Advisory Committee on Assisted Reproductive Technology

Ethical Framework for ACART

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Introduction

1. A major task confronting ACART is to decide challenging ethical matters arising from assisted reproductive treatments and human reproductive research. This task is carried out against a background of international best practice, New Zealand legislation, Waitangi tribunal and Court decisions, public concerns and attitudes, and political perceptions. Consequently, ACART has to work within legal constraints (as reflected in the HART Act (2004), hereafter the HART Act) at the same time as it has the task of determining ethically appropriate guidelines and advice. In order to carry out these tasks an ethical framework is crucial for its deliberations. Such a framework is also essential if it is to be in a position to challenge political positions when required.).

2. ACART also has to take account of public opinion via public consultation. This can prove problematic, since there is no assurance that submissions will be representative of the public at large, nor that any attempt will be made to make explicit the ethical reasoning that underlies the views expressed in them. Experience has shown that some submissions tend to veer towards prohibition and an embryo protection stance, and all too often are made as assertions.[1] The result is a groundswell questioning the assisted reproductive technologies (ARTs) in general. However, most of these procedures are permitted by the HART Act, and therefore lie outside the scope of ACART's decision-making on guidelines. The challenge for ACART is to determine how to take account of these different sources of input (political, social, ethical) and how to incorporate them into guidelines and advice to the Minister.

3. ACART also acts against a background of existing legislation in related areas — for instance, abortion, protection of children, adoption, whāngai, rights of consumers of health and disability services. The HART Act itself and its regulations already determine several significant ethical issues, such as designating in vitro fertilisation (with the associated creation and disposal of embryos) as an established procedure. Such legislation is relevant to ACART's determination of guidelines or advice in any newly emerging ART areas, since certain crucial ethical issues have (as far as ACART's decision-making) already been settled.

4. It is against this background that the following ethical framework has been drawn up. However, care is required in approaching this framework, since it is precisely this - a framework. It is not intended to be a recipe, a checklist, or a set of decision criteria. Having an ethical framework does not eliminate the need for careful consideration and judgement. The framework will not necessarily make complex decisions easier, but it should enable good decisions to be made with confidence, increase transparency and help justify decisions.

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[1] Submissions that advocate for few restrictions can also contain assertions.

5. It is common for tension to arise between different ethical principles, and hence a balancing of competing principles is needed. The ethical framework contained here will be helpful in identifying these circumstances and may assist in resolving them. Nevertheless, decision-makers still need to apply judgement when choices must be made. A helpful approach to resolving these tensions is to assess the relevance of each of the moral principles to the issue at hand, and to weigh each consideration fairly before reaching a reasoned judgement. This may at times involve a degree of compromise.

Aims

6. The principal aims of this framework are to:

- set out the moral principles that guide ACART's deliberations and consequently frame the guidelines and advice it develops
- help ACART make explicit the moral principles underpinning its guidelines and advice and the approach it takes to ethical deliberation.

Scope of ACART's ethical decision-making

7. ACART is foremost a policy-making body and not an ethical think-tank. Its primary responsibility is to formulate policy based on relevant legislation and policy, rather than to develop policy using only ethical thinking. However, on certain issues existing policy and legislation is either not clear, (for example, reproductive liberty), or is almost completely silent (for example, the status of the embryo). At these points ACART is unable to function as merely a policy-making body, and needs to engage in ethical reasoning.

8. ACART's deliberations are guided and limited by the HART Act, which sets the parameters for the scope of ACART's ethical decision-making. The first purpose of the HART Act is "to secure the benefits of assisted reproductive procedures, established procedures, and human reproductive research for individuals and for society in general by taking appropriate measures for the protection and promotion of the health, safety, dignity, and rights of all individuals, but particularly those of women and children, in the use of these procedures and research".[2] Alongside this, the HART Act is intended to prohibit or constrain certain unacceptable or restricted assisted reproductive procedures and human reproductive research,[3] and to prohibit certain commercial transactions.[4] It is also intended to "provide a robust and flexible framework" for regulating ARTs and reproductive research,[5] and to establish "a comprehensive information-keeping regime".[6]

9. As a result, when developing guidelines, ACART is limited by a number of specific prohibitions and restrictions upon ARTs and reproductive research that are explicitly stated in the HART Act. Consequently, no matter where an unpacking of ethical principles might lead, ACART is unable to formulate guidelines that include actions that are prohibited or restricted by the Act. ACART's advice to the Minister of Health could, however, include recommendations about amending prohibitions.

10. The prohibited actions include the artificial formation for reproductive purposes or implantation of a cloned or hybrid embryo; the implantation of an animal gamete or embryo into a human and *vice versa*; and the implantation of genetically modified gametes/embryos or gametes/embryos derived from a foetus.[7] The development of

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[2] s 3(a)

[3] s 3(b)(e)

[4] s 3(c)

[5] s 3(d)

[6] s 3(f)

[7] Schedule 1

an *in vitro* embryo beyond 14 days,[8] and the commercial supply of human embryos or human gametes are also prohibited.[9]

11. The HART Act restricts the selection of embryos for implantation on the basis of sex unless it was performed to prevent or treat a genetic disorder.[10] It also restricts the obtaining or use of a gamete from a minor unless the gamete was obtained for preservation or had been preserved for future reproductive use.[11]

12. Similarly, the HART Act stipulates that some activities can be designated as "established procedures", which may be carried out as routine clinical procedures without requiring ethical approval. Currently these include artificial insemination, collection of eggs or sperm for purposes of donation, egg, sperm and embryo cryopreservation, *in vitro* fertilisation (IVF), intracytoplasmic sperm injection (ICSI), and pre-implantation genetic diagnosis (PGD).[12] This list is limited by a number of exceptions where in specific contexts the procedures are not established procedures.[13] These established procedures are outside the remit of ACART's ethical deliberations on guidelines. However, ACART can advise the Minister of Health if it believes that an existing established procedure should be modified or should cease to be an established procedure.[14] ACART can also advise the Minister if it believes that a procedure, treatment or an application of a treatment or procedure should be declared an established procedure.[15]

13. The HART Act instructs ACART to take into consideration consultation with the public when formulating its guidelines.[16] However, since individuals and communities hold a range of ethical views, this instruction has to take account of the considerable diversity of opinion that exists in relation to assisted reproduction within society. Whilst differing perspectives may not be reconcilable, the Act requires the exploration of these perspectives in a conscientious and meaningful way. If moral pluralism is to be accommodated, viewpoints based on non-shared beliefs should not be allowed to dominate. Adopting an approach of cautious liberalism enables conflicting sides of a debate to pursue their differing ideas of the good life while accommodating their differences as much as possible. However, in no way does it diminish the underlying purpose of the Act, namely, to secure the benefits of advances in assisted reproduction within a protective framework.[17]

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[8] s 9

[9] s 13

[10] s 11

[11] s 12

[12] Part 1 of the Schedule to the Human Assisted Reproductive Technology Order 2005

[13] Part 2 of the Schedule to the HART Order 2005. These include, for example, the use of sperm from a deceased person without prior consent, and PGD for purposes other than the prevention or treatment of a genetic disorder or disease.

[14] s 35(1)(b)(iii)

[15] s.6

[16] s 41(1), s 36(1)

[17] s 3(a)

14. In this context it is pertinent to enquire into the place that reproductive liberty might play in ACART's thinking. Reproductive liberty is commonly defined as a negative right against interference with one's reproductive decisions. It was first established with regard to access to lawful termination of pregnancy but is now often extended to include access to ARTs to assist parents to have healthy, biologically related children. Snelling, Peart and Henaghan (2007) have helpfully explained how the HART Act can support a presumption of reproductive liberty as follows:[18]

> "Although the principle of reproductive liberty is not expressly stated or incorporated in the Act, the objectives and principles taken together do not preclude a presumption of reproductive liberty as a starting point. Rather, the first objective of the Act is to protect and promote the health, safety, dignity and rights of all individuals, and of women and children in particular, in the use of assisted reproductive procedures. The purpose of the Act expressly refers to the promotion of the dignity and rights of individuals in the use of assisted reproductive technology, and clearly expresses a commitment to the preservation of individual rights. Reproductive liberty may be reconciled within the principles which expressly focus on the interests of the individuals involved, particularly women and the prospective children, and the perspectives of the community.
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> … [T]here are strong moral arguments in favour of respecting autonomy and values such as freedom of choice which underlie reproductive endeavours. Individual choices may not be universally endorsed, but this does not mean that certain activities should necessarily be prohibited. The principle of reproductive liberty does not confer a right to unfettered choice or access, but it signals the importance of the interests involved and the respect owed. The question is why and to what extent reproductive liberty should be limited."

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[18] Snelling, Jeanne, Peart, Nicola and Henaghan, Mark, (2007) "Preimplantation Genetic Diagnosis: Testing the Legal Boundaries" in Genes, Society and the Future: Vol. I. Dunedin: Human Genome Research Project, p. 50-1.

Ethical principles stated in the HART Act

15. In addition to the explicit restrictions and prohibitions, the HART Act lists in section 4 the seven principles that are to guide all persons, including ACART members, who exercise powers or perform functions under the Act. The principles are:

    a. the health and well-being of children born as a result of the performance of an assisted reproductive procedure or an established procedure should be an important consideration in all decisions about that procedure:

    b. the human health, safety, and dignity of present and future generations should be preserved and promoted:

    c. while all persons are affected by assisted reproductive procedures and established procedures, women, more than men, are directly and significantly affected by their application, and the health and well-being of women must be protected in the use of these procedures:

    d. no assisted reproductive procedure should be performed on an individual and no human reproductive research should be conducted on an individual unless the individual has made an informed choice and given informed consent:

    e. donor offspring should be made aware of their genetic origins and be able to access information about those origins:

    f. the needs, values, and beliefs of Māori should be considered and treated with respect:

    g. the different ethical, spiritual, and cultural perspectives in society should be considered and treated with respect.

16. These principles provide the most normative content for ethical decision making found in the HART Act. However, the principles are relatively imprecise, allowing variation in how they are interpreted and reflected in policy. The following section offers a brief discussion of each principle in turn.

Principle a

> *“the health and well-being of children born as a result of the performance of an assisted reproductive procedure or an established procedure should be an important consideration in all decisions about that procedure”*

17. The health and well-being of resulting children is an important consideration, but not an overriding one. This means that it can be, and often has to be, balanced against the interests of other parties. It follows that a procedure cannot be forbidden on the basis that it poses a very small risk of harm to a resulting child when other interests, such as reproductive liberty, argue in its favour.

18. There is little agreement about the description and grading of harm to resulting children (for instance, from serious to trivial). Furthermore, there is often considerable uncertainty concerning the ability to predict whether a particular harm will occur to a child and what the seriousness of that harm may be. The risk of harm and the seriousness of that harm must both be considered and found to be serious or likely enough to justify a strong emphasis on the future child's interests in the face of other competing principles. The weighing of the possibilities will often be dependent on a particular medical condition, and there may be a substantial subjective element and considerable variability depending upon social context. A final decision will often be on a case-by-case basis.

19. Additionally, there is debate about how the interests of future children should be viewed. While it is accepted that mature people, using their own values and judgement, should determine for themselves where their interests lie, this is not the case with children. Parental views generally prevail in this case, because it is the parents who are presumed to have more complete knowledge of what is in *their* children's best interests and who will also be expected to provide the bulk of any additional care. However, the judgement of parents can be challenged.

> "Health and well-being" appears to encompass not only physical well-being, but also the social, emotional, psychological and cognitive aspects of a child's welfare. What constitutes sufficient health and well-being is an open question. It may constitute the possession of those abilities required to enjoy a normal range of opportunity and not lacking those aspects generally considered to make human lives worth living.

Principle b

"the human health, safety, and dignity of present and future generations should be preserved and promoted"

20. Decisions and activities should be made or carried out with respect to the health, safety and inherent dignity of human beings. This includes both existing people and possible future generations. This requires giving attention to considerations of intergenerational justice, social responsibility, genetic history, and the greater good of the community.

21. Adherence to this principle requires a consideration of the interests of future generations when making current decisions and entails the duty to prevent intergenerational harm. Cultural components particularly relevant to Māori, such as whakapapa and the significance of broader family networks, should be considered in relation to this principle.

22. This requirement could be interpreted as precluding individuals from knowingly passing on deleterious genes to their offspring, even in the absence of recourse to ARTs. However, the interests of future generations must be balanced against other interests, such as reproductive liberty, which may exclude the imposition of a coercive eugenic philosophy in breach of individual rights.

23. This aspect of the legislation is principally concerned with protecting the interests and rights of those directly involved in assisted reproduction, namely, the future child and the prospective parents, rather than imposing a genetic blueprint for society. Although the concept of intergenerational justice may not be used as a basis for requiring parents to make certain choices, it may and has been used to justify the prohibition of certain choices, such as non-medical sex selection.

Principle c

"while all persons are affected by assisted reproductive procedures and established procedures, women, more than men, are directly and significantly affected by their application, and the health and well-being of women must be protected in the use of these procedures"

24. Provisions must be made to protect the health and well-being of women who undertake assisted reproductive procedures. This principle signals the fact that women, regardless of the circumstances which have required them to seek assisted reproduction, are necessarily required to undertake the greatest burden of assisted reproduction. However, women are also involved in assisted reproductive procedures as surrogates and egg donors, and the well-being of these parties is of no lesser ethical significance. This means that both recipients and donors have ethical interests that may have to be held in tension. This principle does not imply that the health and well-being of women is of paramount importance, or that the interests of men are to be ignored. It draws attention to the significance of protecting women's health and well-being, and this can be variously translated into non-maleficence, or beneficence.

Principle d

"no assisted reproductive procedure should be performed on an individual and no human reproductive research should be conducted on an individual unless the individual has made an informed choice and given informed consent"

25. This principle restates the general principle of informed consent, regarded as foundational within medical treatment. However, in the context of assisted reproduction, decision-making is seldom a solitary endeavour – a procedure often requires the consent of multiple parties, including prospective parents, gamete/embryo donors, and/or surrogates. In addition, consent may be required to span a lengthy period of years in cases where gametes, embryos or reproductive tissue are stored. Under these circumstances, consent given at one point in time may subsequently be revoked, in response to changing circumstances or changing views. Withdrawal of consent has to be taken into account in accordance with this principle, by balancing it against the potential harms to the various parties caused by its withdrawal. Reasonable limitations may therefore be placed upon the right to withdraw consent.

26. The stress upon making an informed choice stems from the additional risks to mother and child associated with assisted reproductive procedures. The ethical and social demands upon the parties involved are increased, making it particularly important that individuals are freely able to choose to participate, and that their choice is a well-informed one. A balancing of interests comes to the fore.

Principle e

"donor offspring should be made aware of their genetic origins and be able to access information about those origins"

27. The HART Act stipulates that an ART service provider must obtain and keep information about a donor, including name, address, ethnicity, relevant medical history, and whānau, hapū or iwi if known.[19] ACART notes that, indirectly, this information may also document waka, ancestor names and geographic locations. Providers must then give access to this information to donor offspring over the age of 18, or to guardians of those under 18, if they request it.[20] Donors under the age of 18 can only be provided with non-identifying information about the donor(s).[21]

28. This principle acknowledges the significance that an understanding of one's genetic origins often has for an individual's personal identity and psychological well-being and the relevance that the donor's medical history may have for their own health.

Principle f

"the needs, values, and beliefs of Māori should be considered and treated with respect"

29. Tikanga as a concept of law has been deliberated in New Zealand courts over many decades, but tikanga has really begun to gain traction as a legal system in its own right, particularly due to the case Takamore v Clarke [2012] NZSC 116, from 2012. Considerations of the Supreme Court judgement in Peter Hugh McGregor Ellis v R [2022] NZSC 115, 07 October 2022 affirmed that tikanga Māori is common law in New Zealand and applies to both Māori and non-Māori.[22] The 2021 **Wai-2522 claim that reinforced the 2011 WAI 262 claim** that **Māori Data is a Taonga** as it is mātauranga

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[19] s 47, 48

[20] s 50(1)(2)

[21] s 50(3)

[22] The Ellis case asserted a general principle that tikanga is a part of NZ common law and will continue to be developed (in the Courts). Tikanga has also permeated many civil proceedings including family law courts and employment law. In line with Te Tiriti, this places a positive duty on us (and the Crown) to ensure it is properly considered and applied within the context of reproductive technology. As a side note, an important aspect within the case was the use of consulting tikanga experts who produced a statement of tikanga, notable as consultation being a principle of the Treaty. Some of the key principles of the case that provide the bedrock of how tikanga fits in NZ law, are: 1 Tikanga is the first law of NZ. This is important because it provides a starting point from which tikanga can be considered, perceived, and applied in contemporary settings (see also Takamore). 2 tikanga will continue to be developed in the common law 3 tikanga can also apply to non-Māori (also see GF v Comptroller of Customs)

and has whakapapa therefore are protected by Te Tiriti signed in 1840 and legislated in 1975. The rights of all Māori that the United Nations recognised in the United Nations Declaration of the Rights of Indigenous Peoples 2007 and signed by New Zealand in 2010 Furthermore, He Whakaputanga/The Declaration of the Independence of New Zealand which was agreed upon by Māori and the British government in 1835.

30. This entails recognising the specific cultural requirements of Māori, hapū, marae and iwi such as whakapapa, wairua, mauri, tapu, cosmology, pre-colonial Māori religious beliefs and genetic ownership and control of genetic information with Māori Data Sovereignty principles.[23] This principle can be expressed by ensuring that Māori are adequately represented in public consultation, meaningful partnerships and community engagements and that Māori viewpoints are respectfully considered in ACART's decision-making.

31. Māori are a diverse democratic culture with a number of social hierarchies and modern day beliefs, multiple religions, social statuses, in the same manner that New Zealand citizens have multiple views and beliefs. Just because a person has whakapapa, does not mean that they are immersed in, or have any knowledge of, Māori culture. They are no less Māori, and their whakapapa is no less tapu than any other Māori.[24]

32. It is also important to note that each Māori individual has genealogical links to at least one, but likely multiple: waka, iwi, hapū and marae of which each have their own and epistemologies, ancestors, dialects, protocols, western and traditional organisational structures. Moreover, with over 250 years of colonial interactions, all Māori individuals have mixed ancestries, mixed cultural beliefs, mixed social and educational lives, and a complex lived life experiences.

33. Having an awareness of this "diverse Māori reality" acts as a reminder to not assume that there is one Māori perspective, or that because Māori individuals or groups may disagree with each other that there is hostility.

Principle g

“the different ethical, spiritual, and cultural perspectives in society should be considered and treated with respect”

34. The HART Act instructs ACART to take into consideration feedback from consultation with the public when formulating its guidelines and advice.[25] ACART then has the task of considering these perspectives and treating them with respect in its decision-making. It should also be remembered that members of ACART also have their own perspectives, and it is unlikely that these will all point in the same direction, especially since members are appointed on the basis of their backgrounds and interests. ACART

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[23] https://taiuru.co.nz/guidelines-for-dna-research-storage-and-seed-banks-with-taonga-materials/

[24] Law Commission Surrogacy Review paragraph 2.54 pg 56

[25] s 41(1), s 36(1)

is not instructed to follow any particular perspectives it encounters, but to take note of them in its deliberations. This principle acknowledges the considerable diversity of opinion that exists in relation to assisted reproduction. In a diverse society like New Zealand moral pluralism needs to be acknowledged.

Ethical framework

35. The ethical principles stipulated in section 4 of the HART Act are relatively imprecise and open to varying interpretations. The Act gives little guidance as to how ACART is to apply these principles or how they relate to one another. In spite of the fact that in many situations one principle may come into conflict with another, the HART Act makes no attempt to delineate a hierarchy among them. As a result, no one principle has *prima facie* overriding authority; leading to the need for additional ethical principles to help navigate through these conflicts. Section 4 also fails to cover a number of generally accepted ethical values that are relevant to ACART's ethical decision making.

36. The following framework incorporates a variety of generally accepted ethical principles in addition to those listed in section 4 of the HART Act. In formulating this framework, reference has been made to the ethics frameworks developed by the Environmental Protection Authority (EPA) Mātauranga Framework,[26] and the HFEA's Ethics Law and Advisory Committee,[27] the UK Human Genetics Commission's report *Making babies: reproductive decisions and genetic technologies*,[28] the Hauora: Report on Stage One of the Health Services and Outcomes Kaupapa Inquiry[29] and the National Ethics Advisory Committee's report *Getting through together: ethical values in a pandemic*.[30] The framework has also drawn on ideas that were presented by the then Environmental Risk Management Authority. (ERMA was disestablished in June 2011.)

37. One set of considerations is centred on respect for persons—this includes considerations of the *welfare* of those persons affected by the procedure, and the *autonomy* of those involved. Other considerations include *altruism, social trust and responsibility,* the *special status of the embryo*, and *justice and equality*.

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[26] https://www.epa.govt.nz/te-hautu/matauranga/

[27] Human Fertilisation and Embryology Authority (2011) ELAC Ethics Framework. Available from: http://www.hfea.gov.uk/docs/2011-06-15_-_ELAC_ethics_framework__for_website_(2).pdf, accessed 21 June 2012.

[28] Human Genetics Commission (2006) Making Babies: Reproductive Decisions and Genetic Technologies. Available from: http://www.hgc.gov.uk/Client/document.asp?DocId=112&CAtegoryId=8, accessed 21 June 2012.

[29] https://forms.justice.govt.nz/search/Documents/WT/wt_DOC_195476216/Hauora%202023%20W.pdf

[30] National Ethics Advisory Committee (2007) Getting through Together: Ethical Values in a Pandemic. Wellington: Ministry of Health. Available from: http://www.neac.health.govt.nz/moh.nsf/pagescm/1090/$File/getting-through-together-jul07.pdf, accessed 21 June 2012.

Kaupapa Māori

38. Kaupapa Māori Health Research Methodologies and Frameworks – The recent Hauora Report produced by the Waitangi Tribunal highlighted a number of issues where non-Māori frameworks do not work for Māori, resulting in health inequities with Māori.[31]

39. Data for Māori Peoples and whānau must be consistent with Māori data sovereignty principles, ensure Māori Peoples and whānau have opportunities to participate in fertility treatment and be afforded appropriate protections, and that Māori perspectives are given due weight when developing guidelines.[32] A range of Māori health frameworks and methodologies should be used in conjunction with other resources.

Welfare

40. The welfare of all parties involved should be considered by respecting their decisions and protecting them from harm, but also by making efforts to secure their well-being (see principles a and b). Two complementary rules address this principle: the obligation to avoid causing harm (non-maleficence); and the obligation to provide benefits and to balance benefits against risks (beneficence). This reflects a purpose of the HART Act, to secure the benefits of ARTs and reproductive research while protecting affected individuals.[33] Considerations of how to protect a person's welfare must also be balanced against respect for their autonomy so that unwarranted paternalism is avoided. Every effort must be made to ensure that no one involved in the ARTs, including donors and surrogates, is used as a means to an end.

41. Particular attention should be given to the protection of vulnerable groups. In the case of ARTs, *women* are more vulnerable than men and so their health and well-being should be accorded special interest (see principle c).

Welfare of the child

42. The interests of any children born as a result of treatment (and of any existing children who may be affected by the birth) are taken into consideration when deciding on the appropriateness of providing treatment (see principle a).

43. There is little agreement about how the interests of potential children should be defined. It is accepted that mature people, using their own values and judgement, should determine for themselves where their interests lie. It is accepted that different people have different views about what will be best for them. When trying to determine what is in the interests of individuals who are unable to speak for themselves, these differences in perception can be impossible to reconcile, and no one person's view is

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[31]

[32] https://taiuru.co.nz/compendium-of-maori-data-sovereignty/

[33] s 3(a)

decisively authoritative. Parental views generally prevail in the case of children, because it is the parents who are presumed to have their children's best interests at heart and who will also be expected to provide the bulk of any additional care. However, the judgement of parents can be, and frequently is, challenged.

44. In many situations harms and benefits need to be held in tension and at times the welfare of different parties may come into conflict. In these situations the various harms and benefits to each party must be weighed against each other. The HART Act specifically instructs that special consideration is given to the welfare of the resulting child and of the women involved. However, the interests of the welfare of these parties are not a paramount consideration and can be balanced against the interests of the welfare of other parties, in addition to other ethical values as outlined below.

Autonomy

45. To respect autonomy is to give weight to autonomous persons' considered opinions and choices while refraining from obstructing their actions unless they are clearly detrimental to others. Concern for autonomy is therefore incompatible with paternalism.

46. Respect for autonomy entails due regard for the following considerations:

- *informed, un-coerced consent.* This includes the right to withdraw or place conditions on consent, subject to certain special limits (see principle d).
- *privacy and confidentiality*
- *access to information* (subject to any confidentiality restrictions). This includes, for example, the information access rights of donor-conceived children (see principle e).
- *reproductive liberty.* Reproductive liberty denotes a requirement to respect a person's autonomous right to control their own body and their choice to try to have (or not to have) children. This includes respect for people's right to:
  - seek or (under certain circumstances) avoid reproducing or becoming a parent;
  - seek to have a healthy child (and avoid a pregnancy with a child who could suffer from a serious medical condition);

47. To a certain degree, reproductive liberty can be seen as a negative right of non-interference (i.e. no unjustified barriers should be placed in the way of people pursuing their reproductive choices). In other words, the presumption is that activities should only be prohibited if there are pressing reasons to do so. These pressing reasons set limits to the pursuit of reproductive choice, and include decisions that may adversely affect broader society, any legal prohibitions and the harm principle. Perhaps the best formulation is that whilst autonomous decision-making should be supported and encouraged, it is legitimate to limit this autonomy where its exercise unreasonably impacts on the autonomy of others, or threatens others with significant harm.

48. It should be noted that valuing a person's autonomy does not necessarily equate with unqualified individualism. A person may wish to involve others in their decision-

making, and to the extent that this is an autonomous decision on their behalf, such a relational expression of autonomy should be welcomed. This is particularly relevant in light of the differing cultural emphases given to individualism versus communitarian values, especially for Māori.

49. At times the autonomy-interests of various parties may come into conflict (for example, between gamete/embryo donors and intending parents). In these situations these competing interests must be weighed against each other. The weight given to each party's interests will vary according to the specific context, but consideration should be given to, among other concerns, the following aspects:

- the magnitude of the harm and/or benefit to the interested party
- the magnitude of the harm and/or benefit to others
- the degree to which the party is directly affected by the ART
- the future responsibility of the party, particularly in relationship to the resulting child.

Altruism

50. One of the HART Act's stated purposes is to "prohibit certain commercial transactions relating to human reproduction".[34] This includes prohibiting the commercial supply of human embryos or human gametes,[35] and commercial surrogacy arrangements.[36] The latter only allows the giving or receiving of compensation for a limited range of "reasonable and necessary expenses" related to the reproductive procedure itself and necessary legal advice.[37]

51. To this extent the HART Act is advocating altruism as the motivating factor behind the donation of human embryos and gametes and in the establishment of surrogacy relationships. In doing this it is emphasizing the ethical value of 'giving' as opposed to selling, and the welfare of all parties involved in all the ARTs. Hence, donation and surrogacy relationships are to be non-coercive, and freely established.

Social trust and responsibility

52. Any decision or activity should respect the relationships between individuals and communities, ensuring equity and encouraging co-operation. This entails respecting the worldview of all peoples or communities including their spiritual beliefs, traditions, cultural identity and ethical perspectives (see principle g).

53. While an individual's right to autonomous decision-making should be highly valued, it may at times need to be balanced against the potential for harm to other individuals or society at large. On occasions the common good may outweigh individual interests,

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[34] s 3(c)

[35] s 13

[36] s 14

[37] s 14(4)

but such occasions are likely to be exceptional, and even in these exceptional circumstances the interests of the individual should still be protected.

Special status of the embryo

54. The HART Act does not make any explicit comment on the moral status of the embryo. However, a number of its provisions suggest that our society does not consider that developing humans, particularly early embryos, have the same rights and protections as children or adult humans. Though this is likely at odds with many Māori who believe that an embryo has a mauri and wairua and therefore should be afforded the same rights and respect as a person.

55. The HART Act makes it an offence to allow an *in vitro* embryo to develop after it has passed the 14-day stage of development. Before this stage, embryos may be used in human reproductive research (subject to prior approval by ECART),[38] imported and exported, and developed outside the womb. The HART Act also sets a maximum time for storing gametes and embryos, with extended storage beyond 10 years, or beyond an approved extended storage period, subject to ECART approval. As it is extremely unlikely that all stored embryos will be implanted and given a chance to develop past the 14-day stage, this provision of the HART Act requires the disposal of human embryos in New Zealand at the expiry of a lawful storage period.[39]

56. However, our society generally affords embryos a special status warranting protection. One indication of this is found in the Human Tissue Act 2008, with its note that: “A human embryo or human gamete is not human tissue for the purposes of any provision of this Act.”[40] Nevertheless, this does not amount to human rights as afforded to (born) persons or the legal protections afforded to the fetus. Because the HART Act does not give any indication of this special status, the degree of protection and respect afforded to the embryo in the context of ACART’s functions is to some extent determined by ACART, informed by public input (including that of Māori), analysis of the international ethical literature, and an assessment of dominant ethical values. When developing guidelines and advice to the Minister, it is incumbent upon ACART to be aware that it is functioning in a pluralist society and that no decisions or recommendations it makes will satisfy all groups within society.

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[38] s 16, s 19(b)

[39] Other relevant legislation includes the Contraception, Sterilisation and Abortion Act 1977 and the Crimes Act 1961, which allow for the termination of a pregnancy in a number of cases, including where the continuation of the pregnancy would result in serious danger to the life of the mother. A child becomes a human being within the meaning of the Crimes Act “when it has completely proceeded in a living state from the body of its mother, whether it has breathed or not, whether it has an independent circulation or not, and whether the navel string is severed or not” (s 159). Developing foetuses and embryos therefore do not enjoy the same rights and protections as infants – for example, a foetus cannot be murdered. However, the Crimes Act does make it a criminal offence to cause “the death of any child that has not become a human being in such a manner that he would have been guilty of murder if the child had become a human being”, although the penalty for this crime is less than that prescribed for murder (s 182).

[40] Human Tissue Act 2008, s 7(2)

57. At one end of the spectrum are those who hold to the moral principle that the destruction of any embryo is unethical and unacceptable, because an embryo is entitled to full human status from fertilisation onwards. At the other end of the spectrum are those who believe that the embryo has no moral status because it is not a human being and does not possess moral personhood. Many other people adopt stances at various points between these two ends of the spectrum, considering that embryos have rights and are owed protections due to their potential to become moral persons that can be harmed and benefited, or to their shared genetic heritage. Nevertheless, these rights and protections exist to a lesser degree than do those of full moral persons. Most people who adopt this umbrella position identify the appearance of the primitive streak as a morally relevant developmental stage. This appears at 14-15 days after fertilisation and marks the earliest beginnings of a nervous system and the individuation of the embryo.

58. Another relevant consideration is the high rate of natural embryo loss, a protective mechanism which serves to eliminate those embryos with severe chromosomal abnormalities. Research into the frequency of spontaneous abortion estimates this to be around 60-70 per cent.[41] This means that even under normal circumstances, without the intervention of the ARTs, less than half of all eggs fertilised result in the birth of a living newborn.

59. Discussions of moral status usually do not take account of the location of the embryo (blastocyst). However, since a blastocyst has to be located in a woman's uterus to have the possibility of developing into an individual, a blastocyst in the laboratory may not have the same moral status as a blastocyst in a woman's uterus.

Justice and equality

60. An injustice occurs when some benefit to which a person is entitled is denied without good reason or when some burden is imposed without good reason. Justice requires that benefits (and burdens) should be distributed fairly in society. Equality requires that individuals be provided with fair access to treatment. Nobody should be denied access to treatment on discriminatory grounds (including race and sexual orientation) or because they are single. Any policy decision to restrict treatment for individuals or a particular group should be based on generally accepted medical grounds (these may include age-related restrictions if harm is likely to result to the party or parties involved) and/or the welfare of the child.

61. This includes:

- *basic opportunity* – all citizens should be secured an adequate level of basic goods.[42]

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[41] Macklon, N., J. Geraedts, et al. (2002). "Conception to ongoing pregnancy: the 'black box' of early pregnancy loss." Human Reproduction Update 8(4): 333-343.

[42] See s 3(a) concerning one purpose of the HART Act being "to secure the benefits of assisted reproductive procedures, established procedures, and human reproductive research for individuals and for society in general"

- *fair opportunity* – while access to certain goods may not be considered a universal right (as above), if they are to be distributed they should be distributed fairly.

62. A major qualifier in considering fairness and access to ART procedures is that of resource allocation. This is a highly relevant ethical consideration, and yet it lies outside ACART's jurisdiction. The most ACART can do is comment, if and when it considers the matter is appropriate, on issues raised by the costs of procedures and any equality issues that may be raised if these are a barrier to access.

Other considerations

63. **Medical and scientific input** – ACART also needs to take into account the *relevant facts* – for example, the details of a clinical procedure, health conditions that may require certain procedures, and types of reproductive research. While the Committee itself has been constituted in such a way that it usually possesses sufficient knowledge within itself, ACART is also able to consult with any persons who, in the opinion of ACART, are able to assist it to perform its functions.[43] This enables ACART to consult externally for further information, where this is considered necessary to assist in making sound ethical judgements.

64. **Relevant legislation** – ACART must also be informed by other relevant legislation and codes of practice for coherency and compatibility as necessary.

65. **Key operating principles** – The following decision-making procedures are consistent with an ethical approach:

    - *Honesty and integrity* – Deliberations should be conducted with independence, impartiality and intellectual honesty, respecting the need for scientific integrity, avoiding conflict of interest, and managing it appropriately.
    - *Transparency and openness* – Decisions should be made transparently and openly, available for appropriate scrutiny by the persons concerned and by society, and be susceptible to informed debate, including in the media. ACART is encouraged to make public the ethical framework on which it is basing its recommendations, and the manner in which the Committee has analysed public submissions.
    - *Sound methodology* – Deliberations should employ the best available information (including scientific and clinical knowledge and cultural understanding), and be considered in a rigorous and principled manner. Ethical principles should be logically consistent, supported by reasoned argument, coherent, plausible in the face of other considered judgments, and compatible with ethical thinking underlying allied practices in the reproductive area.
    - *Community and expert consultation* – Deliberations should take into account the need to reconsider regularly the state of knowledge in the reproductive field, developments in clinical and allied practices, and the need to engage in regular dialogue with appropriate individuals and groups.

- Last updated by Dr Karaitiana Taiuru, Mr Neuton Lambert, Ms Amanda B Lees. February 2024.
- Originally written by D. Gareth Jones and Maja Whitaker. 2012.

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[43] s.35(1)(d)

Glossary

All terms are, unless otherwise stated, derived from Te mātāpunenga: a compendium of references to the concepts and institutions of Māori customary law (2013). Te Mātāhauariki Institute, Benton, Richard, Frame, Alex, Meredith, Paul (Paul Edward).

Hapū

Should be read in conjunction with Iwi, Waka and Whānau.

The term refers to the primary political unit in traditional Māori social organisation at the time of European contact, a relatively cohesive grouping consisting of a n umber of whānau sharing descent from a common ancestor. It was always named, usually named after either the founding ancestor or some critical event in the groups' history.

Sometimes referred to in English as 'sub-tribes'.

Iwi

Should be read in conjunction with Hapū, Waka and Whānau.

Denotes a social grouping with a variety of nuances which are not necessarily mutually exclusive. A group united by common descent from a waka, a superordinate group composed of hapū, or linked directly to whānau.

An iwi, or Māori tribe, is one of the largest kinship groupings and is generally made up of several hapū that are all descended from a common ancestor. Hapū are clusters of whānau where the whānau is usually an extended family grouping consisting of children, parents, often grandparents, and other closely related kin.[44]

Māori

Māori means a person of the Māori race of New Zealand; and includes any descendant of such a person.[45]

Marae

In modern usage the term refers both to the space in front of a community or tribal meeting house and the complex of buildings and land adjacent to the marae.

A marae is a Māori communal facility that belongs to a particular iwi (tribe), hapū (sub-tribe) or whānau (family).[46]

Mauri

Should be read in conjunction with Wairua.

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[44] https://www.tewhatuora.govt.nz/assets/Our-health-system/Digital-health/Health-information-standards/hiso-10094-2022-iwi-affiliation-data-protocols-sep22.pdf

[45] Electoral Act 1993

[46] K.Taiuru

The essence of which gives a thing its specific natural character.

Taonga

A socially or culturally valuable object, resource, technique, phenomenon or idea that denotes tangible and intangible valuables (such as values, traditions, and customs) handed down from antiquity.

Tapu

A key concept in Polynesian philosophy and religion denoting the intersection between the human and the divine. The term is thus used to indicate states of restriction or prohibition whose violation will automatically result in retribution.

Wairua

Should be read in conjunction with Mauri.

The spirit of a person as distinct from both the body and the mauri.

Waka

Symbolises a common history and kinship among members of otherwise autonomous tribal groups and confederations.

Whakapapa

Genealogy. In the verb its meaning is “to trace one’s ancestry back to a particular point of connection”.

Whānau

Should be read in conjunction with Hapū, Waka and Iwi.