

## **Fetal Alcohol Spectrum Disorder Australian Registry: paediatric research informing policy and practice**

Melissa Mei Yin Cheung<sup>1,2</sup>, Marcel Zimmet<sup>3</sup>, Elizabeth J Elliott<sup>1,2</sup>

<sup>1</sup>*The University of Sydney Children's Hospital Westmead Clinical School, Discipline of Child and Adolescent Health, Faculty of Medicine and Health, The University of Sydney, Westmead, Australia;* <sup>2</sup>*Australian Paediatric Surveillance Unit, Kids Research, Sydney Children's Hospitals Network, Westmead, Australia;* <sup>3</sup>*Royal Far West, Manly, Australia*

**Presenters' emails:** [melissa.cheung@sydney.edu.au](mailto:melissa.cheung@sydney.edu.au), [elizabeth.elliott@health.nsw.gov.au](mailto:elizabeth.elliott@health.nsw.gov.au)

**Introduction and Aims:** While fetal alcohol spectrum disorder (FASD) is a significant public health concern with substantial human, social and economic costs, it remains poorly understood and recognised with limited information regarding FASD in the Australian population. The FASD Australian Registry (FASDAR) aims to support collection of national FASD data to inform service delivery, evaluation of treatments, and policy development for FASD.

**Methods:** Within the FASDAR, the Australian Paediatric Surveillance Unit (APSU) conducts national FASD surveillance, collecting de-identified sociodemographic and FASD health data about children aged under 15 years diagnosed with FASD from clinicians using a standardised case report form.

**Key Findings:** During the 5-year period of January 2015 to December 2019, the APSU was notified of 616 confirmed cases of FASD in children under the age of 15. Of these, 110 (18%) were diagnosed with FASD with 3 sentinel facial features and 506 (82%) were diagnosed with FASD with less than 3 sentinel facial features. The median age of diagnosis was 8.4 years (range 1 day–14.96 years), with the majority of the sample being male (68%), Aboriginal and/or Torres Strait Islander (56%), in foster care (46%), and have been under the care of community or child protection services at any time (74%). Cases were largely in Western Australia (37%), Queensland (26%), and New South Wales (20%).

**Discussion and Conclusions:** The FASDAR is the only mechanism monitoring the incidence of FASD in Australia. Our findings demonstrate that FASD is present in all parts of Australia and certain populations may be at a higher risk.

**Disclosure of Interest Statement:** This study and MMYC are supported by the Australian Government Department of Health Fetal Alcohol Spectrum Disorder Australian Registry Grant. EJE is supported by a National Health and Medical Research Council Centre of Research Excellence Grant (1110341) and Medical Research Futures Fund Next Generation Fellowship (1021480).