Advisory Committee on Assisted Reproductive Technology

Import and Export of Gametes and Embryos: Proposed advice to the Minister of Health

Feedback Form

Please provide your contact details below.

Name:	**Fertility Associates, Te Rauhanga O Te Wharetangata**
If this feedback is on behalf of an organisation, please name the organisation:	Fertility Associates
Please provide a brief description of the organisation if applicable:	Assisted reproductive technology provider
Address/email:	Private Bag 28910, Remuera, Auckland 1541
Interest in this topic (eg, user of fertility services, health professional, researcher, member of the public):	Fertility service provider

We will place all feedback on ACART's website, except where we are asked that feedback be withheld in full or part for reasons of confidentiality. We will remove contact information from all feedback.

☐ I **request** that my feedback be withheld in full or part from publication on ACART's website (if you wish a part to be withheld, please clearly indicate which part).

Please note that all feedback may be requested by any member of the public under the Official Information Act 1982 (the Act). If there is any part of your feedback that you consider should be properly withheld under the Act, please make this clear in your feedback, noting the reasons.

If information from your feedback is requested under the Act, the Ministry of Health (the Ministry) will release your feedback to the person who requested it. The Ministry will remove your name and/or contact details from the feedback if you check one or both of the following boxes. Where feedback is on behalf of an organisation, the Ministry will not remove the name of the organisation.

☐ **I do not** give permission for my name to be released to persons under the Official Information Act 1982.

☐ I **do not** give permission for my contact details to be released to persons under the Official Information Act 1982.

We will acknowledge all feedback.

Questions about the proposals discussed in the paper

Question 1: Import and subsequent use of gametes and embryos

Do you agree that the principles and requirements of the Human Assisted Reproductive Technology Act 2004 should apply in all cases where people wish to import into and use in New Zealand gametes and embryos sourced or created in other countries?

Yes [X] No [X]

Please give reasons for your views.

We agree that the principles of the HART Act, set out in section 4 of the Act, should always apply.

To enact these principles, the Act introduces requirements directly through the Act itself - such as prohibition of sex selection and requiring donors to be identifiable. The Act also leads to requirements indirectly - such as through the Order of Council listing established procedures, and through the New Zealand Fertility Standard which defines the maximum number of families per donor.

We know there can be circumstances where the requirements following from the Act contradict the principles of the Act in upholding the well-being of children and their parents. We listed several in our submission in July 2013. One clear example is a couple who have a child using donor sperm in a country where altruistic sperm donation was not readily available, who move or return to NZ, and then want a child by the same donor so their children are full siblings. The prohibition of valuable consideration for donation means the family cannot have children who are full siblings, which is in the best interests of the existing and potential children.

The principles of the law should not be over-ridden by requirements that are in their general sense good, but in an individual circumstance can harm those whom they were designed to protect.

Question 2: Export of gametes and embryos

Do you agree that export of gametes and embryos should be possible, provided that:

- the subsequent use of gametes or embryos is consistent with the principles and requirements of the Human Assisted Reproductive Technology Act 2004, including any prohibitions, and
- all gamete providers, including donors, have given informed consent to the export of their gametes or of embryos created from their gametes?

Yes [X] No [X]

Please give reasons for your views.

We agree that all gamete providers (including donors) should give informed consent to their export of their gametes, and that people with embryos (including embryo donors) should give consent to the export of their embryos.

However, we do not agree that gamete donors need to give consent to the export of embryos created from their gametes. Donors are counselled, accept, and expect that their rights to their gametes stop when their gametes no longer exist because they have been used to create an embryo. Donors can only make decisions about things that can be reversed. This has always been the practice in New Zealand. It provides clarity around boundaries for both donors and recipients and is an integral concept of informed consent relating to gamete donation

Question 3: Decisions about import and export for assisted reproductive procedures

Do you agree that fertility services providers should continue to make decisions about whether the import and export of gametes and embryos for assisted reproductive procedures is consistent with the principles of the Human Assisted Reproductive Technology Act 2004, and New Zealand requirements?

Yes [X] No [X]

If you disagree with the proposal, who or what should make decisions about whether the import and export of gametes and embryos for assisted reproductive procedures is consistent with New Zealand requirements?

Please give reasons for your views.

The 'owner' of the gametes or embryos should have the primary responsibility for making decisions about the import or export of their own gametes or embryos.

Fertility service providers should have the ability to decide whether to accept gametes into their facility based on the principles and requirements of the HART Act, and other legislation (eg. The Human Rights Act), regulations and guidelines.

Fertility service providers should not have the ability to stop people being able to export their own gametes or embryos.

Question 4: Decisions about import and export for human reproductive research

Do you agree that the role of the Ethics Committee on Assisted Reproductive Technology in respect of human reproductive research should explicitly include considering and deciding applications to undertake human reproductive research involving imported and exported gametes and embryos?

Yes [X] No [X]

If you disagree with the proposal, who or what should be responsible for making decisions about research involving imported and exported gametes and embryos?

Please give reasons for your views.

All gametes and embryos in NZ are subject to ECART with respect to human research, whether they were stored locally or imported.

Fertility service providers should not have the ability to stop people being able to export their own gametes or embryos, whether for treatment or research.

Question 5: Regulations

Do you agree that regulations should be made about the requirements for the import and export of gametes and embryos?

Yes [ ] No [X]

If you disagree with the proposal, how should requirements for import and export be set out?

Fertility Associates opposes the implementation of additional regulation in this area. Instead, there should be guidelines based on the principles of the HART Act.

Please give reasons for your views.

Guidelines allow people to apply the principles of the HART Act to specific cases. Where there is conflict between principles (eg in our example in question1, that donation not involve valuable consideration versus parents wanting full siblings), guidelines provide a road to resolution.

Regulations are rules that do not allow consideration of individual circumstances. It is our experience that regulations will be unable to provide for the varied and complex circumstances that people experience.

Decisions on individual cases should involve those who are caring for the patient, since they will know the full circumstances and context.

Question 6: Donor compensation

Do you agree that the Ministry of Health should be asked to consider guidance to fertility services providers that allows for increased levels of donor compensation, particularly for egg donors?

Yes [X] No [ ]

Do you agree that such guidance should, for consistency, include the expenses available to surrogates?

Yes [X] No [ ]

If you agree with the proposals, do you have a view about appropriate maximum levels of compensation to donors?

We suggest that assistance to egg donors in the order of $2-3000 is reasonable, based on practice in the UK and Spain, both countries with a non-commercial framework for gamete donation. This is in line with assistance for Live Organ Donor Assistance in New Zealand

Please give reasons for your views.

We would like to change the conceptual framework around this issue from 'reimbursement' to 'assistance'.

This recognises that altruistic gamete or embryo donation and surrogacy is beneficial to people experiencing infertility and hence to the society in which they live. Live organ donation in NZ provides a model of the concept of 'donor assistance' (http://www.workandincome.govt.nz/individuals/a-z-benefits/live-organ-donor-assistance.html) which could be a starting point for deciding what is appropriate for gamete donors and surrogates.

The level of assistance should not provide a financial incentive to donate, but should remove financial barriers to being an egg donor.

Question 7: Public health information

Do you agree that the Ministry of Health should be asked to consider public health information about:

- the impact of age and other factors on fertility, and
- gamete donation?

Yes [X] No [ ]

Please give reasons for your views.

Fertility Associates spends about $100,000 a year trying to make people aware of the impact of age on fertility, and on making people aware of the need for gamete donors. It is obviously not sufficient. Data from the combined Australian-NZ data collection on IVF treatment shows that even reducing the average age at IVF treatment by one year would increase the success rate by 15%.

Question 8: Data about offshore fertility treatment and outcomes

Do you agree that the Ministry of Health should be asked to consider strategies for collecting data about the use and outcomes of offshore fertility treatment by New Zealanders?

Yes [X] No [ ]

If you agree, do you have ideas about how such information could be collected?

The negative consequences of offshore fertility treatment are largely borne by the resulting children (see below). Hence it would logical to collect information at the time and place of birth.

Please give reasons for your views.

Offshore fertility treatment has potentially negative aspects for the wellbeing of woman and children:

- Children are not able to find the identify of a their donor through Births, Deaths and Marriages
- Many countries where people go offshore for fertility treatment do not practice ART as safely as in NZ, especially in the area of multiple embryo transfer, leading to a high incidence of twins and higher multiple pregnancy

Data could help decide whether some restrictions in the HART Act or elsewhere were having unintended consequences such as people choosing to transfer more than one embryo at a time to minimise repeat visits overseas for treatment

It should be recognised that the data collected may not be comprehensive. A woman may not want to disclose to her LMC that she has had fertility treatment overseas – particularly if this carries a regulatory burden to provide additional information. The more regulation around this area, the less information that is likely to be volunteered.

Question 9: Comments or suggestions

Do you have any other comments or suggestions about the issues discussed in this proposed advice paper?

Thank you for the opportunity to comment on the proposed advice. We have kept our answers brief because we have already presented our thoughts on the same issues in detail in our submission in July 2013. Our conclusions then, based on a huge amount of accumulated experience and consideration, have not changed.

The principle question here is: should there be regulations or guidelines on import or export of gametes and embryos. Our answer is firmly guidelines. Regulations mean anticipating and finding answers in advance that are true (ethically, pragmatically and logistically) no matter the individual circumstance.

Neither guidelines nor regulations are going to be perfect, but we are certain that guidelines will give better decisions more often because they can take into account the myriad of individual circumstances that we have encountered in our 27 years of providing ART resulting in over 14,000 children.