[redacted]

Can you please pass on my opinion regarding **Posthumous collection of sperm.**

Having been involved in such a case in the 1990s, I have had time to reflect on the moral, ethical and practical issues surrounding this practice. This is the only case that I have been linked to during the past 25 years of my career so I would consider it a very rare situation.

To provide background to the case: I was approached as Laboratory Manager of Fertility PLUS late

one afternoon by a local emergency department who had a male in his 20s about to be taken off life support machine after having a collision with a car. During the process of organ donation, his parents and partner asked if his sperm could be retrieved and stored for their future use. There was no time for discussing whether or not this was an accepted practice for our clinic other than it was technically possible to retrieve sperm from dissected testicular tissue for freezing, as was done in the agricultural industry. Testicular biopsies were a recent introduction to our treatment options for patients and involved small amounts of tissue <1cm in diameter. The deceased had agreed to be an organ donor but there was obviously no consent or intention to freeze sperm on his part. The surgeons informed us that they would amputate the testes and deliver them to us asap in a thermos flask. We received the intact scrotum complete with skin and hair at 5pm and began dissecting out the testes. This is something we had never done before and of which there was no written protocol available. For non-medical personal, this procedure was somewhat disturbing to say the least. Once the tissue had been dissected, it took several hours to macerate the huge amount of tissue to extract the sperm then freeze the large quantity of sperm retrieved and we left the laboratory just before midnight. My colleague and I were offered counselling after this event, which we did not take up on, but it is an experience that is etched in my memory.
As far as I know the cost of this procedure and storage of the sperm was not charged to any party and came under the undesignated public funding of the time. Approximately 6 months later the mother and his widowed partner had a consultation with one of our doctors and I was called in to participate in that meeting. My impression was that the mother was a lot more motivated for the widowed partner to use the sperm than she was. Our recommendation at the time was for them to take more than a year to consider this, given the grieving process was still very much in progress. Two years following, we were contacted by the widowed partner to say she was now in another relationship and no longer required the sperm. I can't say for certain how the disposal of that sperm was managed and if his parents were involved in that.

Based on this experience, I have formulated the following personal opinions, which is shared by many of my current scientific colleagues

1. Post humus collection of sperm should not be performed without prior consent from the individual
2. This is not in the best interests of the child – who makes a ruling on this in these cases?
3. There is every reason to consider that these actions may have been abhorrent to the deceased persons wishes
4. In the above case, it would need to be established that there was no coercion from the parents on the deceased person's partner to have a child from this sperm.
5. We should not perform such techniques just because we can
6. We should not institute policies which may lead to proliferation of this practice
7. Consideration should be given to the emotional impact on the scientists who are asked to perform such procedures
8. Proven best practice policies and procedures must be well formulated prior to clinics offering such procedures
9. It should not be publically funded

Thankyou – I am happy to be consulted further on this issue if required
Debbie

PHD
Scientific Director

Sent by:
21/08/2018 04:41 p.m.

To: <acart@moh.govt.nz>,
cc:
bcc:
Subject: ACART First Stage Consultation on Posthumous reproduction

Kia ora,

Please find attached the feedback from the Interchurch Bioethics Council NZ for ACART's first stage consultation on:

Posthumous Reproduction:
A review of the current Guidelines for the Storage, Use, and Disposal of Sperm from a Deceased Man to take into account gametes and embryos

As also written at the beginning of our feedback comments, we have 4 overarching concerns which are fundamental to our answers throughout the survey and which we would like to emphasise again here:

a) this document does not provide any question from the perspective of, or about the rights of, any future child, or the need to provide a community for any future child. Future uncertainty and a supportive community for any child born using posthumous reproduction needs to be ethically considered, with first priority on non-harm and thriving of resulting children.
b) counselling and grief support must surround the partner/family during posthumous reproduction decisions.
c) from both Western and Māori views, these are not individual rights or decisions to be made alone.
d) key questions that Māori would ask need to hold equal priority in this enquiry.

We appreciate being given the opportunity to contribute to this evaluation of current and future regulation in this field of reproduction.

best regards,

on behalf of the InterChurch Bioethics Council, NZ

ICBC posthumous-reproduction-consultation-Aug 2018.docx

Feedback form

Please provide your contact details below.

Name	
If this feedback is on behalf of an organisation, please name the organisation	InterChurch Bioethics Council, New Zealand
Please provide a brief description of the organisation (if applicable)	The InterChurch Bioethics Council (ICBC) is an ecumenical, cross-cultural body elected and supported by the Anglican, Methodist and Presbyterian Churches of Aotearoa, New Zealand (www.interchurchbioethics.org.nz). ICBC members have between them considerable expertise and knowledge in science, ethics, theology, medicine and education.
Address/email	
Interest in this topic (eg, user of fertility services, health professional, researcher, member of public)	Our science, ethics and medical fields include assisted reproductive technologies, with ICBC aiming to present information on the background science and accompanying ethical questions to allow informed discussion in our faith congregations and the general public.

Are you:

☒ Male ☒ Female

Would you like to make a verbal submission in person or using electronic communications?

☒ Yes ☐ No

Which of the following age groups do you belong to?

☐ 13–19 years ☐ 20–24 years ☐ 25–34 years
☒ 35–44 years ☒ 45–54 years ☒ 55–64 years
☒ 65–74 years ☐ 75+ years

Privacy

We may publish all submissions, or a summary of submissions on the Ministry of Health's website. If you are submitting as an individual, we will automatically remove your personal details and any identifiable information. You can also choose to have your personal details withheld if your submission is requested under the Official Information Act 1982.

If you do not want your submission published on the Ministry's website, please tick this box:

☐ Do not publish this submission.

Your submission will be subject to requests made under the Official Information Act. If you want your personal details removed from your submission, please tick this box:

☒ Remove my personal details from responses to Official Information Act requests.

If your submission contains commercially sensitive information that you do not wish to be released, please tick this box:

☐ This submission contains commercially sensitive information.

Consultation Question 1a

Do you agree that posthumous retrieval of sperm should only be permitted with the prior **written** consent of the deceased from whom the gametes are to be retrieved?

If you do not think explicit **written** consent is always required, do you agree that posthumous retrieval of sperm should be permitted **without written** consent from the deceased where:

- there is evidence that the deceased gave verbal consent?
- there is no evidence of consent from the deceased, but there is evidence that retrieval is consistent with the deceased's wishes, feelings and beliefs prior to death? (Inferred consent).
- there is no evidence of consent from the deceased, but there is no reason to think retrieval is inconsistent with the deceased's wishes, feelings and beliefs prior to death? (No consent but no objection).

Response

	1 Strongly agree	2 Agree	3 Neither agree nor disagree	4 Disagree	5 Strongly disagree
Posthumous retrieval of sperm should be permitted:					
only when there is written consent	1	2	3	4	5
when there is evidence of verbal consent	1	2	3	4	5
when there is evidence of inferred consent	1	2	3	4	5
when there is no consent but no objection	1	2	3	4	5

Please add comments about your response if you wish.

Four fundamental concerns ICBC have identified for this entire ethical review are:
a) this document does not provide any question from the perspective of, or about the rights of, any future child, or the need to provide a community for any future child. Future uncertainty and a supportive community for any child born using posthumous reproduction needs to be ethically considered, with first priority on non-harm and thriving of the child.

b) counselling and grief support must surround the partner/family during posthumous decisions.

c) from both Western and Māori views, these are not individual rights or decisions to be made alone.

d) key questions that Māori would ask need to hold equal priority in this enquiry.

Our comments for this section 1a) on sperm posthumous retrieval also apply to our answers for 1b) egg and ovarian tissue retrieval, and are pertinent for several of the other consultation questions:

- We believe explicit consent is critical for this practice to gain approval ie no consent, no retrieval. Written consent already allows legal retrieval, evidence of verbal consent would require thorough ethical examination and clear evidence must be ascertained through previous discussions with the spouse, significant other and/or family, and friends. Absence of donor intent may be tantamount to invasion of privacy, hence, would therefore be a ground for denial of request.

- Due to the nature of the request, despite the short time frames involved for successful retrieval, ethically it is important to identify the motives of the request for retrieval both with written and verbal consent eg. wanting to hold onto the deceased or provide a reminder, or denial of death. We note here that grief support through nursing, social services, spiritual care and mental health services needs to be offered to families during and after bereavement, including while making posthumous reproduction requests with both written and verbal consents. A minimum time before gamete use might allow time for counselling, and a maximum storage limit could reduce potential legal problems.

- The future uncertainty for any child born under circumstances using posthumous reproduction needs to be ethically considered, eg under current law would not have a father noted on the birth certificate. Legislation should address the rights of the children who through no fault of their own, often become victims of new reproductive technologies, rather, than beneficiaries.

- This is not an individual right or decision. Having the 'choice' to create another life utilizing the method of posthumous reproduction, and the principle of 'individual rights,' come from a Western perspective and focus on the individual and not on whānau. This 'choice,' this 'decision,' this 'right to choose,' for Māori does not operate in a vacuum. The impact of this type of decision affects not only whānau, but hapu and iwi. Any decision affecting a whānau member, needs to incorporate all whānau in making the decision. As whānau, we are also answerable to our Atua, our Tupuna, and our people for any decisions we make that impact on all those we whakapapa to. We are also answerable to our mokopuna and future generations. What we decide now impacts on the present, but also the past and the future.

- Even in Western culture there needs to be a strong community ethic as families and communities and society, will be impacted at some stage. The scenarios outlined and questions imply this is a single person choice (the partner who is alive).

- Issues of justice – will this be a procedure only accessible to the wealthy since the collection and storage are costly, as is IVF (and possible screening depending on the nature of conditions leading to death of parent).

- Throughout reflecting on these consultation questions, there is a sense of extending our human penultimate role into areas of the ultimate (to use Bonhoeffers distinction) in the decisions to create life. Moana Jackson asked a key question during the debate around the relevance and significance for Māori of genetic engineering and genetic modification, especially during the Royal Commission on Genetic Modification. His question was: "Always go back to the same question: Do you think our tupuna [ancestors] would have agreed to putting [human] genes in sheep?" A similar question could be asked here: "Do you think our tupuna would have agreed to the creation of life from the method and process of posthumous reproduction?" Similarly, another question posed during this period of the Royal Commission on Genetic Modification, was a question posed by Angeline Greensill:"Tampering with whakapapa is likely to have a negative effect on the mauri of the species involved as well as on the whānau and hapu." This question has relevance with regards to posthumous reproduction.

Consultation Question 1b

Do you agree that posthumous retrieval of eggs or ovarian tissue should only be permitted with the prior **written** consent of the deceased from whom the gametes or ovarian tissue are to be retrieved?

If you do not think explicit **written** consent is always required, do you agree that posthumous retrieval of eggs or ovarian tissue should be permitted **without written** consent from the deceased where:

- there is evidence that the deceased gave verbal consent?
- there is no evidence of consent from the deceased, but there is evidence that retrieval is consistent with the deceased's wishes, feelings and beliefs prior to death? (Inferred consent).
- there is no evidence of consent from the deceased, but there is no reason to think retrieval is inconsistent with the deceased's wishes, feelings and beliefs prior to death? (No consent but no objection).

Response

	1 Strongly agree	2 Agree	3 Neither agree nor disagree	4 Disagree	5 Strongly disagree
Posthumous <u>retrieval</u> of eggs or ovarian tissue should be permitted:					
only when there is written consent	1	2	3	4	5
when there is evidence of verbal consent	1	2	3	4	5
when there is evidence of inferred consent	1	2	3	4	5
when there is no consent but no objection	1	2	3	4	5

Please add comments about your response if you wish.

Our comments for egg and ovarian tissue posthumous retrieval are the same as for 1a) sperm posthumous retrieval.

Consultation Question 2

Who should **authorise** the retrieval of gametes or reproductive tissue?

- The deceased's partner?
- A close relative of the deceased?
- A nominee of the deceased
- ECART?
- A coroner (where an individual is recently deceased)?
- The Family Court?
- The High Court?

Should joint authorisation be required?

Response

	1 Strongly agree	2 Agree	3 Neither agree nor disagree	4 Disagree	5 Strongly disagree
Gamete or reproductive tissue retrieval should be <u>authorised</u> by:					
the partner of the deceased	1	2	3	4	5
a close relative	1	2	3	4	5
a nominee	1	2	3	4	5
ECART	1	2	3	4	5
a coroner (where an individual is recently deceased)	1	2	3	4	5
the Family Court	1	2	3	4	5
the High Court	1	2	3	4	5
Joint authorisation should be required	1	2	3	4	5

Please add comments about your response if you wish.

- Only the legal spouse or partner should be allowed to be the primary requestor for posthumous retrieval of sperm or eggs/ovarian tissue with consent of the deceased person. In no situations should this be a decision for a direct relative eg mother or father retrieving/using gametes of a deceased child, as this directly risks a "replacement" mentality, with psychological risk to any resulting child.
- After the partner's request, consent allowing retrieval (written or verbal) needs to be verified and authorised - written consent by coroner and partner, verbal consent by ECART or Family Court with the partner.
- If time is too short for ECART/family Court decision, then a coroner could authorise retrieval, but ethical decision by ECART/Family Court would be required for use of retrieved material.
- the partner's request also requires whānau/community input and support/counselling where possible.

Consultation Question 3

Should others be able to approve retrieval of gametes from a permanently incapacitated person whose death is imminent, in the absence of prior consent by the person?

Response

	1 Strongly agree	2 Agree	3 Neither agree nor disagree	4 Disagree	5 Strongly disagree
Other people should be able to approve the retrieval of gametes from a permanently incapacitated person who has not previously consented	1	2	3	4	5

Please add comments about your response if you wish.

- Others (whether legal partner or authorisation group) should not be allowed to retrieve gametes from a dying person without their consent because the focus would become what is beneficial for others, rather than what is good for the incapacitated person who is about to die. Without written or strong evidence for verbal consent from a partner, the retrieval process would be invasive and not give dignity to, or be in the best interests of, the dying person.
- Instead, processes of verification of consent and therefore authorisation (to ECART/family court/coroner) by partner could be initiated, for possible and timely gamete retrieval after the person's death.
- There needs to remain the separate policy (as in the Human Tissue Act) between posthumous reproductive tissues and organ donation. As in this Act, gametes, reproductive tissues and embryos have a different value than other organs and tissues, which retrieval and donation can be consented to by next of kin.

Consultation Question 4

Do you agree that posthumous use of gametes taken or embryos created when the deceased was alive and competent should only be permitted with the **written** consent of the deceased?

If you do not think explicit written consent is always required, do you agree that posthumous use of gametes or embryos should be permitted **without written** consent from the deceased where:

- there is evidence that the deceased gave verbal consent?
- there is no evidence of consent from the deceased, but there is evidence that use is consistent with his or her wishes, feelings and beliefs prior to death? (inferred consent)
- there is no evidence of consent from the deceased, but there is no reason to think use is inconsistent with their wishes, feelings and beliefs prior to death? (no consent but no objection)

Response

	1 Strongly agree	2 Agree	3 Neither agree nor disagree	4 Disagree	5 Strongly disagree
Posthumous use of <u>stored gametes</u> should be permitted:					
only when there is written consent	1	2	3	4	5
when there is evidence of verbal consent	1	2	3	4	5
when there is evidence of inferred consent	1	2	3	4	5
when there is no consent but no objection	1	2	3	4	5

Please add comments about your response if you wish.

- Posthumous use of stored gametes should be permitted only with consent, as shown by the score above. Upon collection and storage of gametes, fertility clinics should register (ie written consent) a client's wishes as to what can happen to their gametes if they should die.
- The production of embryos is different and would be the strongest case for verbal and inferred consent to be accepted. Storage of embryos implies a future desire for children and action has already been taken (ie IVF and storage) to indicate this. Presumably in this context – the desire for children was shared by both partners, prior to incapacitation or death.
- However, fertility clinics should be required to have a full record of both parent's wishes upon death. These records should be explicit and in enough detail to clarify all situations (death, incapacitation etc) and be updated if a parent's consent changes.

Consultation Question 5

Do you agree that posthumous use of gametes or reproductive tissue taken from a **deceased** or **permanently incapacitated person** should only be permitted with the **written** consent of the deceased?

If you do not think explicit written consent is always required, do you agree that posthumous use should be permitted **without written** consent from the deceased where:

- there is evidence that the deceased gave verbal consent?
- there is no evidence of consent from the deceased, but there is evidence that use is consistent with his or her wishes, feelings, and beliefs prior to death? (Inferred consent).
- there is no evidence of consent from the deceased, but there is no reason to think use is inconsistent with his or her wishes, feelings, and beliefs prior to death? (No consent but no objection).

Response

	1 Strongly agree	2 Agree	3 Neither agree nor disagree	4 Disagree	5 Strongly disagree
Posthumous use of gametes or reproductive tissue retrieved after should be permitted:					
only when there is written consent	[✓ 1]	2	3	4	5
when there is evidence of verbal consent	1	[✓ 2]	3	4	5
when there is evidence of inferred consent	1	2	3	4	[✓ 5]
when there is no consent but no objection	1	2	3	4	[✓ 5]

Please add comments about your response if you wish.

- As noted in question 3, we do not believe the retrieval (and hence use) of gametes from incapacitated people near death should be allowed, so the above score is only for 'after death'.
- There should be linking of the authorisation of gamete/tissue retrieval and the authorisation of gamete/tissue use, since retrieval implicates a request for a potential future use.
- When a deceased person has consented to sperm/egg/embryo retrieval and 'specific use' before he or she died, this should be verified allowed (as is currently the case with sperm use).
- Without written consent, the process permitting gamete/tissue use should also be tied in with any permission for posthumous retrieval, eg. partner+ECART/Family Court.
- We note here that some couples might be currently planning a family or are in the middle of having a family already with a child or children, when one partnersuddenly dies, and it is unlikely there is written consent as there would be in the case for stored gametes. Close ethical consideration is required for verbal consent of the deceased partner; inferred consent would be too open to manipulation and incorrect estimation of consent. This consideration also has to weigh the benefit for resulting children and their siblings, the emotional health/strength/support of the family for future children, as well as the 'procreative liberty interest' of the surviving partner.

Consultation Question 6

Who should authorise the posthumous use of gametes, tissue or embryos?

- The deceased's partner?
- A close relative of the deceased?
- A nominee of the deceased?
- ECART?
- The Family Court?
- The High Court?

Should joint authorisation be required?

Response

	1 Strongly agree	2 Agree	3 Neither agree nor disagree	4 Disagree	5 Strongly disagree
Posthumous use should be authorised by:					
the partner of the deceased	1	[✓ 2]	3	4	5
a close relative	1	2	3	4	[✓ 5]
a nominee	1	2	3	4	[✓ 5]
ECART	1	[✓ 2]	3	4	5
the Family Court	1	[✓ 2]	3	4	5
the High Court	1	2	[✓ 3]	4	5
Joint authorisation should be required	[✓ 1]	2	3	4	5

Please add comments about your response if you wish.

- In cases where posthumous retrieval of gametes and tissue has occurred, authorisation of gamete/tissue/embryo use should be linked in with the retrieval authorisation.
- Where gametes/tissue/embryos were stored prior to death, authorisation of deceased person's consent recorded by fertility clinic would be required jointly by partner.and ECART or Family Court. This ethical check even with written consent gives the best protection for any unborn child(ren).
- As commented before, close relatives and nominees should not be allowed to request use.

Consultation Question 7

Who should be permitted to use reproductive material from a deceased person?

- The deceased's partner only?
- Family members of the deceased as well as the deceased's partner?
- Anybody?

Response

	1 Strongly agree	2 Agree	3 Neither agree nor disagree	4 Disagree	5 Strongly disagree
Reproductive material should be permitted to be used by:					
the deceased's partner only- gametes	1	2	3	4	5
family members of the deceased as well as the deceased's partner – for embryos	1	2	3	4	5
anybody	1	2	3	4	5

Please add comments about your response if you wish.

- For gametes and reproductive tissue, only the surviving partner should be permitted to use this material. Sibling use of deceased siblings gametes without explicit consent of the circumstances would be unacceptable.
- For embryos, the surviving partner would have priority choice for use. There may be a case for a sibling of deceased or surviving partners to surrogate for a surviving male parent, or a sibling to surrogate then parent if no partners are surviving – this would require considerable ethical deliberation. We do not believe this use should be granted to parents of the deceased.

Consultation Question 8

Should all posthumous use of gametes or embryos be subject to ethics review?

Are there situations in which ethics review should not be required, such as where the person's partner wishes to use the gametes or embryos?

Consultation responses

	1 Strongly agree	2 Agree	3 Neither agree nor disagree	4 Disagree	5 Strongly disagree
All posthumous use of gametes and embryos should be subject to ethics review	[✓ 1]	2	3	4	5
Posthumous use of gametes and embryos should never be subject to ethics review	1	2	3	4	[✓ 5]
Posthumous use of gametes and embryos should not require ethics review if the donor's partner wishes to use them to create a full genetic sibling for an existing child	1	2	3	4	[✓ 5]
Posthumous use of gametes and embryos should not require ethics review if the donor's partner wishes to use them	1	2	3	4	[✓ 5]
Posthumous use of gametes and embryos should require ethics review if a third party wishes to use them	[✓ 1]	2	3	4	5

Please add comments about your response if you wish.

- We strongly agree that all posthumous use of gametes and embryos should be subject to ethics review. This could be carried out with the retrieval authorisation (joint partner and ECART/Family Court) or separately to ensure the situation is the same as when the initial authorisation for retrieval was carried out.
- This ethical consideration over all use of posthumous tissues and embryos ensures best ethical process and consideration of family outcomes for resulting children and to reducing potential harm. Since request for posthumous use is small, this should not prove unsustainable to authorising bodies.
- There should be no posthumous use of gametes by a third party. Ethical consideration is required if use of embryos is requested by a family member with consent from the deceased.

Consultation Question 9

Considering your responses to the previous questions, would your responses be different if the deceased was a minor?

Should the retrieval or use of gametes from a deceased minor under the age of 16 ever be ethically or legally acceptable?

Should it ever be permissible to use gametes collected from a minor during the minor's lifetime after the minor's death?

Is your answer different if the minors in question are 'mature minors'?

Should the provisions in s 12 of the HART Act apply when the individual concerned is deceased?

Response

	1 Strongly agree	2 Agree	3 Neither agree nor disagree	4 Disagree	5 Strongly disagree
The provisions in s 12 of the HART Act should apply to deceased individuals	1	2	3	4	5
It should be permissible to retrieve and use gametes from a deceased minor	1	2	3	4	5
It should be permissible to use gametes collected while the minor was alive and competent after the minor's death	1	2	3	4	5
The provisions in Section 12 of the HART Act should apply to mature minors	1	2	3	4	5

Please add comments about your response if you wish.

- Our responses to the previous questions would change if the deceased person was a minor, since the minor would not have been planning a family with a legal partner during their lifetime as a minor.
- The provisions in s12 of the HART Act should continue to apply when the individual concerned is deceased ie No person may obtain a gamete from an individual under 16 years of age, or use a gamete obtained from an individual under 16, unless they intend to preserve the gamete for the individual's use, or to bring about the birth of a child likely to be brought up by the individual (or legal partner) from whom the gamete was obtained.
- In no cases should material be collected posthumously from a minor.
- In no cases should material collected while a minor was alive, be used if death has occurred as a minor. As with Case 1 supplied for this question, this scenario implies no partner, so parents or others would be making the requests, which we do not agree to. Case 1 highlights the difference between the value and potential of reproductive tissues compared to other organs and tissues (as noted by the Human Tissues Act not including reproductive tissues), and so responsibility for those tissues should not be allowed to be transferred to next of kin.
- In cases where gametes have been retrieved as a minor for medical reasons, and the person dies later as an adult having given consent to a partner for use of those gametes (as in supplied Case 2), ethical consideration should follow a request.
- The provisions of s12 Hart Act should remain if the minor is considered 'mature' ie estimated maturity of a minor would not alter authorisation.

Consultation Question 10

Should ACART consider the regulation of permanently incapacitated individuals, whose death is not imminent, in the future?

Consultation response

	1 Strongly agree	2 Agree	3 Neither agree nor disagree	4 Disagree	5 Strongly disagree
There is a need to consider the regulation of permanently incapacitated individuals, whose death is not imminent, in the future.	1	2	3	4	5

Please add comments about your response if you wish.

- This would only affect a small number of people but is worth considering in the future.
- Prior consent of the incapacitated person would be at the core of this consideration, evidenced by storage of material or by partner's evidence. Dignity of the incapacitated person and benefit to resulting child need to be considered as well as how this incapacitation impacts ability of partner ever to have a child (procreative liberty interest of the partner with capacity).
- The reason for incapacitation also needs to be considered ie genetic conditions that could affect the offspring, accident which interrupts future hopes for a family for both incapacitated person and partner.

Right to Life submission on PAR
Right to Life
to:
acart@moh.govt.nz
10/09/2018 08:29 p.m.
Hide Details
From: Right to Life
To: "acart@moh.govt.nz" <acart@moh.govt.nz>,
History: This message has been replied to.

ACART Secretariat.

Dear Sir,

I wish to submit this submission on PAR. I regret that due to a misunderstanding within our Executive this submission was not forwarded to you before the closing day of 3 September 2018.

I would be most grateful if you were to accept our late submission.

Yours sincerely

Right to Life.

POSTHUMOUS ASSISTED REPRODUCTION

Posthumous assisted reproduction (PAR) is deeply problematic, both at an ethical and practical level. We will begin with three reasons why PAR is problematic and then outline why the arguments in favour of it do not stand up to scrutiny. So why is posthumous reproduction a serious problem for society?

It is our contention that in considering this issue that we give recognition to our Creator's plan for pro-creation. PAR is a violation of God's plan for procreation. God's plan is self - evident and it is that the creation of new life takes place when the sperm of the father fertilisers the ovum of the mother in an act of pro-creation that is open to life within a traditional marriage of exclusively one woman and one man. In pro-creation our Creator invites the man and the woman to join with Him in creating a new unique human being who is an unrepeatable miracle of God's creation.

When man loses sight of his dignity and place in God's plan for procreation there is an increasing danger that man will challenge God's will and will seek to impose his will claiming that it is his body and that it is his right to choose by embracing immoral practices that offend God and violate the human rights of the child.

Firstly, in the overwhelming number of cases, no independent evidence exists that the deceased person would provide consent to such an action being taken, and in such cases, society should err on the side of caution as this is erring on the side of respect for the dead. It is for this reason that respected professional bodies such as the European Society for Human Reproduction and Embryology and the American Society for Reproductive Medicine agree that posthumous sperm conception should only occur where there is written consent from the deceased man. This may, temporarily, make matters difficult for the spouse or partner left behind but it is "the ethically most defensible position based on the presumed rights of the dead or dying patient" (Orr & Siegler, 2002, p. 301).

Secondly, in most cultures, the body of a deceased person should be treated with the utmost respect. Both Western and Maori culture has a long tradition of having a high regard for the way people are treated after their death and in principle consider it disrespectful to use the body of the deceased in a way that was never intended. Just because something is now possible, does not mean it should be practiced. Different countries have different approaches to posthumous reproduction legally. There are outright bans in France, Germany, Sweden and Canada for instance (Bahadur,2002), whereas in the United Kingdom, Human Fertilisation and Embryology Act requires explicit written consent.

Thirdly and most importantly, why posthumous reproduction is problematic is that it is not in the best interests of the child. It deprives the child of any possibility of a relationship with at least one parent, and we know from numerous studies that children from single-parent families have increased rates of promiscuity, teenage pregnancy, imprisonment, poorer educational outcomes, substance abuse and so on (Waldfogel, Craigie & Brooks-Gunn, 2010; Amato, 2005; Krein & Beller, 1988, McLanahan & Sandefur, 1987). This is not in dispute. Moreover, a child has a right to have at least the possibility of access to both biological parents. At times this does not occur, where for instance one parent dies in an accident after the child is conceived but posthumous sperm retrieval results in fatherlessness by design. We should not intentionally be having children who have no possibility of ever knowing their father.

Now let us consider the arguments in favour of posthumous reproduction. One argument is that sperm retrieval is less intrusive than an autopsy or organ retrieval and donation. However, there is a qualitative difference that makes PAR problematic in a way autopsy or organ retrieval is not (Orr & Siegler, 2002). As Orr and Siegler (2002) point out, in the case of an autopsy and organ donation, family are agreeing to a procedure based on altruistic motives, not requesting something that is benefitting themselves. In short, family are giving, as opposed to taking. These procedures benefit others, whereas PAR is all about the family's own desires, which may well contradict the wishes of the deceased.

Another argument in favour of posthumous reproduction is that once a person is dead, he or she no longer has a meaningful interest in the people they leave behind (Delaney and Hershenov, 2009; Kelton and Savulescu, 2016). This argument is based on a blatant disregard for the wishes of the deceased, but more importantly it is simply not true. Our society does and should respect the wishes of the deceased, as one can see from the way we acknowledge and a respect wills and other legal documents that outline and respect a deceased person's wishes. To say otherwise, is intellectually dishonest, as this is a practice that has endured for centuries.

While a surviving spouse may be desperate to preserve something from a deceased loved one, the medical profession enabling this is deeply problematic. Grief impairs one's decision making, and it is likely not clear to the remaining spouse the implications of what they want at that particular time. What he or she needs instead, is the support of family and friends, and if necessary professional counselling. Children are a long-term commitment and seeing them as a way of countering grief is an affront to their intrinsic value and dignity. Furthermore, no society should consider the single parent family as the ideal. All the empirical data emphatically states that children do much, much better with both a mother and a father, and the wellbeing of children should be a priority, especially at a time when governments in the West are having to deal with the effects of the breakdown of the traditional family.

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NEW ZEALAND
NURSES
ORGANISATION
TŌPŪTANGA
TAPUHI
KAITIAKI O AOTEAROA

2018-09/002
T:D105

3rd September, 2018

Advisory Committee on Assisted Reproductive Technologies,
Ministry of Health,
Wellington

by email: acart@moh.govt.nz

Tēnā koe

Posthumous Reproduction: Stage 1 Consultation

The New Zealand Nurses Organisation Tōpūtanga Tapuhi Kaitiaki o Aotearoa (NZNO) welcomes the opportunity to participate in the first phase review of the current *Guidelines for the Storage, Use, and Disposal of Sperm from a Deceased Man* ("the guidelines") taking into account gametes and embryos. We have consulted with members and staff including our 20 colleges and sections, the Board, Te Rūnanga o Aotearoa comprising our Māori membership, and professional nursing, research and policy advisers. We have also encouraged members to respond directly through the survey. The use of assisted reproductive technologies (ART) has been discussed by several Colleges, and we have also received some individual feedback. As anticipated a range of views were expressed, with general consensus on the principles governing access to posthumous reproduction, and the decision-making process.

In general, nurses felt that it was difficult to envisage or anticipate all circumstances in which posthumous reproduction might be feasible, wanted or appropriate, and very few were reluctant to categorically rule it out in all circumstances, particularly considering changes in cultural attitudes, and the potential of new genetic technologies to reduce disease. Confidence was expressed in decision-making processes that were inclusive, and subject to ethical, rather than judicial, review. Ie it was felt that decisions should be made by a Committee such as ACART, rather than a court. However, very strong opposition was expressed by some nurses to retrieval of gametes from permanently incapacitated people, or those in a coma, and there was considerable ambivalence about minors.

It may be worth noting that that this consultation followed considerable discussion on abortion law reform and the role of advanced technologies in expanding access to and clinical practise across the whole continuum of reproduction, from preconception to birth. Posthumous reproduction was considered as a (rarely resorted to) part of this continuum, and for that reason there was general support for clear and consistent principles and guidelines for all ART, and for "case by case" decision-making processes. We also note that new legislation governing therapeutic products, including cell and genetic bio-technologies is reasonably imminent, and we anticipate that this will/should be consistent with the management of ART.

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Te Tiriti o Waitangi
With regard to the Guidelines, NZNO strongly endorses the Tiriti o Waitangi - based bicultural approach to the use of ART outlined in the Guidelines that specifically identifies the importance of:

- *protection of Whakapapa Māori, confidentiality and privacy;*
- *respect for Tikanga Māori and kaumātua counselling. Whānau assistance at the initial interview. Recognition that the donor has the right to refuse or accept this support;*
- *a record of Maori donors be maintained with the following:*
    - *name*
    - *address*
    - *date and place of birth*
    - *name of marae to which donor is affiliated, if applicable, and tribal affiliations*
    - *the names and aliases of an individual's parents and tribal affiliations*
    - *birthplace (if known), iwi [tribal]/hapū contact*
- *and that all information provided by Māori be safeguarded and protected within the health system or as directed by the donor or whānau. (p 2)*

Actual records may need updated and aligned both with Statistics New Zealand and National Health Information data standards, currently being reviewed. The ownership of such data is also important and we refer you to: *Indigenous data sovereignty: a Māori health perspective* (Janson, 2016).

Consultation Questions
1A *Do you agree that posthumous retrieval of sperm should only be permitted with the prior written consent of the deceased from whom the gametes are to be retrieved?*

Informed written consent is the basis for all health interventions However, as indicated above, there may be circumstances in which written consent could be waived on compassionate grounds when it is understood that consent was known and intended. Eg where conversations with people undergoing damaging chemo and radiation therapies about the preservation of their eggs or sperm, may not have been completed. There may also be a correlation here with organ donation? In general, evidence of inferred consent should at least be able to be considered.

1B *Do you agree that posthumous retrieval of eggs or ovarian tissue should only be permitted with the prior written consent of the deceased from whom the gametes or ovarian tissue are to be retrieved?*

As above.

2. *Who should authorise the retrieval of gametes or reproductive tissue?*

Individual circumstances may dictate whether partners and/or families and whānau should be authorise this, as cultural considerations vary.

3. *Should others be able to approve retrieval of gametes from a permanently incapacitated person whose death is imminent, in the absence of prior consent by the person?*

As indicated, this was strongly objected to by some nurses who did not support this in any circumstances.

4. *Do you agree that posthumous use of gametes taken or embryos created when the deceased was alive and competent should only be permitted with the written consent of the deceased?*

As per Question 1

8. *Should all posthumous use of gametes or embryos be subject to ethics review?*

Yes

9. *Considering your responses to the previous questions, would your responses be different if the deceased was a minor? Should the retrieval or use of gametes from a deceased minor under the age of 16 ever be ethically or legally acceptable? Should it ever be permissible to use gametes collected from a minor during the minor's lifetime after the minor's death?*

As per question 3.

10. *Should ACART consider the regulation of permanently incapacitated individuals, whose death is not imminent, in the future?*

Yes.

We trust the above will be useful.

Nāku noa, nā

Reference

Janson, R. (2016). Indigenous data sovereignty: a Māori health perspective. In T. Kukutai & J. Taylor (Eds.), *Indigenous Data Sovereignty: toward an agenda*. Canberra: ANU Press. Retrieved from https://press.anu.edu.au/publications/series/centre-aboriginal-economic-policy-research-caepr/indigenous-data-sovereignty

About NZNO
NZNO is the leading professional nursing association and union for nurses in Aotearoa New Zealand. NZNO represents over 52,000 nurses, midwives, students, kaimahi hauora and health workers on professional and employment related matters. NZNO is affiliated to the International Council of Nurses and the New Zealand Council of Trade Unions.

NZNO promotes and advocates for professional excellence in nursing by providing leadership, research and education to inspire and progress the profession of nursing. NZNO represents members on employment and industrial matters and negotiates collective employment agreements. NZNO embraces te Tiriti o Waitangi and contributes to the improvement of the health status and outcomes of all peoples of Aotearoa New Zealand through influencing health, employment and social policy development enabling quality nursing care provision. NZNO's vision is *Freed to care, Proud to nurse.*

About the New Zealand Nurses Organisation

NZNO is the leading professional nursing association and union for nurses in Aotearoa New Zealand. NZNO represents over 47,000 nurses, midwives, students, kaimahi hauora and health workers on professional and employment related matters. NZNO is affiliated to the International Council of Nurses and the New Zealand Council of Trade Unions.

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Judge D Marshall
CHIEF CORONER

28 August 2018

Chair
Advisory Committee on Assisted Reproductive Technology
PO Box 5013
Wellington 6140

By email: acart@moh.govt.nz

Dear Ms Douglass

Consultation on posthumous reproduction

Thank you for the opportunity to comment on stage 1 of your consultation document.

One of the options you have identified for authorisation of retrieval of gametes or reproductive tissue from a deceased person, is to extend a coroner's powers. Coroners have no existing power to authorise retrieval of gametes.

Most deaths in New Zealand do not require a coronial investigation. The Coroners Act 2006 ("the Act") excludes jurisdiction for deaths from natural causes when the cause of death is known[1]. For coroners to authorise the retrieval of gametes, the Act would need to be amended to allow coroners to make decisions about bodies that would not usually come within the coroner's jurisdiction.

You have identified the "small window of time" in which gametes can be retrieved. When a coroner has taken jurisdiction over a death, this "small window of time" may fall within the period when the body is in the exclusive custody of the coroner[2]. That is why historically coroners have become involved in some requests for gamete retrieval.

Given the time frame available for retrieval, the individual or organisation who can authorise retrieval of gametes would need the capacity to hear and decide applications quickly. Any amendment of the law would also need to address cases where there is a dispute between family members about retrieval.

Currently the coronial service does not have the resources to hear and determine urgent applications.

In summary,

- The Act does not give coroners jurisdiction to authorise retrieval of gametes.
- Coroners currently have no jurisdiction over the majority of deaths from natural causes.
- Coroners have no capacity to deal with urgent applications.

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[1] Coroners Act 2006, s14.

[2] Coroners Act 2006, s19.

Level 7, Auckland District Court, 65-69 Albert Street, DX CX10079, Private Bag 92212, Auckland 1142, New Zealand
Phone: +64 9 916 9151 Fax: +64 9 375 6749
www.justice.govt.nz/coroners

We welcome some clarity as to the legal authority for the circumstances discussed in the consultation document.

Yours sincerely

Judge D Marshal
Chief Coroner

ACART Consultation on Posthumous Reproduction

Two weeks before our son was born, my partner (then aged 28) was diagnosed with non-Hodgkins lymphoma. He was advised to provide sperm to be frozen on the reasonable assumptions he would both recover after treatment and we would want another child. Almost four years later he died, and I never heard anything more about the status of the sperm and have never had any paperwork regarding it. But it didn't matter then as another child was not on my agenda. This happened three decades ago, and I assume the sperm has long since been destroyed.

However, I have since taken an interest in the whole area of posthumous reproduction and the ethics of reproductive technology more generally. The technology has improved incredibly since then including the potential to screen for various characteristics via pre-implantation genetic diagnosis. Our son was eventually diagnosed with autism, and this has also influenced my views.

I realise that it is very difficult to create guidelines about posthumous reproduction as every situation and family is different. However, from my experience I realise that it is vital that the issue of grief is addressed. Why would someone want to be a single parent and create a child who would never have the opportunity to know or have a relationship with their biological father? There might be assumptions about the need for a sibling for the current child. But my experience suggests a main motivation is unaddressed grief. There is a powerful need by the surviving parent and maybe their family to recreate that loved person who has been lost. Or fill a space on the family tree. A little person with half of their DNA might help fill that grief hole. But this a risky strategy for both parent and child.

I would like to see compulsory grief counselling via a suitably qualified counsellor at the time of donation as well as before any ongoing decisions about posthumous reproduction are made. Anticipatory grief is quite different from the grief of an actual bereavement. Decisions made before death and even signed documentation may no longer seem relevant or valid. Emotions around terminal illness are powerful and unrealistic expectations abound. Verbal and written consent need to be revisited after the death of the partner as the circumstances and emotions will be different from the time when the agreement and donations made. Counselling must be made freely available – for years if required - for those who proceed with posthumous reproduction.

The main ethical focus should be what is in the best interests of the child? Frozen embryos are not yet a living breathing child with its own emotions and identity. Is it in the interest of the potential child for it to be created as some sort of compensation for the death of a loved partner – who is an adult? What if the child was quite different to the dead parent – would the remaining parent be disappointed? Single parenting is hard work. A new partner may not welcome a child from a previous relationship - with potential negative consequences for the child. My son grew up to be physically very similar to his father, but he has autism which makes him quite a different adult – not better or worse, but very different from his sociable, high achieving father. (Autism is also a condition for which there is no pre-natal genetic analysis). It has also meant more intensive parenting and required more resources than for a non-disabled child.

If the reproductive tissue is to be used for a purpose other than helping create a new baby (for example as part of cancer treatment) this needs to be considered in the Guidelines as a separate issue. However, all applications for use of tissue need to be approved by ECART.

All records need to be kept at least until any child born is an adult, and be made readily available to them. I would prefer records are archived indefinitely so that my children or I could find out what happened to my late husband's sample, where it was kept and how it was disposed of. Tissue has personal significance and meaning.

We have seen that technological advances mean New Zealand's ethical frameworks and consent processes can be overridden by storage and implantation in another country or another body. But it is vital that New Zealand has internationally leading and robust ethical processes which put the potential child and their future needs at the centre of any decisions.

3 September 2018

Sent by:

30/08/2018 04:47 p.m.

To: acart@moh.govt.nz,
cc:
bcc:

Subject: Posthumous Reproduction Guidelines

I would like to have provided a detailed feedback on the Consultation on Posthumous Reproduction Guidelines but various issues prevented me from addressing this earlier and I only have just received the hard copy of the Consultation Document. Tomorrow I leave to travel overseas.

I have provided feedback on many of the issues in my response to past related consultations and my views on these issues remain unchanged. I refer you to these earlier responses (see attachment for example) Two governing principles are important and are essential to the Guidelines under review. They are;

The health and well-being of the resulting child and in particular psychological, emotional and social is the priority. We should all put ourselves in the position of a child who learns he or she is the result of the use of sperm or egg taken POSTHUMOUSLY. For me this would be a very disturbing revelation.The desires of surviving partner or grand parents must be balanced against the well-being of the children that will be born and it is the well-being of children that must be given primary importance as per the HART Act. The collection of gametes from a comatose or dead person without their prior written consent and approval is ethically completely unacceptable. Where there is prior consent (and only where there is prior consent – see below), the case should be reviewed by ECART and a suitable authority should be involved in the decision making process to represent the well-fare of the resulting child.

The second governing principle is that well informed and written prior consent from the donors of gametes and embryos for their subsequent use and more so in a posthumous situation is ethically essential.

Yours sincerely,

Retired Health ProfessionalACART Informed Consent 2015.docx

the nathaniel centre
THE NEW ZEALAND CATHOLIC BIOETHICS CENTRE

Submission to ACART
on
Posthumous Reproduction:

A review of the current *Guidelines for the Storage, Use, and Disposal of Sperm from a Deceased Man* to take into account gametes and embryos

September 2018

Posthumous Reproduction: A review of the current *Guidelines for the Storage, Use, and Disposal of Sperm from a Deceased Man* to take into account gametes and embryos

Introductory Comments:

1. We welcome the opportunity to provide feedback on the issue of posthumous reproduction. We recognise the inadequacy of the 2000 guidelines and the need for these to be updated to better reflect the societal and technological changes that have taken place since 2000.

2. A Catholic-Christian approach to the moral/ethical issues associated with posthumous reproduction rests on a number of core values and principles. Those that are particularly relevant to this Consultation Document are listed below in no particular order:

(i) Respect for the dead
The bodies of the dead must be treated with respect and charity. A person's identity is always an embodied one and respect for a person involves respect for their bodies, something which holds true in both life and in death. A negative illustration of this is seen in the way both society and church, in the past, used the disposal/burial of a body to indicate inclusion or exclusion of a person from a community. A positive illustration of this is seen in the way that the law protects researchers and others from taking a deceased person's body, their body parts or even small amounts of tissue without explicit prior consent of the person and/or their next of kin.

While enduring respect for a deceased person includes the duty to uphold their previously expressed wishes, this does not mean acceding to all their wishes. Just as a person's wishes are not treated as absolute in life but remain subject to the considerations of others, including the common good of society, so the wishes of a deceased person must be weighed up against the demands and impacts on others.

(ii) Unconditional respect for human life at all stages of its development
Catholic teaching holds that, without exception, the living embryo has, from the moment of fertilisation, an absolute right to life. A unique human life is begun - it is already the human being it will always be and will only grow in size and complexity. On that basis, all embryos are entitled to be treated with the same respect as persons and each has its own 'intrinsic dignity' which is independent of the wishes and desires of any related adults. By virtue of the fact that embryos already possess an inherent right to life, we submit that the posthumous use of gametes and embryos involve different ethical and legal considerations.

(iii) The rights and well-being of the child
This implies a commitment to reflect on the ethical issues from a perspective that actively considers and gives *primacy* to the rights and well-being of the child that is to be conceived. The voice and interests of children are routinely overshadowed in our society, characterised as it is by a neo-liberal framework which privileges autonomy and, de-facto, privileges the rights and choices of adults, in many cases to the detriment of children.

(iv) Upholding the genetic, gestational and social dimensions of parenting
Catholic teaching on the transmission of human life reflects a *commitment to holding together the genetic, gestational and social dimensions of family and parenting*. This

commitment is demanded by our status as relational beings. It is also demanded by the nature of parenthood which, we argue, brings with it a responsibility to 'parent' a child. Within the Catholic tradition of moral teaching, upholding this principle rules out the use of third parties in assisted reproduction. Regarding the posthumous use of gametes, genetic parenting is knowingly disconnected from social parenting; there is the deliberate conception of a child who will be denied the prospect of ever knowing or being cared for by the deceased mother/father.

2. We have consistently argued in previous submissions to ACART that to set out to deliberately deprive children of their genetic or social parent, *for the sake and needs of the adults involved*, constitutes an injustice to the child concerned. When, as sometimes happens, a man dies after conceiving a child but before that child is born, this is rightly considered a tragic event; human experience tells us that this gives rise to significant challenges for the child as well as the mother. While, ultimately, such children can and do grow up well-adjusted, it is ethically speaking quite something else to allow the inherent relational integrity that characterises natural human procreation to be intentionally fractured.

3. We have also previously argued (in our submission on *Proposed Changes to Donation Guidelines*), that no-one has an absolute 'right' to have a child. To the extent that there is a right to have a child, we would argue that it exists as a 'negative right' rather than a 'positive right'. The 1994 *Report on Assisted Human Reproduction* concurs, noting, in addition, that "Any right to found a family must not be seen in proprietary terms. It is not a right to have or own a child, whom many see as a gift."[1] In other words, regulatory approval to employ certain means to conceive a child must ultimately always be subjugated to the optimal well-being and flourishing of the child that will be conceived, *whether or not the means in question represents the only means for a person or couple to have a child.*

4. In our considered view, proper respect for the dignity of any child who might be conceived, for the deceased person and for the nature of human procreation precludes the use of posthumous conception. *Thus, we oppose posthumous conception in all its forms.*

5. We use the term 'conception' very carefully and deliberately to reflect what is an important metaphysical distinction between the moral status of embryos and that of gametes (as noted above). In line with our belief that every embryo represents a unique human life already begun, we argue, drawing on an ethic of care, that embryos (presumably created with the consent of a deceased spouse/partner) already possess a right to be implanted by a surviving spouse or partner without the need for further explicit consent. Thus, in November 2017, when presenting our views on proposed changes to the donation guidelines and surrogacy, and while arguing strongly for the significance and retention of a gestational or genetic link, we wrote: "… we regard the donation and adoption of so-called 'spare' embryos by intending parents who are not biologically connected as ethically and morally distinct from the deliberate creation of such embryos [for a commissioning couple, neither of whom will have a genetic or gestational link]."[2]

6. The previous paragraph highlights the importance of using precise language. We note that the Consultation Document employs rather loose language in a number of places. For example, n.25 refers to a person having "agreed that in the event of their death they wanted to become a parent." Philosophically and socially speaking, we would argue that it is nonsensical to speak in such a way

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[1] Atkin, W. R., & Reid, P. (1994). *Assisted human reproduction: Navigating our future*. Report of the Ministerial Committee on Assisted Reproductive Technologies. Department of Justice. New Zealand. Pp.31-32.

[2] See P. 8, The Nathaniel Centre – the NZ Catholic Bioethics Centre. "Proposed donation guidelines: for family gamete donation, embryo donation, use of donated eggs with donated sperm and surrogacy: feedback form".

given that, in common parlance, parenting implies a commitment to be an active part of the child's life, something that a deceased person cannot do. At best, a person can only give advance consent to become a 'biological father or mother' to a child conceived after their death in the sense of contributing their gametes. The inability of a deceased person to be a parent in the fullest and normal sense of that notion goes to the heart of the issue when considering the implications of posthumous reproduction for the welfare of any child.

7. Looked at like this, it is apparent that posthumous conception is not simply an extension of the normal experience of deciding to have a child made possible by developments in technology. The normal experience of proceeding to have a child involves a commitment to a 'package deal' – genetic and social parenting in the case of a male and a female and gestational parenting for the female partner. Thus, *posthumous conception is most accurately described as a significant deviation from normal human reproduction*, and the legal and ethical processes surrounding such decisions should reflect that, including the need for explicit consent and an external review process (see below).

8. In ethics, attention to language includes recognising that the way in which practices are described shapes one's ethical analysis of the issue at hand. With respect to assisted human reproduction, the legal issues associated with the storage of gametes and embryos and their use often revert to arguments around ownership and control. Numerous high profile legal cases where couples have split up after embryos were created are testimony to this. Recourse to legal solutions has, understandably, encouraged a proprietorial approach to regulating reproductive technologies. We regard this as inadequate for a number of reasons, in particular because a 'property-based' approach that leans heavily on rights and consent fails to adequately acknowledge critical relational notions such as attachment and care. These notions are critical because we are dealing with the creation of 'persons' whose well-being and identity is intrinsically connected to existential issues that include a sense of belonging and the need to be loved unconditionally.

9. Notwithstanding the foregoing, we understand that the current state of regulations in New Zealand already allows for the posthumous retrieval of gametes for the creation of embryos in a limited number of instances. Accepting this is the case, we wish to emphasise **three key points** in our submission:

   (i) *There must be explicit consent* on the part of the deceased or permanently incapacitated and imminently dying person from whom the gametes are to be retrieved before the case for posthumous conception can even be considered.

   (ii) *The well-being of children must be given greater precedence* in guidelines concerning the use of posthumous reproduction than is currently evident in the Consultation Document. In line with the first principle in the HART Act, respect for the consent of the deceased or imminently dying person should be independently weighed against concern for the dignity and well-being of the children who will potentially be conceived posthumously. This should be considered by ECART on a case-by-case basis.

   (iii) In line with the principle that the genetic, gestational and social aspects of parenting need to be held together, we submit that *case by case consideration of the merits of posthumous conception must be limited to surviving spouses or partners* to whom a deceased person was married or in some other type of permanent long-term relationship akin to the committed nature of marriage.

Autonomy and Reproductive Choices:

10. Belinda Bennett[3] has argued for autonomy to be seen as "in connections and relationships with others" (p. 300). She further argues for autonomy to be understood to mean "self-governing moral agency, rather than independent or self-contained decision-making. Self-governing in an ethic of care does not mean governing alone by abstract reasoning and distant observations, but means choosing options with respect to responsibilities, relationships, conversations, and dialogues with others".[4]

11. In Bennett's words, individualised autonomy "provides us with [nothing] other than a basis for competing rights which must then be mediated with reference to some other principle".[5] Accepting her 'ethic of care' model for autonomy enables a more adequate consideration of the relational aspects of posthumous reproduction. Then it can be seen that "... posthumous reproduction changes the shape of the deceased individual's life and the relationships of that individual with others."[6]

> ... The use of an individual's reproductive material for posthumous procreation significantly affects the way that individual's life is remembered and regarded by the decedent's community and family – not least by the resultant child. Posthumous reproduction can alter in ways emotional, psychological, and financial the relationship between the deceased and any offspring already in existence.[7]

12. In the same way that there are justifiable, legally imposed limits on a person's wishes or choices while they are alive, *there are justifiable limits to carrying out a person's wishes after their death*. With respect to a deceased person's expressed wish for posthumous conception, this is clearly so for at least two reasons. Firstly, because the conception of a child rightly takes place within a relationship, there must be willingness and consent on the part of both partners ('gamete providers'). Thus, even if explicit written consent exists on the part of the deceased person for their gametes to be used for posthumous reproduction, no-one would argue that the surviving partner has no choice in the matter – to do so would be to condone a form of physical if not personal violence.

13. Secondly, in considering the merits of any reproductive procedure, including posthumous reproduction, an ethic of care (which the principle 1 of the HART Act arguably points to) demands that the wishes of the adults involved must always be balanced by what is in the best interests of the child being conceived and for whom the 'gamete providers' have the sort of duty of care demanded by the commonly accepted understanding of what is involved in responsible parenting – see below. (For example, the best interests of children are upheld at times when children are placed with persons other than their legal or biological parents by the appropriate State authorities.) As Atkin and Reid noted in 1994: "... individual [adult] rights can be limited when the aim is to protect important societal interests ... that different people's rights overlap, that rights are subject to various limitations ...".[8]

14. While it might be pointed out that the Consultation Document acknowledges the dignity, interests, rights and wellbeing of children *alongside* that of gamete providers and recipients, our considered view is that the 'responses options' ultimately default to an unacceptably narrow legal framework which focuses unduly on the need for 'consent' and 'authorisation' to the neglect of an ethic of care;

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[3] Bennett, Belinda. "Posthumous reproduction and the meanings of autonomy." *Melb. UL Rev.* 23 (1999, p.300.

[4] Ibid., p. 300.

[5] Ibid.

[6] Ibid., p. 306

[7] Schiff, Arising from the Dead. Quoted in Bennett, p. 306.

[8] Atkin, W. R., & Reid, P. Ibid., p.30.

an approach which ultimately fails to give adequate recognition to the well-being of any future children. As Atkin and Reid argue: "... an ethic of care holds, broadly speaking, that moral reasoning is not solely, or even primarily, a matter of finding rules to arbitrate between conflicting interests ... the priority ... is on helping human relationships to flourish by seeking to foster the dignity of the individual and the welfare of the community."[9]

15. There is, in other words, a need for a consideration of issues that goes wider than 'consent' and 'authorisation'.

16. The obvious benefits of collecting and using gametes from a deceased person *for their family or partner*, and the less obvious and tenuous nature of the philosophically thin arguments that the conception of a child 'after death' is potentially in the interests of the deceased gamete provider, mean that the starting point for each and every such case should involve a hermeneutic of suspicion. What is required is a careful deliberation that takes into account a range of factors concerning not just the decedent's wishes. For this reason, we argue that the case for or against posthumous conception can only be properly investigated by an accredited ethics committee such as ECART.

17. Other factors to be considered by ECART include the motivations of the surviving partner and the process of grief, whether and how they have come to accept the absence of the deceased partner and their companionship. The means of death may also be a relevant factor.[10] There would also need to be consideration of the effects on the potential child that assesses legal status and inheritance rights as well as the possible psychological impact on them and on other family members, including other children.

Consent:

18. The notion of 'consent' in the case of posthumous reproduction is complex. The fact that a person wanted to have children is not a clear indication of their wish to have a child *after* they have died. As already noted, in such a situation, the deceased person can never be a 'parent' in the way we commonly understand that term; they cannot care for the child, can never have a relationship with them and the child can never know them.

19. Therefore, it must never be presumed that consent given by a person to have their gametes stored while undergoing treatment, in the hope they could still become a parent at some time in the future post-treatment, implies a consent to have their gametes used to have a child in a situation when they can never parent that child.

20. The consent process and forms used by Fertility Providers must be very specific in this regard. Even then, it is arguably very difficult to anticipate a situation where one does not survive and to make a truly informed decision that one's gametes can be used posthumously to conceive a child.

21. Accordingly, regarding the question of inferred consent, we reject the adequacy of 'substituted judgement' on behalf of a deceased person (Consultation Document, n. 99). We admit that this could (unfairly) rule out some cases where a person might well have wanted their gametes to be used by their partner in order to conceive a child posthumously. However, as Bennett notes: "... it is difficult

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[9] Atkin, W. R., & Reid, P. ibid., p. 28.

[10] As Joseph Parkinson notes: "...does suicide represent the husband's complete cancellation of his 'parenting project'? Even if he had provided normal consent to normal ART procedures, doesn't suicide amount to withdrawal of that consent?". Parkinson, Joseph. Not Dead Enough? Ethical Questions on the Posthumous Collection and Use of Human Gametes. *Chisholm Health Ethics Bulletin*. Vol. 19, No. 1Spring 2013, p. 3

to see why it is any more fair to presume consent on the part of those who have contemplated posthumous conception but who decided against it while omitting to record their objections for posterity."[11]

22. We have considered Nicola Peart's argument that inferred consent to use gametes posthumously would be consistent with the current approach to consent to treatment of an incompetent person (Right 7(4) of the Code). We infer from this that Peart is arguing that the two situations are analogous, a conclusion which seems to reflect the fact that what they have in common is an inability to provide informed consent. However, this is also where the comparisons end. It is inaccurate, linguistically speaking, to argue that the retrieval of gametes is a 'treatment' aimed at the person's recovery. Philosophically speaking, therefore, they are different kinds of action. To put it succinctly, one type of intervention is "life-sustaining" for the person and the other "life-creating".[12]

23. We are aware that New Zealand guidelines allow for families to give consent to the posthumous removal and donation of organs from a loved one in the absence of explicit consent. We also note that analogies are sometimes drawn between posthumous retrieval of gametes for reproduction and the posthumous donation of organs as an argument in support of substituted consent. However, we consider that there are significant differences between the two situations which ultimately override any similarities, differences that are grounded, once again, in the very different outcomes sought – one being "life-sustaining" for one or more anonymous recipients and the other "life-creating".

24. Orr and Siegler offer a valuable insight into the difference between posthumous organ donation and the retrieval and use of posthumous gametes:

> In our view, there is a difference in kind between autopsy and organ retrieval on the one hand, and sperm retrieval. Giving consent for autopsy or for organ retrieval for transplantation is giving to benefit others. But requesting sperm retrieval after death without the consent of the dead man is not the same; in fact it is not giving at all—it is instead taking, because its aim is to benefit the person making the request. While retrieval of organs after death without the explicit consent of the decedent is likewise taking, it is different in that the family who is giving consent is altruistically giving the organs for someone else's benefit. The parents or woman who request sperm retrieval after death without the explicit consent of the dead man are making a request for their own benefit. Thus, proxy "consent" in this situation is not consent at all.[13]

25. As the Consultation Document itself notes with reference to the *Code of Health and Disability Services Consumers' Rights*: "It is not legally permissible to carry out procedures on ... people just because those procedures will benefit someone else" (n. 19). This principle, closely aligned as it is with the notion of informed consent, underpins the whole approach to healthcare and research in New Zealand.

26. Consent from both partners is also consistent with viewing children as a 'gift' rather than a 'right'. That being so, then the means used to conceive a child must be synonymous with a gifting paradigm. Given that human conception is of its nature all about two persons (united in their love for each other and in a commitment to parent a child together), then the action must be describable as a genuine gift on the part of both. This in turn means that human conception must be an intentional act by both

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[11] See Bennett, p. 303.

[12] See Bennett, p. 305.

[13] Orr, R. D., & Siegler, M. (2002). Is posthumous semen retrieval ethically permissible? *Journal of medical ethics*, *28*(5), p.301.

parties, something that is best measured by the presence of explicit consent.

27. In summary, it is our contention that while explicit consent for one's gametes to be used by a surviving partner for the purposes of conceiving a child is a *sine qua non*, it is not of itself *adequate* for the purposes of assessing the merits of posthumous conception in this or that particular case. Consequently, we submit that every application for posthumous conception must (i) be based on verifiable and explicit informed consent from the deceased person or dying person and (ii) must then be subject to independent consideration by the ECART Committee which can then reflect on and review the broader range of issues that are of relevance, taking a perspective that favours a care-based guardianship approach (which gives primacy to the best interests of children) rather than a property-based ownership/rights approach.[14]

Best interests of children:

28. The Consultation Document asks for responses on the issues of: consent, authorisation for removal of gametes or tissue, the best interests of the deceased, who should be permitted to use the material, and ethics review. This is entirely 'adult-centred' and does not consider the impact of a posthumous reproduction policy on the position of children in our society.

29. While it is difficult to consider the 'rights' or 'dignity' of *a child* who would not be born but for the posthumous use and/or retrieval of gametes, it is nevertheless possible to consider the rights and dignity of *children* in general when considering policies that govern these practices.

30. We note that in the section 'Status, rights and wellbeing of resulting children', the Document discusses the particular effects on the 'resulting child', such as inheritance rights or the potential negative effects on the child depending on the motivations of the parents. However, there is a broader effect on 'children in general' of prioritising the 'rights' of a parent to create a child using posthumous gametes that is not considered.

31. Posthumous reproduction potentially springs from and supports a view of children as desired 'products', that can satisfy the wishes and needs of a surviving parent, and even a deceased parent. "The question of a putative 'right' to parent is also ethically fraught: if the gametes of the deceased person are treated at law more or less as 'property' of the surviving partner, are we close to treating any offspring created from those gametes as commodities over which the surviving partner can likewise claim rights? It would be ethically repugnant to most people to treat a human being in this way".[15]

32. This positioning of the child as a 'desired product' for the parent/s not only contravenes the spirit of the Universal Declaration of Human Rights but also contravenes Article 3 of the United Nations Convention on the Rights of the Child: "In all actions concerning children, whether undertaken by public or private social welfare institutions, courts of law, administrative authorities or legislative bodies, the best interests of the child shall be a primary consideration".[16]

33. The Consultation Document (p.14) refers to research that indicates outcomes for children created from material retrieved posthumously "are not different from a child produced by other assisted

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[14] See Bennett, pp. 297-298.

[15] Parkinson, Joseph. ibid., p. 3.

[16] Unicef, 1989. Convention on the Rights of the Child. https://www.ohchr.org/en/professionalinterest/pages/crc.aspx

reproductive technologies". However, the paper cited discussed only four cases, and the oldest child was only seven years of age. This is insufficient evidence for such a claim. In addition, the research paper focuses particularly on physical health, and states: "All children have had close paediatric follow-up and have no health or developmental problems, with the oldest now aged 7 years" (p.2261). There is no evidence presented, positive or otherwise, of the psychological or emotional outcomes for children once they become aware of their origins and have reached an age where this is likely to be of significance to them.

34. As we stated in our submission to ACART on *Proposed Donation Guidelines: for family gamete donation, embryo donation, use of donated eggs with donated sperm and surrogacy*, "the rejection of certain means and situations for conceiving human life, ... is most correctly viewed as the logical and ethical consequence of a positive and intentional commitment to the optimal flourishing of children."

35. We recognise that parents routinely choose to have children for their own reasons and without the broader oversight of an ethics committee. However, given our argument that posthumous conception is a deviation from natural conception rather than simply an extension of it, we believe such scrutiny is warranted. Nicola Peart puts it well: "the health and well-being of the child is the first principle of the HART Act and the unusual circumstance of a child being conceived after the death of one of its parents deserves special consideration."[17] Such consideration requires that policies on posthumous reproduction take account of the broader implications or 'unintended consequences' beyond the desires of intending parents.

Summary:

1. *We oppose posthumous conception in all its forms* on the basis that it is precluded by proper respect for the dignity of any child who might be conceived, for the deceased person and for the nature of human procreation.

2. *Posthumous conception represents a significant deviation from normal human reproduction*. The legal and ethical processes surrounding policy regulations should reflect that fact, including the need for explicit consent and an external review process. The Consultation Document seems to treat posthumous reproduction as a simple *extension* of normal procreation.

3. To speak of a deceased person becoming a 'parent' has a qualitatively different meaning from 'parenting' understood in the normal sense, which implies the ability and willingness to enter into an ongoing relationship of care.

4. Consent given for the collection of gametes prior to treatment in the hope of one-day becoming a parent is not the same as consenting to posthumous conception.

5. Respect for the dead implies respect for their wishes, but *there are justifiable limits to carrying out a person's wishes after their death*.

6. The revised Guidelines need to better reflect a notion of autonomy that is 'relational' – one that considers contextual factors which, in the case of posthumous reproduction, are complex. They include relationships between, and responsibilities towards, the deceased, the surviving partner and

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[17] Peart, N. (2015). Life beyond death: Regulating posthumous reproduction in New Zealand. *Victoria U. Wellington L. Rev.*, *46*, 725.

the child created.

7. There is no 'right' to a child. Children are rightly considered as a 'gift'.

8. In the case of posthumous conception, the 'gift' of the child still involves a giving from two parties, which means *explicit consent for retrieving and using gametes must be provided by both persons.* To countenance posthumous conception without explicit consent from the deceased or dying person would place the practice outside of the ethical and legal parameters which underpin the provision of healthcare in New Zealand.

9. *Applications for posthumous conception should be limited to surviving spouses or partners to whom a deceased person was married or in some other type of permanent long-term relationship akin to the committed nature of marriage.* The idea that a person can provide consent for their gametes to be used posthumously by an unspecified person at an unknown time in the future to create children who will be parented by someone unspecified fails to meet a reasonable standard for *informed* consent.

10. The very different moral status of embryos when compared with gametes should be reflected in a different policy re posthumous reproduction. Embryos (presumably created with the consent of a deceased spouse/partner) should be able to be implanted by a surviving spouse or partner without the need for further explicit consent because the embryos already possess an inherent right to life.

11. Each individual case for posthumous conception should be considered by an accredited ethics committee, such as ECART, that will examine the personal narratives surrounding the application as well as the wider societal issues beyond 'consent' and 'authorisation'. We recommend ECART develop a framework based on an ethics of care (see Appendix 1).

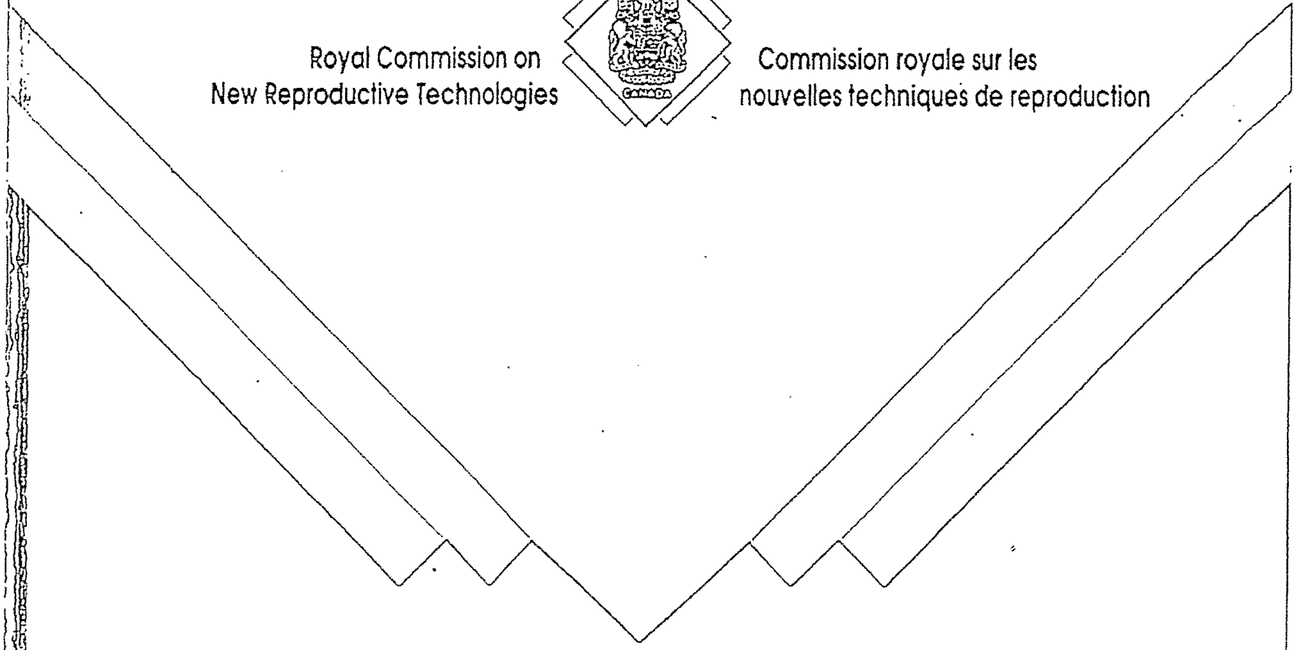
12. The Consultation Document pays insufficient attention to the wellbeing and interests of the child born from posthumous reproduction, subsuming these to the 'rights' and wishes of the parents.

13. There are broader social interests than those of the parents. A focus on the rights and wishes of parents risks commodifying children by reducing them to the status of 'products' that satisfy parents' desires. Rights are subject to limitations, and the rights of parents need to be better balanced against the dignity of children.

Staff of The Nathaniel Centre
September 2018

Royal Commission on
New Reproductive Technologies

Commission royale sur les
nouvelles techniques de reproduction



PROCEED WITH CARE

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NEW REPRODUCTIVE TECHNOLOGIES

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Consistent with the Commission's commitment to full equality between men and women, care has been taken throughout this text to use gender-neutral language wherever possible.

One of the difficulties we saw with adopting one traditional overarching ethical theory was that it would focus attention on the differences between the various theories. We thought it was more useful to focus on what these theories have in common, including a commitment to a moral point of view. All the traditional overarching theories agree that there is such a thing as a moral perspective on issues — a perspective that is distinct from a self-interested or economic perspective — and that it is defined by some notion of equal respect for persons.

From a narrowly self-interested or economic point of view, some people's lives may not matter to others, because they are unable to harm or benefit them. From a moral point of view, all people matter in and of themselves. It matters how well their lives go, and if our decisions affect their well-being, then we must take that into account. Adopting a moral point of view thus requires sympathetic attention to people's interests and circumstances, understanding how things look from their perspective, and taking account of their well-being. The ethic of care resonates with the moral point of view common to all these ethical theories.

The Ethic of Care and the Guiding Principles Approach

Commissioners believe that the approach offered by the ethic of care and our guiding principles gives the most insight into the particular issues the Commission is examining. It provides the greatest opportunity for preventing adversarial situations and offers the possibility of finding agreement on specific issues, even among those who adhere to different overarching ethical theories. The theoretical development of the ethic of care is taking place in many different contexts: in secular mainstream ethics, in feminist theory, and in religious thinking. We have drawn on all these sources to enrich our understanding. Of course, promoting the ethic of care is not entirely new — to a degree it has been reflected over the centuries in various formulations of medical ethics and the duty of physicians.

> The Commission should commit itself to a stated set of guiding principles and use these principles in its ethical deliberations. If there is a broad consensus in favour of each of these principles, then this approach will add considerable credibility to the Commission's conclusions, since these will be seen as neither ad hoc nor merely the result of logrolling among competing interests.
>
> *L.W. Sumner, reviewer, research volumes of the Commission, 1992.*

The Ethic of Care

Although there are differences of emphasis among the ethical thinkers from whose work we have drawn, the ethic of care holds, broadly speaking, that moral reasoning is not solely, or even primarily, a matter of finding rules to arbitrate between conflicting interests. Rather, moral wisdom and sensitivity consist, in the first instance, in focussing on how our interests are often interdependent. And moral reasoning involves trying to find creative solutions that can remove or reduce conflict, rather than simply subordinating one person's interests to another. The priority, therefore, is on helping human relationships to flourish by seeking to foster the dignity of the individual and the welfare of the community.

Where intervention is necessary, its aim should be creative empowerment so that, as far as possible, everyone is served and adversarial situations do not arise. At the very least, intervention must, in this view, avoid causing harm to human relationships. The traditional first principle of medicine, non-maleficence (do no harm), is thus applicable not only to medical practice but to intervention in society generally and is made into a positive commitment to empowerment. The concept of non-maleficence goes beyond simply avoiding actions that might cause harm, to taking steps to prevent harm and create conditions in which harm is less likely to occur and beneficial results are the more likely outcome.

The Guiding Principles

Although most would agree with the goals of the ethic of care, it is less than immediately obvious how these goals can be implemented in practice. Without some further development, the theory remains vague — benign but ineffectual. This is widely recognized by its proponents, who therefore adopt basic principles of justice — often those developed within traditional ethical theories — as a means of applying an ethic of care.

> We live in a scientific and technological culture. Our lives are not only filled with the products of science and technology but both pervade our society as ways of making sense of the world. We see things as problems according to a certain rationale and we expect technology to fix them. Our approach lacks vision and guiding principles, sensibility and accountability.
>
> *A. Burfoot, private citizen, Public Hearings Transcripts, Montreal, Quebec, November 21, 1990.*

Accordingly, while adopting the ethic of care as an orienting ideal, the Commission found it useful to identify eight principles of special relevance to our mandate that enable decisions to be made that give concrete expression to the ideal of care. The principles are to be found in ethical theory generally and biomedical ethics in particular. They are also consistent with what we heard in testimony and submissions from Canadians and with the values and principles implicit in the reports of inquiries in other countries. The eight principles are individual autonomy, equality, respect for human life and dignity, protection of the vulnerable, non-commercialization of reproduction, appropriate use of resources, accountability, and balancing of individual and collective interests.

There is some overlap among these eight principles. For example, the principle of non-commercialization of human beings and human reproduction is largely a conclusion from the other principles, such as equality, protection of the vulnerable, and respect for human life and dignity. Similarly, the appropriate use of resources is often connected to the principle of accountability, and the promotion of autonomy is often seen as requiring equality of access to health care. It may be possible to combine these related principles, although perhaps at the price of losing sight of important issues. Conversely, it may be possible to divide up some of these principles into even finer categories. However, the eight principles seem to capture ethical considerations that are both important and relatively distinct. Since these principles informed our deliberations and infuse our reasoning in the rest of our report, we give a brief account of each of them in the following pages. Moreover, there is no hierarchy here; no principle automatically trumps any other. Different principles are considered as they apply to specific issues.

> Any decision on the regulation of new reproductive technologies must endeavour to balance the interest of all members of society at the same time though the council believes that any policies which are developed must be grounded on the principle that women have the absolute right to decide what happens to our body and to determine our own choices with respect to reproduction and reproductive health care.
>
> *W. Williams, The Provincial Advisory Council on the Status of Women, Newfoundland and Labrador, Public Hearings Transcripts, St. John's, Newfoundland, October 15, 1990.*

Individual Autonomy

By individual autonomy we mean that people are free to choose how to lead their lives, particularly with respect to their bodies and their fundamental commitments, such as health, family, sexuality, and work. Clearly, this is not an unqualified principle. Individual autonomy does not include the freedom to harm others, to use force to coerce them, or to undermine social stability. Moreover, restrictions are sometimes placed on people's freedom of action in circumstances if it is determined that they lack the competence necessary to make reasonable decisions. However, a defining feature of modern culture is that individuals are seen as having the right (and the responsibility) to decide what kind of life they want to lead. From this principle it follows, for example, that actions or decisions that affect people's health, bodily integrity, security, and identity require informed consent.

Equality

The principle of equality means that every member of the community is entitled to equal concern and respect. The view that the well-being of each person matters and matters equally precludes any social practice that reflects or perpetuates the assumption that some people's lives are worth less than others. Adopting the principle of equality keeps this tenet in view.

> Our interpretation of the principles governing human rights in Canada and the current thinking of the leaders in Canadian family law lead us to the following conclusion: all citizens should be equally eligible for medically assisted reproduction services.
>
> Any legitimate restrictions, relating to economic factors or the distribution of scarce resources, should not be used as an excuse for discrimination on the basis of marital status or sexual orientation, but should be implemented in a manner that respects human rights and the basic principles of justice. [Translation]
>
> *G. Létourneau, Président, Commission de réforme du droit du Canada, Public Hearings Transcripts, Montreal, Quebec, November 21, 1990.*

The principle of equality forms the basis for our particular concern with ensuring that the interests and concerns of Canadians in all their diversity are taken into account in decisions about new reproductive technologies. This is why we have examined specifically how the technologies affect women, members of racial and ethnic minorities, people with disabilities, Aboriginal people, and lesbians. We recognize that achieving equality sometimes requires special steps to ensure that groups that have experienced discrimination in the past are placed on an equal footing with other members of society. This is particularly relevant in discussions of access to services, because services must be not only accessible but also designed to take into account the diversity of needs, expectations, and abilities in the populations they are intended to serve.

Equitable access to public services such as health care and education is based on this principle. We heard from many Canadians that they believe treating people with equal respect requires equitable access to basic services. Non-discrimination in access to these services has also become part of Canada's constitutional and legal environment through prohibition of discrimination on the basis of sex, race, and other grounds in the *Canadian Charter of Rights and Freedoms* and in human rights legislation.

Respect for Human Life and Dignity

All forms of human life (and indeed human tissue in general) should be treated with sensitivity and respect, not callousness or indifference. Although the law does not treat zygotes, embryos, and fetuses as persons, they are connected to the community by virtue of their origins (having been generated by members of the community) and their possible future (their potential to become members of the community). Not only all persons but also zygotes, embryos, and fetuses should be treated with appropriate respect because of this. In Part Two of our report we discuss more specifically how this principle applies to zygotes, embryos, and fetuses (see Chapters 22, 30, and 31).

Protection of the Vulnerable

Vulnerability relates to power imbalances, and this principle requires that the welfare of those who are less capable of looking after themselves or who are open to exploitation for various reasons be given special consideration. The most common example concerns the welfare of children. Since children cannot look after all their own needs, parents have the authority to make decisions for them. However, this authority is a trust, to be exercised for the benefit of the children, and the state is responsible for ensuring that this trust is kept. Vulnerability to exploitation may also arise from a person's socioeconomic status, membership in a minority group, or disability. Safeguards exist to ensure that adults who are temporarily or permanently unable to make competent decisions are not ignored or taken advantage of; someone is appointed to make decisions on their behalf and must act in their best interests. Society also has a responsibility to ensure that vulnerability is reduced where possible and that those who are vulnerable are not manipulated or controlled by those in positions of power and authority.

Non-Commercialization of Reproduction

Two concepts are relevant to our discussion of this principle: commercialization and commodification. By commercialization we mean activities involving the exchange of money or goods and intended to generate a profit or benefit for those engaging in this exchange. By commodification we mean the treatment of human beings or body tissues and substances as commodities — as means to an end, not as ends in themselves. Thus, commercialization necessarily includes commodification, but commodification need not entail a profit motive.

Commissioners believe it is fundamentally wrong for decisions about human reproduction to be determined by a profit motive — introducing a profit motive to the sphere of reproduction is contrary to basic values and disregards the importance of the role of reproduction and its significance in our lives as human beings. Commodifying human beings and their bodies for commercial gain is unacceptable because this instrumentalization is injurious to human dignity and ultimately dehumanizing. We therefore consider commercialization of reproductive materials and reproductive services to be inappropriate.

However, as we discuss in Part Two of our report, there may be a legitimate role for commercial interests in certain aspects of reproductive health care — for example, in the development of drugs and medical devices or in certain ancillary services such as storage and transportation. But, for the reasons just discussed, it is important to place strict limits on the extent of commercial involvement in this field and particularly to guard against inappropriate commodification of human tissues, products, and processes. It may sometimes be appropriate to treat human tissues, including reproductive tissues, as means to an end — as in research or therapy intended to benefit people — provided this occurs under strictly defined conditions that ensure respect for the source of the materials or tissues. But it is never appropriate to treat human reproductive tissues or substances as objects of commerce or commodities on which there is a profit to be made.

> First, we strongly believe that neither bodies, nor gametes, nor human embryos, nor any part of our reproductive potential, should be considered fungible or marketable commodities. Permitting the exploitation, conditioning and distribution of the seeds of life, human embryos and infants, in accordance with market forces, ignores the principles of human dignity and individuality.
>
> We demand that the principle of no charge for services that has always guided Canadian law and policy on blood and organ donations be upheld, and we recommend that marketing of gamete and embryo transfers be prohibited. [Translation]
>
> *G. Létourneau, Président, Commission de réforme du droit du Canada, Public Hearings Transcripts, Montreal, Quebec, November 21, 1990.*

Appropriate Use of Resources

The principle of appropriate use of resources recognizes the existence of diverse needs and finite resources, which requires that resources be used wisely and effectively. Resources used to help some people in one way become unavailable to help other people in other ways. Decisions about the provision of programs, procedures, or technologies must therefore be made in accordance with clearly defined public policy priorities. Society must establish its health care priorities, for example, and strive to maintain them in difficult political and economic times. As we discuss in Chapter 4, this will require a shift in attitudes on the part of Canadians, a new orientation in the health care system, and a new approach to medical treatment. Our recommendations concerning the importance of evidence-based medicine, the need for assessment and evaluation of uses of technology in medical practice, and the appropriate roles for prevention and acute care are premised in part on this fundamental principle of making the most appropriate use of available resources.

Accountability

The principle of accountability means that those who hold power, whether in government, medicine, technology, or other fields, are responsible for the way they use that power. This entails the conviction that Canadian society has a right — and a responsibility — to regulate and monitor how reproductive technologies are used to ensure that our values, principles, and priorities are being respected. In the past, these functions have been assumed through the self-regulation of the professions. But as we will see in subsequent chapters, there is increasing dissatisfaction with self-regulation as the sole method of ensuring accountability, because it is seen as an approach in which people from outside the professions have little role in the development or enforcement of policies and codes of practice. The implications of new reproductive technologies are so profound that demands for more active public participation in their regulation are clearly legitimate. Although medical self-regulation does oblige professional organizations to act in the public interest, a self-regulating profession is not necessarily best equipped to assess the social, ethical, and economic implications of the technologies and may be insufficiently accountable to those whose needs they are meant to serve, particularly in the absence of a broader regulatory system.

Balancing Individual and Collective Interests

This principle reflects our belief that both individual and collective interests are worthy of protection, and that individual interests do not automatically take precedence over collective interests, or vice versa. The individual interests with which we are concerned include those of women or couples seeking assisted conception or prenatal diagnosis services, those of gamete donors, and those of children born as a result of a new reproductive technology. The

> Here in the Northwest Territories where Dene and Inuit peoples predominate, community life is built around family life. Child bearing is considered a gift and a privilege. Infertility is indeed a tragedy for many childless couples, and we affirm the right of such couples to pursue methods of child bearing which do not jeopardize the inherent value, rights and dignity of the persons involved.
>
> *L. Hudson, Tawow Society, Fort Smith, Public Hearings Transcripts, Yellowknife, Northwest Territories, September 12, 1990.*

collective interests include those of society as a whole, as well as those of identifiable groups within society, such as women, children, people with disabilities, and members of racial and ethnic minorities. We discuss the application of this principle later in this chapter.

What We Heard: Support for This Approach

Ethical issues were the focus of many of the interventions and submissions we received during our consultation process. There was a widespread public perception that the ethical implications of reproductive technologies require greater attention and a more systematic response than they have received to date.

Some of the individuals and groups we heard from presented their ethical reasoning in the form of specific principles. These principles varied from sector to sector and, to a lesser extent, within each sector. No social grouping had a single approach to ethical issues — their priorities, applications, and belief systems varied. However, we saw evidence of extensive support for the guiding principles we adopted. Although different groups focussed on different principles, the principles are complementary rather than competing; the eight principles we identified thus reflect widespread consensus in Canadian society on the ethical basis that should guide decision making.

> We must bear in mind that the principle of respect for individuals is proclaimed in the Universal Declaration of Human Rights and the constitutions of most countries. It is recognized as a key principle.
>
> Its theoretical grounds are the same as the basic principles of bioethics:
>
> 1. the principle of respect for individuals and their autonomy;
> 2. the principle of compassion;
> 3. the principle of justice or equity.
>
> These three principles are the basis of the right to privacy, to free and informed consent, to confidentiality, and to justice. [Translation]
>
> *Y. Grenier, private citizen, Public Hearings Transcripts, Montreal, Quebec, November 21, 1990.*

Indeed, these principles were endorsed by a very broad range of groups — professionals and laypeople, women and men, religious and secular groups, members of racial and ethnic minorities, people with disabilities, doctors, and patients. That these principles were endorsed by groups with diverse experiences and interests confirms our belief that they capture important ethical considerations. Moreover, principles similar to those we adopted have been found useful in other inquiries regarding new reproductive technologies. Many of the international inquiries we examined appeal to principles of autonomy, respect for human life and dignity, and protection of the vulnerable. There was also considerable support for principles of non-commercialization and equitable access.

Finally, there is a growing trend in the bioethics literature to the guiding principles approach. Our review of the literature revealed the following principles at the core of bioethics: beneficence (and non-maleficence), justice, informed consent, respect for human life and dignity, honesty, and confidentiality. The differences between these principles and our own stem from the fact that bioethics developed originally to deal with the relationship between doctor and patient, whereas our principles are intended to deal with broader issues of public policy as well.

Given this level of consensus, we believe that the guiding principles we adopted provide concrete and constructive guidance with respect to the issues raised by new reproductive technologies.

Applying the Guiding Principles

Setting out the guiding principles is only the first step; many questions of priority setting and application remain. Each principle points to a legitimate concern that may be applicable to groups that are affected by new reproductive technologies. To apply the principles, therefore, we also need to identify the individuals and groups that are potentially affected by the use or non-use of these technologies. How each decision and recommendation will affect them needs to be considered explicitly. Moreover, as we discussed in Chapter 2, all of society is affected indirectly, whether by the social and ethical precedents that are established or by the fact that resources are directed here rather than elsewhere. Identifying the range of groups to be considered, in conjunction with the guiding principles, enabled us to take a comprehensive and consistent approach to decision making. Ensuring that we have given proper consideration to all those affected by the technologies provides the basis for morally responsible recommendations.

There is, of course, a danger of oversimplification in describing the guiding principles approach in this way; it is not a magic formula for resolving all moral disputes. There will be disagreements about the interpretation of the guiding principles and about the extent to which one or another applies in particular cases. Some of these disputes may not be resolvable. Although there is consensus on the principle of respect for human life and dignity, for example, Canadians are deeply and seemingly irresolvably divided over how to interpret that principle. Where we encountered such differences in preparing our report, we used our guiding principles to help identify and explain the nature of the disagreement as clearly as possible.

We believe, however, that many disputes are resolvable by a variety of means. First, many of the ethical concerns that arise about the use of reproductive technologies do so because some people believe that the use of these technologies will lead, over time, to disastrous social consequences for women, families, and people with disabilities, among others. Others believe that these negative effects will not occur because society is capable of preventing abuse through regulation. This is an important dispute, but it is a dispute more about facts than about values. To some extent, the dispute can be resolved by generating and disseminating better information and by establishing a system of public accountability that gives all groups in society a say in the future development of these technologies. The development of the Commission itself is a step in this direction.

Some debates can be left for future decision-making bodies. Given that the technologies are changing constantly and that not all have reached a stage of development where we know enough about them to make informed decisions, some decisions about future development or use cannot be made at this time. Establishing decision-making bodies with clear mandates and responsibilities for making and reviewing decisions in light of the latest available evidence has worked well in other jurisdictions.

Finally, some options will be more appropriate or feasible than others in light of Canada's legal, political, economic, and cultural context, existing institutions and practices, as well as our obligations as a member of the international community. Although ethical arguments are of fundamental importance, public policy must also recognize the existence of social and economic constraints, and these may help narrow the range of feasible options. Adopting a guiding principles approach does not guarantee a satisfactory resolution of all moral issues. It does, however, illuminate the ethical implications of new reproductive technologies and provide a clear and constructive approach for evaluating these implications and establishing public policy in light of them.

Individual and Collective Interests

The need to balance individual and collective interests arises in all areas of public policy. But the conflict can be especially poignant in the area of reproductive technologies, and in this we faced some of our most difficult decisions.

Defining the Problem

On one hand, the interests of people who are infertile, people at risk of having children with a genetic disease or severe anomalies, or people with diseases that may be treatable using knowledge from zygote or fetal tissue research are important and deeply felt human concerns. On the other hand, we cannot ignore the obligation of society to weigh the broader implications of making available medical services in these areas, to allocate scarce resources in an appropriate manner, and to monitor and regulate health care so as to assure the safety of the population and future generations.

We do not accept the view, sometimes expressed, that liberal democracy differs from some other forms of government because individual rights always take precedence over the interests of the collectivity. Canada's constitutional history demonstrates unequivocally that in a liberal democracy, individual rights can be limited when the aim is to protect important societal interests. Indeed, we believe that framing a need or desire in the language of "rights" may not be the most helpful way of approaching this issue.

The ethic of care involves an outlook premised on seeking creative ways to accommodate diverse interests. It requires balancing individual and collective interests to forestall, as much as possible, competitive or adversary stances. We believe that weighing individual and collective interests in this way (facilitated by our guiding principles and considering the range of individuals and groups affected) may lead to more humane and caring policies.

We uphold the value of rights. There are many examples of how rights can promote people's self-respect and mobilize them to remedy injustices — the women's movement, the civil rights movement, and the development of human rights instruments through bodies such as the United Nations are among the prime examples. But it is also important to recognize that different people's rights overlap, that rights are subject to various limitations, and that rights usually come with responsibilities attached. To claim a right does not by itself resolve policy issues — or resolve how to assess whether a given claim is indeed a right. Moreover, although rights are important, they can be understood only within a larger context of societal limitations and individual responsibilities. And this leads us back to questions about the proper relationship between individual and collective interests.

Throughout our deliberations and in formulating our recommendations, Commissioners have sought to understand the nature of individual rights, interests, and responsibilities, as well as the interests and responsibilities of society as a whole. We have also sought to understand, as part of the balancing process, the rights, interests, and responsibilities of various groups in Canadian society. Finally, we have sought to reflect on these issues from the general perspective of the ethic of care.

The Role of the Charter

The *Canadian Charter of Rights and Freedoms* sets out a range of individual rights, including the right to life, liberty, and security of the person, the right to equality, and the right to freedom of expression and association, among others. These represent and protect the legitimate aspirations of individuals and groups, and the Supreme Court is empowered to strike down government legislation and policies that violate these aspirations.

Individual rights are qualified by other sections of the Charter, reflecting Canada's approach to the continuing tension between individual and collective. For instance, section 1 of the Charter says that any right in the Charter can be limited in ways that are "demonstrably justified in a free and democratic society." But to be demonstrably justified, these limits cannot be based on mere convenience or prejudice. Where there is a legitimate social objective, and where reasonable limits on individual rights are necessary to achieve that societal goal, then the good of the collective can be held to limit the rights of the individual. Similarly, section 33 of the Charter, the notwithstanding clause, allows governments, as the elected representatives and the expression of the will of the collective, to limit individual rights for the good of society. Any decision on the part of a government to limit individual rights in a particular piece of legislation is temporary, however, and subject to review after five years.

Individual rights are also qualified by the existence of a third category of rights: the rights of specific groups within Canadian society. The rights of Aboriginal and multicultural communities are protected (sections 25, 27, and 35), as are the rights of linguistic and religious groups (sections 23 and 29). There is also constitutional protection for programs that may limit the rights of the individual in order to redress collective wrongs to historically disadvantaged groups.

These sections of the Charter provide some protection to government policies that are aimed at promoting the interests of specific groups from a rigid insistence on individual rights. In these and other ways, the Charter both affirms and limits individual rights. It insists that individual rights cannot be limited for reasons of convenience or prejudice, but it recognizes that valid societal interests can justify some limitation on them. Thus, the Charter both expresses and reflects a uniquely Canadian framework for relations between individuals and the state. Its introduction both was based on and accelerated a trend toward acknowledging pluralism and rights-based participation in Canadian society. We believe that an interpretation of rights that balances individual and collective interests remains deeply rooted in Canada's political culture and is applicable to public policy decisions in the areas covered by our mandate.

Given its significant impact on the relationship between governments and citizens, it is not surprising that the Charter raises various issues in relation to the regulation of new reproductive technologies. For example, section 7 (which guarantees "life, liberty, and security of the person") has implications for the right to informed consent before medical treatment, including the right of pregnant women to refuse unwanted medical treatment; for issues surrounding gamete donors' rights to privacy and the locus of control of the use of their gametes; and for the right of children born through the use of new reproductive technologies to learn about their social and medical histories. Section 15 raises the issue of the permissibility of restrictions on access to new reproductive technologies based on an individual's age, marital status, sexual orientation, economic status, or other prohibited grounds of discrimination. This does not necessarily mean that courts would find that discrimination had occurred — in the case of age, for example, medical grounds may make this appropriate.

> The legislation [should] include underlying principles and establish a framework and process for assessing the appropriateness of new technologies as well as ongoing research. The principles would include: the rights of women to control their own reproductive destiny; the rights of individuals to make their own decisions based on all information; the right to accessibility of treatment for everyone; the non-commercialization of reproductive services, and an assurance of compliance with equality guarantees and the *Charter of Rights and Freedoms*.
>
> *B. Suek, Charter of Rights Coalition/Manitoba, Public Hearings Transcripts, Winnipeg, Manitoba, October 23, 1990.*

As well as providing a benchmark against which government policies and legislation can be tested and challenged, the existence of the Charter has altered the way some Canadians think about government policy. As a result, law is seen by some as an agent of social policy, rather than a technical tool for administering government policy; legal judgements are seen as the way to resolve conflicts between individual and collective interests.

Situations Where Individual and Collective Interests May Differ

There is no inherent conflict between individual and collective interests. On the contrary, a community can flourish only when its individual members are flourishing, and individuals can flourish only within a larger social context. It is important for society to care for its members, to ensure that it is a society worth belonging to. In some situations, however, protecting the interests of some individuals would be harmful or prohibitively costly for the rest of society.

In some cases, the pursuit of an individual's objective may be inherently detrimental to collective values or requirements for public health and safety. In other cases, an individual activity may be tolerable if it occurs rarely but harmful to society if it crosses a certain threshold and becomes more commonplace. In yet other cases, solving the legitimate problems of an individual may require so great an investment of societal time, energy, and resources as to affect our ability to meet other societal needs. For example, some people think that heart/lung transplants should not be publicly funded because there are other more pressing unmet medical needs, and they think the cost of these operations is so high for the likelihood of benefit that society could spend the money more effectively elsewhere, providing greater benefit to a greater number of people.

There is an important distinction between the third and the first two cases, specifically that there is nothing socially harmful about the individual's desire for the surgery. On the contrary, the operation is good from both an individual and a collective point of view, and so society would provide it if possible. Unfortunately, it may not be possible, given the full range of health priorities. Fulfilling the individual desire would not harm the collective good, but it would not contribute much compared to other possible uses of scarce resources — thus, its "opportunity cost" may be too high. Some have argued that the Charter can be interpreted as imposing an affirmative duty on the state to make new reproductive technologies available, so that those who are unable to become parents in the usual way can enjoy the same reproductive "rights" as other members of society. It is highly unlikely, however, that the courts would uphold such claims, given the broader social interest in providing basic health care for all Canadians and the existence of finite resources with which to do so.

It is not always easy to distinguish among the situations in which individual and collective interests may differ, because the three categories (inherently detrimental, threshold situations, opportunity costs too high) are often connected in the context of a particular reproductive technology and are sometimes mixed together in the public debate. Furthermore, full information on the cost and likelihood of success of particular procedures may not be available initially, making decisions more difficult. But it remains important to distinguish among these different objections, because the appropriateness of a particular policy depends in large part on the category of situation it is intended to address.

Individual Rights and Social Interests

Individual and group rights claims made under the Charter must be taken into consideration as well as societal interests. As the discussion throughout our report makes clear, the impact of new reproductive technologies extends well beyond the individuals directly involved in their use. The research, development, and application of new reproductive technologies affect not only the prospective biological and social parents, but the children born as a result of their use, women as a group, and society as a whole. The presence of group and societal interests may well qualify the right to become a parent through the use of new reproductive technologies and condition the other individual rights involved.

It is impossible to formulate a rule about whether the interests of individuals or society are more important. Rather than subordinating one to the other, it would be more appropriate to say that each qualifies and shapes the other and that a delicate balance is required. Thus, a strategy that encompasses both individual and social interests should always be the first and preferred approach. Moreover, it is potentially misleading to talk about "individual versus collective" conflicts, as if all uses of reproductive technologies could be lumped together or resolved in the same manner.

There is no single formula for weighing individual and collective interests that would allow us to resolve all these issues. Rather, we need to look at given situations on their merits and consider how individual interests affect society's values, norms, and resources, and vice versa. As we deliberated, we were acutely aware of the need to take individual, group, and societal interests into account, in line with both our ethical principles and the requirements of the Charter. Our thinking and recommendations with respect to the individual technologies and the ethical issues they raise are discussed in Part Two.

Conclusion

The Commission saw one of its responsibilities as promoting informed public debate on new reproductive technologies. In deciding how to approach our ethical deliberations, therefore, we felt it was important to adopt a perspective that draws upon the language and principles of Canadian public debate. Our aim was neither to mirror the existing views of Canadians nor to transcend them radically. Rather, we hope to improve public understanding and the capacity to engage in social debate by identifying shared ethical principles in a considered approach that can help to guide future public policy making. We hope that our approach will help Canadians see how profound the implications of reproductive technologies are and why it is so important to ensure that, if they are used, they are used in an ethical manner. Nor need this approach be limited to the new reproductive technologies — it offers a perspective that society could apply to other emerging technologies and other social policy issues.

The Commission saw one of its responsibilities as promoting informed public debate on new reproductive technologies. In deciding how to approach our ethical deliberations, therefore, we felt it was important to adopt a perspective that draws upon the language and principles of Canadian public debate.

Setting public policy also requires careful attention to and consideration of the values and attitudes of Canadians. Many of these values and attitudes are embodied in the Constitution, particularly in the Charter. At the same time, the opinions Canadians hold may sometimes differ from how the Charter is applied in particular cases. This is sometimes the case with equality issues, for example, where public opinion on a given question may differ from the values entrenched in section 15 of the Charter. The legitimacy of public policies is therefore a function of both their consistency with constitutionally entrenched values and their congruity with the values and attitudes of a broad range of Canadians.

This brief sketch of the Commission's guiding principles conveys our ethical stance in somewhat general and abstract terms. Their full dimensions and nuances and how the principles apply will become clearer as we explain our reasoning and recommendations with respect to specific technologies and the real-life decisions to which they give rise in Part Two of our report.

Just as important as the ethical basis for individual and societal decisions about the use or non-use of new reproductive technologies is society's capacity to implement our collective decisions. How are Canadian systems and institutions structured to implement society's decisions? How are priorities set, policies established, and services designed and delivered? Do they currently have the capacity to respond to the demands of public policy making in an increasingly diverse, knowledge-based society on the verge of the twenty-first century? What changes, if any, are needed? Understanding Canadian systems and institutions was an important part of the context for our study of new reproductive technologies. Among all the systems that will be affected by our recommendations, the health care system is the central one. This is where ethical dilemmas, medical decision making, and service delivery converge. The next chapter of this part of our report is devoted to an overview of the health care system as the context within which the provision of reproductive technologies is possible.

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