Senate Inquiry into Effective approaches to prevention, diagnosis and support for Fetal Alcohol Spectrum Disorder

We provide responses to questions on notice and additional information requested on notice in relation to evidence provided by teleconference with the Senate Inquiry Committee members on 19 May 2020 by FASD Research Australia - the NHMRC Centre of Research Excellence, represented by Professor Elizabeth Elliott, Dr Hayley Passmore, Professor Carol Bower (5 June 2020).

Additional information on notice

International and Australian evidence of the economic burden of FASD.

International research provides an indication that the costs associated with FASD are extensive. For example, the total cost of FASD in Canada in 2013 was conservatively estimated at $CND 1.8 billion (Popova et al., 2015). This estimate considered direct costs associated with medical and health services, law enforcement, children and youth in care, special education, supportive housing, long-term care, prevention and research, and indirect costs such as productivity losses due to increased morbidity and premature mortality. Productivity losses were the highest contributor at 41% of the total costs, followed by corrective services at 29%, and health care at 10%. Further investigation into the economic burden in Australia is needed as outlined below in a summary project proposal.

The need for funding for an economic analysis of FASD in Australia

FASD is a neurodevelopmental disorder caused by prenatal exposure to alcohol, and is the most common preventable cause of intellectual disability in high income countries. FASD can have profound effects on learning and behaviour, and is associated with disengagement from school and vocational endeavours, and increased risk of contact with the justice and child protection systems. Given the pervasive impact of alcohol on the developing fetus, individuals with FASD are also at risk of multiple physical and mental comorbidities. Accordingly, the burden for individuals living with FASD and their families is immense. Previous work in the US, Canada, and New Zealand has identified substantial costs attributable to FASD, including the provision of special education, healthcare services, productivity losses, and justice-system costs. A detailed estimation of the economic burden of FASD in Australia is crucial to identify potential cost-savings of prevention approaches and highlight opportunity for reallocation of resources to reduce the immense social and economic impact of the condition.

This can be achieved through identifying the health and life outcomes among individuals notified with fetal alcohol spectrum disorder to the Western Australian Register of Developmental Anomalies, and linked to state data on mortality, hospital morbidity, intellectual disability, education, child protection and justice in Western Australia. This data linkage capability in WA provides a unique opportunity to understand the associations between FASD and adverse outcomes across health, child protection, education and justice, and assess their economic impact, and identify the implications for policy, service delivery and prevention.

Researchers R Watkins, H D'Antoine, C O'Leary, S Hamilton, A Finlay-Jones, C Bower, E Geelhoed, M O'Donnell have designed and have the skills to carry out this research. Funding is required for the costs of data linkage and analysis.

Additional questions on notice

Please note that data obtained from the Register and included in responses to the questions below are currently being prepared for publication. They have been provided through personal communication by Dr Marcel Zimmet (Lead Investigator APSU study) and Dr Melissa Cheung (FASDAR Manager), on behalf of the Australian Paediatric Surveillance Unit (APSU) FASDAR Investigator Group, which includes Professor Elliott and Professor Bower.

Can you please clarify the following points regarding the national FASD register:

1. **Who owns and operates that register? Is it wholly FASD Research Australia? If so, does its continued existence rely on your renewed/ongoing funding?**

The FASD Australia Register (FASDAR) is funded by an Australian Government grant awarded to the University of Sydney. It is run by the Australian Paediatric Surveillance Unit, which conducts national, prospective, active surveillance for FASD, with monthly reporting of new (incident) cases diagnosed by paediatricians and other child specialists, including at FASD assessment services nationally. Clinicians who report a case are asked to provide de-identified data on a Case Report Form. The study Protocol and Case Report Form for this surveillance study are available at http://apsu.org.au/studies/current/. Data obtained through surveillance are stored in the secure FASDAR database.

The Register is considered an output of FASD Research Australia.

The Register relies on renewable competitive grant funding and does not have ongoing infrastructure funding. The Register has been unfunded since the previous grant period ceased. Despite this, data collection by the APSU has continued, funded by the APSU. An application for ongoing funding was submitted on 3 January 2020 by the University of Sydney on behalf of a national consortium (Australian Government Grant No GO2535). The outcome is pending.

2. **In evidence you mentioned 80% of the children registered were in out of home care – is that correct? Is that a consistent proportion each year?**

Overall, 21% of the 590 children identified with FASD live with one or two biological parents and the remaining approximately 80% live in out-of-home care: 20% live with their grandparents, 49% live in foster/adoptive care, 9% live with extended family and a small number are in institutional care. This proportion has been consistent over the study period.

3. What information does the register contain?

Currently, the register contains information on 590 cases of FASD newly diagnosed in Australia in children under the age of 15 years and reported to the APSU in the period 1 January 2015 to 31 December 2019 by clinicians throughout the country. Data collected on additional cases notified in 2020 have not yet been analysed.

Standardised detailed demographic data (gender, age, ethnicity, geographic location), data on prenatal exposures (alcohol and other drugs), data on the place and mode of diagnosis, clinical data (congenital anomalies, facial features, microcephaly, domains of neurodevelopmental impairment, growth), results of investigations (e.g. genetic testing), and service use are collected for each case.

Of the children, 68% were male and over 55% were Aboriginal or Torres Strait Islander. The median age at diagnosis was 8.4 years (range 1 day - 15 years). A paediatrician was involved in diagnosis in every case. In over 80% of cases the diagnosis was made by a paediatrician in conjunction with a multi-disciplinary team, usually in one of several specialist FASD assessment services. Of the children, most had confirmed prenatal alcohol exposure at risky or high risk levels; all had severe impairment in at least three domains of neurodevelopment; one fifth had all three sentinel facial features; and one fifth had microcephaly (small head).

4. You mentioned the register is voluntary but there is good engagement from paediatricians. Is that consistent across jurisdictions (ie, is it balanced nationally, or dominated by select states)?

The APSU was established in 1993. Approximately 1500 paediatricians and other child health specialists receive a report card from the APSU each month. For over 25 years the return rate of monthly cards has been over 90%, including during the FASD study period. A completed Case Report Form containing the data described in Q3 (above) was provided for 92.5% of all FASD cases notified to the APSU.

Engagement is representative across jurisdictions. Table 1 (below) shows the number and proportion of clinicians who report to the APSU and of children aged 0-14 years nationally and by Australian State and Territory in 2019.

5. You mentioned the median age of diagnosis is eight years. Is that consistent across the years, or has that changed now that the register is able to accept notifications for children aged up to 15 years?

The median age at diagnosis was 8.4 y ears (range 1 day - 15 years). This has been consistent over time (2015-197). The APSU/FASDAR register has always been able to accept notifications for children up to 15 years of age.

In evidence provided to the Inquiry on 19 May 2020 we referred to the age limitations for reporting to congenital anomaly (or birth defects) registers in States/Territories. These registers normally accept notifications to 12 months of age, although some accept notifications to a later age e.g. SA (5 years) and WA (6 years). Individual congenital anomalies that may occur in FASD may be reported to all State/Territory collections. All but the NSW register also accept notifications of FASD.

Table 1.

APSU contributors N=1429	N (%) contributors	Children 0-14 years	% children 0-14 years
Australia			
Paediatricians	1334 (93.4%)	4,741,629	100
Other specialties[a]	95 (6.6%)		
New South Wales (NSW)			
Paediatricians	498(34.8%)	1,499,863	31.7
Other specialties	41 (2.9%)		
Victoria (VIC)			
Paediatricians	322 (22.6%)	1,201,923	25.3
Other specialties	20 (1.4%)		
Queensland (QLD)			
Paediatricians	227 (15.9%)	989,916	20.9
Other specialties	12 (0.8%)		
Western Australia (WA)			
Paediatricians	139 (9.7%)	511,842	10.8
Other specialties	9 (0.6%)		
South Australia (SA)			
Paediatricians	85 (6.0%)	308,953	6.5
Other specialties	4 (0.3%)		
Tasmania (TAS)			
Paediatricians	26 (1.8%)	94,123	2.0
Other specialties	3 (0.2%)		
Australian Capital territory (ACT)			
Paediatricians	20 (1.4%)	81,390	1.7
Other specialties	6 (0.4%)		
Northern Territory (NT)			
Paediatricians	17 (1.2%)	52,840	1.1
Other specialties	0 (0%)		

[a]Other specialties included surgery, psychiatry, anaesthetics, general practice, nuclear medicine, obstetrics, sexual health medicine

6. Are the cases on the national FASD register only those at the more severe end of the spectrum, or do they represent a broad range of impairments, from mild to severe?

All cases of FASD should be considered severe because the diagnosis *requires* documentation of severe impairment in at least three of ten domains of neurodevelopmental function. That said, some children have impairment in more than 3 domains. All cases included in the register fulfil the diagnostic criteria described in the Australian Guide to the Diagnosis of FASD **https://www.fasdhub.org.au/fasd-information/assessment-and-diagnosis/guide-to-diagnosis/.**

7. **In your evidence you called for an audit of diagnostic services. Many submitters have said that diagnostic capability in Australia is woefully inadequate. Are you able to quantify what is available nationally, across each state and territory? And are there particular states or territories where diagnostic service provision is particularly inadequate?**

All children with prenatal alcohol exposure and developmental problems deserve equitable access to services that can provide a reliable assessment of their strengths and needs, to guide therapy and support. Many children with FASD have complex, chronic disabilities, and challenging behaviours. Some are disadvantaged socially and economically; others have experienced early life trauma; and many live in out of home care. Some are in child protection or involved with the juvenile justice system It is therefore imperative that all children have equal access to a high quality, trauma and FASD-informed, and cost-free public health service.

Diagnostic services are patchy nationally and often poorly funded. There is no State/Territory in which the service is particularly inadequate, however specialised FASD assessment services with access to multi-disciplinary teams are available in some states and not others. Such services are beneficial but not essential, because the diagnosis of FASD can also be made in child development units and in general and community paediatric practices in conjunction with allied health and psychological services. Many remote regions have poor access to health services in general, including child development services.

Some children are only diagnosed as part of a clinical research project. For example, in the Lililwan study in very remote WA, where 19% of primary school age children born 2002-3 had a diagnosis of FASD, none had been previously diagnosed and there was not ready access to a multi-disciplinary assessment team. Similarly, in youth detention in WA, only two of the 36% of young people with FASD had previously been diagnosed. These projects were funded by the NHMRC and Australian Government.

All FASD diagnoses reported to the APSU/FASD register involved a paediatrician and most came from specialised FASD assessment services. The funding source for these services is variable, is often short term, and few if any services have access to a *full time* multi-disciplinary team. As a result, most services have demand exceeding capacity and hence long wait lists of many months. Funding is variously provided by State governments e.g. NSW Health (CICADA FASD Assessment Service), the Australian Government e.g. Monash or from a combination of funding sources. Some services have been established with short term grant funding. Some services are run as a private enterprise e.g. PATCHES Paediatrics.

We am not able to provide detailed information about all services in Australia as this is not readily available – hence the call for an audit. The FASD Hub provides a Service Directory including a list of FASD assessment clinics and self-nominated, FASD-informed clinicians at https://www.fasdhub.org.au/services/.

Additional response to the question asked by Senator Hughes on continuity of care and communication between services (general practice and maternity, obstetric, neonatal, child and adolescent health services).

This issue is being addressed in various jurisdictions and health services. Such continuity is important for a whole range of health and developmental problems in children, of which FASD is one. Pathways of care are being developed to facilitate referral from one group to another. The Electronic Medical Record will also assist clinicians to obtain information from previous assessments. Also, our work in disseminating information and training about diagnosis of and interventions for FASD has involved health professionals from all these groups across the lifespan, to upskill them all and enable informed communication between groups.

In addition, several years ago Australian clinicians formed a FASD Clinical Network. Two years ago we combined with NZ clinicians to become the Australian New Zealand FASD Clinical Network. This network has over 400 members from a range of disciplines and is co-chaired by an Australian and a NZ member. The network aims to: provide collegiate support in establishing and expanding FASD diagnostic and intervention services; align our approach to clinical assessment, diagnosis, data management and follow-up interventions; promote consistency in training related to FASD and continuing professional development; contribute to and provide opportunity for national and international collaboration in clinical research, policy and practice; support for the development of continuing professional development tools for use by health and other professionals in Australia & New Zealand; support national accreditation of continuing professional development in FASD; support allied workforce development in the provision of FASD interventions; contribute to the development and maintenance of regional and national FASD databases; ensure people with FASD and their families/whānau are enabled to contribute to professional development and clinical discussion; promote cultural competence to respect all communities; recognize Indigenous people as the original inhabitants of the land/tangata whenua and partners in all FASD-related work. The network regularly meets virtually to enable discussion of clinical, service and other issues; provides some educative opportunities e.g. webinars; and is represented on some committees relevant to national activities in Australia including committees relating to FASD Research Australia, the FASD Hub; the Australian Guide to FASD; and the FASD Australian Register.