

The Committee Secretary
Senate Standing Committees on Community Affairs

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

28 August 2019

I am now retired after a long career as a senior executive in companies, both in the United States and Australia, providing ART services, assessment and implementation AR technologies, and most recently, a Director of the Victorian Assisted Reproductive Treatment Authority (VARTA). I remain an international consultant providing risk minimisation strategies and strategic guidance to providers of assisted reproduction.

Senator Griff proposes that information from individual clinics be collected and collated by AIHW and made available to the public as a searchable online data base.

In his *Explanatory Memorandum*, the senator is correct in asserting that the information published by ANZARD does not allow for direct comparison of the performance of individual clinics nationally. However, that ART clinics operating in Victoria are, and have been for some years, required under the ART Act (Vic) 2008 *et seq* to submit data annually to VARTA and that comparisons among these identified clinics are published in each VARTA annual Report is ignored.

The value of the Senator's otherwise worthwhile proposal is further diminished by an apparent failure to consult those with experience in assisted reproduction. This is evident in an overly simplistic view of the determinants of success in assisted reproduction and the very dated definition of assisted reproduction (see Schedule 1; Amendment 1; Section 3; *Definition of Assisted Reproduction*). The Senator cites maternal age and reason for fertility as being the only two of several factors known to affect the likelihood of pregnancy and live birth. In that, the Senator's proposal is unlikely to achieve his declared objective.

The selective exclusion by clinics of treatments with likely poor outcome represents a major issue in regard to the reliability of information provided by the proposed web queries. Notwithstanding the challenges presented by each, several possible strategies are available to AIHW to ensure for the first time all treatment cycles initiated in Australia are reported;

- The registration, by way of the AIHW web site, of each treatment cycle within 24 hours of initiation and assignment of a specific AIHW treatment number.
- Comparison of registered treatments with Medicare and PBS medication records. Medicare item numbers are applied to various components of each treatment cycle and medications are provided under the PBS. This would require specific Medicare item numbers to be associated with each treatment. Such a strategy will have to be implemented if ART services provided under Medicare are to be restricted in future.
- Audits of cryo specimen inventories.

The requirement that each treatment cycle be assigned a unique AIHW treatment identifier at the time of initiation will facilitate the efficient and targeted audit of clinics as each clinic would receive in the days

immediately prior to an audit a list of treatments to be examined in detail. The standard reference for these audits would remain the current RTAC Code of Practice.

Experience is that the more data are 'categorised' the less amenable are these data to subsequent analysis and less able to accommodate future changes in treatment strategies and technology.

I therefore suggest that rather than have clinics submit summary data, a far more efficient approach would be to have clinics submit a standard set of data in three phases; (1) at the time each treatment cycle is initiated, (2) on completion of treatment, (3) the result of pregnancy ultrasound and (4) the number of infants born alive as a result of the particular treatment. These data (as set out in the accompanying table) could then be queried by answering questions to each of the several data points defining prognosis and treatment strategy.

For treatments commenced in any financial year, clinical pregnancy data would be complete by the end of September and available soon thereafter for 'public' query. Live birth data would not be available until September in the following year. In each instance, this information would be available far earlier than is now the case with clinics submitting summary data tables which require further extensive validation and formatting prior to publication.

In addition to satisfying Part IIA, s19A *Accredited ART centres must give certain statistical information to the Institute*, this strategy facilitates immediate and automatic audit and error trapping in submitted data, effective and meaningful comparisons and provides the flexibility needed to accommodate future developments in ART strategies.

The suggested information management strategy accommodates all prognostic groups, all treatment strategies, all possible outcomes and satisfies s19B of the proposed amended AIHW Act.

Finally, the proposed amendments to the AIHW Act do not consider whether or how the use of comparative data for commercial advantage is to be managed.

I thank the Committee for their consideration of my comments and trust they are found to be of some use in assuring the successful passage of the proposed Amendment.

Sincerely,

Ronald S Carson BSc(Hons), MSc, PhD

Clinic	ID (RTAC registered number)	
	Insemination location	Identity of geographic site
	Embryo transfer location	Identity of geographic site
Patient	ID (assigned by clinic)	
	DoB	
History	Number of previous clinical pregnancies	
	Date of most recent clinical pregnancy	
	Treatments (excl current) initiated since most recent clinical pregnancy	
	Number of previous live births	
	Date of most recent live birth	
	Treatments (excl current) initiated since most recent live birth	
Current Treatment	Date initiated	Standard method for determining D1 of each type of treatment is defined.
	Source of oocytes	Autologous or Donated
	Oocytes previously cryopreserved	Yes / No
	Source of sperm	Partner or Donor
	Collection method	Ejaculate, testicular biopsy, testicular aspirate, epididymal aspirate
	Sperm reviously cryopreserved	Yes / No
Treatment Record	Insemination method	IVF (in vitro) or IUI (in vivo)
	Number of oocytes thawed	
	Number of oocytes inseminated	
	Number of oocytes donated (without insemination)	
	Number of oocytes cryopreserved	
	Number of embryos thawed	
	Number of embryos transferred	
	Number of embryos cryopreserved	
Outcome	Number of intrauterine foetal heart beats	
	Number of infants born alive	