Whole group discussion – sharing feedback from small groups

Afternoon:

- Small group discussion – priority setting
- Whole group discussion – prioritising and agreeing on final top ten list



Top ten priorities for research

Indigenous research priorities:

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 professional's knowledge about alcohol in pregnancy
10. What is the best/most effective support for those with FASD?

Non-indigenous research priorities:

1. Changing society views and beliefs about alcohol use during pregnancy
2. Doctor and/or other health professional's 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?

Consensus reached!!



Acting on Project Outcomes

Prevention

Understanding behaviours

Society views

Public Health Campaign

Health professional knowledge
- non-judgmental support
- Trauma-informed care

Educating high school students



Diagnosis & Management

Training in Diagnosis

Identifying effective support

Training in support for people
with FASD

Supporting parents and
families

Links to research, practice and policy

2018

- Informing new activities
- Support for grant submissions
- Conference objectives
- Advocacy submissions
e.g. National Strategy for FASD

Short Term

- Inform Centre Review
- Members involved in new activities
- Key element of *Strategic Priority Framework* for FASD research in Australia

Long Term

- Priority Setting Process
an example for other research centres

Thank you ...

Project Team

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Survey Respondents

Workshop Participants

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