



## RESEARCH SUMMARY

### FASD Diagnostic Instrument Trial and Implementation

*Fetal Alcohol Spectrum Disorder (FASD) is characterised by brain damage from prenatal alcohol exposure, the effects are lifelong and may not be seen at birth.*

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### What was this research about?

In 2012, the Australian FASD Collaboration submitted a report to the Commonwealth Department of Health and Ageing on recommendations for a diagnostic instrument for FASD in Australia.

[Read about this project](#)

Prior to national implementation, the proposed diagnostic instrument for FASD in Australia and draft guide require expert review and piloting in the clinical environment to evaluate their feasibility, utility and appropriateness for the Australian context.

### What did we do?

- Developed an activity implementation plan
- Established a Steering Group and Expert Review panel to oversee implementation of the project and to provide expert advice on development and final review of the diagnostic instrument and Guide for its use

- Completed retrospective case reviews using the draft diagnostic instrument, with members of the Expert Review Panel making recommendations for revisions to the instrument and guidelines prior to the feasibility trial in a clinical environment
- Conducted a feasibility trial with clinicians from a range of settings (metropolitan, regional, rural, remote) to trial the diagnostic instrument across Australia.
- Parents and guardians of children undergoing diagnostic assessment were also invited to provide feedback on their experience of the diagnostic process and the resources for families
- Revised the diagnostic instrument and Guidelines based on the feedback from the trial and submitted a draft final report to the Commonwealth Department of Health (DoH) in December 2015.
- Due to the release of new Canadian FASD guidelines, the Australian Diagnostic Instrument was reviewed and a final report submitted to DoH in April 2016.

The Expert Review Panel decided to harmonise the Australian Instrument with the diagnostic subcategories recommended in the [Canadian Guidelines](#) and to accept the overarching diagnostic term of FASD and the diagnostic subcategories relating to the presence or absence of the three sentinel facial features.

#### Australian Diagnostic Subcategories

- FASD with three sentinel facial features (similar to the previous diagnostic category of Fetal Alcohol Syndrome)
- FASD with less than three sentinel facial features (which encompasses the previous diagnostic categories of Partial Fetal Alcohol Syndrome and Neurodevelopmental Disorder – Alcohol Exposed)

[Read the Australian Guide to the Diagnosis of FASD](#)

E-Learning modules to support the use of the Australian FASD Diagnostic Instrument and Guide were developed. Access the modules [here](#)

#### Who conducted this research?

Chief Investigators:

- Professor Carol Bower, Principal Senior Research Fellow Telethon Kids Institute
- Professor Elizabeth Elliott, Professor in Paediatrics and Child Health University of Sydney

Expert Review Panel and National Steering Group: [Read more about the Expert Review Panel and Steering Group](#)

Project Team:

- Dr Rochelle Watkins, Post –Doctoral Research Fellow
- Juanita Doorey, Senior Research Officer

#### How did consumers and the community participate in this research?

Consumers were involved in our earlier research to develop the diagnostic instrument, and this led to the development of guidelines for parents/carers relating to diagnosis.

Parents and guardians of children undergoing diagnostic assessment were invited to provide feedback on their experience of the diagnostic process and the resources for families.

Consumer representatives were members of the Steering Group and assisted us in providing resources to health professionals and families about diagnosis and management of FASD.

#### How will this research help?

The benefits of this research include:

- Improved diagnostic capacity
- Earlier diagnosis of children and therefore earlier interventions and better outcomes for children with FASD and their families
- Better understanding of how common FASD is in Australia and thus better evidence to advocate for prevention and therapy services

This project was funded the Commonwealth Department of Health.

#### Alcohol and Pregnancy & FASD Research Team at Telethon Kids Institute

We have a comprehensive program of research in partnership with community & stakeholders to achieve our goals of developing prevention strategies; building the capacity of health, justice and other professionals to recognise and diagnose FASD; and implementing and evaluating programs for children and young people with FASD and their families.

For information on alcohol & pregnancy, FASD, our research projects, resources and publications visit our website: [www.alcoholpregnancy.telethonkids.org.au](http://www.alcoholpregnancy.telethonkids.org.au)

There is no safe time or amount of alcohol to drink while planning a pregnancy, when pregnant and when breastfeeding which is why the Australian Guidelines state 'not drinking alcohol is the safest choice'.

