



New South Wales
Council for Civil Liberties

NSWCCL SUBMISSION

**NHMRC DRAFT ETHICAL
GUIDELINES ON ASSISTED
REPRODUCTION TECHNOLOGY**

17TH September 2015

About NSW Council for Civil Liberties

NSWCCL is one of Australia's leading human rights and civil liberties organisations, founded in 1963. We are a non-political, non-religious and non-sectarian organisation that champions the rights of all to express their views and beliefs without suppression. We also listen to individual complaints and, through volunteer efforts; attempt to help members of the public with civil liberties problems. We prepare submissions to government, conduct court cases defending infringements of civil liberties, engage regularly in public debates, produce publications, and conduct many other activities.

CCL is a Non-Government Organisation in Special Consultative Status with the Economic and Social Council of the United Nations, by resolution 2006/221 (21 July 2006).

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The Council for Civil Liberties (NSWCCL) thanks the NHMRC for its invitation to make a submission to the National Health and Medical Research Council concerning the draft ethical guidelines on the use of assisted reproduction technology in clinical practice and research.

1. General Comment

NSWCCL supports the draft guidelines.

They provide for satisfactory arrangements concerning the rights of providers of gametes or embryos, of the birth mothers and their partners, and of children who may be born as a result of the use of technology. We applaud the support for the autonomy of all involved, and their rights to 'detailed, accurate, contemporary and relevant information' concerning the procedures and concerning the legal and other consequences of their decisions. We support the stringent arrangements for consent. In particular we support the entitlement of a gamete provider to withdraw permission for the use of their gametes before the treatment cycle of the recipient commences or before the creation of an embryo, the provisions over the ownership of embryos, and the rejection of 'unknown directed donation' in section 5.1.

We support the recognition of the rights of persons to pre-determine the fate of their gametes after their deaths.

We appreciate the difficulties in providing guidelines for pre-implantation genetic testing and consequential action, and recommend support for further research on the ethical difficulties involved.

We note that there are no changes proposed at present to the guidelines on research.

2. Specific questions for which comment is requested by the NHMRC

a. Payment for the risks and labour involved in egg donation.

NSWCCL notes that there is already provision for the reimbursement of medical and counselling costs, loss of earnings, travel and accommodation costs, insurance related to the donation and legal advice. Rather than pay for the risks involved, NSWCCL believes it would be better to compensate women properly if the risks are realised. Payment for risk is likely to have two unwanted consequences: that women in straightened circumstances may be encouraged or pressured to volunteer in order to obtain money and with disregard to the risk to themselves, even concealing circumstances which heighten those risks; and that adequate compensation will be withheld if the risks are realised, on the ground that compensation has already been paid.

Similarly, payment for the labour involved (on top of compensation for loss of earnings) may lead to exploitation or incautious volunteering, and to the commodification of reproduction.

In our view, the possible benefit, that more eggs may be provided as a result, do not offset these risks.

b. Sex selection on non-medical grounds.

NSWCCL is not in favour of this proposal. Though refusing parental choice of children is an intrusion on their freedom, allowing such choice will lead to unreasonable expectations being placed on the resultant child. There is no guarantee that boys or girls will be different from

his older siblings in the ways that the parents expect; and attempts to ensure that they are are an intrusion on their autonomy. There is more than enough damage done already by unreasonable expectations placed upon children.

c. Establishment of an Australian egg bank.

NSWCCL has no comment to make concerning this proposal per se. However, if it is combined with paying women to provide eggs, the risks noted under a above should tell against it.

This submission was prepared by Dr. Martin Bibby PhD on behalf of the New South Wales Council for Civil Liberties. We hope it is of assistance to the NHMRC in finalising these important ethical guidelines.

Yours sincerely,

A handwritten signature in grey ink, appearing to read "Lesley Lynch".

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