



FASD Hub Australia



Identifying the need

- Identified as a priority by the National FASD Technical Network chaired by Professor Elizabeth Elliott
- Key goal: to develop a one-stop shop for Australian FASD information that is evidence based
- Developed in 2017 by an alliance of organisations – University of Sydney, Telethon Kids Institute, NOFASD Australia, Menzies School of Health Research and FASD Clinical Network



Advisory Group

Professor Elizabeth Elliott AM, University of Sydney (Chair)

Professor Carol Bower, Telethon Kids Institute

Magistrate Catherine Crawford, Justice representative

Heather D'Antoine, Menzies School of Health Research

Louise Gray, NOFASD Australia

Narelle Mullan, FASD Research Australian Centre of Research Excellence

Sue Miers, Consumer & Community representative

Dave McNally, Australian Government Department of Health

Neil Reynolds, Consumer & Community representative

Assoc Prof Doug Shelton, Australian & New Zealand FASD Clinical Network

Sue Thomas, Education representative

Project Team

Heather Jones
Pete O'Malley



Funded by



Australian Government
Department of Health

Information for

- Health professionals
- Educators
- Justice professionals
- Researchers
- Service providers
- Parents & carers
- People living with FASD
- Policy makers



Informing development

- 90 plus individuals and organisations consulted
- Workshops with parents & carers
- Interviews with parents & carers, health professionals, researchers, government and policy makers
- Informed development of key user journeys, functional design and content
- Content developed by the Project Team with advice from a Working Group and key stakeholders





Videos produced by the FASD Hub

- Overview FASD in Australia
- Challenges and strengths
- Michael and Lina's story
- Jazpa's story
- Diagnosing FASD
- A doctor's story
- Journey to diagnosis
- Managing FASD

<https://www.fasdhub.org.au/fasd-information/understanding-fasd/fasd-hub-videos/>



What can you find

- What is FASD?
- Living with FASD
- Alcohol use in pregnancy
- Common myths
- Preventing FASD
- Diagnosing FASD
- Managing FASD
- Videos
- Resources
- Training opportunities
- Service directory
- Research
- Publications
- Latest news
- Support groups

<https://www.fasdhub.org.au/>



FASD Hub Australia

Find information on Fetal Alcohol Spectrum Disorder (FASD) for Australian health professionals, teachers, justice professionals, service providers, researchers or parents and carers.

Watch video: FASD in Australia ▶

Evaluation 2017

- Most responders to the online survey were health professionals (54%) and parents/carers (33%)
- Majority of participants found the website:
 - easy or very easy to use
 - met their needs very well or extremely well
 - trustworthy and evidence-based
- Top 3 sections
 - Understanding FASD
 - Managing FASD
 - Assessment & diagnosis



Evaluation – new content requested

- Series of targeted fact sheets
- User-friendly diagram of referral/assessment process
- More detailed information on alcohol use in pregnancy
- More detailed information on behaviours, managing extreme or inappropriate behaviours
- Stories or videos about the behavioural challenges, to balance the more positive stories the FASD Hub website currently has
- Information relevant to adult diagnosis and management
- Content appropriate for CALD and Indigenous communities



What have we done in 2018?

Outcome #1

- Established 30-member Subject Matter Editorial Panel (SMEP) comprising diverse skills and knowledge:
 - lived experience of person with FASD or caring for a person with FASD
 - health and other professionals, researchers in the field of alcohol and pregnancy and FASD and policy makers

Improving Accessibility

Outcome #2 Disability access

- Conducted an independent audit followed by technical improvements to the Hub
- Hub now meets international WCAG2.0AA accessibility standards

Outcome #3 CALD access

- Culturally and linguistically diverse (CALD) communities are now provided *free* access to a telephone interpreter service
- Fact Sheet developed and will be translated into 12 top languages spoken at home in Australia
- Working with Aboriginal Interpreter Services to identify appropriate services across Australia

Developing new content

Outcome #4

- Additional information on alcohol and pregnancy
- New infographic on the assessment & diagnostic process
- Information on managing complex behaviours
- Information on dual diagnoses
- Australian language guide

Australian Guide to the Diagnosis of FASD

Outcome #5

- The primary location for the Guide is now the FASD Hub – to allow monitoring of use and single authoritative site
- 900+ page views in October – the most visited page on the website
- The Guide and eLearning modules are currently being evaluated – get more information from the FASD Hub display table

Other outcomes

Outcome #6

- Quarterly E-Newsletter
- Social media channels on Facebook and Twitter
- FASD Hub promoted at 11+ conferences & workshops in Australia and internationally

Outcome #7

- Dedicated section for Indigenous research and resources

Growing success



Most popular pages

- Australian Guide to the diagnosis of FASD
- Videos
- Understanding FASD
- What is FASD

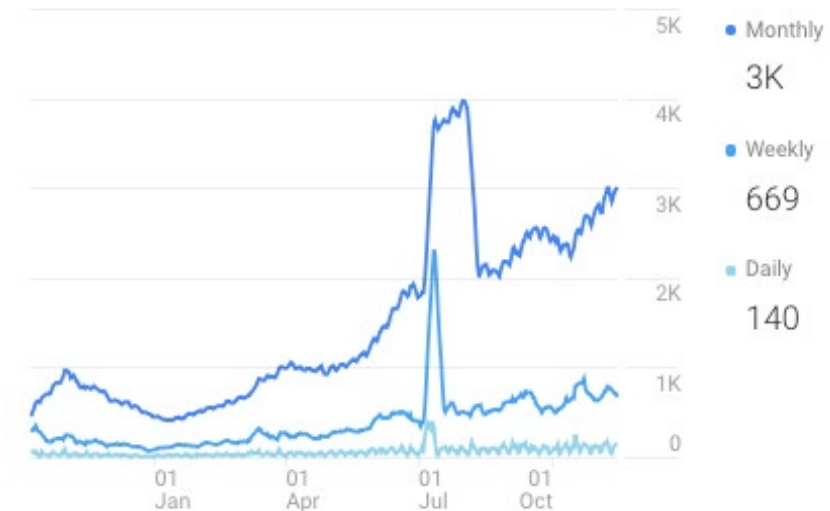
460% increase in web visits (since Nov2017)

700+ visitors to Hub every week

323 pages viewed every day

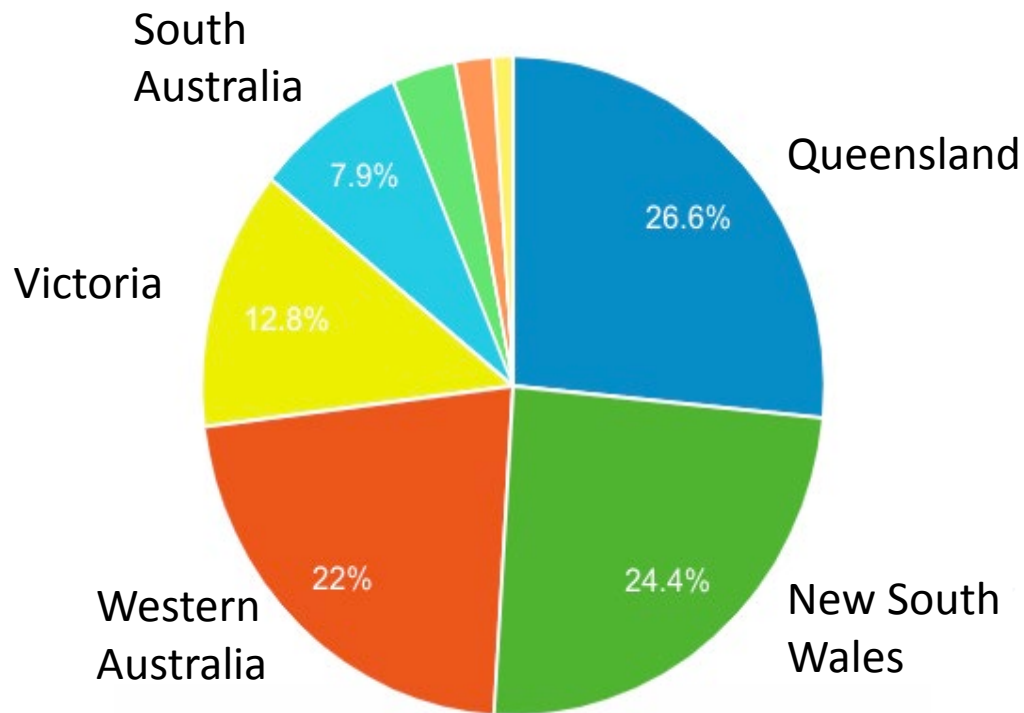
Other facts

- 68 major Australian websites linking to the Hub
- 74% accessing Hub on their desktop or laptop showing it's a resource in the office or home



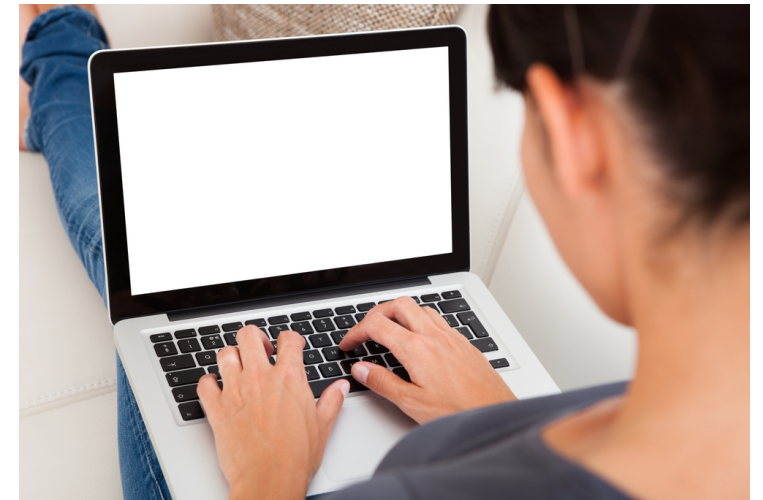
Audience

- 79% female
- 54% in 22 – 44 year age demographic
- 96% from Australia



Evaluation 2018

- Come to our display table – complete the survey online or via a hard copy
- We will also be conducting short interviews with people to get more in-depth feedback
- Evaluation survey closes at the end of November



Contact:

Heather Jones

E: heather.jones@telethonkids.org.au

P: 08 6319 1824 / 0417 068 601



Follow FASD Hub on:



Pete O'Malley

E: peter.omalley@sydney.edu.au

P: 0419 670 078