

Legislative Affairs Legislation Committee

ANSWERS TO QUESTIONS ON NOTICE

HEALTH PORTFOLIO

Inquiry into the Australian Institute of Health and Welfare Amendment (Assisted Reproductive Treatment Statistics) Bill 2019

Ref No: 1

Topic: Review of transcript

Type of Question: spoken

Spoken: Senator O'NEILL

Question:

Could I indicate that I would really appreciate both Dr Webster and Ms Essex, on notice, reviewing the transcript from this morning's evidence and providing us with any insights that they have in response to the fresh evidence that we secured this morning.

Answer:

- **Commonwealth Department of Health**

The Commonwealth Department of Health has reviewed the transcript and has no further comments or additional insights in response to the evidence provided during the Community Affairs Legislation Committee's hearing for the inquiry into the AIHW Amendment (Assisted Reproductive Treatment Statistics) Bill 2019 (the Inquiry).

- **Australian Institute of Health and Welfare**

The AIHW has also reviewed the transcript from the Inquiry and has the following additional information to add. This has been written from the perspective that the draft legislation is recommending the AIHW is the agency proposed to undertake this work.

Static reporting

It was noted that the commentary during the hearing included the degree to which the AIHW's reporting is 'traditionally static'. It is difficult from the transcript to ascertain precisely what is meant by this, however, it appears to imply that users have little ability to interact with the data to generate information tailored to their needs.

For close to a decade the AIHW and other statistical reporting agencies have been transitioning away from static printed reports and progressively adding online interactive presentation of data and information to our releases. Over recent years, the AIHW has developed over 3,400 interactive data visualisations. Interactive data visualisations are now ubiquitous across the online content we produce, including [MyHospitals](#), [GEN](#), [Housing data dashboard](#) and the [AIHW's main website](#).

Expertise requirements and data source issues

The AIHW also notes commentary regarding:

- the expertise required to fulfil the reporting responsibilities outlined in the proposed Bill whilst avoiding potential unintended negative consequences.
- The need to evolve data and reporting over time to reflect changes in technology and practice.
- Certain advantages and disadvantages to the data being sourced directly from clinics versus via the ANZARD collection.

As Australia's national health information agency, the Institute has for more than 30 years covered many different health and welfare related fields, including health expenditure, cancer, diabetes, chronic kidney disease, maternal health and hospital performance. To do this the Institute collates data from many different data systems, registries and administrative collections. It also works closely with expert advisory committees including data providers, clinicians, academics, consumers, government and non-government members. The input of these experts ensures the data and information that is published is technically appropriate given the data sources and meaningful without being misleading. It also ensures reporting evolves to reflect emerging issues and changes in technology and practice over time.

There does not appear to be anything about the reporting requirements or the specific subject area covered by the proposed Bill to suggest this approach would not be equally successful in this context. The only unusual aspect relates to the mandated nature of reporting via the AIHW Act, including the specification of specific data fields for provision in legislation. This is unprecedented and may create unintended consequences, such as preventing the sort of evolution over time that is a feature of the Institute's other work.

There does not appear to be anything exceptional about the context to suggest that either sourcing data directly from clinics or via the ANZARD collection would be unachievable.

It would appear to be more efficient to use data already collected via ANZARD. It is noted, however, that data provision to ANZARD is effectively voluntary on behalf of the sector and funding of the registry staff appears to be at the discretion of the University of New South Wales. Reliance on ANZARD for the data may, therefore, inhibit the Institute's ability to comply with the Bill.

Resourcing

There are several references to funding and the resourcing required to fulfil the obligations outlined in the Bill. For the AIHW to deliver on the various elements of the Bill there would be a need for resourcing.

Penalties

Regardless of what organisation is assigned the work of reporting, it may be worth considering that the issuing of penalties for non-compliance be managed by a different entity. This will ensure that the independence and neutrality of the data and the reporting agency remains clear.

Legislative Affairs Legislation Committee

ANSWERS TO QUESTIONS ON NOTICE

HEALTH PORTFOLIO

Inquiry into the Australian Institute of Health and Welfare Amendment (Assisted Reproductive Treatment Statistics) Bill 2019

Ref No: 2

Topic: IVF Analysis

Type of Question: spoken

Spoken: Senator GRIFF

Question:

There were some examples looking at the different groups of people that have participated in IVF, and there's basically a seven-fold difference between those in the top quartile versus those in the bottom quartile. Have you, as the department, done any analysis of the actual cost for those in the bottom versus the top at all? Have you analysed that at a clinic level?

a) Yes, that would be very much appreciated. It would be of particular interest to us to also have a look at the individual consumer out-of-pocket costs, if you're able to get the data. I imagine you'd be able to source it.

Answer:

In the time available, the Department has not undertaken an analysis of data reported by the Australian and New Zealand Assisted Reproduction Database (ANZARD) in relation to Out of Pocket (OOP) costs incurred by individuals.

The Department can respond to the Committee with more detail in the coming weeks if the raw data set is made available by the Perinatal Epidemiology and Statistics Unit (NPESU), the data custodian of the Australian & New Zealand Assisted Reproduction Database (ANZARD).

Using the data that is available to the Department, the average out of pocket cost for a fresh IVF cycle, which includes MBS items 13200, 13209, 13212 and 13215 was \$3,699.79 for the 2018/19 financial year. For a frozen cycle (MBS items 13218, 13209 and 13215) it was \$1,678.35.¹

¹ Data sourced from COGNOS (internal Department of Health Medicare data system).

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ANSWERS TO QUESTIONS ON NOTICE

HEALTH PORTFOLIO

Inquiry into the Australian Institute of Health and Welfare Amendment (Assisted Reproductive Treatment Statistics) Bill 2019

Ref No: 3

Topic: Technical Matters

Type of Question: spoken

Spoken: Senator O'NEILL

Question:

On the technical matters with the bill that you referred to in your verbal testimony this morning, on notice, could you formalise that and write to the committee about that? That would be very helpful for us going forward.

Answer:

Potential inconsistency between subclause 19B(2) and subclause 19B(6)

Subclause 19B(2) states that in causing the publication of statistical information under subsection (1), the Institute must ensure the accredited ART centre to which the information relates is specified in the publication. Subclause 19B(6) goes to on state that the Institute must not include in the publication of the statistical information or the list any information that is likely to enable the identification of an individual, unless the individual is an accredited ART centre.

The use of the word 'must' removes any element of discretion that the Institute would have in terms of compliance with subclause 19B(2), and compliance with this requirement alone could result (particularly in a geographically small or isolated region, such as a regional centre) in a risk of identification or re-identification of an individual person, if the information that the AIHW has to publish could be linked to other information that was in the public domain. This could then prevent the Institute from being able to comply with the requirements of Subclause 19B(6). A possible approach to addressing this could be to specify that subclause 19B(6) applies subject to the requirements of subclause 19B(2).

Threshold for identification

Subclause 19B(6) states that the Institute must not include in the publication of the statistical information or the list any information that is likely to enable the identification of an individual, unless the individual is an accredited ART centre. This is a lower threshold than that required under the Privacy Act, which requires no reasonable likelihood of re-identification. Consideration could be given to aligning this point to the test in the Privacy Act.

Penalties

As outlined in response to Question 1, it may be worth considering that the issuing of penalties for non-compliance be managed by a different entity. This will ensure that the independence and neutrality of the data and the reporting agency remains clear.

It may also be worth considering if there are any potential unintended consequences following from the 'strict liability' nature of the arrangements under the Bill. This would appear to provide little opportunity for the exercise of judgement in administering penalties under the Bill, for example considering exceptional circumstances, or first versus third or fourth offences.