# PARLIAMENTARY INQUIRY QUESTION ON NOTICE

## Australian Institue of Health and Welfare

## Community Affairs

## Effective approaches to prevention, diagnosis and support for Fetal Alcohol Spectrum Disorder

## 19 May 2020

**PDR Number:** IQ20-000239

**Question Subject:** Congenital anomalies data collection

**Type of Question:** Spoken

**Hansard Page number:** 12

**Senator:** Rachel Siewert

### Question

CHAIR: Thank you, Mr Frost. I have two questions up-front. One is: you touched on the area that I was going to follow up on, which is the congenital anomalies data collection. You said that you're working on getting that back up and running again. What's the expected date for that to be operating?
Mr Frost: We have already begun the process of requesting 2016 data from jurisdictions. Obviously, it's something that takes a bit of time, because congenital anomalies have different reporting dates up to age five or age six. So we're going some way back to start off. We've made those requests and have conducted preliminary work to support reporting of that information. I'm just trying to find for you the date that we anticipate that occurring. It should not be too long from here. Perhaps while I look through my papers I can find an answer for you and you can ask your other question.
CHAIR: Or you could take it on notice.
Mr Frost: Yes, I can take that on notice and send it to the committee.

### Answer:

The AIHW is re-establishing the National Congenital Anomalies Data Collection (formerly called the Australian Congenital Anomalies Monitoring System).The Collection is currently operational and we expect to report 2016 data by December 2020. These data will be from all jurisdictions with the exception of the Northern Territory, which does not have congenital anomalies data available.

The AIHW is working with jurisdictions to determine the future scope of the Collection and the possibility of including Fetal Alcohol Syndrome in future reporting.

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**PDR Number:** IQ20-000240

**Question Subject:** National Hospital Morbidity Database request

**Type of Question:** Spoken

**Hansard Page number:** 13

**Senator:** Wendy Askew

**Question**

Senator ASKEW: I have one quick question to follow up from Senator Dodson's questions. I noticed that you were talking about the 1981 to 2008 collection of details in regard to national congenital anomalies. In your submission you also talked about the National Hospital Morbidity Database. In there, you talked about hospital separations for principal diagnosis of fetal alcohol syndrome, where there are only very low cases. But you mentioned that the data is available on request. Is it possible to have that provided to the committee as a question on notice?

Mr Frost: Yes, we can look into that. As was mentioned in our submission, there are very few hospital separations with a principal diagnosis of fetal alcohol syndrome or with the code of a fetus or newborn affected by maternal use of alcohol. For example, there were no separations in 2017-18 and in that second category there were fewer than 10 separations in 2017-18, in the category for fetal alcohol syndrome. We do think that those conditions are more likely to be recorded as an additional diagnosis—that is, somebody has a hospital separation that relates to something else but that it's also noticed that they might have one of these conditions. That's the data that we could look into providing on notice.

Senator ASKEW: If you could, that would be great, thank you.

Mr Frost: It's important to note that it would be indicative of the effect on the hospital system. It wouldn't necessarily shed a lot of light on the level of FASD in the community, because it's really only those people who are reaching hospitals at that point.

Senator ASKEW: That's true. Okay, thank you.

**Answer:**

**Table 1: Separations for Fetal Alcohol Syndrome**

| | Principal diagnosis | Additional diagnosis | Total |
|---|---:|---:|---:|
| 2015–2016 | 8 | 95 | 103 |
| 2016–2017 | 12 | 83 | 95 |
| 2017–2018 | 10 | 145 | 155 |

**Table 2: Separations for fetus or newborn affected by maternal use of alcohol**

| | Principal diagnosis | Additional diagnosis | Total |
|---|---:|---:|---:|
| 2015–2016 | 0 | 13 | 13 |
| 2016–2017 | 0 | 16 | 16 |
| 2017–2018 | 0 | 21 | 21 |

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

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**PDR Number:** IQ20-000241

**Question Subject:** Alcohol consumption during pregnancy submissions by jurisdiction

**Type of Question:** Spoken

**Hansard Page number:** 13

**Senator:** Stirling Griff

**Question**

Senator GRIFF: You expect all jurisdictions to provide data on the six standardised data elements of alcohol consumption during pregnancy, but your submission states that the data you've been collecting since 2009 have only been provided by three jurisdictions. Which jurisdictions are they?
Mr Frost: I may have to take that on notice. I don't have the three to hand, but I can provide that information to the committee after this date.

**Answer:**

Since 2009, the National Perinatal Data Collection has included a voluntary non-standard data item on alcohol consumption status during pregnancy (alcohol consumed/alcohol not consumed). Three jurisdictions have provided this information: Tasmania, the Australian Capital Territory and the Northern Territory.

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**PDR Number:** IQ20-000243

**Question Subject:** Perinatal data collection for First Nations communities

**Type of Question:** Spoken

**Hansard Page number:** 15

**Senator:** Malarndirri McCarthy

**Question**

Senator McCARTHY: In relation to your data collection, can you just walk us through—or, if it's too long, table for us—how you do that with First Nations communities and organisations?
Mr Frost: Sorry, with which collection? The Perinatal Data Collection?
Senator McCARTHY: That's correct, yes; sorry. In terms of collating your data, what's your process with First Nations communities and organisations?
Mr Frost: In broad terms, we don't engage with the broader communities and organisations. We are provided the data by states and territories, in accordance with agreed national specifications and minimum datasets. They form their perinatal data collections, and from that we get a subset of that information that is the agreed National Perinatal Data Collection. As you foreshadowed in your question, it might be better to table the process to explain that in a bit more detail—how precisely that occurs—rather than talk through it now. We have in there what are called mandatory elements and voluntary elements. The new alcohol in pregnancy indicators and consumption and frequency and level indicators are still voluntary collections, but all jurisdictions have said that they will supply them.
Senator BILYK: Okay. If you can, table that. Also how do you break down though, within that collation of data from state and territory, First Nations statistics?
Mr Frost: Where available, we do provide statistics on Aboriginal and Torres Strait Islander mothers and babies from the collection. We hope to be able to do that in this regard as well.
Senator BILYK: Thank you very much.

**Answer:**

Perinatal data are collected after each birth, usually by midwives or other birth attendants from clinical and administrative records and information systems, including records of antenatal care, the care provided during labour, and the delivery and care provided after the birth. Each state and territory has its own notification form and/or electronic system for collecting data on each birth, which is forwarded to the relevant state and territory health departments to form the state or territory perinatal data collection.

A standardised extract of electronic data from each state and territory collection is provided to the Australian Institute of Health and Welfare (AIHW) annually to form the National Perinatal Data Collection (NPDC).

The NPDC includes a subset of data items that form the Perinatal National Minimum Data Set. This is a set of data items agreed for mandatory collection and reporting at a national level. One of these data items is Indigenous status, which is collected for both the mother and the baby. This enables all data from the NPDC to be disaggregated for Aboriginal and Torres Strait Islander mothers and babies. While the provision of the Indigenous status data items by states and territories to the AIHW is mandatory, it is voluntary for an individual to identify as Indigenous and a not stated response is valid. Data are complete for 99.8% of mothers and 98.9% of babies in 2018.

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**PDR Number:** IQ20-000244

**Question Subject:** Understanding of the prevalence of FASD

**Type of Question:** Spoken

**Hansard Page number:** 15-16

**Senator:** Rachel Siewert

**Question**

CHAIR: Have you done any work—and you might need to take this on notice—looking at how we could improve our understanding of the prevalence, given what you just said in terms of the difficulty in diagnosis? I presume that, therefore, we'd have to improve our processes for early diagnosis. Have you looked into that? Do you want to take that on notice to look at what has been done in Australia to look at how we can get a better idea of prevalence?

Mr Frost: Yes, I can take on notice the information we have in regard to processes to improve estimates of FASD. The difficulties are both clinical difficulties in diagnosis and collection difficulties, in part because it may be that people are diagnosed quite late in life as well, so they are outside the scope of many collections. At the moment, I believe Queensland is a jurisdiction that requires notification of fetal alcohol syndrome diagnoses up to the age of six. That is the scope of its collection. Some other jurisdictions have up to the age of five. I don't know if there's an average level, but there are diagnoses that happen at age 11, age 15 and so on, and with small numbers they will make a difference. So those are parts of the challenge as well. Many of those sorts of things are outside of the scope of what we might be able to do.

Certainly in regard to FAS we are starting to collect that information as part of the national congenital anomalies data collection, which will improve the picture somewhat in regard to that more severe diagnosis. I can take on notice the question about what information we have in regard to what could be done to improve the estimates of FASD more broadly.

**Answer:**

The AIHW is unable to comment on how to improve early diagnosis. Clinicians are the best placed to comment on this issue.

In a 2014 paper, the AIHW recommended that prevalence data on FASD could be improved through the establishment of a national notification register for the purposes of monitoring incidence and prevalence of all FASD conditions—Fetal Alcohol Syndrome (FAS), partial Fetal Alcohol Syndrome (pFAS) and Alcohol-related neurodevelopmental disorder (ARND). A sustainable approach to facilitate this would be to build upon the existing infrastructure of each jurisdiction's congenital anomalies/conditions register (AIHW, 2014). Consideration would need to be given to ensuring that FASD conditions (only) were notifiable up to the age of 15 to ensure appropriate scope and coverage.

A register such as this could provide essential information to researchers, clinicians and policymakers to develop and implement an appropriate response to this preventable condition. Further research facilitated by data linkage to other data collections such as disability services could provide information on outcomes for FASD-affected children and provide information on long-term management.

**Reference**

AIHW: Bonello MR, Hilder L & Sullivan EA 2014. Fetal Alcohol Spectrum Disorders: strategies to address information gaps. Cat. no. PER 67. Canberra: AIHW. https://www.aihw.gov.au/reports/mothers-babies/fetal-alcohol-spectrum-disorders-info-gaps/contents/table-of-contents