



## **Minutes of the Sixty Second Meeting of the Advisory Committee on Assisted Reproductive Technology**

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Held on 12 August 2016 at the Wellington Airport Conference Centre, Wellington

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### **Present**

Alison Douglass (Chair)  
Mike Legge (Deputy Chair)  
Karen Buckingham  
Jonathan Darby  
Gillian Ferguson  
Kathleen Logan  
Sue McKenzie  
John McMillan  
Catherine Poutasi  
Barry Smith

### **Non-members present**

Michelle Stanton (ECART)  
Martin Kennedy (ACART Secretariat)  
Isabel Ross (ACART Secretariat)  
Betty-Ann Kelly (Retiring ACART Secretariat, 11.45am – 1.30pm)  
Judge Andrew Becroft (Children's Commissioner, 11.45am – 1.30pm)

## **1. Welcome**

- 1.1 The Chair welcomed the Committee members and guests. New members of ACART and the Secretariat introduced themselves.

### **1.a Opening comments**

- 1.2 Gillian Ferguson gave the opening comments, reflecting on her role as a consumer member and reporting on her meeting with the Executive Committee of Fertility New Zealand in June. She noted the importance of engaging and consulting with a full range of consumers, and the diversity of the consumer experience.
- 1.3 Fertility New Zealand has experienced difficulty with the timeframes ACART allows it to consult with consumers. It can take two to three months to get member feedback and coordinate a Board response. ACART members suggested giving Fertility New Zealand advance notice of upcoming consultations.
- 1.4 Alison commented on progress to find a replacement for Karen. Alison also welcomed Isabel who recently joined the Secretariat.

## **2. Apologies**

- 2.1 There were no apologies.

## **3. Approval of the agenda**

- 3.1 Members approved the agenda.

### **Action**

- *Secretariat to place the August 2016 agenda on ACART's website.*

## **4. Declarations of Interests**

- 4.1 There were no declarations of interests.

## **5. Minutes of ACART's meeting of 10 June 2016**

- 5.1 The minutes were approved.

### **Action**

- *Secretariat to place the June 2016 minutes on ACART's website.*

## **6. Actions arising from the previous minutes**

- 6.1 Members noted the status of actions arising from the June 2016 meeting.

## **7. Work programme — current status**

- 7.1 Members noted the status of items on the programme.

## **8. Informed consent: update**

- 8.1 Members considered an updated draft of the advice to the Minister of Health on requirements for informed consent in respect of human assisted reproduction.
- 8.2 The Health and Disability Commissioner had considered a previous draft and had suggested some minor changes to the wording, which did not change the meaning. The Secretariat has made these changes and the Working Group has seen them.

8.3 Members agreed various editorial changes to some recommendations and the text.

#### **Actions**

- *Secretariat to send the Chair a revised document showing track changes.*
- *Secretariat to forward the finalised advice to the Associate Minister of Health, copied to the Minister of Health, the Chief Executive of the Ministry of Health, and ECART.*
- *Secretariat to prepare a response to Anthony Hill thanking him for his letter.*

### **9. Review of the donation guidelines: consider the working group report and recommendations**

9.1 Members considered a paper presenting the Working Group's recent discussions and recommendations. Members reviewed a table of proposed provisions to include in the revised guideline, and made some editorial changes.

9.2 Members noted that, even with revision, some provisions will not apply across the board, so there will need to be three separate sections or subheadings. In particular, some items in the current surrogacy guidelines are incompatible with other guidelines. Members agreed it was preferable to take commonalities as far down the document as possible.

9.3 The principle of counselling in addressing gamete donations was discussed, as established procedures do not go through ECART. The guidelines will need to differentiate between what is required and what should be considered.

9.4 Members noted a stance on on-donation of embryos needs to be spelt out. Questions were raised about who owns embryos where there is a surplus, and whether you can continue to on-donate until there full genetic siblings in two families. The Secretariat will refer back to the Working Group notes.

9.5 Members noted that clarification about medical justification is required in the guidelines. 'Medical need' is ambiguous and clarification is required as to whether this is an absolute requirement.

9.6 Members noted that the Working Group will have to consider if there are any discriminatory grounds in the guidelines.

9.7 The Working Group noted that the preference for a genetic link reflects societal preferences, and is based on a policy decision rather than submissions. It is important to recognise the difference in views in New Zealand society about what a family is, and that such views are not static. John McMillan offered to write a literature review on this subject.

#### **Actions**

- *Secretariat to draft a discussion document for the Working Group's consideration.*
- *Secretariat to refer to the April 2016 ACART paper on the review of the guidelines.*

## **10. Amending birth certificates: consider the letter to the Minister**

- 10.1 The Secretariat outlined the history of this work. ACART noted the limitations on children being able to learn their genetic history, as they relied on parents to tell them. The Law Commission had considered ways to ensure that children were told, and decided that a signal on birth certificates was the best way.
- 10.2 The Secretariat suggested ACART write to the Associate Minister to express disappointment with the Government's lack of progress with the Commission's recommendations.
- 10.3 Members discussed whether there has been any research into what proportion of parents makes donor offspring aware of their genetic origins. It was noted that Ken Daniels has done research in this area and found approximately 60 percent do tell and 40 percent do not tell their children. However, members noted it is a moving population and there is an increasing tendency to tell. Nobody has turned 18 since the HART Act received Royal assent, and this will be the first group to access the HART Register.
- 10.4 Members agreed that they want to alert the Minister about this issue, and note that this is an issue that has come out in the revision of the donation guidelines, and would be included in the consultation document.

### **Action**

- *Secretariat to amend the letter to the Minister, so it informs him that ACART intends to include this issue as part of the consultation document for the revised donation guidelines.*

## **11. Cryopreserved ovarian tissue: consider the report on submissions**

- 11.1 Members discussed the submissions and proposed responses suggested by the Secretariat. Nearly all submissions were in favour of the proposal, but there were a few suggested amendments. Members agreed to the proposed responses and suggested editorial and text changes.
- 11.2 It was noted that it is important to refer to restoring 'ovarian function' rather than 'fertility' throughout the document.
- 11.3 Members discussed the need for the document to be clear about treatment recommendations regarding women with leukaemia and active cancer. These are ultimately clinical judgements, and there is not enough knowledge about this topic yet. The sector has safeguards, such as the involvement of oncologists. The advice will be amended to clearly state that the procedure is not recommended for use in girls/women who have leukaemia or haematological cancer.
- 11.4 It was noted that the guideline for pre-implantation genetic diagnosis is an example of how to set straightforward guidelines. Members requested further information about what can be added to the HART Order.

- 11.5 Members agreed the document needs to note the involvement of minors in the consent process, noting that the use of COT involves two-stage consent. John McMillan may have some wording that can be used.

#### **Actions**

- *Secretariat to consult Health Legal about how it interacts with the Parliamentary Counsel Office and what can be added to the HART Order.*
- *Secretariat to draft advice to the Minister and circulate it to members, and to prepare a letter from the Chair to the Minister.*

### **12. ACART's monitoring role: consider the draft policy statement**

- 12.1 Members agreed that it is important to document what it means that ACART has a statutory obligation to monitor the outcomes of ECART decisions. Members had previously agreed that ACART needs a policy and that the policy should be on its website.
- 12.2 The Secretariat presented material summarising ACART's obligations and current monitoring activities, and suggested it create a policy statement from this material. Members agreed to this and noted there needed to be a statement at the beginning to make it clear that ACART is not doing horizon scanning.

#### **Action**

- *Secretariat to create a statement about ACART's monitoring policies from the material suggested.*

### **13. Governance**

#### **13.a Chair's report**

- 13.1 The committee noted the report.

### **14. Secretariat report to ACART**

- 14.1 Members noted the report.

#### **Additional item: deceased and comatose reproduction**

- The Working Group, Secretariat, and Health Legal have met to discuss this project. It was noted that ECART has sought advice from ACART on this issue, as it is considering whether it can make a decision on a particular case. There are uncertainties in the law about this issue. Members noted that there needs to be an accessible law and procedure, as people will enquire about such procedures whether or not there are guidelines.
- Members discussed what the revised guidelines should include. Members mentioned the need to refer to reproductive tissue, not just sperm, eggs and embryos. They also noted that people sometimes request post-mortem collection of sperm.

- The Chair suggested holding Working Group meetings in Dunedin, and raised the possibility of co-opting Nicola Peart to the Working Group.

**Additional item: visit from Judge Andrew Becroft, Children’s Commissioner**

- Judge Becroft, Children’s Commissioner, joined the meeting. The Chair outlined the function of ACART and its links with the Office of the Children’s Commissioner. She also explained ACART’s review of the donation guidelines.
- Judge Becroft outlined his priorities for his first 100 days in his new role. He expressed an interest to continue to be involved in ACART, though it is not one of his priorities.

**15. An ACART member to volunteer to be the “member in attendance” at the next ECART meeting**

- 15.1 Alison Douglass will be member in attendance at the September ECART meeting.

**16. Conclusion of meeting**

- 16.1 The next ACART meeting is scheduled for 14 October 2016 and will be held at the Wellington Airport Conference centre.
- 16.2 The meeting closed at 2.30pm.