27th February 2018

The Program Manager
Reproductive Technology Unit
Patient Safety & Clinical Quality
Clinical Excellence Division
Department of Health
189 Royal Street
Perth WA 6004

Dear Sir/Madam,

Re: Review of the Western Australian Human Reproductive Technology Act 1991 and the Surrogacy Act 2008

Our submission is provided in our roles as Approved Infertility Counsellors under the HRT Act (1991) working within WA ART clinics. We have addressed several of the Terms of Reference.

Please find attached our submission for your review.

Thank you for the opportunity to participate in this review.

Yours faithfully,

Iolanda Rodino
Clinical Psychologist

Antonia Clissa
Clinical Mental Health Social Worker

Terms of Reference

- **Research and experimentation on gametes, eggs in the process of fertilisation and embryos. In particular consider the current disparity between the *HRT Act* and relevant Commonwealth legislation and need to adopt nationally consistent legislation regarding excess assisted reproductive technology (ART) embryo research and prohibited practices.**

We support the need to adopt nationally consistent legislation regarding excess assisted reproductive technology (ART) embryo research and prohibited practices.

- **Genetic testing of embryos**

Consistent with Directions 9.9-9.11 we support the use of genetic testing of embryos. However with reference to Direction 8.7 and 8.8 restrictions on collection of eggs, in order to streamline the process, we would support the creation of up to 6 embryos of the same biological parentage without the need for further submission to Council for the approval of additional oocyte collection.

- **Posthumous collection, storage and use of gametes and embryos, including the consent required, conditions for use, and any impact on other legislation such as the *Human Tissue and Transplant Act 1982, Artificial Conception Act 1985, Births Deaths and Marriages Registration Act 1998, Administration Act 1903* and *Family Provision Act 1972*.**

The HRT Act recognises that ART procedures in WA may only be carried out where there has been consideration given to the welfare and interests of the participants and the child that is likely to be born as a consequence of the procedure.

In principle we do not support the posthumous collection, storage and use of gametes. Currently there is insufficient clinical and research evidence about the longitudinal legal, psychological and social wellbeing of children/individuals who are conceived following these processes.

In the event of legislative changes that do permit lawful posthumous gamete retrieval, storage and use we recommend that the following conditions are in place

- The recipient of the posthumous gamete must be eligible for ART treatment in line with the HRT Act
- That the deceased has left prior **written** expressed consent to posthumous use rather than expressed consent as set out in the NHMRC[1] Guidelines
- The gametes are allocated to a specific person (i.e. the deceased person's partner (or equivalent);
- Gamete use must not proceed prior to a clinically determined grieving period being undertaken
- Specifications of a time frame for use of gametes post death (this may be less than the statutory 15 year limit)
- The recipient of posthumous gametes must receive counselling by an Approved Counsellor under the HRT Act prior to use;

- Evidence of such counselling must be provided in writing to the Reproductive Technology Council
- The Reproductive Technology Council must approve the application for use

With respect to use of existing stored embryos where there has been previous consent for use, we propose that there should still be a specific requirement of explicit written evidence in place about consent for posthumous use. In those situations of advanced direction we further propose that this consent is insufficient without evidence of adjunct counselling by an approved counsellor under the HRT Act to ensure the longitudinal implications of an advanced direction have been explored in depth by the participants.

Rights to storage of gametes and embryos including –

- **rights upon separation or divorce, or the death or the physical or mental incapacity of an individual, or one or both members of a couple.**
- **rights of third parties such as subsequent spouses, and the rights of other relatives**.

We do not support rights being vested in third parties but all decisions to be limited solely to the eligible participants and their legally defined partners who were directly involved in the ART procedures and for whom the embryo(s) was developed.

- **The Chief Executive Officer's (CEO) power to issue directions, the power to make a Code of Practice, regulations and guidelines, and the scope and effect of the existing directions and regulations under the *HRT Act*.**

We support the Chief Executive Officer's (CEO) powers to issue directions, the power to make a Code of Practice, regulations and guidelines and the scope and effect of the existing directions and regulations under the *HRT Act*.

- **Whether there should be a process of review or appeal of decisions made (by the Reproductive Technology Council (Council)) under the *HRT Act*.**

We would support a process of review or appeal of decisions made by the Council possibly by the State Administrative Tribunal.

- **The impact on the *HRT Act* of relevant Commonwealth and State legislation, and aspects of legislation of other jurisdictions which could be incorporated into the *HRT Act*.**

We support amendment of the HRT Act to be consistent with other relevant Commonwealth legislation (for example the Sex Discrimination Act 1984).

We propose that the eligibility criterion precluding ART treatment in individuals who are medically deemed post-menopausal by age (Section 23 (1) (d) of the HRT Act) is maintained. We further recommend that ART providers treating the patient must

maintain a record of the reasons for a decision about eligibility for IVF treatment in accordance with standards of good medical practice.

- **Management of information / the Reproductive Technology Registers, including;**
  - **Use of data for research,**
  - **Use of data for purposes of national data collection and;**

In acknowledgement of the importance of research we support access and use of data on Reproductive Registers and the Voluntary Register for the purposes of research approved by the Reproductive Technology Council. We further support national data collection such as that by ANZARD.

- **Access to information about donation, genetic parentage and donor conception,**

We support access to information about donation, genetic parentage and donor conception. We recommend that release of identifying information to any participant of a donor assisted conception programme should include at least one session of implications counselling with an Approved Counsellor under the HRT Act or 'counsellor equivalent' (for e.g. counselling members of ANZICA, BICA or ASRM mental health professionals).

We recommend that a process is in place for the notification to donors whose identifying details have been released to donor conceived individuals from the Reproductive Technology Register.

Given the increase in cross border reproductive care (CBRC) we recommend the consideration of the development of a national unique donor identity reference system to support donor-recipient linkage and governance of family limits

Furthermore to facilitate information release from the mandatory register for donor conceived individuals we would recommend a structure for funded payment. This includes:

Independent Donor Conceived 'Mature' Minors i.e 16-18year olds

- One session of counselling for the Donor Conceived Person (DCP) with an Approved Counsellor to be funded by the Department of Health (DoH). (This may also include another funded session of counselling with their parents/family as a support for the donor conceived mature minor.)

Donor Conceived Adults (18 years or older who are financially disadvantaged – e.g. full time students; unemployed; still financially and legally dependent upon their parents)

- One session of counselling for the adult DCP to be funded by the DoH.
- Responsibility for counselling of donor conceived families rests with the family.

- **The Voluntary Register (donor-assisted conception).**

We note the inconsistency in the capacity of a donor conceived person to access identifying information to other parties of a donor assisted conception programme dependent upon the register (16 years for the mandated Reproductive Technology Register and 18 years for the Voluntary Register). We recommend that there is consistency of age across both registers.

We further note that there is no legislated established protocol for the release of identifying information to participants of a donor assisted conception programme. Prior to release of information from the Voluntary Register we would recommend that

- The Voluntary Register (donor-assisted conception) be subsumed under the purview of the Reproductive Technology Registers held by the Reproductive Technology Unit (RTU)
- Release of information protocol is co-ordinated by the Reproductive Technology Unit
- A minimum of one session of implications counselling by an Approved Counsellor of the HRT Act or counselling equivalent to each participant involved in a donor assisted conception programme is completed prior to information release
- Relevant sections of the ANZICA Guidelines for Professional Standards of Practice : Donor Linkage Counselling to be used as a guide for counselling
- Considerations of funding by the DoH for one session of implications counselling for donor conceive adults (18 years adult or older who are financially disadvantaged – eg. Full time students; unemployed; still legally or financially dependent upon their parents).
- Confirmation to the RTU in writing confirming the undertaking of implications counselling by the Approved Counsellor or "counsellor equivalent"
- Relevant to pre HRT Act records we support the creation of a Voluntary DNA bank to assist with the verification of genetic links where no or incomplete donor treatment records exist.
- The development of a data base for follow-up and research of information release and donor linkage outcomes

- **The effectiveness of the operation of the Council and committees of the Council;**

Due to the social and psychological complexities and ramifications associated with assisted reproductive technology and associated legislations we recommend an established and ongoing role for the Chair of the Reproductive Technology Counselling Committee to attend Council meetings.

For the purposes of good governance we recommend that the roles of Deputy Members be reviewed to include minimum number of meetings required to attend Council meetings annually.

- **The need for the continuation of the functions conferred, on the Council and on the CEO respectively by the *HRT Act*.**

We support the need for continuation of functions conferred, on Council and on the CEO respectively by the HRT Act including the

- giving of Advice to the Commissioner of Health and Minister of Health,
- research
- and the promotion of public informed debate and education on matters relating to assisted reproductive technology.

The review of the *Surrogacy Act 2008* to include the effectiveness and operation of the *Act* with particular reference to:

- **The impact on the *Surrogacy Act* of relevant Commonwealth and State legislation and aspects of legislation of other jurisdictions, which could be incorporated into the Act, including consideration of harmonisation of domestic surrogacy legislation;**

We support the development of nationally consistent surrogacy legislation to minimise the current confusion for those seeking surrogacy arrangements, service providers and regulators. This will further serve to reduce the complications associated with arrangements when the arranged parent(s) and birth mother (surrogate) reside in different states.

With a nationally consistent legislation we would support

- the development of a government regulated, central advisory agency to provide information on Australian domestic surrogacy legislation, ART clinical services and approved counselling support services
- the introduction of Medicare for medically indicated surrogacy arrangements
- the development of a database for the registration of surrogacy arrangement outcomes and for use in research

We further seek clarification on the

- maternity and paternity leave entitlements for participants involved in a surrogacy arrangement and
- access to government and social security payments, including who should apply

With respect to the Western Australian Surrogacy Act (2008) we recommend consideration of

- amendments to the Surrogacy Act (2008) to comply with the Sex Discrimination Act 1984 in regards to access to surrogacy for same sex male couples and single men.
- eligibility criteria to be amended to facilitate embryo creation in those women with urgent medical need (e.g. imminent fertility loss due to cancer treatment) –i.e. (s23 HRT ACT – Surrogacy Direction 7)
- clarification of Section 11 of the Surrogacy Act such that fertility experts/counsellors/lawyers are able to advise the community of their concerns about CBRC without fear of reprisal that they will be inadvertently implicated as having helped people with an overseas/illicit arrangement.
- provision for clinics to be able to advertise and recruit potential surrogates consistent with recruitment of gamete donors

- continued support for the current age stipulations of the Surrogacy Act (2008) although we would recommend that Council is to be given powers of discretion for younger suitably evaluated arranged parents (i.e. arranged parents aged between 18 to 25 years)
- the expansion of the provision of implications counselling by other suitably defined equivalent infertility counsellors (e.g. ANZICA counsellors)

- **The need for continued prohibition on commercial surrogacy;**

We support the continued prohibition on commercial surrogacy arrangements.

We do support continued payment of reasonable expenses relevant to an altruistic surrogacy arrangement however we recommend further delineation and careful expansion of what these expenses are so as to prevent exploitation and/or coercion of potential surrogates.

- **International commercial surrogacy arrangements;**

We support national management and surveillance of international commercial surrogacy arrangements and birth comes. This might include

- Data collection of these births trends with Birth Death and Marriage Registers
- Improved information and educational strategies on the legal complexities involved with the parenting arrangements issued following an overseas commercial surrogacy

- **International trade in gametes and embryos;**

We support the ban on international trade in gametes and embryos

- **Whether there should be a process of review or appeal of decisions made (by Council) under the *Surrogacy Act.***

We support that there should be a process of review or appeal of decisions made (by Council) under the Surrogacy Act possibly by the State Administrative Tribunal.

- **Other Issues – HRT ACT/Surrogacy Act**

There remains inconsistency in the HRT Directions (2004) regarding cooling off periods post initial implications counselling in cases of known donation – these being egg/embryo donation (3 months) when compared to known sperm donation (6 months). For consistency we propose a minimum of 3 months cooling off period for all forms of known donation.

In cases of same sex oocyte donation in established defacto couples we propose that eggs/embryos can be used by the partner with medically established infertility needs following implications counselling with an Approved Counsellor under the HRT Act without this use being considered a form of surrogacy or known donation arrangement.

In keeping with Section with 23 (1) (e) of the HRT Act concerning the welfare of participants and any child born we recommend that donors of gametes/embryos be able to state conditions for donation in cases of on-donation to recipients (for example ethnicity).

We support further clarification of Directions 7.2 and 7.3 (Eligibility and Assessment) concerning the use of sibling donor gametes by non-genetic siblings but who were raised as legal siblings.[2]

With reference to cases concerning the re-allocation of donated embryos we recommend that this is made explicit in the HRT Act and is consistent with the NHMRC[1] guidelines 6.1.3 and 6.2.1.

References:

(1) NHMRC Ethical Guidelines on the use of assisted reproductive technology in clinical practice and research (2017) https://www.nhmrc.gov.au/_files_nhmrc/file/guidelines/ethics/16506_nhmrc_-_ethical_guidelines_on_the_use_of_assisted_reproductive_technology-web.pdf

(2) ASRM Ethics Committee - Using family members as gamete donors or gestational carriers (2012) http://www.asrm.org/globalassets/asrm/asrm-content/news-and-publications/ethics-committee-opinions/using_family_members_as_gamete_donors_or_gestational_carriers_an_ethics_committee_opinion.pdf