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Secretariat
Advisory Committee on Reproductive Technology
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Informed Consent and Assisted Reproductive Technology – proposed advice to the Minister of Health

Introduction

1. The New Zealand Law Society (Law Society) appreciates the opportunity to comment on the Advisory Committee on Reproductive Technology's (ACART) discussion document, *Informed Consent and Assisted Reproductive Technology: proposed advice to the Minister of Health* (discussion document).

2. The Law Society considers that the legal framework currently in place for informed consent in this context (i.e. the Code of Health and Disability Services Consumers' Rights (Code)) is adequate, but welcomes those recommendations in the discussion document aimed at putting in place "best practice" standards, beyond the minimum requirements of the law.

3. The Law Society makes a number of recommendations which it considers would make the proposed advice set out in chapter 3 of the discussion document clearer. The Law Society is not in a position to comment on the bioethical issues raised in the discussion document and its comments are limited to the legal implications of the proposals.

Recommendations for improving the clarity of the proposed advice in Chapter 3

4. The Law Society questions the statement at paragraph 50 of the document that access to the information that must be disclosed to patients and donors is not a "provider compliance issue". Right 6 of the Code provides that every consumer has the right to the information that a reasonable consumer, in that consumer's circumstances, would expect to receive. Providers are required to comply with that obligation.

5. ACART has concluded (paragraph 51) that there needs to be better access to the information that is required to be provided to donors and patients. The "accessibility" of information can mean the physical ability to obtain it (for example acquiring a copy of the Fertility Services Standard which is not freely available), but also the presentation and tailoring of information to ensure it is comprehensible to its audience. Right 5 of the Code provides that every consumer has the right to effective communication in a form, language and manner that enables the consumer to understand the information provided. The Law Society considers that the reference to "better access" in the document could be made clearer to reflect this.

6. Paragraph 54 of the discussion document refers to Right 6; this should refer to Right 7(6).

7. With regard to the proposals concerning written consent, the Law Society has no concern about the prospect of imposing additional "best practice" requirements on providers (over and above the legal requirements), but notes that verbal withdrawal of consent is legally valid and a failure to obtain a written record of the withdrawal of consent does not negate that withdrawal. This should be made clear at paragraph 63 of the discussion document.

8. The Law Society questions the statement at paragraph 65 of the discussion document that there is no formal requirement for donor consent to be obtained for the use of donor gametes, or embryos created from their gametes, in the training of embryologists and clinicians. This would appear to be a matter covered by Right 6 of the Code. It would be useful for this to be addressed in the proposed advice to the Minister for Health, and any guidelines that result from it.

9. Paragraph 77 could be re-phrased to make clearer that donors give consent subject to any conditions they choose to place on that consent (rather than "prior to giving consent").

10. The Law Society notes, with reference to paragraph 82, that there are exceptions to the HART Act prohibition on procedures that aim to influence whether an embryo will be of a particular sex, where there is a risk of gender-related medical conditions. It might be helpful to refer to such exceptions in the discussion document.[1]

11. The Law Society questions the accuracy of the statement at paragraph 91 that people are unable to set conditions as to who may use their donated organs if they die. The Human Tissue Act 2008 allows a person (while living) to qualify their consent to the use of their human tissue after their death (for example by limiting consent to transplantation into a specific recipient).[2]

12. It would be helpful if the discussion document specified whether the proposal at paragraph 96 includes ongoing conditions (i.e. beyond fertilisation, after the resulting child is born) or is limited to what can be done with the gametes.

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1 Section 11(3) of the HART Act provides a defence to a breach of section 11(1) where the procedure has been undertaken to prevent a genetic disorder or disease, and the ACART Guidelines on Preimplantation Genetic Diagnosis allow sex determination in the use of PGD for the purposes of the prevention and treatment of a genetic disorder or disease where: (i) a familial sex-linked disorder has been identified in the family or whānau, and (ii) there is a 25 percent or greater risk of an affected pregnancy, and (iii) no specific test for the particular mutation that causes the disorder is available, and (iv) there is evidence that the future individual may be seriously impaired as a result of the disorder.

2 See sections 9, 19 and 31, Human Tissue Act 2008.

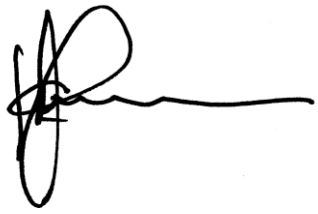
13. With regard to whether gamete donors should be given the option of receiving ongoing information on the use of their gametes (paragraphs 97 – 107), Right 6 of the Code already requires the provision of ongoing information (or at least notification that such information is not going to be provided).

14. On the question of whether gamete donors should be able to withdraw or vary consent to the use of their gametes up to the point of fertilisation, in practice it could be very difficult to let a donor know when fertilisation is about to happen. It would be undesirable to create an obligation that cannot be complied with or enforced. It would be preferable to place the onus on the donor to inform the clinic if they wish to withdraw or vary their consent.

15. With respect to disputes and the proposed 12 month "cooling off" period (paragraphs 134 – 152), it would be useful to specify when that period would commence.

This submission has been prepared with the assistance of the Law Society's Health Law Committee. If you wish to discuss the comments, please do not hesitate to contact the committee secretary Jo Holland (04 463 2967, jo.holland@lawsociety.org.nz).

Yours sincerely,



Chris Moore
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