Dear AHEC and ART Review Committee,

I write to respond to the DRAFT Ethical Guidelines on the Use of Assisted Reproductive Technologies in Clinical Practice and Research – released for comment in 2015.

My overall reaction to the draft is that it has in a number of places taken away the paramount consideration of the interests of the child to be born as a result of such practices, and has replaced it with emphasis on ‘reproductive rights’ and an over-emphasis on principles based upon a very liberalist view of the ‘autonomy’ and ‘choice’ concerning the adults involved.

The guidelines present themselves as being premised on a ‘rights’ based framework, but then fail in a true sense of that framework in a number of ways.

I make specific comments about where this is of particular concern, and recommendations for how the current draft should be amended following:

Page 14 - If the new guidelines are to be premised on a 'rights' based framework, then they should recognise the rights of the child as standing above all others.

The Convention on the Rights of the Child emphasises the child’s best interest (Article 3): The determining factor in all actions dealing with any child should be his or her best interest. In all cases, the best interests of the child take precedence over the interests of the adults concerned (e.g. parents, teachers, guardians).
This draft of the ethical guidelines has removed that fundamental value and it should be returned. The ethical guidelines should clearly state that:

In all cases, the best interests of the child born as a result of assisted reproduction should take precedence over the interests of the adults concerned, be they the intended parents, donors, and/or clinicians with an interest in assisted reproduction.

Page 15, paragraph 3.1 - Again, it is not acceptable to see the interests of women and intended parents; gamete and embryo donors listed above those of persons born as a result of ART; or for them to all be listed together as they are. There should be a clear statement that the interests of persons born as a result of such practices are paramount. I therefore suggest the following drafting:

Clinical decisions should take primary focus upon the children who will result; they must then also respect women, intended parents, and donors.

Paragraph 3.2 – What does ‘give serious consideration’ mean/entail?

Paragraph 3.4 – I suggest this statement include a minor change to acknowledge that individual/couple autonomy is limited by the law. The paragraph should be redrafted to read:

3.4 Clinical Decision-making about ART activities must recognise and respect the autonomy of each individual or couple involved

Individuals and couples involved, or considering involvement in, ART activities have the right to decide for themselves whether or not to take part in the proposed activities provided they are acting within the law. It is important to recognise that social relationships and social context may enable, shape, or constrain an individual’s or couple’s autonomy (i.e. autonomy is relational).

....

Paragraph 3.5 – The words ‘the reason(s) for seeking assisted conception’ should be removed. They are too broad and do not add anything to the stated considerations of non-discrimination.

Paragraph 3.7 – The statement regarding privacy should recognise that there are situations in law in which privacy is not protected, and that a right to privacy is not absolute in Australia. Privacy should not be an overarching ethical value in the guidelines. I suggest the following amendments:

All individuals and couples involved in ART activities, including gamete and embryo donors, and persons born, are entitled to privacy to the degree that it is protected by law. Clinics must
respect operate within the law in relation to the privacy of each party and confidentiality of all records. Clinics must have a privacy policy that ensures compliance with relevant legislation.

**Paragraph 4.2.5.** – The inclusion of the statement at Paragraph 4.2.5 is very worrisome. An individual or couple may make an ‘autonomous’ decision to travel overseas to engage in practices that are neither ethical nor legal. Placing an ethical burden on a clinician to continue to advise them poses both ethical and legal risks to the clinician; and places the clinician in the position of possibly supporting unethical and illegal activities. Also – if the individual or couple are seeking treatment overseas – why are they still considered the clinician’s patient (they are not being treated here)?

I suggest amending this statement to:

Clinicians are not obliged to provide advice to individuals or couples who decide to travel overseas to engage in practices that may not be considered ethical or are illegal in Australia. An Australian clinician’s ethical obligations to such person(s) would be to the extent of providing advice regarding any concerns about the standard of care of the overseas clinic (if such a standard is known), or acknowledging when the standard of care is unknown.

**Paragraph 4.4.3** – Again the current draft appears to over-emphasise the interests of the individual/couple who are seeking treatment. This paragraph states they should be ‘supported’; and that ‘consideration’ should be given regarding multiple relocations of embryos. Given that significant psychological impact may ensue for the donor conceived person and that this is recognized – it would be more appropriate (and ethical!) to state that such situations should be limited if not avoided all together.

**Paragraph 5.6.5** – The current drafting from ‘Mandating that potential recipients….’ appears opinionated and loaded. This does not offer ‘ethical’ guidance and is unacceptable.

I suggest the second paragraph should instead read:

Mandating that potential recipients disclose to their children their genetic origins is ethically problematic and is practically difficult and counterproductive. A more productive way to encourage this disclosure is for clinics to provide ongoing opportunities to support parents, to help them to understand the potential significance of the biological connection between their children and donor(s), as well as any half-siblings, and the benefits of early disclosure. Clinics should assist parents to find effective ways of disclosing to their children their genetic origins.

**Paragraph 5.9.1.** – As currently worded is ambiguous and unsatisfactory. It also waters down previous obligations of clinics to actively engage in seeking the consent of donors in such circumstances. It emphasizes privacy over and above the interests of the donor-conceived person who seeks information. This again is unacceptable. I note again that privacy is not paramount nor absolute in Australian law, and it is not acceptable that those drafting the ethical guidelines appear to be seeking to make it so. The statement should be amended as follows:
the clinic should make an appropriate effort, consistent with the original consent document and the privacy rights of the donor, to seek to contact the gamete donor and obtain his or her consent to the release of information.

**Paragraph 5.13.1 – Drafting should read …**

Working in collaboration with relevant professional organisations, clinics should use forums for public information to encourage people who were gamete donors before the introduction of the 2004 edition of these Ethical Guidelines, and those born from these donated gametes, to **consider contacting** contact the clinic and **register** register their consent for the release of information about themselves (as outlined in paragraphs 4.2.3 and 5.8) to persons born from the donated gametes or genetic siblings and half-siblings, respectively.

I.e. amend tense and drafting to read ‘… donated gametes, to contact the clinic and register their consent for the release of information….’ (delete ‘considering’ and amend ‘registering’)

**SURROGACY**

I welcome the continued stance against commercial surrogacy. I recommend two changes regarding the reimbursement of expenses:

**Paragraph 8.11.1 – Loss of earnings:** The reimbursement of ‘loss of earnings’ is too broad. It leaves open the question of whether a surrogate could claim loss of earnings during the entire process, i.e. during time she is undergoing ART, duration of pregnancy and post-birth. This clearly would be unacceptable, and would equate in many people’s eyes to the payment of a wage for 10 or more months. In allowing for reimbursement of reasonable expenses, one needs to ensure that you are not in fact opening the way for so much fluidity in interpretation that what in fact occurs is commercial surrogacy under the guise of altruistic surrogacy.

The ethical guidelines should be more pointed in their stipulation. The guidelines should state:

‘**loss of earnings may be reimbursed when the surrogate mother is not entitled to any other maternity payments and must take time off work due to the pregnancy or birth. Such a period must be limited to no more than two weeks immediately before and two weeks after birth, unless there are complications with the pregnancy which render the surrogate mother medically unfit for work for a more extensive period of time and she is not entitled to other benefits (for example sick leave, sickness benefits, insurance payments that cover loss of earnings). Such complications must be verified by an independent medical practitioner.’**

Such wording would reflect a reasonable period of time off work that a woman would have pre-birth; and a period after birth in which the mother would need to physically and psychologically recover, and would ensure that the surrogate receives no financial benefit other than actual losses incurred).

The **guidelines should also limit travel and accommodation costs** to those incurred within Australia, to avoid the situation of clinics/commissioning individuals/couples encouraging
people from abroad to travel to Australia to engage in donation/surrogacy services. The guidelines should therefore read

‘for travel and accommodation within Australia directly related to the ART treatment, pregnancy and/or birth of the child’

On the other specific matters raised in the document that are being considered:

   a) **Sex selection for non-medical purposes**

   I do not support sex-selection for non-medical purposes.

   The scenarios presented raise interesting issues, but none of them should be used as a reason to introduce sex-selection in Australia.

   I also note the argument that things are done more ‘ethically’ in Australia then in some overseas jurisdictions. This is not, and has not always been, true. It also does not make sense to introduce something that is unethical on the premise that at least it would be conducted in a more ethical manner in Australia – this in fact is a nonsense.

   b) **Compensation of Australian women for the reproductive effort and risks associated with donating their eggs**

   I do not support compensation of Australian women for egg donation. No matter how you dress this up, or use words such as ‘compensation’ for ‘reproductive effort and ‘risks’, this is a move to provide money in return for the donation of eggs.

   The commercialisation of human reproductive capabilities is unacceptable.

   The payment of money in exchange for human tissues and organs is something that is not accepted in our society.

   c) **Establishment of an Australian egg bank**

   I would need much more information that provided in the scenarios to comment on the establishment of an Australian donor egg bank.

   As presented, I do not support the establishment of an Australian egg donor bank.

Finally, I note the statement in the draft document that aligns Australia’s ethics with those of the United Kingdom. I question this narrow view and alignment of the population of Australia with the United Kingdom, when Australia is in fact much more multicultural. To make a statement about the ethics of the Australian people requires looking more broadly than its historical ties
with the United Kingdom. The majority of the world prohibits the practices being considered (or suggested) by the current review committee, including a majority of countries across Europe, the middle-east, Asia and the Asia Pacific.

Australia should not join the minority of countries that may permit (or do not regulate) practices that are considered unethical and illegal in many nations across the world.

I thank you for taking the time to consider my submission,

Kind regards,

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