AUSTRALIAN CATHOLIC BISHOPS CONFERENCE
Bishops Commission for Pastoral Life

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The Project Officer – ART Guidelines
Health and Research Ethics
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Dear Sir/Madam

**Part B of the Ethical Guidelines on the Use of Assisted Reproductive Technology in Clinical Practice and Research, 2007**

This submission is from the Australian Catholic Bishops Conference (ACBC) as prepared by the Bishops Commission for Pastoral Life (BCPL).

The ACBC is a permanent institution of the Catholic Church in Australia and the instrumentality used by the Australian Catholic Bishops to act nationally and address issues of national significance.

The BCPL is one of a number of commissions established by the ACBC to address important issues both within the Church and in the broader Australian community. The BCPL has responsibility for life issues, including assisted reproductive technology.

The ACBC appreciates the opportunity to make a submission on the *Ethical Guidelines for the Clinical Practice of ART* (the ART Guidelines).

The ACBC makes this submission noting that:

- Many couples face great pain and sadness associated with infertility. There is a natural and commendable desire to bear children, but Assisted

Reproductive Technology (ART) raises issues affecting the dignity of each of the participants[1];

- Human beings have inherent dignity and their rights as people must be respected including their right to life from the moment that the first cell of the human zygote is formed by whatever means it comes to be[2];
- ART may involve the discarding of human embryos and the formation of an embryo by a laboratory procedure replacing the personal, life giving nature of the intimate expression of love through marital intercourse between husband and wife with a technical procedure[3];
- The interests of children are paramount and this is a principle upheld in international law to which Australia is a signatory[4]. Children have a right to an identity and family relations[5], and as far as possible, the right to know and be cared for by[6], and maintain personal relations and direct contact with both natural parents.[7] The origins of a child in the laboratory, where the child may be considered "spare" and never have a relationship to parents and a family, places the child at risk in his or her origins as a laboratory product subject to quality control and domination[8], including selection and destruction. Further, the use of donor gametes threatens the above rights of the child to inherit his or her relationship to natural parents;
- The ACBC therefore is critical of the provision of ART services because of these significant ethical concerns and the violation of the human dignity and rights of the child as an embryo and as a child born or to be born. But given these services exist the ACBC wishes to contribute to the discussion over ethical boundaries to protect the child and his or her parents from harm;
- Where there are issues of such ethical importance, it is important to have guidelines that effectively guide ART practitioners, their patients and clients, and those who own and operate ART services. There is a danger in a deregulated environment that some will advocate leaving these serious issues to the market. ART is not an issue that can be safely left to either market forces or good will;
- The danger with guidelines is that to an administrator, ethics can seem just another administrative process or an obstruction to overcome to meet the objectives of their organisation. Guidelines must also educate administrators on the serious ethical issues involved and there must be systems in place to

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[1] Congregation for the Doctrine of the Faith, *Donum Vitae: Instruction on Respect for Human Life in its Origin and on the Dignity of Procreation: Replies to Certain Questions of the Day*. 22 February 1987, #5; Instruction Dignitas Personae on Certain Bioethical Questions, 20 June 2008, #16.

[2] Instruction Dignitas Personae on Certain Bioethical Questions, 20 June 2008, #4, 6.

[3] Instruction Dignitas Personae on Certain Bioethical Questions, 20 June 2008, #16; Catholic Health Australia, *Code of Ethical Standards for Catholic Health and Aged Care Services in Australia*. Catholic Health Australia, 2001. #2.1.

[4] UN Convention on the Rights of the Child Art. 21
http://www.ohchr.org/en/professionalinterest/pages/crc.aspx

[5] Ibid. Art. 8

[6] Ibid. Art. 7

[7] Ibid. Art. 9

[8] *Dignitas Personae* 2008, # 17 and *Donum Vitae* 1987, II, B, # 5

ensure that they meet their obligations to monitor compliance with the guidelines.

Noting these comments, the ACBC has detailed in the attachment its response to the consultation on the ART Guidelines.

Yours sincerely in Christ,

**Bishop Eugene Hurley**

Chair, Bishops Commission for Pastoral Life

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| **Name:** | **Bishop Eugene Hurley** |
| **Organisation:** | **Australian Catholic Bishops Conference** |

**Attachment**

## 5 Ethical principles for clinical practice of ART

**General Questions**

**Q1.** Have you encountered any difficulties in the interpretation and/or application of the current ethical guidance in Section 5?

Section 5.2, states

> In the course of clinical practice, clinicians must limit the number of embryos created to those likely to be needed by the participants in the course of their treatment.
>
> 5.2.1 To limit the number of embryos created, clinicians should:
>
> - minimise ovarian stimulation;
> - limit the number of ova fertilised and embryos stored; and
> - not start new treatment cycles for patients when clinically suitable embryos are in storage.

This provision seems to be more honoured in the breach of it than in compliance. There does not seem to have been significant effort to limit the numbers of embryos produced. In Queensland there have been reports from couples who did not realise they were consenting to the production of "extra embryos", but thought they were simply consenting to the storage of eggs. For many couples this is a significant difference and there would appear to be a need to make the distinction clearer in the information supplied and consent given.

Section 5 also contains detailed requirements on the information to be kept, made public and provided to participants. It is a matter of deep concern that it is very difficult for those considering IVF as an option to know what their chances of conception are with and without the intervention. The clinics' advice to clients differs remarkably from the information they make available to governments. Thus for instance it is not uncommon to have success rates provided in misleading ways in terms of clinical pregnancies rather than live births and for results to be exaggerated. As a matter of contrast, the information required by statute law to be kept in the state of Victoria, for instance, shows the last completed cycles recorded for the 2009-10 year. In that year in Victoria there were:

- 7330 women treated with IVF (inc. ICSI)
- 50,249 embryos formed (eggs fert.)
- 2208 Clinical pregnancies (elev. HCG)

- 1700 confinements (gave birth)
- 1855 babies born
- 23% of women treated gave birth
- 3.5% of embryos survived to birth.[9]

Thus despite one of the leading teams Melbourne IVF claiming, "we would expect that 85% of couples will conceive within six months of trying to get pregnant"[10], in fact 77% of woman treated in the most recently assessed period did not achieve the birth of a child and 96.5% of embryos did not survive to be born. These figures are not generally known to women or their partners when they make decisions to undergo treatment. Nor is it generally made known what proportion would conceive naturally. Further, a Monash University study, published in the *Australian and New Zealand Journal of Obstetrics and Gynaecology* (2013), examined the rates of unexpected conception in Australian women who had a first child through assisted reproductive technology (ART). The study of 236 women who had a baby through assisted reproductive treatments found 33 per cent of them conceived a second child naturally within two years of their first birth. Those involved in assisting women with fertility awareness report natural pregnancy rates of above 50% in women who had been trying unsuccessfully for more than 12 months.[11]

**Q2.** Do you think that there are gaps in the current ethical guidance in Section 5?

Section 5 is evidently not being consistently applied. That may require an addition concerning due diligence by which the administrators take greater care to ensure that the data required to be made available is comprehensive and accurate. There should not be a distinction between the data available to governments and the data used to promote IVF to patients.

**Q3.** Should Section 5 recognise the significance of the 'biological connection' (e.g. between donor-conceived persons and the donors of gametes, between donor-conceived persons and their siblings or half-siblings, or between persons conceived from donated embryos and their genetic parents) as an additional ethical principle for the clinical practice of ART? (see also questions in relation to Paragraphs 6.1.1 and 6.1.2 and Section 9.2).

The ACBC submits that the profound significance of the biological link between

[9] www.varta.org.au/annualreports

[10] http://mivf.com.au/about-fertility/how-to-get-pregnant

[11] A unpublished retrospective study undertaken by the Ovulation Method Research and Reference Centre of Australia Inc. noted that of couples who had been trying unsuccessfully for more than 12 months, over 54% conceived within an average of less than five months after learning fertility awareness.

gamete donors and the children who result must be recognised and respected in the ART Guidelines. This is more than ensuring donor-conceived people have access to records and contact details for their biological parents, important as that is. It is ensuring that the technology is never used so as to prevent a child not only knowing the identity of his or her biological parents, but having a right to be identified as the natural child of a biological parent, in addition to having social parents, and to have access to that parent even if the law has arranged that he or she cannot make an inheritance claim. The falsification of a birth certificate so that it does not contain the names of biological parents is a great wrong to the child. This is creating a whole new stolen generation of children dispossessed of their connectedness, personal, biological and cultural to their natural parents and family. It also raises issues about consanguinity if they have children by someone who is in fact a half sibling. The link is even more relevant to children who are conceived using two donated gametes (or donated embryo) and therefore will not be raised by either of their biological parents.

The connections between people and their biological families are so important because:

> "... genetic relationship goes to our deepest roots of who we are and to whom we bond. One only has to look at one of the primary uses of the internet – genealogical research – to see how important it is to most of us to know who we come from. And those bonds are not just to parents, but also to brothers and sisters and other genetic relatives. We have ethical obligations to heed these sentiments."[12]

It should be noted that it is not just a matter of genetics. A child dispossessed of a relationship to a genetic parent, may also be brought up in a totally different culture and feel quite unfamiliar with those who do not share his or her genetic, racial or cultural background. That is not such of an issue if the child knows from the outset and is encouraged to form cultural links. However, deception or suppression of information and falsification of records or not keeping accurate records makes it very difficult for the child to later trace his or her family and cultural inheritance.

These genetic relationships are confused by ART where rather than parents being biological, gestational and nurturing, these roles may be split between a number of people:

> "Psychologists often refer to the issue of genealogical bewilderment as children, perhaps later in life, seek to discover their origins and to identify their own identity in circumstances in which the genetic parents may be completely unknown to them or become known to them at a later stage. The relationship between a child and his or her parents is

[12] Somerville, M, Dispossessed and forgotten: the new class of genetic orphans. *Mercatornet*, 18 September 2007.

complex. So much of our sense of identity is based upon that relationship. When it is fragmented, that can be hurtful and confusing."[13]

In considering the needs of children who will be conceived by ART, "... the principle of 'anticipated consent' requires that, when a person seriously affected by a decision cannot give informed consent, we must ask whether we can reasonably anticipate that he or she would consent if able to do so. If not, it is unethical to proceed."[14]

The frequent frustration that has been expressed by people tracing their natural parents highlights the fact that they would not have consented to decisions being made not in their interests but the interest of their parents and the clinics. That issue is now even more complicated with the increasing use of surrogacy arrangements. A child's connection to the mother who conceived and nurtured him in the womb is of great significance. For most of the first year she was his mother. Forever she remains the woman who sacrificed herself for him as his birth mother. She may or may not be genetically connected, but she will always be his mother. She will always have that biological and spiritual connection of having been so intimately connected within her body.

**Q4.** Are there any further ethical principles for the clinical practice of ART which should be included in Section 5?

There is a need to publish the results of long term medical outcomes for children who were IVF conceived. The national database for IVF outcomes is the National Perinatal Statistics Unit, which keeps data on neonates, but the data on IVF outcomes is limited and there is little if any long-term follow-up. However there have been some recent studies indicating insulin resistance and cardiometabolic differences in the adult population who were IVF conceived.[15] It is a newish area but the results are indicating concern that may not be specific to IVF but could reflect the use of ovarian stimulation in IVF. The future may bring significant development of illness and disease in middle-aged and older adults who were IVF conceived. There is also a need for long-term follow-up studies of the effects of new technologies, especially the ovarian stimulation, on women on IVF programs. As the data becomes available in the medical journals,

[13] Associate Professor Nicholas Tonti-Filippini, Submission No.2 to the NSW Parliamentary Inquiry into Inclusion of Donor Details on the Register of Births, 18 November 2011.

[14] Tobin, B, Donor-conceived people: Are they entitled to identifying information about their biological parents? *Bioethics Outlook*, Vol.24(1), page 6.

[15] Bower C and Hansen M. *Assisted reproductive technologies and birth outcomes: overview of recent systematic reviews*. Reprod Fertil Dev 2005;17:329-333. *Manon Ceelen, Mirjam M. van Weissenbruch, Jan P.W. Vermeiden, Flora E. van Leeuwen, Henriette A. Delemarre-van de Waal* Cardiometabolic differences in children born after in vitro fertilization: follow-up study *Journal of Clinical Endocrinology and Metabolism,* 2008, 93: 1682-1688

the guidelines need to ensure that it is made available to those considering accessing IVF technologies. That is especially so when you consider that half of them may have avoided IVF and instead had their children by natural conception, as the data above indicated. Knowing the greater short and long term risks of IVF conception, they might well have chosen treatment to restore natural fertility and waited for a natural result.

**Specific Questions**

**Section 5.1**

**Q5.** Is more guidance needed on what constitutes the 'welfare of those involved'?

What constitutes "welfare" is a vexed topic. The major aspects of welfare that are threatened by the ART technologies are those that relate to family formation and the way in which the ART technology separates the coming to be of a child born or to be born from the automatic connection to the loving intimacy of natural parents and the security of their relationship in their love for each other, which is then embodied in their child who is genetically, biologically, psychologically and spiritually connected to them through having come to be as a consequence of their love. In IVF those close connections are in a sense initially non-existent and the establishment of the connections is optional. Relationship to natural parents has profound significance for the identity of the child and the adult he or she will become. There is no shortage of evidence of the impact on children, most particularly adolescents, and then later as adults, of being denied material information about their natural mother or father. There is much evidence indicating that the absence of a relationship to natural parents increases the risks of adolescent and adult outcomes, such as early sexual initiation and its attendant risks of sexually transmissible infection, an unplanned pregnancy, and mental health complications, especially those related to break up of an early sexual relationship, including suicide and self harm.[16] The long term welfare of ART conceived children is at risk if the connections are not maintained. Indentifying with natural parents is a most significant aspect of the formative context.

**Section 5.2**

**Q6.** Paragraph 5.2.1 – Should there be exceptions to the restrictions/limitations on accumulating gametes/embryos in some situations? e.g. for fertility preservation in children, young people and adults undergoing chemotherapy, for the

[16] Christina Lammers, Marjorie Ireland, Michael Resnick, Robert Blum, "Influence on Adolescents' Decision to Postpone Onset of Sexual Intercourse: A Survival Analysis of Virginity Among Youths Aged 13 to 18 Years" *Journal of Adolescent Health* Volume 26, 2000; pp. 42-48; *Netto,* Ivan S. and Shah, Nilesh "Psychological support for fathers of artificial insemination donor children" Indian J Psychiatry. 2010 Jul-Sep; 52(3): 282–283.

purposes of preimplantation genetic diagnosis, and/or for women with reduced ovarian reserve.

The preservation of ovarian tissue, transplantation and subsequent use of the transplanted ovarian tissue to achieve pregnancy has emerged as a more successful approach to this issue in girls and women, with successful transplant and pregnancy using both autologous and heterologous tissue.[17] The storage of mature ova has not been as successful. Ova are very fragile in culture and do not survive freeze-dried storage as well as sperm. The mitotic spindle is inclined to break down preventing successful fertilization and subsequent mitotic cell divisions after thawing and rehydration.

Ovarian transplantation also may avoid the need for subsequent ART to achieve pregnancy, with all the vicissitudes of the technology. The couple can seek to conceive normally for subsequent pregnancies.

The freezing of human embryos is not ethically acceptable because it leaves the embryo in a state of virtual suspended animation and in danger, including danger of disposal. It is, for obvious reasons, not likely to be a solution, either, for young people who are not yet in a relationship. So that simply leaves sperm storage. Any collecting of sperm, ova or ovarian tissue needs to be addressed in terms of the age of the person and the social, moral, psychological and spiritual complexity involved. Those issues as well as any physical risks need to be addressed in terms of protecting the interests of the young person. The practice also raises issues to do with posthumous use of the gametes and gamete donation. The reasons for collecting the gametes or tissue need to be clear and the terms of storage and disposition addressed from the outset allowing for the possibilities that may occur.

5.2.1 appears not to have been written with these matters in mind and they do need to be taken into account. There should be no storage of human embryos in these circumstances. The production of embryos should be limited to intended use in a transfer procedure. There should be no likelihood of creating an excess.

**Q7.** Should there be a mandatory requirement for clinics to have policies and procedures around embryos which are excess to the requirements of patients?

[17] Donnez J[1], Dolmans MM, Pellicer A, Diaz-Garcia C, Sanchez Serrano M, Schmidt KT, Ernst E, Luyckx V, Andersen CY. **"**Restoration of ovarian activity and pregnancy after transplantation of cryopreserved ovarian tissue: a review of 60 cases of reimplantation"**.** Fertil Steril. 2013 May;99(6):1503-13. doi: 10.1016/j.fertnstert.2013.03.030.

There should be no excess embryos. In the event that there are they ought not be available for destructive research but should be treated with the respect owed to a dying person because an embryo not transferred to the safety of a woman's body is in a precarious position.

> Cryopreservation is *incompatible with the respect owed to human embryos*; it presupposes their production *in vitro*; it exposes them to the serious risk of death or physical harm, since a high percentage does not survive the process of freezing and thawing; it deprives them at least temporarily of maternal reception and gestation; it places them in a situation in which they are susceptible to further offense and manipulation.[18]

The official view of the Church is thus to reject the use of so-called "spare embryos" for destructive research or for use by another woman to achieve pregnancy, so-called "prenatal adoption"[19] Pope John Paul II appealed "to the conscience of the world's scientific authorities and in particular to doctors, that the production of human embryos be halted, taking into account that there seems to be no morally licit solution regarding the human destiny of the thousands and thousands of 'frozen' embryos which are and remain the subjects of essential rights and should therefore be protected by law as human persons".[20]

**Section 5.3**

**Q8.** Paragraph 5.3.1 – Should financial transparency be included in this list of protocols?

The rapid increase in costs for ART suggests the need for more oversight and transparency in how charges are calculated.

A report by consumer organisation Choice says that the cost of three IVF cycles in Sydney can vary widely from $1870 at the Westmead Fertility Centre to almost $9000 at Genea and IVF Australia. The report implies some of the cost difference may be because Genea and IVF Australia are accountable to shareholders and a private equity company respectively.[21]

[18] *Dignitas Personae* # 18; Donum vitae, I, 6: *AAS* 80 (1988), 84-85.
[19] Ibid. # 19
[20] John Paul II, Address to the participants in the Symposium on "*Evangelium vitae* and Law" and the Eleventh International Colloquium on Roman and Canon Law (24 May 1996), 6: *AAS* 88 (1996), 943-944.
[21] Mihm, Uta, IVF Costs. *Choice*, 8 February 2013.

Last year it was reported that the cost of one fresh IVF cycle at a particular clinic had increased over the five years to 2012 from about $3833 to $8640 or 13 per cent a year, which is many times the rate of inflation for health services.[22]

Professor Robert Norman, founding director of Adelaide University's Robinson Research Institute says some clinics set prices to drive patients to spend more: "There is evidence of prices going up quite high for the simple interventions to persuade people to go for the complicated interventions".[23]

The entry of major commercial players into the IVF sector raises the danger the profit motive will clash with the duty of care clinics owe patients. This is especially so given clinics are often the primary source of information for people considering IVF.[24]

A major factor for profit-driven clinics is the absence of actually managing infertility. The clinic aims to produce a child, but most women on IVF will not in the end have a child from the program. In general little is done to assist them to accept infertility. Counselling and other support needs to begin from the outset, but it is not in the commercial interests to have couples accept their infertility. Their interest is in having women go though as many treatment cycles as possible. The ART clinics tend not to take a holistic approach. Greater transparency, awareness of profit factors and being able to compare different approaches would help patients make choices more suited to their needs. The Manningham Fertility Assessment Clinic is currently conducting research on patients to compare their experiences between IVF clinics and medical clinics that seek instead to maximise the possibilities of natural conception. Research of that kind needs to be undertaken so that women and their partners can assess what is best for them. Of course, the approaches are not mutually exclusive. Some patients will attend IVF clinics at the same time as seeking the assessment, treatment and support available from a medical practice focussed on achieving natural conception.

One way to improve the confidence of people considering IVF would be to improve transparency and accountability for the clinics themselves. This would not just be about ART clinics being required to provide standard comparable information on costs and success rates on their websites, but would include the package of multi-disciplinary support available, including assistance to cope with likely failure of IVF to result in the birth of a child, relationship counselling and information about treatment options other than IVF and which increase the chance of natural conception.

[22] Medew, J and Baker, M, IVF costs soar as infertility business booms. *WAtoday.com.au*, 18 October 2013.
[23] Medew, J and Butler, M, Making babies, *Good Weekend* smh.com.au, 19 October 2013.
[24] Ewing, S, When a duty of care clashes with the profit motive. *The Sydney Morning Herald*, 3 May 2005.

**General Comments on Section 5**

There is a clear distinction between medical fertility assessment and treatment clinics and ART clinics. The former often use the phrase "natural procreative technology" or "Naprotech" though that has become the brand name for one particular group. The fertility assessment doctors have quite a different approach because their goal is to explore the factors that have caused the problem with fertility and to treat those factors.

Since the advent of IVF, it has become standard for a couple experiencing difficulty with infertility to be referred directly to an ART clinic, thus bypassing a phase of exploration and treatment to actually identify and treat the factors that cause infertility in order to maximise the chances of natural conception. There is a range of endocrine and surgical treatments that are usually not offered to couples by the ART clinics and many do not know that there are alternatives to IVF. In fact the data that has been gathered on the naturally procreative approaches indicate at least comparable success rates to the IVF birth rates.[25]

Before a couple is asked to make a decision about IVF treatment, as a matter of obtaining informed consent they should have information about the alternatives for managing their infertility with the aim of achieving natural conception.

The West Australian newspaper reports a consultant to two IVF clinics, Dr Anne Jequier, saying there is "... a worrying trend to push couples to IVF without doing the basic science, including checking men thoroughly for medical issues."[26] This is acknowledged especially by the IVF pioneers who often now lament the fact that younger gynaecologists do not seek to treat infertility but bypass it by referring directly to ART. The guidelines could address this issue by requiring that couples be presented with full information about the actual live birth rates per treatment cycle of IVF procedures and about the alternative treatments for infertility for females and males.

[25] For comparative data see Tonti-Filippini, Nicholas, *About Bioethics Volume IV: Motherhood, Technology and Embodied Love*, Connor Court 2013 pp. 80-111

[26] O'Leary, C, Doctor fears IVF used too much. *The West Australian*, 20 July 2013.

## 6 Use of gametes in reproductive treatment programs

***Questions 11 – 17 & 22 - 23 also relate to Section 7 - Use of donated embryos.***

**General Questions**

**Q9.** Have you encountered any difficulties in the interpretation and/or application of the current ethical guidance in Section 6?

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| People conceived through gamete or embryo donation prior to the era in which donors were informed that anonymity could not be guaranteed are in a difficult position and the clinics now face a substantial ethical issue in relation to having entered into an agreement with the donors that excluded critical interests of those people conceived that way. The clinics had no right to enter into agreements that excluded those interests and therefore the agreements cannot be considered valid. Since 2007 when the Guidelines were drafted this issue has been the subject of several State parliamentary enquiries that have favoured release of identifying information. The awareness of the needs of donor conceived children has intensified and the wrong done by agreeing to donor anonymity has become more apparent. The guidelines now need to address this issue more directly and insist that the presumption should be in favour of releasing that information to donor conceived individuals who request it unless the donors can establish that they would suffer significant harm to mental health if the information were released. |

**Q10.** Do you think that there are gaps in the current ethical guidance in Section 6?

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| See our remarks under section 5, Q.3 and the previous section. There is now a gap in relation to those who were conceived when anonymity guarantees were improperly given to donors. |

**Specific Questions**

**Section 6.1** (see also Section 7.1)

**Q11.** Should there be a standard way that data is collected and stored to facilitate linkage?

- If so, how?
- Should this guidance be included in the ART guidelines?

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| The information about donors should be kept in such a way that access to identifying information is available upon request to people who are donor conceived. Ideally |

that information would be recorded in the same way as information about births, deaths and marriages are recorded and counselling should be available to those affected. In the absence of those State-run services not requiring donor information and providing counselling services, the clinics should build that service into their donor arrangements.

**Q12.** What is best-practice to facilitate a first contact between donor/s and the donor-conceived person?

- Should this guidance be included in the ART guidelines?

There should be no discrimination between donor conceived and adopted people. The counselling services available to adoptees should also be available to those who are donor-conceived. The rights under the UN Convention on the Rights of the Child mentioned earlier need to be protected but in a context that assists the participants to deal with the personal and social issues involved.

**Q13.** Does the statement in Paragraph 6.1.2 need to be strengthened? *(see also questions in relation to Section 5 and Section 9.2)*

- If so, in what ways?

Section 6.1.2 needs to be strengthened so as to make it clear to parents that because the child will eventually be informed that they have a donor parent and the identifying information about the latter may be made available when the child requests it, it would be better for the child to know the truth from the outset rather than to foster an untruth and thus cause damage to the relationship with the child's social parents or parent. It is not enough to merely encourage the parents to inform the child. This should now be expressed as an obligation based on the child's right to the information.

**Q14.** What assistance is required to support parents in telling their children about their genetic origins?

- Should this guidance be included in the ART guidelines?
- How, and by whom, should this assistance be provided? e.g. Is there a role for community practitioners such as GPs and maternal-child health nurses?

The counselling that parents receive should include assistance with how they might discuss this matter with the child from the outset, and how they might avoid fostering an untruth.

**Q15.** Paragraph 6.1.3

- Who should be involved in the dissemination of information to gamete donors (or gamete providers for donated embryos) about children born as a result of their donation? *(see also questions in relation to Section 6.12)*
- How can gamete donors and donor-conceived persons be encouraged to register their consent to being contacted?
  - Should this guidance be included in the ART guidelines?

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| The issue should no longer depend on consent from the donor. As discussed above, the awareness of this issue has progressed. Where anonymity was previously given, there is a need to offer counselling by those who are professionally qualified counsellors – social workers, psychologists or psychiatrists. |

**Section 6.2** *(also relevant to donated embryos)*

**Q16.** In the best interest of the child, should there be an age limit for:

- male gamete donors?
- female gamete donors?
- Male and female gamete providers for donated embryos?

If so, what do you think the age limit(s) should be?

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| The decision to become a gamete donor has long term implications for the donor. That is especially the case if the children conceived are the only children the donor ever parents. Such a decision requires a level of maturity not likely to be possessed by a young person. Donors should not be under the age of 25. |

**Q17.** Should there be an age limit for female recipients of gamete or embryo donation?

- If so, what do you think this age limit should be?

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| The complications of conceiving a child require a great deal of maturity for a young person. Setting the minimum age at 25 when a young person is likely to be vocationally settled would help to indicate the gravity of the decision not only for the young person but for the child conceived. |

**Section 6.3**

**Q18.** Is more guidance required to enable clinics to take all reasonable steps to reduce the numbers of genetic relatives created through donor gamete programs? What guidance do you recommend?

While it is important to help donor-conceived people to know their genetic parents and limit the number of people born from a single donor, there is also the imperative to limit the number of donated gametes used to one donor so a child has the chance to be nurtured by at least one biological parent. The importance of biological links was explained in our comments at question 3.

**Section 6.4**

**Q19.** Should paragraph 6.4.1 be revised?

- If so, how?

No. It remains important to prevent disease transmission.

**Section 6.5**

**Q20.** In view of developments in other countries allowing women to receive compensation above medical and travelling expenses for donating eggs, should it be permissible for Australian women to also be compensated for the reproductive effort and risks associated with donating their eggs? *(See also Section 13 Surrogacy)*

The ACBC does not support allowing direct or indirect inducements, such as a monetary payment for human gametes and only supports compensation for donors for documented expenses which are directly relevant to the donation. The standard should be the level of expense documentation required by the Australian Taxation Office in relation to documenting work related expenses. The matter of inducements for participation in research was addressed in detail by the Australian Health Ethics Committee in a document which suggested questions for Human Research Ethics Committees to ask in relation to separating reimbursement from offering a financial incentive or inducement.[27]

The issues involved in paying for human eggs are also related to a document the NHMRC produced entitled "The commercialization of human tissue and human tissue products" in 2011. The document referred to several issues including:

- the danger that payments would adversely affect the social capital and community benefit involved in altruistic donation for transplantation to the blood, bone-marrow and eye banks;
- creation of perverse incentives leading to vendors acting in ways in which they would not have acted without the inducement, including, for instance,

[27] Using the National Statement 1: Payments to Participants in Research, Particularly Clinical Trials. NHMRC, October 2009.

not providing important information such as information about risk activities for infection, or poor people being exploited;
- the genomic significance of tissue or tissue products being sold which contain genetic information thus affecting not only the donor but also family members, especially if the genomic significance involves a unique value;
- the commodification of the donor's body in parts being bought and sold, which many of those who submitted to that enquiry thought involved a loss of respect for human dignity.[28]

All of those matters are significant in relation to women being paid for egg donation above the reimbursement of documented expenses incurred in the provision of their eggs.

A crucial ethical issue is the commodification of the bodies of the women involved. As Pope John Paul II expressed it, donating tissue is not just a matter of giving away something that belongs to us but of giving something of ourselves, for "by virtue of its substantial union with a spiritual soul, the human body cannot be considered as a mere complex of tissues, organs and functions . . . rather it is a constitutive part of the person who manifests and expresses himself through it".[29] He went on to say, "any procedure which tends to commercialize human organs or to consider them as items of exchange or trade must be considered morally unacceptable because to use the body as an "object" is to violate the dignity of the human person."[30]

Allowing inducements would mean treating the human body and hence the person as a mere commodity, undermining the existing social capital in existing systems of donation that depend on altruism and a commitment to the common good, and exploiting the poor who lack alternative ways of earning an income. Individuals and the common good are best protected by maintaining the existing prohibitions on trading in human eggs.

The medical team involved in living organ donation have a special responsibility to ensure the safety of the donor and in general that has proved to be the case. The opposite, however, has proven to be true when organs are traded rather than given altruistically and this is a strong reason for opposing trade in human tissue. Further, a key difficulty in allowing the trade in human ova would be it would allow disadvantaged women in need of cash to sell their ova at risk to their own health. Where women are short of money, they are not exercising the choice freely to donate their ova.[31] In fact, to allow women to have true informed consent to donating their ova, inducements must continue to be banned.[32]

[28] NHMRC Ethics and the exchange and commercialisation of products derived from human tissue - background and issues 2011 pp 27ff
[29] Pope John Paul II address to the 18th International Congress of the Transplantation Society 2000
[30] Ibid.
[31] George, K, What about the women? Ethical and policy aspects of egg supply for cloning research. *Reproductive BioMedicine Online*, Vol 15(2), page 132.
[32] Rao, R, Coercion, Commercialisation, and Commodification: The Ethics of Compensation for Egg Donors in Stem Cell Research. *Berkeley Technology Law Journal*, Vol. 21(3), February 2014. Page 1059.

There is also the danger of inducements other than money, which are harder to track, such as staff in ART settings offering their ova to please their employer.[33] Advancing women on waiting lists or giving them a discount rate or not charging for services are all ways which provide an inducement to donate eggs when they might otherwise have been unlikely to do so.

Staff in ART clinics and anyone else in a dependant relationship, such as medical students, should be prohibited from making donations where there is a relationship between the clinic or its staff and the university in which the students are enrolled.

**Q21.** Should more guidance be given about the reimbursement of legitimate expenses? What guidance would you recommend?

Payments to egg donors reportedly range from $3500 to $5000 to cover their costs. Donors dedicate about 20 hours to the donation over 3-5 months.[34] To ensure that these payments are justified and do not stray into the area of inducement, they should only be made for receipted, directly relevant expenses.[35]

As mentioned above, the NHMRC has already provided some guidance on interpretation of the Guidelines.[36]

The documentation standard should be the same standard that applies to claimable work related expenses for the purposes of assessing income tax by the Australian Taxation Office.

**Section 6.7** *(see also Section 7.5)*

**Q22.** Are there any specific relationships that give rise to particular concerns between donor and recipient that should be included in the guidelines? e.g. egg or embryo donation from a daughter to her mother.

Sections 6.7 and 6.8 are inconsistent. If it is wrong because incestuous for a man's sperm to be used to fertilise an egg of a close relative, then similar issues arise if an egg is used to achieve pregnancy in the close relative of the donor especially if using

[33] Rao, R, Coercion, Commercialisation, and Commodification: The Ethics of Compensation for Egg Donors in Stem Cell Research. *Berkeley Technology Law Journal*, Vol. 21(3), February 2014. Page 1059.
[34] Medew, J, IVF deal sees American eggs heading Down Under. *The Sydney Morning Herald*, 10 March 2013.
[35] Baylis, F and McLeod, C, The stem cell debate continues: the buying and selling of eggs for research. Journal of Medical Ethics, Vol 33, 2007, page 730.
[36] Using the National Statement 1: Payments to Participants in Research, Particularly in Clinical Trials. NHMRC, October 2009.

her partner's sperm. The conventions in relation to prevention of incest have a time honoured wisdom and significance. The relationships between close relatives are complex involving especially capacity for emotional pressures and entanglements that can be exploited to make free consent unlikely. The use of closely related donors also confuses the relationships between the related parties and the parenthood of a child born or to be born and should not be facilitated by ART clinics.

**Section 6.9** (see also Section 7.6)

**Q23.** Should conditional donation of sperm, eggs or embryos such as stipulating certain race or social attributes be permitted? e.g. a sperm donor not wanting his sperm to be used for a single woman, a lesbian couple, or a particular race?

This is a complex issue for its underlying appearance of racism or other discrimination. However, biological connectedness is a factor for the child born or to be born, and being brought up in a household that is racially, religiously or culturally different from the context that would have occurred if the child were nurtured by both genetic parents is a factor to be considered. Decisions should be based on the best interests of the child and it is emerging more and more that decisions made about parenthood in relation to an infant can have serious repercussions later in the child's life. It is not unreasonable that for cultural or religious reasons a donor might want the child to be nurtured in a home that reflects his or her own culture and or religion. The original assumptions of anonymity and treating gametes donation as though it were just a service to infertile couples are no longer acceptable.

**Section 6.10 – 6.11**

**Q24.** Do you think that the current ethical guidance is adequate?

- Should information about the number and sex of half-siblings be available to donor-conceived persons?
- Do you think that more information about half-siblings should be available to donor-conceived persons? e.g. identifying information.

For reasons given earlier, 6.10 and 6.11 no longer reflect the level of awareness that demands not just non-identifying information, but identifying information. The medical needs dealt with in these two sections overlook the social and mental health needs of those conceived using donor gametes in forming links to their genetic parents. There are issues of identity involved in knowing one's biological family and antecedents. It is not appropriate to limit information sharing to non-identifiable information. Further, even genetic diagnosis and prognosis of many conditions,

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| including many cancers, depends on combining genetic testing with knowing the history of the disease in genetic relatives. Often the nature of the disorder associated with a particular gene sequence can only be predicated on the basis of its nature in a relative with the same sequence. |

**Q25.** Do you consider 18 years of age too late to have access to this information?

- Should earlier access to the information be possible?

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| The identity and information about genetic parent(s) is the child's right from the outset. |

**Q26.** What is best-practice to facilitate a first contact between the half siblings?

- Should this guidance be included in the ART guidelines?

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| Contact between half siblings while any of them are children is a decision requiring the consent of the parents of each child. The circumstances are too variable to permit a single answer. |

**Section 6.12**

**Q27.** Should the donor be able to receive identifying information with the consent of the donor-conceived person?

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| As discussed earlier, the ethical obligation is to provide that information to the donor conceived person, except in the circumstances in which anonymity has been guaranteed and there are reasonable grounds for thinking that breaching that obligation would cause significant mental health problems to the donor. Such agreements ought not to have been made and are therefore not enforceable because the child as a vitally interested third party with critical interests at stake was not afforded protection of his or her rights to know and to have access to his or her natural parents. |

**Q28.** Should donor and recipient information be completely confidential or do you think that this information should be available to all individuals involved?

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| No it should be available to all the parties. |

**Section 6.14**

**Q29.** Is it reasonable for a sperm donor to be able to vary or withdraw their consent for donation at any time before insemination or fertilisation? Is the point of treatment commencement or ovarian stimulation a more reasonable point at which a sperm donor can vary or withdraw their consent for donation? *(see also Sections 7.3 & 9.6)*

- Should the right of gamete donors (or gamete providers for donated embryos) be restricted to the time before a woman begins treatment in anticipation of using specific gametes or receiving specific embryos?

It does make sense that once treatment is commenced with the consent of the donor that the consent for that particular treatment should not be able to be revoked.

**Section 6.15** *(see also Section 8.4)*

**Q30.** Should restrictions on posthumous donation require written expressed direction from the donor or should the requirements allow less explicit and/or implied expressions?

Section 6.15 and 6.16 reflect strong reservations on the part of AHEC and the NHMRC about the posthumous use of gametes because of concern for the rights of the child. It is a tragedy for a child to lose a mother or father. These are circumstances in which that loss is deliberately engineered. We know enough about the needs of children, the effects of grief upon them and the interests of the child being paramount to know we should not deliberately produce a child in circumstances which prevent the child's right to be brought up by his or her natural parents.[37]

**Q31.** Is it acceptable to take donations from dying or deceased persons?

- If so, under what circumstances?
- Should this rely on prior consent?

To use donated gametes from a person who has died would violate the child's right to know and to have access to his or her natural parents. This right is recognised by the UN Convention on the Rights of the Child and referred to earlier. There would therefore not be much point in securing a donation from a dying person.

**Section 6.17**

[37] Congregation for the Doctrine of the Faith (1987) *Donum Vitae* II A 3

**Q32.** Do you think that Section 6.17 is still relevant to the clinical practice of ART?

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| Section 6.17 should be re-written to ban the practice of making hybrid embryos to test sperm. From the ethical standpoint, procedures involving the formation of a hybrid using a human sperm with an animal egg "... represent an offense against the dignity of human beings on account of the admixture of human and animal genetic elements capable of disrupting the specific identity of man."[38] The limitation to the stage up until the formation of the mitotic spindle involves the formation of the human zygote and its use from the stage that the first cell has formed until the mitotic spindle forms some 16 hours later. The latter is the stage immediately prior to the first cell division.[39] |

**General Comments on Section 6**

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| The use of donor gametes and embryos is contrary to the unity of marriage, to the dignity of the spouses, to the vocation proper to parents, and to the child's right to be conceived and brought into the world in marriage and from marriage.[40] The practice should be discouraged because it cannot be made entirely consistent with the rights of the child to know, to have access to and to be brought up by his or her natural parents protected by the UN Convention on the Rights of the Child referred to above. Those rights will at least be endangered, particularly as the aim is likely to be to exclude donors from the nurturing of the child, and the practice fragments the relationship of the natural parents into the roles of donor, gestational mother and her partner, and the social mother and father in the various combinations of those roles that may be formed. |

## 7 Use of donated embryos

***In addition to questions 11 – 17 & 22 – 23.***

**General Questions**

**Q33.** Have you encountered any difficulties in the interpretation and/or application of the current ethical guidance in Section 7?

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| Yes, see the general comment below. |

[38] Congregation for the Doctrine of the Faith Dignitas Personae n. 33
[39] O'Connell, Christopher B., Khodjakov, Alexey L. Cooperative mechanisms of mitotic spindle formation. Cell Science, May 15, 2007 N. 120, pp. 1717-1722.
[40] Congregation for the Doctrine of the Faith Donum vitae, II, A 1-3

**Q34.** Do you think that there are gaps in the current ethical guidance in Section 7?

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| Yes. See the general comment below. |

**Specific Questions**

**Section 7.2**

**Q35.** Paragraph 7.2.1 – Is the practice of on-donation of donated embryos acceptable if all parties are involved in the counselling process?

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| No. The guidelines are right to prohibit the on-donation in the interests of the child referred to in comments on section 6. |

**General Comments on Section 7**

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| We refer to the appeal made by Pope John Paul II "to the conscience of the world's scientific authorities and in particular to doctors, that the production of human embryos be halted, taking into account that there seems to be no morally licit solution regarding the human destiny of the thousands and thousands of 'frozen' embryos which are and remain the subjects of essential rights and should therefore be protected by law as human persons".[41]<br><br>There should be no excess embryos created; no embryos kept in frozen storage; and therefore none in the position of being no longer needed for reproductive treatment for the person or couple for whom they were created. |

## 8 Storage of gametes and embryos

**Specific Questions**

**Section 8.3**

**Q38.** Should limits apply to the duration of storage of gametes - recognising that if stored for fertility preservation purposes, they may not be used for decades?

- If yes, what do you think the maximum duration should be?

[41] John Paul II, Address to the participants in the Symposium on "*Evangelium vitae* and Law" and the Eleventh International Colloquium on Roman and Canon Law (24 May 1996), 6: *AAS* 88 (1996), 943-944.

- If no, what difficulties do you perceive and how should the storage of gametes be managed?

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| If storage occurs it would be irresponsible to continue it indefinitely, first because the state of cryo-storage is a state of great peril and indignity and second because it is not in the interests of the child. There is no evidence as to the safety of long term storage for the child born or to be born. Further the longer the delay the greater the age difference between the embryo and the genetic parents and presumably those for whom the embryo was formed. |

**Section 8.7**

**Q39.** Paragraph 8.7.1 – In the case of stored embryos where the couple is in dispute, should embryos be kept in storage until the dispute is resolved or should there be time-limited storage?

- What do you think the maximum duration should be for time-limited storage?
- Should advance directives about the future of any excess ART embryos be obtained prior to the embryo being formed, so that in the event of a dispute a process for either disposal or donation is known?

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| The time limit should remain. |

**General Comments on Section 8**

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| In response to the questions for section 7 we argued that there should be no storage of human embryos. The issues considered in section 8 only serve to highlight some of the reasons why storage should not occur. The storage of embryos imperils them and creates unsolvable problems. They should not be created in such numbers. |

## 9 Information giving, counselling and consent

**General Questions**

**Q40.** Have you encountered any difficulties in the interpretation and/or application of the current ethical guidance in Section 9?

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| The data provided on success rates by the IVF teams is almost always misleading |

and it is often not presented in an accurate way to reflect the couples' needs. Allowing the data to be tailored to a couple prevents couples receiving accurate information because there is no standard. Couples should be given access to data such as is available on the Victorian Assisted Reproductive Technology Agency website and required to be supplied by statute law. As discussed earlier, the data provided directly to patients by clinics greatly exaggerates the success rates and does not match the data they supply to the regulator in Victoria. The Victorian data provides birth rates per treatment cycle which is what couples need to know.

**Q41.** Do you think that there are gaps in the current ethical guidance in Section 9?

As discussed earlier, there is no requirement to inform couples of alternative treatments such as endocrinological or surgical treatments to restore fertility and the advantage of learning to chart cycles to identify the symptoms of the fertile window, ovulation and peak fertility.[42]

**Specific Questions**

**Section 9.2**

**Q42.** Among the information which should be discussed, should there be specific reference to the significance of biological connection between donor-conceived persons and the donors of gametes, and to the right of these donor-conceived persons to knowledge of their genetic parents and siblings? *(see also questions in relation to Section 5 and Paragraphs 6.1.1 and 6.1.2)*

The ACBC supports the clear need for donor-conceived children to have information about their genetic parents. See the comments at question 3 regarding the need to acknowledge this profound biological connection.

**Section 9.8**

**Q43.** When a child or young person with stored gonadal tissue or gametes reaches adulthood, how should the ongoing consent arrangements be managed? i.e. the transition from parental consent to the consent of the individual.

The information should have been available from the outset at any time that the child requested it. As discussed, a child has a right to know and to access both

[42] Tonti-Filippini, Nicholas, 2013, pp 108-111

natural parents. How it is communicated is a matter for parents but not whether it should be communicated.

**Section 9.9**

**Q44.** Do you think that the guidance in Section 9.9 is appropriate?

Ideally the information should be possessed by and the counselling services should be provided by the Registrars of Births, Deaths and Marriages. There should be no distinction between children who are adopted and children who are donor conceived in that respect. Storing the information only in the clinics is not reliable enough. They have conflicts of interest such as has happened when the wrong gametes or embryos were used. This has happened in many cases, including a case in Melbourne that was taken to the Supreme Court of Victoria.[43]

**General Comments on Section 9**

The consent and information provisions are important and need to be strengthened in the ways indicated above.

## 10 Record keeping and data reporting

**General Questions**

**Q45.** Have you encountered any difficulties in the interpretation and/or application of the current ethical guidance in Section 10?

The issues raised earlier about access to identifying and other information about donors create great burdens for the clinics into the future. These are matters that really ought to be dealt with in the same way in which adoption information is managed. There is a need for State governments to manage the information and counselling services so that many of the responsibilities of the clinics could be met by registering the information with the Registrar of Births, Deaths and Marriages instead of having private services having to replicate government services.

Q46. Do you think that there are gaps in the current ethical guidance in Section 10?

[43] AAA v Backwell (1994) Supreme Court of Victoria

There are now studies being done following up the long term health of people who are conceived through ART and the women who underwent the procedures. For instance, there is considerable evidence now indicating that there are cardio-metabolic differences in the population of adults who were ART conceived.[44] Material of that nature needs to be gathered and made available in an accessible way for people who are considering using ART services so that they can make informed choices. The guidelines could add a line to that effect.

**General Comments on Section 10**

See above comments.

## 11 Sex selection

**General Questions**

**Q47.** Have you encountered any difficulties in the interpretation and/or application of the current ethical guidance in Section 11?

No.

**Q48.** Do you think that there are gaps in the current ethical guidance in Section 11?

There are some general issues with Preimplantation Genetic Diagnosis (PGD) that are dealt with in the following section.

[44] Seggers J, Haadsma ML, La Bastide-Van Gemert S, Heineman MJ, Middelburg KJ, Roseboom TJ, Schendelaar P, Van den Heuvel ER, Hadders-Algra M. Is ovarian hyperstimulation associated with higher blood pressure in 4-year-old IVF offspring? Part I: multivariable regression analysis. *Hum Reprod* 2013; Published online ahead of print 22 December 2013; DOI 10.1093/humrep/det396; La Bastide-Van Gemert S, Seggers J, Haadsma ML, Heineman MJ, Middelburg KJ, Roseboom TJ, Schendelaar P, Hadders-Algra M, Van den Heuvel ER. Is ovarian hyperstimulation associated with higher blood pressure in 4-year-old IVF offspring? Part II: an explorative causal inference approach. *Hum Reprod* 2013; Published online ahead of print 22 December 2013; DOI 10.1093/humrep/det448.

**Specific Questions**

**Section 11.1**

**Q49.** Are there any circumstances under which it is appropriate to allow sex selection for non-medical purposes? e.g. for family balancing, to replace a lost child, for cultural purposes?

The ACBC objects to the disposing of any human embryos, whether that be for sex selection for medical or non-medical purposes. That is because such actions would instrumentalise human embryos, treating them as part of a production process where they can be kept or disposed of subject to arbitrary judgements.[45] This of course does not respect the embryos' inherent human dignity.

This disapproval is shared by the Australian people. One Australian opinion survey on this issue found "seven percent of respondents approve or strongly approve the use of IVF for sex selection, 24% neither approve nor disapprove, and 69% disapprove or strongly disapprove.[46] A second survey of Australians found similar results with 73% saying "social gender selection" should not be allowed.[47]

Kippen et al hypothesised that, based on opinion data,"... widespread use of sex-selective technology could lead to a preponderance of first-born boys; where a preference is expressed, Australians tend to prefer first-born sons over first-born daughters."[48] Whether or not Australian culture would be as male preferring as some other cultures does not seem to have been resolved on the basis of evidence. The pressure seems to be for sex selection for the purpose of what is called "family balancing" in which a couple who already have a child or children of one gender want a child of the other gender. This issue was addressed in a case in Melbourne in which a couple had already aborted several male pregnancies in their desire to have a daughter and sought access to IVF for the purpose. The Victorian Civil and Administrative Tribunal (VCAT) addressed the issue on appeal after the matter was dealt with negatively by the Patient Review Panel established under the ART Act 2008. On appeal VCAT found "arguments based on completion of family, replacement of a child, or family balance do not advance the welfare or interests of a child born to fulfil that end." The tribunal rejected the application.[49]

[45] Velez, J, An Ethical Comparison between In-Vitro Fertilisation and NaProTechnology. *The Linacre Quarterly*, Vol. 79(1), page 61.
[46] Kippen, R et al, Australian attitudes toward sex-selection technology. *Fertility and Sterility*, Vol 95(5), April 2011, page 1825.
[47] Kovacs, G, McCrann, J, Levine, M and Morgan, G, The Australian Community Does Not Support Gender Selection by IVF for Social Reasons. International Journal of Reproductive Medicine, Vol 2013.
[48] Kippen, R et al, Australian attitudes toward sex-selection technology. *Fertility and Sterility*, Vol 95(5), April 2011, page 1826.
[49] JS and LS v Patient Review Panel (Health and Privacy) [2011] VCAT 856 http://docs.health.vic.gov.au/docs/doc/61EEBF4FD349D1F8CA257AB5001916FE/$FILE/JS%20and%20LS%20v%20Patient%20Review%20Panel%20(Health%20and%20Privacy)%20[2011]%20VCAT%20856.pdf

Gender selection would seem to be based on premises that view the child merely as an object of desire, rather than seeing children as ends in themselves to be welcomed whatever their gender or other features such as disability.

**Q50.** Do you think that it is ethically acceptable for ART to be available to individuals solely for non-medical sex selection purposes, e.g. for family balancing, to replace a lost child, for cultural purposes, when the individuals are neither infertile (physically or socially), nor have reduced fertility?

Several States have prohibited using IVF for non-medical sex selection. The guidelines should continue to prohibit making IVF available for gender selection.

**Q51.** Is it possible to define a "serious genetic condition" for the purposes of allowing sex selection? If so, please provide a suitable definition.

There has been a degree of fluidity in this respect. Recently the issue of autism has been advanced as a reason for gender selection on the basis that autism is more likely in boys.[50] The argument would seem to be no stronger than arguing that gender selection should be allowed because, for instance, those with a Y-chromosome are eight times more likely to be gaoled for violent offences. There is a need to be more specific about what is meant by "serious genetic condition".

**General Comments on Section 11**

There is a need to make the exception more specific to prevent it being abused.

[50] O'Leary, C, Baby Sex Checks for Autism. The West Australian, 19 October 2013.

## 12 Preimplantation genetic diagnosis

### General Questions

**Q52.** Have you encountered any difficulties in the interpretation and/or application of the current ethical guidance in Section 12?

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| It requires an impossible task of ethics committees to determine that PGD will not adversely affect the welfare and interests of the child who may be born. How can one assess the effect of being born at the expense of the death of one's siblings through deliberate selection? What does it mean to be born into circumstances in which the parental welcome is conditional upon not having a disability? See the discussion below. |

**Q53.** Do you think that there are gaps in the current ethical guidance in Section 12?

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| The guidelines presume that PGD is a successful technology. However the data available suggest otherwise. In the most recent data available through the Victorian Assisted Reproductive Technology Authority (VARTA) for the 2012-3 year there were 428 cycles in which the embryos formed were subjected to PGD, undertaken on 325 women, involving 2996 embryos with just 17 confinements resulting[51] – indicative of a live birth rate of less than 4% per treatment cycle and an embryo survival rate of less than 6 per thousand. That raises a practical question as to whether PGD can be considered to meet the requirements of section 14.1.1 in relation to safety and efficacy. Yet the websites of the teams involved in submitting this data do not indicate the low success rates. The Monash IVF website states, "in 1996 we were proud to report the birth of Australia's first PGD babies and since then we have performed over 3,000 PGD cycles with proven high success rates."[52] Yet Monash had just one confinement from 85 treatment cycles in 2012-13.[53] The Melbourne IVF website claims, "Melbourne IVF offers an internationally recognised PGD program and is a leader in the development of PGD testing in Australia. The program has helped hundreds of couples conceive healthy babies, many after long periods of infertility or with serious genetic diseases in the family." |

[51] Victorian Assisted Reproductive Technology Authority Annual Report 2013 http://www.google.com.au/url?sa=t&rct=j&q=&esrc=s&frm=1&source=web&cd=1&ved=0CCgQFjAA&url=http%3A%2F%2Fwww.varta.org.au%2Fsecure%2Fdownloadfile.asp%3Ffileid%3D1005753&ei=OyxXU5__Ioj08QW_poKoBA&usg=AFQjCNFfWVGE9Lm6OlgNlGnUFP4yyVMtCw&bvm=bv.65177938,d.dGc

[52] http://monashivf.com/treatment/qld/treatments-available/embryo-genetic-testing/

[53] VARTA, ibid

Hundreds? In 2012-3 they had just 16 confinements from 343 egg pick up cycles where PGD was involved.[54] Melbourne IVF also claims that it has the technology "to perform full chromosomal screening on all 24 chromosomes in a developing embryo, allowing selection of the embryo with the greatest likelihood of success".[55] How can the results allow them to speak of success in this connection?

The lack of efficacy would indicate that section 12 of the guidelines that treats PGD as though it was an established and effective practice needs considerable re-writing to reflect the experimental state of the technology.

**Specific Questions**

**Section 12.1 – 12.2**

**Q.3** Under what situations do you think the use of preimplantation genetic diagnosis is ethically acceptable?

None. Preimplantation genetic diagnosis expresses a eugenic mentality that accepts selective destruction of embryos in order to prevent the birth of children affected by various types of anomalies. "Such an attitude is shameful and utterly reprehensible, since it presumes to measure the value of a human life only within the parameters of 'normality' and physical well-being, thus opening the way to legitimizing infanticide and euthanasia as well".[56]

The use of PGD involves "reproductive discrimination" against people with disabilities.[57] "Dignity belongs equally to every single human being, irrespective of his parents' desires, his social condition, educational formation or level of physical development. If at other times in history, while the concept and requirements of human dignity were accepted in general, discrimination was practiced on the basis of race, religion or social condition, today there is a no less serious and unjust form of discrimination which leads to the non-recognition of the ethical and legal status of human beings suffering from serious diseases or disabilities."[58]

[54] VARTA, Ibid.
[55] http://mivf.com.au/fertility-treatment/genetic-testing-pgd
[56] Congregation for the Doctrine of the Faith Dignitas Personae n. 22
[57] Tonti-Filippini, Nicholas, "Reproductive Discrimination" University of New South Wales Law Journal Forum Volume 12 No 1 August 2006

[58] Dignitas Personae n. 22

**General Comments on Section 12**

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| The above indicates that PGD is not a successful technology and that it is being used for discriminatory purposes. |

## 13 Surrogacy

**General Questions**

**Q55.** Have you encountered any difficulties in the interpretation and/or application of the current ethical guidance in Section 13?

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| There is a lack of definition of what "commercial surrogacy" means. What fees may be charged? What reimbursement may be paid? Would expense claims be subject to the kind of requirement imposed on work related expenses by the Australian Taxation Office? Might the surrogate also be paid for her time, or for her hardship? |

**Q56.** Do you think that there are gaps in the current ethical guidance in Section 13?

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| The lack of definition of "commercial surrogacy" is an obvious gap that can be easily exploited. |

**Specific Questions**

**Section 13.2**

**Q57.** In view of developments in other countries, should there be compensation, more than expenses, for gestational mothers congruent with the reproductive effort contributed?

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| The ACBC opposes surrogacy, whether it is commercial or not. The surrogate mother must attempt to control any love for the unborn child when she surrenders the child she has carried for nine months to the nurturing parent. That has proven not to be achievable for some women. The act of surrogacy denies the child the right to be conceived, carried, born and brought up by his or her genetic parents. It sets up, to the detriment of families, a division between the physical, psychological and moral elements which constitute those families.[59] |

[59] Tonti-Filippini, N, 2013. Pages 106-107.

All forms of surrogacy should be prohibited, not just commercial surrogacy. The possibility for emotional blackmail in which a fertile woman in a family is pressured to have a child for the sake of an infertile relative is a likely result of allowing surrogacy. Banning commercial surrogacy would not prevent women from being exploited as surrogates.

There is clear evidence with regard to overseas commercial surrogacy that the women providing the service are financially disadvantaged and exploited. Social commentator Melinda Tankard Reist wrote recently of Thai surrogate mothers "... eliminated from the children's history, treated as nothing more than disposable uteruses. The physical, emotional, spiritual bonds between mother and child that develop during a pregnancy are rendered null and void by a monetary transaction."[60]

In India, "the poor, illiterate women of rural background are often persuaded in such deals by their spouse or middlemen for earning easy money."[61]

Saxena et al comment as Indians that "it seems ironical that people are engaging in the practice of surrogacy when nearly 12 million Indian children are orphans."[62]

Women in commercial surrogacy in Australia would have better conditions, but there is no doubt that ultimately they would, in the main, be disadvantaged women who would have few rights with regard to the children they bear.

The payment of fees for surrogacy exacerbates what is already an abuse of women and a violation of the rights of children. All forms of surrogacy should be prohibited by the guidelines.

**Q58.** Paragraph 13.2.1 – Is this guidance still appropriate?

No-one should profit from surrogacy. Now that almost all ART clinics in Australia are owned by for-profit entities, the charging of fees for providing ART procedures to achieve pregnancy in a woman in a surrogacy arrangement must continue to be prohibited. Otherwise the ban on commercial surrogacy is easily avoided.

[60] Reist, MT, Overseas Surrogacy: Wombs for rent but no room for birth mothers. *The Age*, 16 February 2014.
[61] Saxena, P et al, Surrogacy: Ethical and Legal Issues. *Indian Journal of Community Medicine*, Vol.37(4), Oct-Dec 2012, pp211-213.
[62] Saxena, P et al, 2012.

**General Comments on Section 13**

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| The guidelines should prohibit all forms of surrogacy. |

## 14 Innovations, training and quality assurance

**General Questions**

**Q59.** Have you encountered any difficulties in the interpretation and/or application of the current ethical guidance in Section 14?

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| ART has continued to evolve so that much of what happens at any time is experimental but it is rarely treated as medical research. Changes to protocols and existing practices should always be subject to an HREC review, but seemingly that is not so. Hospital and university administrators where there are ART programs need to be informed that they have obligations under the National Statement on the Ethical Conduct of Human Research to ensure that all such experimentation is subject to HREC review. The guidelines could state that more clearly in section 14. |

**Q60.** Do you think that there are gaps in the current ethical guidance in Section 14?

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| The issue referred to above of ensuring that there is long term follow up of the health of those who are conceived through ART or who received ART treatment and the collections and accessibility of that data needs to be part of the quality assurance. |

**General Comments on Section 14**

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| See above. |