Feedback form

Please provide your contact details below.

Name	New Zealand College of Midwives
If this feedback is on behalf of an organisation, please name the organisation	New Zealand College of Midwives
Please provide a brief description of the organisation (if applicable)	The New Zealand College of Midwives is the professional organisation for midwifery. Members are employed and self-employed and collectively represent 90% of the practising midwives in this country. There are around 2,900 midwives who hold an Annual Practising Certificate (APC). These midwives provide maternity care to on average 60,000 women and babies each year. New Zealand has a unique and efficient maternity service model which centres care around the needs of the woman and her baby. It provides women with the opportunity to have continuity of care from a chosen maternity carer (known as a Lead Maternity Carer or LMC) throughout pregnancy and for up to 6 weeks after the birth of the baby, and 92% of women choose a midwife to be their LMC. Primary maternity services provided by LMC midwives are integrated within the wider primary care and maternity services of their region or locality. The College offers information, education and advice to women, midwives, district health boards**,** health and social service agencies and the Ministry of Health regarding midwifery and maternity issues. Midwives interface with a multitude of other health professionals and agencies to support women to achieve the optimum outcome for their pregnancies, health and well-being.
Address/email	PO Box 21 106 Edgeware Christchurch 8143 Tel (03) 377 2732 Facsimile (03) 377 5662 email nzcom@nzcom.org.nz
Interest in this topic (eg, user of fertility services, health professional, researcher, member of public)	The New Zealand College of Midwives is the professional organisation for midwifery and interested in women's health, women's rights, reproductive rights, and all aspects of pre-conception, conception, pregnancy, birth and the postnatal period. Midwives provide care to the majority of women who will be using ACART services and therefore the College is interested in ACART issues, and maternal and infant outcomes and wellbeing.

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Question 1: Rescinding the biological link policy
Refer to section 3.
ACART is proposing that:
- the guidelines should no longer require intending parents to have a genetic or gestational link to a resulting child
- instead the guidelines should require ECART to be satisfied that where intending parents will have neither a genetic nor a gestational link to a resulting child, the lack of such links is justified.

(a) Do you agree? Yes ☐ No ☐

(b) Do you believe there are cultural implications associated with the proposed removal of the biological link policy?

Yes ☑ No ☐

If so, please describe these implications.

1.1 The New Zealand College of Midwives (the College) agree with the proposed change to a degree but we have some concerns.

1.2 Until the policy has had full consultation with Māori the cultural implications associated with the proposed removal of the biological link are inappropriate in a bicultural society. The obligations of partnership, protection, autonomy, and self-determination mean that there is a duty to consult Māori about their views. The document references to Māori, in terms of the implications of assisted reproduction and genetic lines, refer only to what Māori may be "likely" to think. "Likely", as a term is insufficient.

1.3 The College recognise that family diversity is no longer exceptional or alternative, but we consider that the cultural aspects require some recognition and protection as part of any proposed changes.

1.4 Alongside this there is a need for transparency in terms of the ECART guidelines for determining the justification for individual applications. These guidelines should be reviewed prior to any formal changes being made.

1.5 The College is also concerned with structural inequalities, in terms of who will be able to access such services, the potential for unrestricted commercial gain, and the potential for exploitation of women.

1.6 In terms of 1.5, because the College is interested in the health and wellbeing of all women, we consider that the prevention of infertility requires more attention. The prevention and treatment of sexually transmitted infections is an area of public health concern that should not be ignored in favour of infertility treatment. Alongside the prevention model, which the College recommends should be the first objective, in terms of fertility matters, infertility treatments need to be affordable, and much less costly to address access and equity issues.

Question 2: Access to information held on birth certificates
Refer to section 3.

ACART is interested in hearing views about potential strategies to strengthen a donor offspring's access to information about their origins, which is held on their birth certificate.

Do you have suggestions? Yes ☑ No ☐

Please give reasons for your views

2.1 The College notes that the reasons why donor-conceived children (DCC) are interested in access to origin information include:
- To understand any medical risk
- To avoid consanguineous relationships
- To connect with 'roots;
- To complete a life history (Ravelingien)[1]

2.2 The variance described in the analysis by Ravelingien et al, illustrates how some motivations are driven by strong deterministic misconceptions. The challenge as described by Ravelingien et al is to treat all identity seekers' needs as of equal concern, and to help assess the various motivations.

2.3 The College considers that counselling and support would be a necessary service for all DCC rather than, as described by Ravelingien et al, "offering a one-size-fits-all solution."

2.4 Ravitsky suggests that parents require the provision of education and counselling to support them in telling children the truth about the circumstances of their conception, and considers that this supports and allows the agenda of the DCC without violating the rights of parents to privacy.

2.5 Ravitsky also suggests that addressing some of the needs of DCC without violating the rights of the donors could be achieved by supplying complete and updated medical histories and medically relevant genetic information and supplying non-identifying personal 'narrative' information about the donor/s. [2]

2.6 The College hopes that the different needs of all parties involved are taken into account throughout all processes.

2.7 The College would recommend avoidance of the "one-size-fits-all solution" and we also have some concerns that the technology is advancing much faster than the protections that will be required to support these changes.

[1] Ravelingien, A., Provoost, V., & Pennings, G. (2013). Donor-conceived children looking for their sperm donor: what do they want to know? *Facts, Views & Vision in ObGyn*, *5*(4), 257–264

[2] Ravitsky, V. (2010). "Knowing where you come from": The rights of donor-conceived individuals and the meaning of genetic relatedness. *Minnesota Journal of Law, Science and Technology*, 11(2): 665-683.

2.8 In reference to 2.2 - 2.7 the College considers that extensions to ACART services should not occur without corresponding increases in support services. Issues of availability, affordability, timeliness, equity, and access would require attention.

2.9 In reference to 2.8 the College notes that Fisher et al found increased rates of mild to moderate maternal depression and early parenting difficulties in women who had ART conception.[3] This indicates that an increase in support services will be essential, as will be the involvement of midwives and midwifery care.

Question 3: Format of the proposed guidelines
Refer to section 4.1.

ACART is proposing to issue one set of guidelines to ECART that encompass family gamete donation, embryo donation, the use of donated eggs with donated sperm and clinic-assisted surrogacy.

Do you agree with the format of the proposed guidelines? Yes ☑ No ☐
Please give reasons for your views

3.1 The College does not see any reason why the guidelines should not be combined but recommend that these draft guidelines should also be sent out for consultation.

Question 4: Justification to use a procedure
Refer to section 4.2.

ACART is proposing that ECART should be satisfied the proposed procedure is the best or only opportunity for intending parents to have a child and the intending parents are not using the procedures for social or financial convenience or gain.

Do you agree? Yes ☐ No ☐
Please give reasons for your views

4.1 The College agrees that ECART should feel assured that any proposed procedure is ethically robust, and the "best or only opportunity for intending parents to have a child", but we would like an explanation as to what ACART consider the "social" reasons for the procedure would be.

4.2 The College has some questions about 104. We find it interesting that ACART appear to be recommending a far more complicated procedure for a lesbian couple or a single woman – donated embryo assisted reproduction – as opposed to the more informal access to donated sperm outside of the clinical setting. ACART is suggesting that having access to a donated embryo would reduce the incentive to use donated sperm in an informal way. The College considers that information about using donated sperm outside of a clinical setting should be freely available so that women can make their own informed decisions as to which route they take. In situations where access to donated sperm in a clinic setting is unavailable, navigating the options involved requires that non-coercive information should be available to these women. The College is aware of the myriad of ethical issues involved in these processes and the availability of unbiased literature is essential.

[3] Fisher, J. R. W., Hammarberg, K., & Baker, H. W. G. (2005). Assisted conception is a risk factor for postnatal mood disturbance and early parenting difficulties. *Fertility and Sterility*, 84,(2):426-430.

4.4 The College note some recent media discussion about the waiting lists for sperm donors via fertility clinics, and the suggestion by one fertility clinic director that sperm may be sourced from overseas donors. The College has some concerns about this suggestion which links to the ACART Q104 and to the question about access to origins. We would have serious concerns about the legal issues involved in the importation of donor sperm from other countries where laws around both ART and access to information differs.

Question 5: Consent by gamete and embryo donors
Refer to section 4.3.

ACART is proposing that, where a procedure will involve the use of an embryo created from donated eggs and/or donated sperm, the gamete donor(s) must have given consent to the specific use of their gametes:

- at the time of donation; or
- when a procedure using such an embryo is contemplated.

In either case, the affected parties should receive counselling on the implications of using gametes before the gamete donor gives specific consent.

If consent is given, the gamete donor can vary or withdraw their consent only up until an embryo is created (in cases where consent is given before the embryo is created).
In addition, where a procedure will involve the use of a donated embryo, the person(s) for whom the embryo was created must give consent to the specific use of the donated embryo:

- at the time of donation; or
- when a procedure using such a donated embryo is contemplated.

Once an embryo is created, the decision to vary or withdraw consent up to the time the embryo is transferred to the womb should remain with the people for whom the embryos were created.

Do you agree? Yes ☐ No ☐
Please give reasons for your views.

5.1 The College notes that ACART appear to be suggesting that consent is only necessary up until the gametes or embryos are used in a specific procedure. The College considers that informed consent is necessary at every stage.

Question 6: Taking account of potential coercion
Refer to section 4.4.

ACART is proposing that ECART should take account of any factors in a relationship that might give rise to coercion or unduly influence a donor's or surrogate's consent to take part in a procedure.

Do you agree? Yes ☑ No ☐

Question 7: Limit to number of families with full genetic siblings
Refer to section 4.5.

ACART is proposing that full genetic siblings should continue to be limited to no more than two families.

Do you agree? Yes ☑ No ☐

Question 8: Legal advice
Refer to section 4.6.

ACART is proposing that ECART must be satisfied that:
- where an application includes a surrogacy arrangement, each affected party has received independent legal advice
- where an application does not include a surrogacy arrangement, each affected party has considered seeking independent legal advice
- any legal reports show that all affected parties understand the legal implications of the procedure(s).

Do you agree? Yes ☐ No ☐
Please give reasons for your views.

8.1 The College fully agrees that all affected parties understand the legal implications of any procedures and arrangements. We have some concerns about equitable access to independent legal advice and would like further information about how access to legal support is managed in these situations. The College suggests that consideration of legal advice is insufficient for any ART procedure managed in a clinical setting, and that the barriers to accessing independent legal advice should be explored, discussed, and outlined.

Question 9: Regulation of all family gamete donations
Refer to section 5.

ACART is of the view that all family gamete donations through a fertility services provider should be regulated by guidelines and thus require ECART approval.

Do you agree? Yes ☐ No ☐
Please give reasons for your views

9.1 The College considers that this proposal requires cultural consultation prior to any changes, as it will affect Māori extended whānau and culturally recognised family groupings. There is obviously a financial issue involved as we note the costs to the consumers of applications to ECART. This financial issue related to consumers has not been addressed in the document and the College again is concerned about equity, access, and affordability.

Question 10: Donation of embryos created from donated gametes
Refer to section 6.1.

ACART is proposing that the guidelines should enable ECART to approve the donation of embryos created from donated eggs and/or donated sperm, provided ECART takes account of the potential complexity of resulting relationships and the gamete donors have given specific consent to the procedure.

Do you agree? Yes ☐ No ☐
Please give reasons for your views

10.1 The College would like reassurance that all concerned have access to the unbiased information necessary to make informed decisions.

10.2 Regarding what the document describes as the “surplus embryos”, the College does not have any specific objections to the donation of embryos as described, but again the issue of informed consent and legal counsel is paramount, and we would like to be reassured that all parties involved have equal access to the information necessary, regardless of their financial circumstances. In cases of financial hardship the College would be interested to learn what provisions are being proposed to mediate this problem and to support consumers.

Question 11: Embryo on-donation and re-donation
Refer to section 6.2.

ACART is proposing that surplus donated embryos:
- should not be able to be on-donated by the recipients
- but can be returned to the donors, in accordance with any agreement between the parties, for re-donation to another party, subject to a new approval by ECART.

Do you agree? Yes ☑ No ☐
Please give reasons for your views.

11.1 The College considers that "on-donation" of "surplus embryos" is complex and there are numerous ethical concerns. Therefore we consider that ECART should continue to be involved in all agreements.

11.2 The College agrees that on-donation by recipients should not be supported generally, but we would also be interested in the potential development of a process which would support individual cases to be discussed further.

Question 12: Clarification of the status of embryo donation in the regulatory framework
Refer to section 6.3.

ACART is of the view that the regulatory framework should clarify that:
All embryo donation cases are regulated by guidelines and thus require approval by ECART
Embryo donation does not include cases where an embryo created for a couple is used by one of the couple in a new relationship with the informed consent of the previous partner.

Do you agree? Yes ☐ No ☑
Please give reasons for your views

12.1 The College considers that unbiased information should be available for all parties, and that the conditions for both informed consent and informed refusal need to be met satisfactorily.

12.2 The College has some concerns about the suggestion that an embryo donation in some instances would not be considered an embryo donation, and therefore not require further approval if used in situations where relationships have changed. We consider the ethical considerations in these situations to be complex and feel that ECART should remain involved.

Question 13: Regulation of all clinic-assisted surrogacies by guidelines
Refer to section 8.
ACART proposes to recommend that all clinic-assisted surrogacy cases be regulated by guidelines and thus require ECART approval.

Do you agree? Yes ☑ No ☐

Thank you for the opportunity to provide feedback on these proposals.

You will note that the College of Midwives posed some questions throughout the submission and we would welcome clarification in regards to these questions.

Yours faithfully

Carol Bartle
Policy Analyst