



Australian Government  
Australian Institute of  
Health and Welfare



Ms Jeanette Radcliffe  
Committee Secretary  
Senate Standing Committees on Community Affairs  
PO Box 6100  
Parliament House ACT 2600

Dear Ms Radcliffe

**Submission to the inquiry into effective approaches to prevention, diagnosis and support for Fetal Alcohol Spectrum Disorder**

The Australian Institute of Health and Welfare (AIHW) welcomes the opportunity to provide a submission to the inquiry into effective approaches to prevention, diagnosis and support for Fetal Alcohol Spectrum Disorder.

The AIHW is a nationally recognised independent information management agency. Our mission is to provide authoritative information and statistics to promote better health and wellbeing. The AIHW provides accessible information and statistics on a wide range of topics about Australians' health and wellbeing. We aim to inform good decisions—and improve the health and welfare of all Australians—through strong evidence that is timely, reliable, relevant and trusted.

I trust you find this information useful to your inquiry. Should the Committee have any further queries about the information in this submission, please contact Bernice Cropper, Head, Maternal and Perinatal Health Unit

Yours sincerely

Barry Sandison  
CEO  
22 November 2019



# **AIHW submission to the inquiry into effective approaches to prevention, diagnosis and support for Fetal Alcohol Spectrum Disorder**

## **Introduction**

The Australian Institute of Health and Welfare (AIHW) welcomes the opportunity to provide a submission to the inquiry into effective approaches to prevention, diagnosis and support for Fetal Alcohol Spectrum Disorder (FASD), with particular reference to the need for improved perinatal data collection and statistical reporting on FASD and maternal consumption of alcohol during pregnancy.

The AIHW is a national independent statutory agency established under the *Australian Institute of Health and Welfare Act 1987 (Cth)* (AIHW Act). The AIHW's purpose is to create authoritative and accessible information and statistics that inform decisions and improve the health and welfare of all Australians.

The AIHW currently performs the following key roles in the context of the health and welfare of Australians:

1. the development and collection of comprehensive data, including making this accessible to others;
2. analysing and reporting on data (from national data collections that the AIHW has custody of, as well as other credible data sources);
3. developing and improving performance indicators and targets for national agreements;
4. providing data linkage services that have been approved by the AIHW's Ethics Committee; and
5. the development and maintenance of national metadata standards, housed in the AIHW's Metadata Online Repository (METeOR).

The AIHW Act enables the release of information for public benefit while protecting the identity of individuals and organisations and ensuring that data providers can be confident that the AIHW will adhere to data supply terms and conditions. As a statistics and information agency, the AIHW relies on strong data governance arrangements to retain the trust of our many data providers, data recipients and other stakeholders.

## **Availability of national data from the AIHW**

The AIHW manages the following national data collections which include information related to FASD or maternal consumption of alcohol during pregnancy:

### **National Drug Strategy Household Survey**

The National Drug Strategy Household Survey (NDSHS) collects information on alcohol and tobacco consumption, and illicit drug use among the general population in Australia. It also surveys people's attitudes and perceptions relating to tobacco, alcohol and other drug use. The survey has been conducted every 2 to 3 years since 1985.

According to the latest NDSHS, the majority of women (56%) did not drink alcohol during pregnancy, and of those who did, most drank infrequently (monthly or less) and consumed 1–2 standard drinks. Among pregnant women who drank alcohol during pregnancy in 2016:

- about 8 in 10 (81%) drank monthly or less, and 16.2% drank 2–4 times a month
- most (97%) usually consumed 1–2 standard drinks.

Pregnant women were also asked if there was any time during their pregnancy that they were not aware they were pregnant and what their alcohol consumption behaviours were during this time. More women consumed alcohol before they knew they were pregnant (49%) than after they knew they were pregnant (25%) in 2016 (AIHW 2017).

Results of the 2019 NDSHS are expected to be released in the third quarter of 2020.

## **National Perinatal Data Collection**

The National Perinatal Data Collection (NPDC) is a national population-based cross-sectional collection of data on pregnancy and childbirth. The data are based on births reported to the perinatal data collection in each state and territory in Australia. Midwives and other birth attendants, using information obtained from mothers and from hospital or other records, complete notification forms for each birth. A standard de-identified extract is provided to the AIHW on an annual basis to form the NPDC.

The NPDC has included a voluntary non-standardised indicator on alcohol consumption during pregnancy since 2009. However, data have only been provided by 3 jurisdictions and the quality of the data has not been assessed.

### **Data development**

From 1 July 2019, the AIHW National Perinatal Data Collection (NPDC) will include 6 voluntary standardised data elements relating to maternal consumption of alcohol during pregnancy:

*Alcohol in pregnancy indicator:*

- [Female—alcohol consumption in the first 20 weeks of pregnancy indicator, yes/no/not stated/inadequately described code N](#)
- [Female—alcohol consumption after 20 weeks of pregnancy indicator, yes/no/not stated/inadequately described code N](#)

*Alcohol consumption frequency:*

- [Female—alcohol consumption frequency in the first 20 weeks of pregnancy, code N](#)
- [Female—alcohol consumption frequency after 20 weeks of pregnancy, code N](#)

*Number of drinks:*

- [Female—number of standard drinks consumed when drinking alcohol in the first 20 weeks of pregnancy, total N\[NN\]](#)
- [Female—number of standard drinks consumed when drinking alcohol after 20 weeks of pregnancy, total N\[NN\]](#)

These data elements are consistent with the dose and frequency questions of the AUDIT-C—a brief alcohol screening tool that identifies hazardous drinking or active alcohol use disorders.

All states and territories have agreed to collect these data items according to the specified standards. However, timeframes for national data availability are not known as the data elements are voluntary and jurisdictions are at various stages of implementation.

As data collection of these items commenced on 1 July 2019, the data will not be received by the AIHW until late 2020 or early 2021. The release of data will be subject to an assessment of the quality and completeness of the data by the AIHW. It is anticipated that the quality and completeness will improve over time as the data elements are fully implemented into jurisdictional perinatal data collections and subsequently provided to the NPDC.

The data elements have been developed by the AIHW in conjunction with the National Perinatal Data Development Committee, the National Maternity Data Development Project Advisory Group and the Clinical Data Reference Group, with funding from the Australian Government Department of Health under the National Maternity Data Development Project.

### **National Congenital Anomalies Data Collection**

The AIHW has commenced work to establish a national, ongoing congenital anomalies data collection. The AIHW is currently working with jurisdictions to determine the scope of the collection and the possibility of including FASD in any future reporting.

### **National Hospital Morbidity Database**

The National Hospital Morbidity Database (NHMD) is a compilation of episode-level records from admitted patient morbidity data collection systems in Australian public and private hospitals.

There are very few hospital separations with principal diagnoses of Fetal alcohol syndrome (ICD-10-AM code Q86.0) (less than 10 separations in 2017–18) or Fetus and newborn affected by maternal use of alcohol (ICD-10-AM code P04.3) (no separations in 2017–18). These conditions are more likely to be recorded as additional diagnoses—this data is available on request.

### **References**

Australian Institute of Health and Welfare (AIHW) 2017. [National Drug Strategy Household Survey 2016: detailed findings](#). Drug Statistics series no. 31. Cat. no. PHE 214. Canberra: AIHW.

AIHW 2019. [Principal Diagnosis data cubes: Separation statistics by principal diagnosis \(ICD-10-AM 10th edition\), Australia, 2017–18](#). Cat. no. WEB 216. Canberra: AIHW.