Informed Consent and Assisted Reproductive Technology: Proposed advice to the Ministry of Health

Submission to the Advisory Committee on Assisted Reproductive Technology (ACART)

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Contact

[redacted]

[redacted] | www.nzno.org.nz

NEW ZEALAND NURSES ORGANISATION | PO BOX 2128 | WELLINGTON 6140

About the New Zealand Nurses Organisation

NZNO is the leading professional nursing association and union for nurses in Aotearoa New Zealand. NZNO represents over 46,000 nurses, midwives, students, kaimahi hauora and health workers on professional and employment related matters. NZNO is affiliated to the International Council of Nurses and the New Zealand Council of Trade Unions.

NZNO promotes and advocates for professional excellence in nursing by providing leadership, research and education to inspire and progress the profession of nursing. NZNO represents members on employment and industrial matters and negotiates collective employment agreements.

NZNO embraces Te Tiriti o Waitangi and contributes to the improvement of the health status and outcomes of all peoples of Aotearoa New Zealand through influencing health, employment and social policy development enabling quality nursing care provision. NZNO's vision is *Freed to care, Proud to nurse*.

EXECUTIVE SUMMARY

1. The New Zealand Nurses Organisation (NZNO) welcomes the opportunity to comment on ACART's proposed advice to the Minister of Health on informed consent and assisted reproductive Technology applying to gamete donors.

2. NZNO has consulted its members and staff in the preparation of this submission, including members of relevant nursing colleges and sections, Te Rūnanga, and professional nursing and policy advisers.

3. This is an excellent and timely document which achieves its purpose of providing a clear policy and legislative platform to support practice guidelines and processes around informed consent for gamete donors at the initial point of consent and beyond.

4. The issues are well canvassed and the rationale is sound.

5. In general, NZNO supports the recommendations, with the exception of donors being given information if the gamete is about to be used and being able to withdraw or vary consent to the use of gametes up to the point of fertilisation.

6. We also argue that where there is a dispute over an embryo created for a couple, precedence should be given to the female donor, and subsequently, the female recipient.

7. While outside the scope of this paper, we take this opportunity to draw your attention to the contradictory approaches to fertility evident in legislation and practice. We support the public policy principle stated in s141 that women have control over their own bodies, and would welcome that principle being applied to *all* reproductive technologies, not just assisted reproduction.

8. Abortion remains part of the Crimes Act, for example, and there are significant cost and access barriers for women, especially rural and Māori women, to appropriate medications and devices to control their reproduction. These women often do not have the opportunity to be informed or consent to timely and affordable reproductive treatments or procedures which are widely available.

9. Removing regulatory barriers to nurse practitioners and nurses (as well as pharmacists), to ensure equitable access to funded medications, treatments and devices, including Mirenas, emergency contraceptive pill (ECP), etc. is urgently required.

10. We would welcome ACART progressing equal access to *all* assisted reproductive technologies in Aotearoa New Zealand through its advisory role.

Initial consent process

A. There should be better access to the information that must be disclosed to patients and donors prior to consent.

Question 1

a) Do you agree there is a need for better access to the information that must be disclosed to patients and donors prior to consent?

Yes. The inability to freely access health service (and other industry) standards is not confined to the Fertility Services Standard ('the Standard') and is highly disempowering for consumers. It is also discriminatory in that it privileges those who can afford to buy the Standard document. Service standards assure public safety and must be publicly available to maintain trust in the integrity of the system. Online access largely removes the cost barrier of making the standard freely available.

b) Is there other information that should be given to patients and donors as part of the informed consent?

The most important consideration appears to be achieving the right level and amount of information at the right time, in language and a format that is easily understood by, and satisfies, consumer needs. Too much information can be overwhelming and may be irrelevant and

unnecessary; health practitioners are trained to meet consumers information needs, and should be supported with appropriate material and, if necessary personnel (eg interpreters). Access to clinical, technical and legal information (eg the Standard, the Health and Disability Code) must be assured. People should be made aware of common potential scenarios ('what if…'), and supporting written information must be available to clients to take home.

b. Consent to all assisted reproductive procedures, where consent is required, must be in writing.

Question 2

a) Do you agree that consent to all assisted reproductive processes, where consent is required must be in writing?

Yes. Unequivocally.

b) Do you have any other comments?

No

c The consent of donors should be obtained if their gametes, or embryos created from their gametes, may be used for training purposes

Question 3

a) Do you agree that the consent of gamete and embryo donors should be obtained if their gametes, embryos created from their gametes, may be used for training purposes?

Yes.

b) Do you have any other comments?

We foresee both ethical and practical challenges in having to convey information to gamete donors about the use of gametes in research, education, and training and in equipping health practitioners, biomedical research scientists and technicians with the skills to use and develop assisted reproduction technologies. However, we believe there is significant value in developing better public understanding of the science and the ethical considerations and constraints that govern practice. Nurses are well placed to develop and deliver this information, as they are scientifically trained and regulated, and have a principle role in the interpretation and exchange of information between the medical profession and consumers.

In identifying procedures for 'training' purposes, the regulation will need to balance the flexibility required for experts to be able to keep up with new developments, with the public need for transparency and certainty for the donor.

Ongoing involvement of gamete donor

d. Gamete donors should continue to be able to place conditions on their consent.

Question 4

a) Do you agree that donors should continue to be able to set conditions on their consent?

Yes, but we emphasise the importance of extent of information and consent for use at the point of donation. Ideally, the donor should be informed and given options to place (and understand) limitations on use *before* donation e.g. yes to IVF, yes to stem cell research, no to cloning experiments.

b) If so should there be any limits on the conditions placed?

We have been unable to arrive at a consensus position on this, mainly because donors' unlimited discretion to impose conditions has the potential to limit the opportunities of certain groups to access assisted reproductive technologies. We would be reluctant to 'codify' the ability to discriminate, but recognise that this is a human rights issue. Accordingly, we are happy to be guided by ACART's expertise.

c) Do you have any other comments?

No

e. Gamete donors should be given the option of receiving ongoing information on the use of their gametes.

Question 5

a) Do you agree that gamete donors should be given the option of receiving ongoing information on the use of their gametes for the following situations:

(i) If the gamete is about to be used?

No. We agree that donors could be given the option of receiving ongoing information but would be reluctant to see this as a requirement

for every procedure, since, at this stage, there is no outcome to be informed about. We believe this would be unnecessarily intrusive for both donors and recipients and would compromise the privacy of the latter, who have a right to patient confidentiality and to choose with whom to share personal information eg with regard to menstrual cycles, or in the event of a miscarriage.

For reasons outlined in s102 and s103, we can see that it would be problematic to keep donors fully informed. Nurses are well aware of the time and administrative and financial burden of contact tracing, for example for immunisation and for infectious disease. For this reason we would agree with the suggestion in s193 and s105 that donors who wish to be informed must be responsible for updating their contact details.

Timing is an issue with assisted reproductive technologies, and prospective parents are vulnerable and under stress as they have usually been through years of treatment and procedures. There is a risk that this could lead to delayed procedures, the impact of which would be disproportionate and adverse to the recipient.

(ii) on the outcomes(s) of the donation?

Yes, if that is what the donor chooses and if the donor is responsible for ensuring his/her contact details are accurate. Information at this point will not affect the outcome or the recipient.

b) Is there any other information that you think should be offered to gamete donors after consent has been given?

No

g Gamete donors should be able to withdraw or vary consent to the use of their gametes up to the point of fertilisation

Question 6

a) Do you agree that gamete donors should be able to withdraw or vary consent to the use of their gametes up to the point of fertilisation?

No. We do not consider it appropriate for withdrawal at any time once a procedure to unite egg and sperm is started. In the case of IVF for example, there is a considerable period of preparation involved before the 'point of fertilisation' and it would be unacceptable and inhumane to risk it being cancelled part way through. Donor insemination is more straightforward, but while it may be easier to stop at the point of insemination, it is no less traumatic for the recipient. We do not envisage that this provision would be used often, but the possibility would negatively and unfairly affect the recipient's state of mind.

b) If not, when do you consider the 'point of no return' should be?

Before the cycle of a treatment or procedure begins.

Partner and family/whanau rights and interests

g The consent of partners or family/whānau to the donation or use of a donor's gametes should not be required

Question 7

a) Do you agree that the consent of **partners** to the donation or use of a donor's gamete should not be required?

Yes. A woman or man should be able to donate if they wish to do so. As acknowledged in s125, New Zealand is a diverse society and the question of what constitutes a partner under what circumstances (the person to whom you are legally separated? the person who's partner is mentally no linger capable of making such decision, but to whom they are married? the de-facto partner with whom you have co-habited for 2+ years?) is a personal one, as is the decision to donate.

However, we suggest donors should be counselled, but not pressured, to consider the views of their partner and would encourage donor partners to be informed and counselled. Donors are more certain and less likely to change their minds about donating gametes when their partners are informed and supportive.

b) Do you agree that the consent of **family** or **whānau** to the donation or use of a donor's gamete should not be required?

Yes. As above.

h Where one party of a couple disputes the future use of embryos that have been created for them, there should be a 'cooling-off' period of 12 months

Question 8

a) Do you agree that where one party in a couple disputes the future use of embryos that have been created for them there should be a cooling off period of 12 months – and if not why not?

Yes; this would be a useful provision and consistent with the regulatory trend towards mediation and dispute resolution in other areas such as employment and consumer law.

b) Do you agree that, if the couple cannot agree about the use of the embryos within that period the embryos should be disposed of – and if not why not?

No. Although not explored in the paper, there is a significant imbalance of power between men and women which needs to be considered in relation to reproductive rights. Gender disparities in employment, income, leadership etc. are ubiquitous and translate readily into disparities in power and control. They are fundamentally related to the unequal value accorded to productive, as opposed to reproductive, labour in our society, though equal participation in employment is expected.

The physical and health implications of parenthood for women and men are also hugely disparate, as is the reproductive period. Therefore, where there are disputes over reproduction, including whether embryos should be disposed of, we suggest that the woman's decision must take precedence. I.e. the decision lies firstly with the creator of the egg, and secondly, in the case of a willingly donated egg, with the female recipient.

Regulations

i. Requirements for informed consent should be set out in Regulations, where appropriate.

Question 9

a) Do you agree that requirements for informed consent should be set out in regulations?

Yes, as this would ensure consistency and transparency

b) Do you have any other comments?

No

Question 10

a) Do you have any general comments or suggestions about the requirements for informed consent?
b) Do you have any general comments or suggestions about the issues discussed in this consultation document?

No, but we again draw your attention for the need to remove barriers and progress equitable access to all reproductive technologies. NZNO would be happy to be contacted to discuss this.