VicFAS
FETAL ALCOHOL SERVICE

Monash Children's Hospital

Apolline Kohen
Principal Research Officer
Senate Standing Committees on Community Affairs
Department of the Senate
Parliament House
PO Box 6100
Canberra ACT 2600

10 July 2020

Dear Ms Kohen

Please find attached responses below to the Committees for Community Affairs - Questions on Notice.

1. **Who/to which registry does VicFAS report diagnosed cases and statistics to?**
    a. **Up to what ages does VicFAS report? Does this capture all/most diagnoses? If not, to what age do you believe you should be able to report?**

All cases in which FASD is diagnosed are reported to the Australian Paediatric Surveillance Unit (APSU). These reports include detailed data about assessments completed, outcomes, prenatal alcohol exposure, co-morbidities and demographics. There is no age restriction on reports to APSU. As VicFAS focusses on referrals for children aged 3-10 years, the majority of reported cases are in this range. However VicFAS has seen several children outside the age range of 3-10 years for individual or exceptional circumstances and in each case a report has been sent to APSU. Dr Harris also provides reports to APSU for children diagnosed with FASD through the Monash Children's Hospital Developmental Paediatrics team who may be aged 0-18 years.

Additionally, the APSU registry does not include cases where a child was assessed as being 'at risk' of FASD. There is benefit in recording these children as they meet some but not all of the criteria for FASD under Australian guidelines.

2. **What will happen to the VicFAS database when/if VicFAS ceases?**

The data collected as part of this FASD Diagnostic Clinic assessment is stored on an existing clinical database. This VicFAS clinical database is housed on the Monash Health server using REDCap (Research Electronic Data Capture). All cases seen by VicFAS are then consented either in person upon attendance at the VicFAS Diagnostic Clinic or Developmental Paediatrics Clinic (with FASD diagnosis) as suitable or via phone (with email signature) to store this clinical data on the VicFAS research database. For consenting families, this information is stored in a de-identified format and this data is maintained in accordance with Monash University and Monash Health Human Research Ethics requirements (HREC Ref: RES-19-0000-706A). The data is stored on a REDCap research database housed on a Monash University server. Access to a REDCap database is restricted and password protected and can only be accessed by members of the VicFAS study team.

In accordance with HREC requirements, all data will be stored for at least 15 years after the completion of the study or until the youngest participant has turned 25 years old. Although it is the intention to retain the data indefinitely, should VicFAS cease to operate, data would be retained for at least 15 years following closure of the registry or until the youngest participant reaches 25 years, whichever is longer. The research information may be destroyed or kept indefinitely in secure storage after this time.

3. Your submission recommends the development of a FASD Paediatric consultation advisory service for professionals to help give community paediatricians confidence and back them up in their efforts to understand and diagnose FASD until they are able to do this independently (p.14). Could this be broader – one that any health professional can access?

   a. Who do you think should run such a service?

There would be clear benefits in establishment of a FASD consultation advisory service which could be accessed by allied health providers in addition to paediatricians, to answer specific queries about assessments and diagnosis. This would be of value to any clinicians who are conducting assessments for children and young people where FASD may be present. Such a service would best sit within a clinical setting such as a tertiary paediatric hospital, in order to draw upon the expertise of paediatric and allied health clinicians who are part of a FASD diagnostic team.

VicFAS has received a number of enquiries from a broader range of professionals including education, community allied health (social work, speech and occupational therapy, neuropsychology), family services, child protection and youth justice, child trauma and mental health services, seeking information about accessing diagnosis and support services, referral pathways, management strategies and access to supports. There is clearly a need for more information about FASD to be available within the community, and a need for specific information about local options and supports, in addition to the general information already provided by agencies such as FASD Hub/NOFASD Australia.

To meet this broader need, there would be benefits of establishing a statewide FASD advisory service similar to that available for families and children with Autism Spectrum Disorder through Amaze (Victoria), which provides an Autism Advisor Service to families, carers, individuals and professionals, providing information about diagnosis, assessments, education, NDIS, referrals to services in Victoria and support. The agency also provides training, education and other resources. See: https://www.amaze.org.au/support/autism-advisor-service

This type of service could delivered by a community based agency in order to service a wide range of enquiries across Victoria.

4. **Your submission notes that diagnostic services are very limited and to manage demand VicFAS has to prioritise children aged 3-10 for whom alcohol exposure has been confirmed. As far as you're able to calculate, what is the estimated level of unmet need in Victoria? (Would it be fair to extrapolate this nationally?)**

Prevalence of FASD in Australia is estimated conservatively at 1% of the population[1] which means that as many as 64,000 Victorians may be affected. However, this is an estimate only. Exact rates in Victoria are unknown due to the lack of any prior existing diagnostic service data and no prior research in this population in Victoria. There is some data that points to particular groups with higher prevalence rates of FASD compared to the general population include children in the child protection system (est. 25% in the US), the corrections systems (36% of children in custody in WA), Aboriginal populations and children at specialist schools.

Identification of those at risk of FASD in the community requires:

- Acknowledgement of alcohol use during pregnancy
- Access to diagnosis
- Awareness of referral pathways

Prior to establishment of VicFAS, there was no centralised system to record requests for FASD diagnosis. VicFAS can only accept referrals from paediatricians, and many Victorian children at risk of FASD may not have been referred for diagnosis due to:

- Lack of awareness of FASD and lack of experience in screening for FASD in the Victorian clinical networks/appropriate professionals
- Not having access to paediatric care
- Being on waitlists for assessments with General Paediatrics, Developmental Paediatrics, Child and Youth Mental Health Services, and behavioural psychology
- Prenatal alcohol exposure not having been identified, or lacking the level of evidence require to establish it

---

[1] Popova, S. et al. (2019) Prevalence of fetal alcohol spectrum disorder among special subpopulations: a systematic review and meta-analysis, *Addiction*, July 2019, Vol 114, Issue 4, pp 1150-1172.

In particular, children in out of home care may present with behavioural or developmental concerns which may be attributed to other factors such as abuse, neglect, attachment or trauma. Children who have had multiple placements may not have a clearly documented developmental history and their behavioural concerns may be attributed to lack of stability. Lack of documentation of prenatal alcohol exposure, along with lack of awareness of FASD among professionals, may result in the risk of FASD being overlooked, or not prioritised when other, more immediate risk factors are present.

In addition, referrals received by VicFAS reflect children with a complex developmental history and significant concerns. These referrals do not capture children with a less significant level of impairment who may however meet criteria for FASD.

Of the referrals/enquiries received by VicFAS in 2019-20:

- 22% proceeded to assessment
- 24% were waitlisted.

This reflects an unmet need for diagnosis particularly for those who did not meet the referral criteria due to age or other factors, but where a risk of FASD has been identified.

It should be stated that the data above is likely to underestimate potential demand in Victoria for FASD assessed due to:

- New establishment of the service, and limited publicity since establishment to cope with service demand
- COVID-19 impacting on referral pathways since March 2020.

Please contact us if the Committee requires any further information. Thank you again for the opportunity to address the Inquiry,

Yours sincerely,

Dr Katrina Harris
Paediatrician, Head of Unit, Developmental and Community Paediatrics and Head of VicFAS

Dr Ali Crichton
Clinical Coordinator/Neuropsychologist

Prue Walker
Social Worker/Service Coordinator.