



## Position on the Posthumous Collection and Use of Gametes

### 1. Background

- 1.1. In recent years a small number of WA Supreme Court (WASC) Orders have been issued to permit the posthumous collection of gametes potentially for reproductive use (PCUG). The posthumous collection of gametes is a relatively new technical possibility which is not specifically foreseen in either of the Acts relevant to PCUG – namely the *Human Reproductive Technology Act 1991* (HRT Act) and the *Human Tissue and Transplant Act 1982* (HTT Act).
- 1.2. The Reproductive Technology Council (Council) is charged among other responsibilities with:
  - advising the Minister for Health on matters of reproductive technology and the administration of the *HRT Act*,
  - advising the Commissioner for Health on matters relating to licensing and administration,
  - regulating practices through a Code of Practice (Directions), and
  - promoting informed public debate on ethical, social, and other issues arising from assisted reproductive technology (ART).<sup>1</sup>
- 1.3. Council is naturally concerned that current and future practices – including PCUG – should be consistent with the *HRT Act*, the objects which include:
  - to allow beneficial developments in reproductive technology, but to discourage, and if required to prohibit, developments or procedures that are not both proper and suitable;<sup>2</sup>
  - that the prospective welfare of any child to be born consequent upon a procedure to which this Act relates is properly taken into consideration;<sup>3</sup>
  - to require that equity, welfare and general standards prevailing in the community are taken into account in the practice of reproductive technology.<sup>4</sup>
- 1.4. Council is therefore required to ask whether PCUG is a ‘proper and suitable’ practice; how best to consider the prospective welfare of children who could be born after PCUG; whether PCUG meets the requirements of equity, welfare and general community standards; and to advise the Minister accordingly.
- 1.5. This Position Paper identifies some of the ethical and social questions Council believes must be taken into consideration and states, in light of those considerations, Council’s preferred position on PCUG.

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<sup>1</sup> *HRT Act*, 14(1).

<sup>2</sup> s.4 (1) (c)

<sup>3</sup> s.4 (1) (d) (iv)

<sup>4</sup> s.4 (1) (e)

## 2. Ethical and Social Considerations

### Relating to the interests of particular parties

- 2.1. The *HRT Act* requires Council to give consideration to the welfare and interests of participants of any HRT procedures (which include PCUG) and any child likely to be born as a result of such procedures.<sup>5</sup> The nature of these interests is not defined in legislation and Council in its deliberations over many years has consistently included a range of ethical and social issues in considering ‘welfare and interests’.<sup>6</sup>
- 2.2. Further, Council recognises that in some instances the interests of immediate participants (i.e. those making application for PCUG) may not be paramount and may need to be viewed in light of potentially competing ethical and welfare considerations (including justice and equity) in relation to the deceased or dying person, to any siblings if there are any, and to relevant other persons (e.g. other family members).<sup>7</sup>
- 2.3. Appropriate consideration for the deceased or dying person may include requiring proof that the dying person has given effective consent specifically to posthumous use by the surviving partner for reproductive purposes;<sup>8</sup> confirmation that the deceased person gave effective consent to posthumous collection of gametes for reproductive purposes; and assuming effective consents have been given, observing a ‘cooling off’ period before gametes can be used posthumously.
- 2.4. Appropriate consideration for the welfare of the surviving partner making application for PCUG may include the need to allow an appropriate time for grieving, and a requirement to undertake counselling,<sup>9</sup> both of which may also relate to the validity of the *surviving partner’s* consent to PCUG.
- 2.5. Appropriate consideration for any siblings and/or other relevant persons (e.g. other family members) may include providing opportunities for the interests and views of these persons to be heard prior to Council reaching a determination.
- 2.6. Appropriate consideration of the welfare and interests of any child likely to be born pursuant to PCUG may include issues of justice and equity in relation to the child’s ‘right’ to have contact and form a relationship with his or her genetic parent, the surviving partner’s capacity to provide adequate long-term parenting for the child, and communication issues relating to the child’s right to know his or her origins, among other matters.

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<sup>5</sup> s.23 (1) (e)

<sup>6</sup> Council, *Minutes of Extraordinary Meeting 2 October 2012*, 3.1: “Council endorsed the general operative principle that some advice offered by Council will rest on ethical arguments as much as or more than legal arguments.”

<sup>7</sup> *Minutes 2 October 2012*, 3.3. See also *Minutes of PUCG Working Party 15 November 2012*.

<sup>8</sup> National Health and Medical Research Council [NHMRC], *Ethical Guidelines on the use of Assisted Reproductive Technology in Clinical Practice and Research 2004* (Revised 2007). *Guideline 8.4*: “Clinics must not store or use gametes from deceased persons or from persons who are unable to consent to the procedure, for example, due to post-coma unresponsiveness (‘vegetative state’) unless there is a clearly expressed and witnessed directive from the person that gives his or her consent to the use of the gametes.”

<sup>9</sup> See NHMRC, *Ethical Guidelines*, 6.15.

### In relation to the 'intention to parent'

- 2.7. In relation to PCUG Council has consistently given consideration to the social meaning of 'parenting' and the 'intention to parent',<sup>10</sup> which is also relevant to the matter of valid consent.
- 2.8. A person's understanding of 'parenting' generally includes an intention to form an ongoing social and familial bond with the child, including exercising a formative role in the child's life. In the case of PCUG such an ongoing parenting role will never be possible. In view of this it is reasonable to question whether, had he or she known they would die before their gametes were used (or even collected), a deceased person might have wished to reconsider or withdraw altogether from the parenting project.

### In relation to use of posthumous gametes in storage

2.9. Council distinguishes clearly between:

- Posthumous collection of gametes – that is, collection of gametes from a person who has already died;
- Posthumous use of gametes which have been collected from a living person consequent to their effective consent, and which are currently stored in an ART clinic; and
- Posthumous use of gametes already collected pursuant to Supreme Court Orders – that is, that small number of gametes collected posthumously under WASC Orders and currently stored "in accordance with the *Human Reproductive Technology Act 1991* (WA)."<sup>11</sup>

2.10. Direction 8.9 specifically prohibits a clinic from knowingly using gametes for a fertilisation procedure after the gamete provider has died. Consistency would seem to require that the same prohibition on *use* should apply regardless of whether the gametes were collected before or after death, which *a fortiori* begs the whole question of posthumous *collection*.

2.11. In view of the WASC Orders; in recognition of the complex social, legal and ethical questions involved; and, as far as possible, in order to balance many potentially competing interests: Council has carefully considered and unanimously adopted the following position on the posthumous collection, storage and use of gametes.

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<sup>10</sup> Minutes 2 October 2012, 3.3.

<sup>11</sup> Re Section 22 of the Human Tissue and Transplant Act 1982 (WA); Ex parte C [2013] WASC 3. 19.

### 3. Council Position

#### Posthumous Collection of Gametes

- 3.1. Council does not support the posthumous collection of gametes for reproductive use,<sup>12</sup> and recommends that the *HRT Act* be amended to expressly prohibit the posthumous collection of gametes.

#### Posthumous Storage of Gametes

- 3.2. Council recognises that gametes collected posthumously under WASC orders are currently stored in clinics but cannot be used until further orders are made.<sup>13</sup> Recognising that this undesirable situation requires a temporary resolution, and only in relation to the gametes posthumously collected and currently stored under WASC orders, Council recognises a need to permit ongoing storage of these gametes until their final use can be determined.

#### Posthumous Use of Gametes

- 3.3. Council supports the current prohibition on posthumous use of gametes for reproductive purposes (Direction 8.9).
- 3.4. However along with the National Health and Medical Research Council, Council also recognises that in individual cases 'exceptional circumstances' may exist in which posthumous use may be thought reasonable.<sup>14</sup>

#### 'Exceptional Circumstances' Defined

- 3.5. If the posthumous use of gametes is to be permitted in 'exceptional circumstances', Council unanimously agrees that 'exceptional circumstances' should be defined as follows:
- a) the deceased or dying person has given prior, valid, express consent to the posthumous use of their gametes for reproductive purposes by a named natural person;<sup>15</sup> and
  - b) such use is restricted to this person such that these gametes may not be donated to another person or stored or used for any other purpose; and
  - c) the person receiving the deceased person's gametes undertakes to receive specific counselling covering grief, parenting and communication issues (e.g. how to inform a child born as a result of such donation that their other parent died before conception); and
  - d) an appropriate 'cooling off' period will normally apply between the death of a gamete provider and posthumous use<sup>16</sup>; and

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<sup>12</sup> *Minutes 2 October 2012.*

<sup>13</sup> *Re Section 22 of the Human Tissue and Transplant Act 1982 (WA); Ex parte C [2013] WASC 3. 19.*

<sup>14</sup> *Minutes 2 October 2012, 3.2.* See also NHMRC, *Ethical Guidelines*, 6.15. Depending on future WASC orders the gametes referred to in (2) above, whose final use remains to be determined, may constitute such 'individual cases'.

<sup>15</sup> See NHMRC, *Ethical Guidelines*, 8.4:

<sup>16</sup> See NHMRC, *Ethical Guidelines*, 6.16.

- e) consistent with Direction 3.1,<sup>17</sup> a 'use expiry' period will normally apply after the cooling off period, within which time the gametes must be used in accordance with the deceased's express consent; and
- f) there is clear understanding among all parties that upon expiry of the 'use' period all remaining gametes will be destroyed.

#### 'Other Considerations'

- 3.6. Council agrees that applications to it for posthumous use of gametes in 'exceptional circumstances' must also demonstrate that sufficient consideration has been given to:
- a) the welfare of the child/other participants; and
  - b) gender equity issues

#### Implementation

- 3.7. Council recognises that it currently has no power to permit posthumous use of gametes currently in storage, even in 'exceptional circumstances', until appropriate amendments are made to both the *HRT Act* and *Directions* (specifically, Direction 8.9).
- 3.8. If the *HRT Act* is so amended, Council would then be able to consider on its merits each application that meets the above criteria for 'exceptional circumstances' in light of the consideration each application gives to the matters identified in (3.6) above.
- 3.9. Given the complexity of circumstances surrounding individual applications, each application for posthumous use would have to be considered entirely on its own merits, such that no decision of Council would automatically establish a precedent for subsequent decisions.

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<sup>17</sup> Direction 3.1: "Subject to Directions 6.8 and 6.9, the licensee must ensure that consent to store gametes is renewed every 5 years."