PRE-EMPTIVE HEALTHCARE IN THE CONTEXT OF VOLUNTARY ASSISTED DYING AND ASSISTED REPRODUCTION: EXPANDING THE PAIN AND SUFFERING JUSTIFICATION

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The development of ethical justifications for voluntary assisted dying practices have formed the basis of the newly implemented legal frameworks for voluntary assisted dying in Australia, removing previous constraints on these practices and expanding the recognition of pain and suffering. This article argues that the growing recognition of pain and suffering has provided an ethical justification for the creation and/or expansion of pre-emptive healthcare practices particularly in the instance of voluntary assisted dying and assisted reproduction. The concept of pain and suffering in assisted reproduction is mainly considered in new pre-implantation practices involving genome editing of human embryos and whether these practices can be effectively implemented in Australia. By using the internationally recognised four pillars of medical ethics, this article analyses the current regulation of voluntary assisted dying and assisted reproduction in Australia, particularly considering pre-implantation embryonic practices, comparing the justifications for expanding assisted dying regulations and continuing to constrain assisted reproduction. This analysis concluded that pre-implantation embryonic practices would be ethically justifiable under recent expansions of pain and suffering considerations and could be effectively implemented through selective legislation.

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I INTRODUCTION

The concept of pre-emptive healthcare has been a subject of debate amongst legal and ethical commentators since the gradual implementation of assisted dying regulations. At the forefront is recognition of the impact pain and suffering can have on a person's mental state and quality of life. The standard of recognition in Australia progressed significantly with the implementation of state based voluntary assisted dying legislation.[1]

This recognition has opened the door to a similar discussion of new assisted reproduction techniques which allow genome editing of human embryos.[2] The unprecedented benefits of this development has attracted attention from legal and ethical commentators in how regulation of such a contentious topic should be approached.

The four recognised pillars of medical ethics represent a framework for analysing issues within healthcare policy and practice which are applicable to both discussions of assisted dying and assisted reproduction.[3] These pillars are comprised of autonomy, — the freedom to choose — the complementary principles of beneficence and non-malfeasance — the duty to do good and do no harm — and the overarching requirement of justice, according to which practitioners must ensure fairness.[4] Efforts to reflect these pillars are evidenced in the newly implemented Australian assisted dying legislative framework which provide extensive considerations to pain and suffering in their justification.[5]

1 *Voluntary Assisted Dying Act 2022* (NSW); *Voluntary Assisted Dying Act 2021* (Qld); *Voluntary Assisted Dying Act 2021* (SA); *End-of-Life Choices (Voluntary Assisted Dying) Act 2021* (Tas); *Voluntary Assisted Dying Act 2017* (Vic); *Voluntary Assisted Dying Act 2019* (WA).

2 Puping Liang et al, 'CRISPR/Cas9-mediated gene editing in human tripronuclear zygotes' (2015) 6(5) *Protein & Cell* 363.

3 'Medical Ethics', *The Medic Portal* (Web Page) <https://www.themedicportal.com/application-guide/medical-school-interview/medical-ethics>.

4 Ibid.

5 *Voluntary Assisted Dying Act 2022* (NSW) s 16(1)(d)(iii); *Voluntary Assisted Dying Act 2021* (Qld) s 10(1)(a)(iii); *Voluntary Assisted Dying Act 2021* (SA) s 26(1)(d)(iv); *End-of-Life*

This article endeavours to determine the extent of pain and suffering recognition in Australia's development and application of legislative and ethical regulations. Through an analysis of approaches to voluntary assisted dying and assisted reproduction, this article will investigate whether current recognition standards would permit for the expansion of assisted reproductive regulations to include pre-implantation embryonic practices.

II VOLUNTARY ASSISTED DYING

Euthanasia, often referred to as Voluntary Assisted Dying ('VAD'), is the process of intentionally terminating a person's life to reduce pain and suffering.[6] Euthanasia practices are commonly divided into passive and active categories.

Passive euthanasia refers to the withholding or withdrawal of medical treatment at the patient's request to end the patient's life,[7] whereas active euthanasia refers to medical intervention at the patients request to end the patient's life.[8]

A *The Australian Framework*

Passive euthanasia has been permitted across Australia in various forms and regulations since the implementation of palliative care and advanced care directives legislation.[9] However, it was not until 2017 that legislation of VAD laws began to regulate active euthanasia across the Australian states.[10] Prior to

Choices (Voluntary Assisted Dying) Act 2021 (Tas) s 6(2); *Voluntary Assisted Dying Act 2017* (Vic) s 9(1)(d)(iv); *Voluntary Assisted Dying Act 2019* (WA) s 16(1)(c)(iii).

6 Australian Human Rights Commission, *Euthanasia, human rights and the law* (Issues Paper, May 2016) 3.

7 Ibid 4.

8 Ibid 10.

9 Australian Human Rights Commission (n 6) 13–16; *Consent to Medical Treatment and Palliative Care Act 1995* (SA) s 17(1); *Guardianship and Administration Act 1990* (WA); *Criminal Code Act 1899* (Qld) s 282A; *Medical Treatment Act 1988* (Vic); *Medical Treatment (Health Directions) Act 2006* (ACT) s 17; *Criminal Code Act 1924* (Tas) s 154; *Advance Personal Planning Act 2013* (NT).

10 Kerstin Braun, 'Looking back to look forward – the history of VAD laws in Australia and future law reform in the Australian territories' (2023) 00(0) *Medical Law Review* 1, 3.

2017, anyone who actively assisted another person in ending their life was criminally liable regardless of whether the person requested or gave consent.[11]

1 *Legislative History*

The first instance of Australian VAD legislation was in 1993 through the unsuccessful *Voluntary and Natural Death Bill*.[12] Despite this, in 1995 the Northern Territory passed the *Rights of the Terminally Ill Act*,[13] becoming the first place in the world to legalise assisted dying.[14] The Act allowed a patient over 18 years of age, who suffered from an incurable terminal illness to request assistance in dying from a medical practitioner.[15] The Act successfully provided access to VAD for four people in the Northern Territory.[16]

In March 1997, the Australian Federal Government invoked their power under the *Australian Constitution*,[17] to pass the *Euthanasia Laws Act*,[18] invalidating the Northern Territory law and depriving the territories of the power to legislate on assisted dying in the future.[19] Between 1993 and 2017 there were 57 Bills attempting to implement voluntary euthanasia practices across Australian jurisdictions.[20] The first VAD laws were successfully introduced in Victoria through the *Voluntary Assisted Dying Act 2017*[21] which commenced

11 *Crimes Act 1900* (ACT) s 16; *Crimes Act 1900* (NSW) s 31A; *Criminal Law Consolidation Act 1935* (SA) s 13A(1); *Crimes Act 1958* (Vic) s 6; Braun (n 10) 3.

12 Voluntary and Natural Death Bill 1993 (ACT).

13 *Rights of the Terminally Ill Act 1995* (NT).

14 Braun (n 10) 4, citing Garima Jain and Sanjeev Sahni, 'Euthanasia: A review on Worldwide Legal Status and Public Opinion' (2018) 1/2018 *Criminology and Criminal Law Review* 63, 73.

15 *Rights of the Terminally Ill Act 1995* (NT) ss 7(a–b), 4.

16 Braun (n 10) 5, citing Sharon Fraser and James Walters, 'Death-Whose Decision? Physician-assisted Dying and the Terminally Ill' (2002) 176(2) *Western Journal of Medicine* 120, 120; David Kissane, Annette Street and Philipp Nitschke, 'Seven Deaths in Darwin: Case Studies Under the Rights of the Terminally Ill Act, Northern Territory, Australia' (1998) 352 *The Lancet* 1097, 1098–101.

17 *Australian Constitution* s 122.

18 *Euthanasia Laws Act 1997* (Cth).

19 *Northern Territory (Self-Government) Act 1978* (Cth) s 50A; *Australian Capital territory (Self-Government) Act 1988* (Cth) s 23(1A–1B).

20 Braun (n 10) 6.

21 *Voluntary Assisted Dying Act 2017* (Vic).

in 2019. This was subsequently followed by Western Australia,[22] Tasmania,[23] South Australia,[24] Queensland[25] and New South Wales.[26]

In December 2022, the *Restoring Territory Rights Act*[27] repealed the limitations on the territories,[28] leading to the introduction of the *Voluntary Assisted Dying Bill 2023*[29] in the Australian Capital Territory and a commitment from the Northern Territory to an Expert Advisory Panel and Consultation.[30]

2 *Current Legislative Framework*

VAD is defined in legislation as 'the administration of a voluntary assisted dying substance and includes steps reasonably related to such administration.'[31] This definition is identical in most Australian jurisdictions with the exception of Tasmania which defines VAD as 'the administration to a person, or the self-administration by a person, of a VAD substance.'[32] VAD may occur through a medical practitioner who administers a lethal substance to a person to bring about their death (practitioner administration) or through a person taking a prescribed lethal substance to cause their own death (self-administration). Self-administration is the preferred and primary method across the Acts.[33] Practitioner administration regulations vary, however, in

22 *Voluntary Assisted Dying Act 2019* (WA).

23 *End-of-Life Choices (Voluntary Assisted Dying) Act 2021* (Tas).

24 *Voluntary Assisted Dying Act 2021* (SA).

25 *Voluntary Assisted Dying Act 2021* (Qld).

26 *Voluntary Assisted Dying Act 2022* (NSW).

27 *Restoring Territory Rights Act 2022* (Cth).

28 Ibid.

29 Voluntary Assisted Dying Bill 2023 (ACT).

30 Northern Territory Government Department of Chief Minister and Cabinet, *Terms of Reference – Expert Advisory Panel: Voluntary Assisted Dying legislation in the Northern Territory* (Report, 2023) 2–3.

31 *Voluntary Assisted Dying Act 2022* (NSW) sch 1; *Voluntary Assisted Dying Act 2021* (Qld) sch 1; *Voluntary Assisted Dying Act 2021* (SA) s 3; *Voluntary Assisted Dying Act 2017* (Vic) s 3; *Voluntary Assisted Dying Act 2019* (WA) s 5.

32 *End-of-Life Choices (Voluntary Assisted Dying) Act 2021* (Tas) s 5.

33 *Voluntary Assisted Dying Act 2022* (NSW) ss 59–60; *Voluntary Assisted Dying Act 2021* (Qld) ss 52–3; *Voluntary Assisted Dying Act 2021* (SA) ss 63–4; *End-of-Life Choices (Voluntary*

most states it may be permitted where the person is incapable of self-administration, or where self-administration is inappropriate.[34] A complete choice between practitioner and self-administration is only provided in New South Wales.[35]

A person seeking to access VAD in any Australian jurisdiction must meet the eligibility criteria. These criteria are broadly as follows:

The person:

- Is at least 18 years of age[36]
- Is an Australian citizen or permanent resident[37]
- Has lived in the respective State for at least 12 months[38]
- Has decision-making capacity[39]
- Is acting freely and without coercion[40]

Assisted Dying) Act 2021 (Tas) s 86; *Voluntary Assisted Dying Act 2017* (Vic) ss 45–6; *Voluntary Assisted Dying Act 2019* (WA) s 56(1)(a–b).

34 *Voluntary Assisted Dying Act 2021* (Qld) s 50(2); *Voluntary Assisted Dying Act 2021* (SA) ss 64(c)(i), 66(3); *End-of-Life Choices (Voluntary Assisted Dying) Act 2021* (Tas) s 86(5); *Voluntary Assisted Dying Act 2017* (Vic) s 48(3)(a); *Voluntary Assisted Dying Act 2019* (WA) s 56(2).

35 *Voluntary Assisted Dying Act 2022* (NSW) s 57.

36 *Voluntary Assisted Dying Act 2022* (NSW) s 16(1)(a); *Voluntary Assisted Dying Act 2021* (Qld) s 10(1)(d); *Voluntary Assisted Dying Act 2021* (SA) s 26(1)(a); *End-of-Life Choices (Voluntary Assisted Dying) Act 2021* (Tas) s 10(1)(a); *Voluntary Assisted Dying Act 2017* (Vic) s 9(1)(a); *Voluntary Assisted Dying Act 2019* (WA) s 16(1)(a).

37 *Voluntary Assisted Dying Act 2022* (NSW) s 16(1)(b); *Voluntary Assisted Dying Act 2021* (Qld) s 10(1)(e)(i–ii); *Voluntary Assisted Dying Act 2021* (SA) s 26(1)(b)(i); *End-of-Life Choices (Voluntary Assisted Dying) Act 2021* (Tas) s 11(1)(i–ii); *Voluntary Assisted Dying Act 2017* (Vic) s 9(1)(b)(i); *Voluntary Assisted Dying Act 2019* (WA) s 16(1)(b)(i).

38 *Voluntary Assisted Dying Act 2022* (NSW) s 16(1)(c); *Voluntary Assisted Dying Act 2021* (Qld) s 10(1)(f); *Voluntary Assisted Dying Act 2021* (SA) s 26(1)(b)(ii–iii); *End-of-Life Choices (Voluntary Assisted Dying) Act 2021* (Tas) s 11(1)(b); *Voluntary Assisted Dying Act 2017* (Vic) s 9(1)(b)(ii–iii); *Voluntary Assisted Dying Act 2019* (WA) s 16(1)(b)(ii).

39 *Voluntary Assisted Dying Act 2022* (NSW) s 16(1)(e); *Voluntary Assisted Dying Act 2021* (Qld) s 10(1)(b); *Voluntary Assisted Dying Act 2021* (SA) s 26(1)(c); *End-of-Life Choices (Voluntary Assisted Dying) Act 2021* (Tas) s 10(1)(c); *Voluntary Assisted Dying Act 2017* (Vic) s 9(1)(c); *Voluntary Assisted Dying Act 2019* (WA) s 16(1)(d).

40 *Voluntary Assisted Dying Act 2022* (NSW) s 16(1)(f–g); *Voluntary Assisted Dying Act 2021* (Qld) s 10(1)(c); *Voluntary Assisted Dying Act 2021* (SA) s 26(1)(e); *End-of-Life Choices*

- The request is enduring[41]
- Has been diagnosed with a disease, illness or medical condition that is:
    - Incurable;[42] and
    - Advanced, progressive and will cause death;[43] and
    - Expected to cause death within 6 months[44] (12 months for neurodegenerative disease);[45] and
    - Causing suffering which the person considers intolerable.[46]

(Voluntary Assisted Dying) Act 2021 (Tas) s 10(1)(d); *Voluntary Assisted Dying Act 2019* (WA) s 16(1)(e).

41 *Voluntary Assisted Dying Act 2022* (NSW) s 16(1)(h); *Voluntary Assisted Dying Act 2019* (WA) s 16(1)(f).

42 *Voluntary Assisted Dying Act 2021* (SA) s 26(1)(d)(i); *End-of-Life Choices (Voluntary Assisted Dying) Act 2021* (Tas) s 6(1)(a); *Voluntary Assisted Dying Act 2017* (Vic) s 9(1)(d)(i).

43 *Voluntary Assisted Dying Act 2022* (NSW) s 16(1)(d)(i–ii); *Voluntary Assisted Dying Act 2021* (Qld) s 10(1)(a)(i); *Voluntary Assisted Dying Act 2021* (SA) s 26(1)(d)(ii); *End-of-Life Choices (Voluntary Assisted Dying) Act 2021* (Tas) s 6(1)(b); *Voluntary Assisted Dying Act 2017* (Vic) s 9(1)(d)(ii); *Voluntary Assisted Dying Act 2019* (WA) s 16(1)(c)(i).

44 *Voluntary Assisted Dying Act 2022* (NSW) s 16(1)(d)(ii)(B); *Voluntary Assisted Dying Act 2021* (Qld) s 10(1)(a)(ii); *Voluntary Assisted Dying Act 2021* (SA) s 26(1)(d)(iii); *End-of-Life Choices (Voluntary Assisted Dying) Act 2021* (Tas) s 6(1)(c)(i); *Voluntary Assisted Dying Act 2017* (Vic) s 9(1)(d)(iii); *Voluntary Assisted Dying Act 2019* (WA) s 16(1)(c)(ii).

45 *Voluntary Assisted Dying Act 2022* (NSW) s 16(1)(d)(ii)(A); *Voluntary Assisted Dying Act 2021* (SA) s 26(4); *End-of-Life Choices (Voluntary Assisted Dying) Act 2021* (Tas) s 6(1)(c)(ii); *Voluntary Assisted Dying Act 2017* (Vic) s 9(4); *Voluntary Assisted Dying Act 2019* (WA) s 16(1)(c)(ii).

46 *Voluntary Assisted Dying Act 2022* (NSW) s 16(1)(d)(iii); *Voluntary Assisted Dying Act 2021* (Qld) s 10(1)(a)(iii); *Voluntary Assisted Dying Act 2021* (SA) s 26(1)(d)(iv); *End-of-Life Choices (Voluntary Assisted Dying) Act 2021* (Tas) s 6(2); *Voluntary Assisted Dying Act 2017* (Vic) s 9(1)(d)(iv); *Voluntary Assisted Dying Act 2019* (WA) s 16(1)(c)(iii).

Compliance with this framework decriminalises conduct which in other circumstances may attract criminal liability under offences of murder, manslaughter,[47] or aiding, abetting or counselling a suicide.[48]

B *The Ethical Justification*

The topic of euthanasia or VAD is underpinned by ethical and moral considerations which are frequently contested. When implementing VAD legislation, Australian states as well as international governments were faced with contending these debates to ethically justify the implementation of such practices.

1 *International Human Rights*

As a party to the *International Covenant on Civil and Political Rights*,[49] the Australian Human Rights Commission ('AHRC') considered arguments for and against VAD implementation to ensure recognition and compliance. This involved submissions and considerations of the following:[50]

- Right to life[51]
- Right to freedom from cruel, inhuman or degrading treatment[52]

47 *Crimes Act 1900* (ACT) s 12; *Crimes Act 1900* (NSW) s 18; *Criminal Code Act 1983* (NT) s 156; *Criminal Code Act 1899* (Qld) ss 302–3, 305; *Criminal Law Consolidation Act 1935* (SA) ss 11, 13; *Criminal Code Act 1924* (Tas) ss 156, 158–9; *Crimes Act 1958* (Vic) ss 3, 5; *Criminal Code Act 1913* (WA) ss 279–80.

48 *Crimes Act 1900* (ACT) s 17; *Crimes Act 1900* (NSW) s 31C; *Criminal Code Act 1983* (NT) s 162; *Criminal Code Act 1899* (Qld) s 311; *Criminal Law Consolidation Act 1935* (SA) s 13A(5); *Criminal Code Act 1924* (Tas) 163; *Crimes Act 1958* (Vic) s 6B(2); *Criminal Code Act 1913* (WA) s 288.

49 *International Covenant on Civil and Political Rights*, opened for signature 19 December 1966, 999 UNTS 171 (entered into force 23 March 1976).

50 Australian Human Rights Commission (n 6) 26–34; Senate Standing Committee on Legal and Constitutional Affairs, Parliament of Australia, *Rights of the Terminally Ill (Euthanasia Laws Repeal) Bill 2008* (Report, June 2008).

51 *International Covenant on Civil and Political Rights*, opened for signature 19 December 1966, 999 UNTS 171 (entered into force 23 March 1976) (ICCPR) art 6(1); Australian Human Rights Commission (n 6) 26–9.

52 *International Covenant on Civil and Political Rights*, opened for signature 19 December 1966, 999 UNTS 171 (entered into force 23 March 1976) (ICCPR) art 7; Australian Human Rights Commission (n 6) 29–30.

- Right to privacy[53]
- Right to freedom of thought, conscience and religion[54]
- Rights of people with disabilities[55]

In concluding their analysis, the AHRC found:

> … there is no one identifiable right that necessarily requires the legalisation of voluntary euthanasia, nor is there one identifiable right that prevents its legalisation, provided stringent safeguards are instituted. It would seem from a human rights perspective, the option exists to support legalisation of voluntary euthanasia practices provided that sufficient safeguards are put in place to prevent 'arbitrary' (including discriminatory) deprivations of life. [56]

2 The *Four Pillars of Medical Ethics*

(a) Autonomy

The autonomy principle would suggest that a competent individual should have the right to determine how and when to die.[57] This was considered under many enquiries as a strong argument for legalisation of active euthanasia.[58] However, this principle led to concerns that if active euthanasia were legalised,

[53] *International Covenant on Civil and Political Rights*, opened for signature 19 December 1966, 999 UNTS 171 (entered into force 23 March 1976) (ICCPR) art 17; Australian Human Rights Commission (n 6) 30–2.

[54] *International Covenant on Civil and Political Rights*, opened for signature 19 December 1966, 999 UNTS 171 (entered into force 23 March 1976) (ICCPR) art 18; Australian Human Rights Commission (n 6) 33–4.

[55] Australian Human Rights Commission (n 6) 32–3.

[56] Ibid 35.

[57] Nargus Ebrahimi, 'The ethics of euthanasia', *Australian Medical Student Journal* (Feature Article, 24 May 2012) <https://www.amsj.org/archives/2066>, citing Lorana Bartels and Margaret Otlowski, 'A right to die? Euthanasia and the law in Australia' (2010) 17(4) *Journal of Law and Medicine* 532.

[58] Australian Human Rights Commission (n 6) 12–13; Senate Standing Committee on Legal and Constitutional Affairs, Parliament of Australia, *Rights of the Terminally Ill (Euthanasia Laws Repeal) Bill 2008* (Report, June 2008) 34–6.

more vulnerable people would be at risk, particularly if they feel they may be a burden to family or society.[59]

Active and passive VAD practices, to mitigate this risk, require multiple assertions from patients at various stages of the process to confirm active consent.[60] These are complemented by the decision-making capacity safeguard,[61] as well as the 'free and without coercion' provisions.[62]

(b) Beneficence / Non-Malfeasance

The availability of modern medical technology in many instances, would suggest that taking someone's life, even with their consent, would be against the duty to do no harm.[63]

However, it is argued that voluntary euthanasia is the compassionate and merciful answer to insoluble pain, suffering and indignity in the case of terminal illness.[64] The beneficence argument also incorporates patient autonomy — to do good is to respect the choices and decisions of the patient.[65]

Balancing the beneficence and non-malfeasance principles led to the implementation of the 'conscientious objection' safeguard in VAD practices.[66]

[59] Senate Standing Committee on Legal and Constitutional Affairs, Parliament of Australia, *Rights of the Terminally Ill (Euthanasia Laws Repeal) Bill 2008* (Report, June 2008) 52–3.

[60] *Voluntary Assisted Dying Act 2022* (NSW) ss 19–20, 43, 48, 59(1)(b), 90(1)(b); *Voluntary Assisted Dying Act 2021* (Qld) ss 14–15, 37, 42, 65(b); *Voluntary Assisted Dying Act 2021* (SA) ss 29–30, 52, 55; *End-of-Life Choices (Voluntary Assisted Dying) Act 2021* (Tas) ss 18, 30, 53, 82; *Voluntary Assisted Dying Act 2017* (Vic) ss 11–12, 34, 37, 57(b), 58(b); *Voluntary Assisted Dying Act 2019* (WA) ss 18–19, 42, 47.

[61] *Voluntary Assisted Dying Act 2022* (NSW) s 16(1)(e); *Voluntary Assisted Dying Act 2021* (Qld) s 10(1)(b); *Voluntary Assisted Dying Act 2021* (SA) s 26(1)(c); *End-of-Life Choices (Voluntary Assisted Dying) Act 2021* (Tas) s 10(1)(c); *Voluntary Assisted Dying Act 2017* (Vic) s 9(1)(c); *Voluntary Assisted Dying Act 2019* (WA) s 16(1)(d).

[62] *Voluntary Assisted Dying Act 2022* (NSW) s 16(1)(f–g); *Voluntary Assisted Dying Act 2021* (Qld) s 10(1)(c); *Voluntary Assisted Dying Act 2021* (SA) s 26(1)(e); *End-of-Life Choices (Voluntary Assisted Dying) Act 2021* (Tas) s 10(1)(d); *Voluntary Assisted Dying Act 2019* (WA) s 16(1)(e).

[63] Bernadette Spina, 'Ethical Justifications for Voluntary Active Euthanasia' (1998) 3(1) *Richmond Journal or Law and The Public Interest* 71, 72.

[64] Senate Standing Committee on Legal and Constitutional Affairs, Parliament of Australia, *Rights of the Terminally Ill (Euthanasia Laws Repeal) Bill 2008* (Report, June 2008) 36–37; Spina (n 63) 74–6.

[65] Spina (n 63) 73.

[66] Australian Human Rights Commission (n 5) 35; *Voluntary Assisted Dying Act 2022* (NSW) s 9; *Voluntary Assisted Dying Act 2021* (Qld) s 84; *Voluntary Assisted Dying Act 2021* (SA) s

This allows practitioners and certain facilities the right to refuse to participate in VAD practices and register as such.[67]

(c) Justice

The justice principle prompts an analysis of whether the implementation of a medical practice may lead to unfairness or unequal opportunities for accessibility.[68] The consideration of justice is beneficial to ethically justifying the new VAD framework as it has the ability to remove socioeconomic disparity that arises from 'suicide tourism'. The term 'suicide tourism' refers to when a person plans to travel outside of their place of residency to a country where euthanasia practices are permitted.[69] Though some countries like the United Kingdom have frequently contended with 'suicide tourism',[70] there were no restrictions on the practice for Australian citizens.[71] The ethical problem with suicide tourism is the socioeconomic disparity where not every person wishing to engage in euthanasia will have the ability to afford the additional travel costs, undermining the justice principle.

This issue would supposedly be resolved by the new implementation of the VAD framework,[72] however, doctors and patients who are involved in the VAD process have expressed a new limitation to its accessibility.[73] It is

10; *End-of-Life Choices (Voluntary Assisted Dying) Act 2021* (Tas) s 64; *Voluntary Assisted Dying Act 2017* (Vic) s 7; *Voluntary Assisted Dying Act 2019* (WA) s 9.

67 Ibid.

68 'Medical Ethics: Justice', *The Medic Portal* (Web Page) <https://www.themedicportal.com/application-guide/medical-school-interview/medical-ethics/justice/>.

69 Hadeed Al-Alosi, 'A Time to Fly and a Time to Die: Suicide Tourism and Assisted Dying in Australia Considered' (2016) 17(2) *Marquette Benefits and Social Welfare Law Review* 257, 261; Sascha Callaghan, 'Death tourism' (November/December 2011) *Precedent* 35.

70 *R (Pretty) v Director of Public Prosecutions* [2001] UKHL 61; *R (Purdy) v Director of Public Prosecutions* [2009] UKHL 45.

71 Al-Alosi (n 69) 264–77; Callaghan (n 69) 36–7.

72 *Voluntary Assisted Dying Act 2022* (NSW); *Voluntary Assisted Dying Act 2021* (Qld); *Voluntary Assisted Dying Act 2021* (SA); *End-of-Life Choices (Voluntary Assisted Dying) Act 2021* (Tas); *Voluntary Assisted Dying Act 2017* (Vic); *Voluntary Assisted Dying Act 2019* (WA).

73 Roger W Hunt, 'Voluntary assisted dying in Australia: emerging questions' (2023) 219(5) *Medical Journal of Australia* 208, 208–9; Melissa Davey, 'Voluntary assisted dying costs are creating 'substantial barriers' for patients, Queensland doctors say', *The Guardian* (online, 15

reported that the costs of VAD are creating 'substantial barriers' for patients wishing to access the practice due to it not currently attracting Medicare benefits.[74] The current Medicare benefits schedule explicitly states that all euthanasia services will not attract a Medicare benefit, however any counselling/assessment about the service will attract benefits.[75] The reported implications this policy is creating on the accessibility of VAD in Australia is impeding the justice principle creating an issue that should be addressed to ensure the promotion of this ethical principle.

Arguments against VAD in Australia were overwhelmingly outweighed by extensive public support — showing 76% of Australians supported VAD in 2021[76] — as well as the clear and logical analysis of the autonomy and beneficence principles. The heavily weighted recognition of pain and suffering in the ethical justification of these policies highlights that this was a strong indicator to public and political support of this legislation.[77]

III ASSISTED REPRODUCTION

Assisted reproduction is the process of using treatment directed at fertilisation of a human ovum by artificial means including 'clinical treatments, counselling services and laboratory procedures for the assessment and preparation of human oocytes, sperm or embryos.'[78] Assisted Reproductive Technology ('ART') has been continuously developed over the last four decades into a series of mainstream medical interventions that have resulted in

August 2023) <https://www.theguardian.com/australia-news/2023/aug/15/voluntary-assisted-dying-costs-are-creating-substantial-barriers-for-patients-queensland-doctors-say>.

74 Ibid.

75 Department of Health and Aged Care, 'Medicare Benefits Schedule – Note GN.13.33' *MBS Online* (General Explanatory Note) <https://www.mulr.com.au/aglc/AGLC4-June-2020-v2.pdf>.

76 The Australia Institute, *Polling – Voluntary assisted dying and the territories* (Report, April 2021) 3.

77 Tracee Kresin et al, 'Attitudes and Argument in the Voluntary Assisted Dying Debate in Australia: What Are They and How Have They Evolved Over Time?' (2021) 18(23) *International Journal of Environmental Research and Public Health* 1, 7; Braun (n 10) 10–12.

78 Reproductive Technology Accreditation Committee, *Code of Practice for Assisted Reproductive Technology Units* (2021) 5.

the birth of more than 10 million children worldwide.[79] Recent national estimates indicate that 5.4% of all women who gave birth in Australia in 2021 received some form of ART treatment.[80] These practices are regulated under Commonwealth and state legislation,[81] as well as quasi-legal ethical guidelines.[82]

A *Pre-Implantation Genetic Testing*

ART also offers the potential to select embryos once they have been conceived.[83] Preimplantation Genetic Testing ('PGT') is described by the Fertility Society of Australia and New Zealand as:

> … a sophisticated scientific technique which can be used to test embryos for either a specific known single-gene condition or chromosome variation. … Genetic testing enables chromosomally healthy embryo or those unaffected by a specific disorder to be selected for transfer during an IVF cycle, increasing the chance of a healthy baby.[84]

PGT can currently identify over 20,000 types of gene mutations including mutations related to Spinal Muscular Atrophy,[85] which affects the nerves connected to muscles (motor neurons) and can cause death in infants and

79 Jade E Newman, Repon C Paul and Georgina M Chambers, 'Assisted reproductive technology in Australia and New Zealand 2021 (Report, University of New South Wales, September 2023) 1.

80 Ibid.

81 *Prohibition of Human Cloning for Reproduction Act 2002* (Cth); *Research Involving Human Embryos Act 2002* (Cth); *Assisted Reproductive Technology Act 2007* (NSW); *Assisted Reproductive Treatment Act 1988* (SA); *Assisted Reproductive Treatment Act 2008* (Vic); *Human Reproductive Technology Act 1991* (WA).

82 National Health and Medical Research Council, *Ethical guideline on the use of assisted reproductive technology in clinical practice and research 2017 (updated 2023)* (E79, 2023) 15; Reproductive Technology Accreditation Committee (n 78) 4.

83 Margaret EC Ginoza and Rosario Isasi, 'Regulating Preimplantation Genetic Testing across the World: A Comparison of International Policy and Ethical Perspectives' (2020) 10(5) *Cold Spring Harbor Perspectives in Medicine* 1, 1–2.

84 Fertility Society of Australia and New Zealand, 'Genetic Testing', *Genetic Testing* (Web Page) <https://www.fertilitysociety.com.au/preimplantation-genetic-testing-australia-new-zealand/>.

85 Ibid.

young children in serious instances,[86] Cystic Fibrosis,[87] which causes lung infections and can lead to difficulty breathing,[88] and Fragile X Syndrome,[89] which is the most common cause of genetically inherited intellectual disability.[90] This allows individuals or couples to undergo ART to select against genetic conditions, diseases or abnormalities that would severely limit quality of life.[91] PGT can also be used to conduct human leukocyte antigen (HLA) matching, to select an embryo with compatible tissue for subsequent stem cell therapy intended for a parent, sibling or other relative, commonly referred to as a 'saviour child'.[92] Additionally, the practice can be used to select for any genetically determined characteristic, including sex and certain physical characteristics.[93]

1 *Limitations of Pre-Implantation Genetic Testing*

Despite the many beneficial applications of PGT, there are several technological and ethical limitations to the technique which have impacted its regulation and accessibility.

From a technical perspective, PGT is limited by the number of embryos available for the testing as well as the genes it can test for. The biopsy procedure performed on embryos to undergo PGT can limit the ability of the testing for certain diseases or conditions.[94] Diseases with a polygenic contribution, such as schizophrenia, and some common dispositions to diseases will not be addressed by PGT without radically increasing the numbers of embryos.[95] The cost of the practice is also determined by the number of embryos being tested, increasing the potential impact of this

86 'Spinal muscular atrophy (SMA)' *healthdirect* (Web Page, November 2023) <https://www.healthdirect.gov.au/spinal-muscular-atrophy-sma>.

87 Fertility Society of Australia and New Zealand (n 84).

88 'Cystic fibrosis (CF)' *healthdirect* (Web Page, April 2023) <https://www.healthdirect.gov.au/cystic-fibrosis-cf>.

89 Fertility Society of Australia and New Zealand (n 84).

90 'Fragile X syndrome' *healthdirect* (Web Page, October 2023) <https://www.healthdirect.gov.au/fragile-x-syndrome>.

91 Ginoza and Isasi (n 83) 1.

92 Ibid.

93 Ibid 1–2.

94 Julian Savulescu et al, 'The moral imperative to continue gene editing research on human embryos' (2015) 7(7) *Protein & Cell* 476, 477.

95 Ibid.

limitation. PGT is also limited in its ability to avoid carrier genes of conditions, meaning transmission of the condition may occur in the next generation if a carrier is transferred.[96]

PGT has also faced consistent criticisms for its potential impacts on social perceptions of gender and/or disability.[97] Many commentators refer to a risk of demographic change or gender inequality that could arise from the use of PGT for sex selection, particularly the use of sex selection for non-medical/preferential purposes.[98] In the context of ART, the term 'sex selection' refers to the 'selection and transfer of an embryo on the basis of genetic sex'.[99] It is argued that permitting non-medical sex selection could lead to a disproportionate number of males or females and compound existing inequalities, particularly in cultures that have shown preferences for a specific sex.[100] Regardless of the reason behind the use, many argue that non-medical sex selection will perpetuate gender discrimination and encourage the idea that a child's worth is determinative of their sex.[101] These arguments encourage an ethical limitation on PGT that would prevent the technique being used for non-medical purposes.

The use of PGT has also been criticised for its potential to perpetuate disability discrimination and stigmatisation.[102] As previously mentioned, PGT can be used to identify over 20,000 types of gene mutations which can lead to a series of genetic conditions, diseases or disabilities.[103] This application has attracted commentary about how this usage could have a negative impact on disability rights. The popularisation of PGT as well as a growing focus on genetics in

96 Ibid.

97 Ginoza and Isasi (n 83) 9–10.

98 Michelle Taylor-Sands et al, 'Non-Medical Sex Selection in Australia: Public Views and Bioethical Concerns' (2018) 18(2) *QUT Law Review* 44, 49.

99 National Health and Medical Research Council (n 82) 48.

100 Taylor-Sands et al (n 98) 49, citing Giuseppe Benagiano and Paola Bianchi, 'Sex-Preselection: an aid to couples or a threat to humanity?' (1999) 14(4) *Human Reproduction* 868.

101 Taylor-Sands et al (n 98) 49.

102 Seppe Segers, 'Heritable genome editing: ethical aspects of a developing domain' (2023) 38(11) *Human Reproduction* 2055, 2059; Briana Keogh, 'Preimplantation Genetic Testing: The Conflict Between Reproductive Autonomy and Disability Rights with the UK, Ireland and Portugal as Case Studies' (EMA Thesis, 2021/2022) 61; Ginoza and Isasi (n 83) 7–8.

103 Fertility Society of Australia and New Zealand (n 84).

medicine is said to be encouraging a 'social assumption that disability should be avoided where possible'.[104] Some argue that there is a risk of creating a 'genetic underclass'[105] that could lead to an entrenched stigma, marginalism and discrimination against a supposed 'underclass'.[106] However, it is recognised that this risk can be mitigated through carefully considered bioethical policies and public education.[107] This has often led to the implementation of strict 'medical necessity' requirements for any PGT applications.[108]

Similar to the criticisms regarding non-medical sex selection, the use of PGT to produce a 'saviour child' through HLA matching has also received extensive commentary.[109] The use of PGT to produce a 'saviour child' has highlighted several key ethical considerations: instrumentalisation of the child, possible psychological harm and/or physical harm to the child.[110] The decision to produce a 'saviour child' can indicate a wrong procreative motive,[111] which is said to violate the beneficence principle in medical ethics,[112] but also go against philosopher Immanuel Kant's categorical imperative formulation.[113] These two ethical structures follow a similar thought, beneficence would suggest medical ethics is infringed since there is no medical benefit for the saviour sibling,[114] while the categorical imperative requires every rational being to exist as an end in itself and never be used merely as a means to an end.[115] This

[104] Keogh (n 102) 63.

[105] Ibid 65 n 297–8.

[106] Ibid.

[107] Ibid 65.

[108] Ginoza and Isasi (n 83) 8.

[109] Ibid 1–2.

[110] Chee Ying Kuek et al, 'Conception of Saviour Siblings: Ethical Perceptions of Selected Stakeholders in Malaysia' (2021) 13(2) *Asian Bioethics Review* 167, 170–2.

[111] Karen E Adams, 'Ethical considerations of applications of preimplantation genetic diagnosis in the United States' (2003) 22(3) *Medicine and Law* 489.

[112] Kuek et al (n 110) 170–2, discussing Salam Abdalmeer Alnasir, Mahmoud Reza Ghorban-Sabbagh and Masood Khoshsaligheh, 'Examining the Moral and Ethical Dilemmas of Creating Saviour Siblings' (2020) 9(17) *Religious Enquiries* 83.

[113] Ibid.

[114] Ibid.

[115] Immanuel Kant, *Groundwork of the metaphysics of morals*, tr Mary Gregor (Cambridge University Press, 2006).

argument is against the treatment of a 'saviour sibling' as a 'mere tool to treat its ailing elder sibling.'[116] Similarly, there are often concerns that saviour siblings could suffer psychological harm or distress if they are viewed as a mere means, potentially receiving only conditional love and value.[117] The reference to potential physical harm encourages considerations about the type of treatments the 'saviour child' would be used for, ensuring awareness about the potential source of the stem cells, how they will be collected and what risks are associated for the donor.[118]

These technical and ethical limitations indicate a strong imperative for strict legislation and guidelines to ensure PGT can be used in an ethically acceptable way.

2 *The Australian Framework for Pre-Implantation Genetic Testing*

Australian regulation of ART is comprised of state legislation, national professional standards and ethical guidelines.[119] Currently four states have implemented legislation that regulate certain practices required for ARTs — New South Wales,[120] South Australia,[121] Victoria[122] and Western Australia.[123]

The Australian National Health and Medical Research Council ('NHMRC') provide extensive ethical guidelines on the use of assisted reproductive technology in both clinical practice and research.[124] The guidelines provide an overarching framework that is to be read 'in conjunction with federal and state or territory legislation to create a robust framework for the conduct of ART in Australia.'[125] This includes specifically determining and regulating the

[116] Kuek et al (n 110) 170.

[117] Ibid 170, 172–3.

[118] Ibid 171.

[119] Taylor-Sands et al (n 98) 45.

[120] *Assisted Reproductive Technology Act 2007* (NSW).

[121] *Assisted Reproductive Treatment Act 1988* (SA).

[122] *Assisted Reproductive Treatment Act 2008* (Vic).

[123] *Human Reproductive Technology Act 1991* (WA).

[124] National Health and Medical Research Council (n 82).

[125] Ibid 11.

ethically acceptable circumstances of PGT and sex selection.[126] According to these guidelines, PGT may only be used:[127]

- To select against genetic conditions, diseases or abnormalities that would severely limit the quality of life of the person who would be born.
- To select an embryo with compatible tissue for subsequent stem cell therapy intended for a parent, sibling or other relative ('saviour child').
- To increase the likelihood of a live birth.

For the purposes of clinical practice, the guidelines include comprehensive listed considerations for clinicians when engaging with PGT in the circumstances listed above.[128] In doing so, these considerations also provide significant reference to contentious ethical debates regarding the use of PGT.[129] The permissible circumstances allowing PGT to be used to produce a 'saviour child' specifically includes a requirement for an independent body to assure the person born would be a 'welcomed [and] respected member of the family unit,'[130] as well as a requirement to ensure this use of the practice would not significantly affect the welfare of the person born.[131] Similarly, the considerations for the permissible use of PGT to select against genetic conditions, diseases or abnormalities specifically notes why this use of PGT must be carefully considered under ethical guidelines.[132] This includes references to quality of life, public perceptions of genetic conditions as well as the risks that selecting against certain conditions may lead to discrimination and stigmatisation.[133] These ethical considerations form the basis of a careful selection criteria that is left to the discretion of the clinician as well as an independent body if they are required.[134]

[126] Ibid 48–52 [8.13]–[8.17].

[127] Ibid 51 [8.15.1].

[128] Ibid 51–2 [8.16]–[8.17].

[129] Ibid.

[130] Ibid 52 [8.17.2].

[131] Ibid.

[132] Ibid 51–2 [8.16].

[133] Ibid 51 [8.16].

[134] Ibid 52 [8.16.2].

On the issue of sex selection, the NHMRC guidelines state that 'sex selection techniques may be used to reduce the risk of transmission of a genetic condition, disease or abnormality that would severely limit the quality of life of the person who would be born.'[135] Additionally, the guidelines also consider the ethical acceptability of non-medical sex selection — also known as preferential sex selection — stating that the practice is not currently supported by the NHMRC.[136] In rationalising this, the guidelines referred to the relevant factors on the issue which were considered by the Australian Health Ethics Committee ('AHEC').[137] Despite recognition that non-medical sex selection could be consistent with the guiding principles of the NHMRC guidelines in certain circumstances, the AHEC determined that there was 'an ethical difference between a desire to introduce variety to the existing sex ratio of a family and the desire to design the sex of the offspring based on the preferential selection of a particular sex due to an individual's or a couple's cultural or personal bias, influences or desires.'[138] The AHEC also acknowledged that the motivations of those seeking the practice cannot be easily identified.[139] This ultimately led to the specific inclusion in the guidelines that non-medical sex selection is not supported by the NHMRC.[140]

The determination on non-medical sex selection is also supported in most of the current state legislation. South Australia, Victoria and Western Australia currently impose eligibility criteria limiting ART services to those who have a medical need for them.[141] In addition to this, Victoria explicitly prohibits non-medical sex selection,[142] imposing a penalty of up to 240 penalty units and two years imprisonment for breaching this provision.[143] The combination of this legislation with the ethical guidelines above highlights an ethical and legal framework that permits and regulates therapeutic applications of PGT and

[135] Ibid 48 [8.13.1].

[136] Ibid 50 [8.14].

[137] Ibid 49–50.

[138] Ibid 50.

[139] Ibid.

[140] Ibid 50 [8.14].

[141] *Assisted Reproductive Treatment Act 1988* (SA) s 9; *Assisted Reproductive Treatment Act 2008* (Vic) s 10; *Human Reproductive Technology Act 1991* (WA) s 23.

[142] *Assisted Reproductive Treatment Act 2008* (Vic) s 28(1–2).

[143] Ibid s 28(1).

permitting its non-therapeutic applications including non-medical/preferential sex selection.

Despite these restrictions, in 2021 it was reported that PGT was performed in 8,807 cycles,[144] totalling approximately 8% of the 111,253 ART treatment cycles reported in Australia and New Zealand.[145]

3 *An Ethical Basis*

The national guidelines regulating the use of PGT as described above set out extensive ethical considerations for both clinicians and patients involved in PGT.[146] These considerations refer to the ethical acceptability of the various practices and circumstances where PGT is permitted.[147] These inclusions suggest a significant ethical basis for the regulation of PGT and encourage an analysis of the included considerations as well as other ethical concerns within the four pillars of medical ethics.[148]

(a) Autonomy

Reproductive autonomy is the consideration that a person has the power to make and act on their own decisions about reproduction.[149] It is argued that ART is one of the highest forms of reproductive autonomy, allowing people to choose the circumstances in which they have children.[150]

The availability of PGT promotes reproductive autonomy by increasing the choices available to prospective parents, particularly those at a high risk for genetic diseases.[151] Though it is arguable that allowing preferential sex selection through PGT would also promote reproductive autonomy, perhaps to

144 Newman, Paul and Chambers (n 79) 46.

145 Ibid 4.

146 National Health and Medical Research Council (n 82) 48–52 [8.13]–[8.17].

147 Ibid.

148 'Medical Ethics', *The Medic Portal* (Web Page) <https://www.themedicportal.com/application-guide/medical-school-interview/medical-ethics/>.

149 Segers (n 102) 2058.

150 Giulia Cavaliere, 'Genome editing and assisted reproduction: curing embryos, society or prospective parents?' (2018) 21(2) *Medicine, Health Care and Philosophy* 215, 218.

151 Maria Siermann et al, 'A systematic review of the views of healthcare professionals on the scope of preimplantation genetic testing' (2022) 13(1) *Journal of Community Genetics* 1, 10; Cavaliere (n 150) 218.

a greater extent, the numerous ethical considerations that argue against this practice provide a compelling counterargument.[152]

The Australian regulatory framework for PGT requires clinicians to have regard to a specific listed series of ethical considerations that are relevant to ensuring reproductive autonomy.[153] This includes provisions protecting and ensuring informed consent practices and promoting available support and counselling services.[154]

(b) Beneficence / Non-Malfeasance

As evidenced by the current regulatory framework for PGT as well as other ARTs, the overarching benefits to the welfare of the child as a result of the practice became the key consideration in allowing therapeutic use of PGT.[155]

PGTs applications to select against genetic conditions, diseases or abnormalities which impact quality of life serves to potentially prevent lifelong pain and suffering. It's other applications, including increasing the likelihood of a live birth and increasing the likelihood of stem cell therapy for an intended recipient also serve to limit the pain and suffering of others.

As is the concern for many ARTs, the potential safety issues with PGT must be considered under the non-malfeasance principle. The practice of PGT requires a biopsy be undertaken on an embryo to then be tested.[156] The nature of this procedure presents a risk that the embryo will not survive the procedure.[157] Due to potential technical challenges, there are also risks associated with the results of the tests, including a risk of false positives, false negatives or results that do not reflect the true health of the embryo.[158] The

[152] Ibid; Taylor-Sands et al (n 98) 49, citing Giuseppe Benagiano and Paola Bianchi, 'Sex-Preselection: an aid to couples or a threat to humanity?' (1999) 14(4) *Human Reproduction* 868.

[153] National Health and Medical Research Council (n 82) 48–52 [8.13]–[8.17].

[154] Ibid 53–54 [8.18].

[155] Cavaliere (n 150) 218.

[156] Daniel Cimadomo et al, 'The Impact of Biopsy on Human Embryo Developmental Procedure during Preimplantation Genetic Diagnosis' (2016) *BioMed Research International* 7193075:1–10, 1–6.

[157] Ibid.

[158] Victorian Assisted Reproduction Treatment Authority, *The pros and cons of pre-implantation genetic testing for aneuploidy (PGT-A)* (Information Sheet, 2021) 2–3.

implementation of extensive informed consent practices aims to limit the negative impact of this and any other potential risks.[159]

(c) Justice

A common limitation within the justice principle for many ARTs is the risk of socioeconomic inequality in the availability and accessibility of these practices. An IVF cycle with PGT requires the patient to pay for the cost of the IVF technique, the hospital stay as well as the cost of the PGT technology.[160] These extensive costs may impact the availability of this technique.

In efforts to promote justice, a Medicare rebate for PGT was introduced in November 2021 which would allow patients to claim a Medicare rebate for several types of pre-implantation genetic tests.[161] The rebate is available for three types of PGT tests:[162]

- PGT-M (monogenic) for couples at risk of passing on recessive, autosomal dominant, or mitochondrial disorders
- PGT-SR (structural rearrangements) for carriers of chromosomal rearrangements
- PGT for sex selection for couples at risk of passing on X-linked disorders

The addition of this Medicare rebate promotes the justice principle by expanding the availability of PGT, particularly to people who would be able to benefit from the results of the practice.

The Australian regulation of PGT places significant importance on the consideration of ethical acceptability in regulating the use of the technique. This indicates a primary objective to ensure and uphold current standards of

[159] National Health and Medical Research Council (n 82) 53–4 [8.18].

[160] Victorian Assisted Reproduction Treatment Authority (n 158) 2–3; IVF Australia, 'How much does PGT cost?', *Pre-implantation Genetic Testing* (Web Page) <https://www.ivf.com.au/treatments/preimplantation-genetic-testing-pgt/pre-implantation-genetic-testing>.

[161] Department of Health and Aged Care, 'Pre-implantation Genetic Testing (PGT)' *MBS Online* (Fact Sheet, 20 July 2021) <https://www.mbsonline.gov.au/internet/mbsonline/publishing.nsf/Content/Factsheet-Pre-imp-Gentest>; IVF Australia, 'What PGT tests are covered?', *Medicare rebate for Pre-implantation Genetic Testing* (Web Page) <https://www.ivf.com.au/medicare-rebate-for-pre-implantation-genetic-testing-faqs>.

[162] Ibid.

medical ethics particularly when regulating ethically questionable or contentious practices. The ethical guidelines consistently refer to mental and/or physical pain and suffering in several key ethical considerations.[163] This highlights the importance of the beneficence and non-malfeasance principles when analysing the ethical acceptability of a medical practice. The references to the pain and suffering justification are similar to the use of the principle to justify the current VAD framework. Similar to the analysis for VAD, the beneficence principle — specifically PGTs ability to alleviate or remove potentially lifelong pain and suffering — was significant in justifying the use of the technique. This analysis highlights how the expanded pain and suffering justification which permitted the VAD legislative framework has also contributed significantly to the ethical justification and regulation of PGT in Australia.

B *Genome Editing of Embryos*

Despite its evident carefully constructed legal and ethical framework, the now common practice of PGT may soon be superseded by the development of human Germline Gene Editing ('GGE') which has the potential to alter the genetics of a human genome for medical or non-medical purposes.[164] These developments have led to discussions on the legal status of genome editing of embryos as compared to the ethical considerations these practices present.

Gene editing techniques have the potential to improve treatments for serious conditions with a known genetic cause.[165] The technique can also be used to introduce genetic changes in germ cells, such as early human embryos, eggs, or sperm.[166] GGE could potentially be used to 'edit out' an unwanted mutation in an in-vitro embryo or may be used to engineer DNA changes that are linked with particular genetic advantage, such as mutations associated with enhanced levels of physical performance and endurance.[167] This is now recognised as the risk of 'designer babies.'[168]

[163] National Health and Medical Research Council (n 82) 51–2 [8.15]–[8.17].

[164] Cavaliere (n 150) 215–16.

[165] Jeanne Snelling, 'Paul Enríquez, Rewriting Nature: The Future of Genome Editing and how to Bridge the Gap Between Law and Science' (2023) (00) *Medical Law Review* 1, 1–2.

[166] Segers (n 102) 2056.

[167] Snelling (n 165) 2.

[168] Ibid 3.

The publication of this technique sparked debate on the legal and ethical status of GGE practices, attracting the attention of clinical and academic medical researchers and practitioners, lawyers and policy makers.

1 *The Legal Position*

The 1997 *Universal Declaration on the Human Genome and Human Rights*[169] strongly encouraged prohibition of any cloning practice using human genomes and recommended strict limits on research and application of genome editing for reproductive purposes.[170]

As a result, in 2002, the Council of Australian Governments agreed they would introduce nationally consistent legislation to ban human cloning and other unacceptable practices.[171] The Australian Government passed the *Prohibition of Human Cloning for Reproduction Act 2002*[172] and the *Research Involving Human Embryos Act 2002*.[173] Section 15 of the *Prohibition of Human Cloning for Reproduction Act 2002* provides that a person will commit an offence punishable by imprisonment of 15 years if they 'alter the genome of a human cell in such a way that the alteration is heritable by descendants of the human.'[174]

2 *A New Technique for Human Germline Gene Editing ('GGE')*

In 2015 a group of Chinese scientists published their findings on the development of a new technique of human GGE using clustered regularly

[169] *Universal Declaration on the Human Genome and Human Rights*, GA Res 53/152 (9 December 1998).

[170] Ibid arts 10–11.

[171] National Health and Medical Research Council, 'Commonwealth and State Legislation', *Embryo Research Licensing* (Web Page, December 2005) <https://www.nhmrc.gov.au/research-policy/embryo-research-licensing/commonwealth-and-state-legislation>; *Human Cloning and Embryo Research Act 2004* (ACT); *Human Cloning for Reproduction and Other Prohibited Practices Act 2003* (NSW); *Research Involving Human Embryos Act 2003* (NSW); *Research Involving Human Embryos and Prohibition of Human Cloning for Reproduction Act 2003* (Qld); *Prohibition of Human Cloning for Reproduction Act 2003* (SA); *Research Involving Human Embryos Act 2003* (SA); *Human Cloning for Reproduction and Other Prohibited Practices Act 2003* (Tas); *Human Embryonic Research Regulation Act 2003* (Tas); *Research Involving Human Embryos Act 2008* (Vic); *Prohibition of Human Cloning for Reproduction Act 2008* (Vic); *Human Reproductive Technology Act 1991* (WA).

[172] *Prohibition of Human Cloning for Reproduction Act 2002* (Cth).

[173] *Research Involving Human Embryos Act 2002* (Cth).

[174] *Prohibition of Human Cloning for Reproduction Act 2002* (Cth) s 15.

interspaced short palindromic repeats-Cas9 (CRISPR/Cas9).[175] This has led to significant academic commentary on the moral and ethical arguments in favour and against GGE practices in human embryos.

After the initial publication, there were suggestions to inhibit research into germline applications of CRISPR/Cas9 and calls for voluntary moratoria on clinical applications, for fear of the potential for research to be exploited for non-therapeutic modifications.[176]

Therapeutic use of GGE has, however, garnered support in the academic community if regulated to the proper safety standards before clinical implementation.[177] In considering therapeutic applications, GGE is not constrained by many of the technical limitations of PGT previously discussed. GGE could allow a much wider range of dispositions to be tackled as it would no longer be constrained by the number of embryos required and could also prevent future generations from transmission through carrier genes.[178]

The risk of designer babies can be compared to the risk of non-therapeutic application of PGT.[179] The development of PGT for therapeutic practices likewise has non-therapeutic potential which could be taken advantage of.[180] To mitigate this, Australia implemented practical regulations preventing these non-therapeutic practices.[181] From an ethical and academic perspective, these risks did not justify a ban on such practices due to their greater benefits.[182] Similarly, the slippery slope argument does not constitute a good reason to not use these technologies to avoid genetic disease.[183] It would be more reasonable to prohibit the development of GGE technologies to enhance normal traits or prevent these specific applications in clinical practice.[184]

[175] Liang (n 2) 363–6.

[176] Savulescu et al (n 95) 476–7.

[177] Ibid; Segers (n 102) 2058; Cavaliere (n 150) 223.

[178] Ibid.

[179] Savulescu et al (n 94) 477.

[180] Ibid; Segers (n 102) 2058–9.

[181] National Health and Medical Research Council (n 82) 48–50 [8.13]–[8.14].

[182] Savulescu et al (n 94) 477.

[183] Segers (n 102) 2057–8; Savulescu et al (n 94) 478.

[184] Savulescu et al (n 94) 478.

3 *Ethical and Moral Ambiguity*

In combination with the legal and academic perspectives, the development of pre-implantation practices to GGE would present many ethical considerations in regulating the practice as an ART (Assisted Reproductive Technology). These concerns have been addressed by academics and policy makers under consideration of the four pillars of medical ethics.[185]

(a) Autonomy

As previously discussed, the concept of reproductive autonomy reframes the ethical consideration of autonomy when discussing ARTs. This specifies that autonomy within a reproductive setting must always promote a person's power to make and act on their own decisions about reproduction.[186]

In considering an expansion of current pre-implantation practices to also permit GGE practices, GGE technology could be argued as a comparatively better practice than PGT. The ethical analysis of autonomy highlighted how PGT can expand reproductive autonomy by increasing the choices available to prospective parents. GGE would offer an alternative in the circumstances where PGT is not effective or would not provide the desired effect.[187] By this reasoning, GGE would enhance reproductive autonomy.[188]

Reproductive autonomy as a consideration for other ARTs has been effectively managed under national guidelines to prevent stringent limitations on bodily autonomy while also addressing the public concern for non-therapeutic applications.[189] A similar guideline could be applied to GGE.

Non-therapeutic GGE also has a strong argument under the expansion of reproductive autonomy in the sense that 'reproductive autonomy may no longer be restricted to decisions whether to have children, when, with whom and how, but may widen the scope of choice about 'what type of child to have'.'[190]

[185] 'Medical Ethics', *The Medic Portal* (Web Page) <https://www.themedicportal.com/application-guide/medical-school-interview/medical-ethics/>.

[186] Segers (n 102) 2058.

[187] Cavaliere (n 150) 218.

[188] Segers (n 102) 2058–9.

[189] National Health and Medical Research Council (n 82) 48–52 [8.13]–[8.17].

[190] Segers (n 102) 2059.

(b) Beneficence

The ethical guidelines for ART draw constant reference to considerations on the welfare of future children born as a result of the practices.[191] The beneficial implications of PGT on child welfare were significantly influential in permitting and regulating the technique.[192] As was the case with autonomy, it is argued that GGE would be an expansion of this beneficence consideration.[193] GGE would prevent the occurrence of genetic diseases in future generations, while PGT can sometimes only prevent the occurrence of genetic diseases in the child that develops from the implanted embryo.[194] As aforementioned, PGT is also limited in its abilities to detect disease based on the number of embryos.[195] GGE is not limited in this respect and would have broader applications.

This is a strong ethical argument supporting regulated clinical applications of therapeutic GGE as an expansion on the benefits already derived from therapeutic PGT and its justifications.[196]

(c) Non-Malfeasance

To do no harm is frequently a question in considering ARTs involving testing, alteration or editing of a human embryo. The main concern with GGE is the potential safety issues.[197] As is the case with new technologies, the full understanding of potential risks has not yet been developed due to the initial lack of usage and testing.[198] It has been recognised that gene editing techniques have the potential of 'off-target mutations' which could cause significant defects and disabilities.[199] This safety concern could also extend to future generations where changes in the genome are heritable.[200] It would be highly

[191] Cavaliere (n 150) 221–2.

[192] Ibid 218.

[193] Ibid.

[194] Savulescu et al (n 94) 477.

[195] Ibid.

[196] National Health and Medical Research Council (n 82) 48–52 [8.13]–[8.17].

[197] Cavaliere (n 150) 218.

[198] Savulescu et al (n 94) 477.

[199] Ibid.

[200] Ibid.

unethical to implement these techniques until their safety can be further assured.[201]

The question of safety can be addressed under standard procedures for implementation of new medical technologies.[202] Extensive trials and research would need to be confirmed to ensure the initial and lasting risks are understood.[203] If the safety of the genome editing process is carefully assessed, GGE would be considerably preferable to PGT.[204]

(d) Justice

Potential issues of justice arise under socioeconomic equality and discrimination. Clinical practice is an expensive and costly process for those undergoing any form of ART.[205] As is the case with costly medical practices, access is limited to those who can afford it.

Applications of GGE directed to 'avoid' disease and disability may present a negative message which has the potential to diminish respect and support for people with supposedly less-favoured characteristics, essentially fostering discriminatory attitudes and behaviour.[206] It is likely any implementation of GGE would also prohibit non-therapeutic applications (i.e. trait and characteristic alterations), and limit accessibility criteria for therapeutic applications as was considered for PGT.[207]

Standard ART practices aim to assist individuals and couples facing fertility issues for a variety of reasons. GGE is the expansion and development of this idea which is currently facing legal, academic, and ethical scrutiny. Regardless of the current legal restrictions on any pre-implantation embryonic practices, the academic and ethical scrutiny currently facing GGE are similar to those which were presented against PGT. The legal and ethical analysis of PGT highlighted how Australian medical ethics standards have created a successful formula for these delicate issues which could also be utilised to implement

201 Cavaliere (n 150) 217–18.

202 Savulescu et al (n 94) 476–7.

203 Ibid.

204 Cavaliere (n 150) 220.

205 Ibid 222.

206 Segers (n 102) 2059.

207 Ibid.

GGE.[208] As was the case for PGT, in many of its ethical arguments, the potential benefits of GGE outweigh the risks which could be effectively managed under national systems.[209]

IV THE RECOGNITION OF PAIN AND SUFFERING

Legal and ethical commentary on VAD and ART is consistently referring to the welfare of parties, quality of life and greater benefit than harm, all of which reference mental/physical pain and suffering. Current recognition of pain and suffering is limiting the possible applications of ARTs which could pre-emptively limit or remove lifelong suffering. However, the growth in recognition of the importance of these concepts ultimately led to the VAD framework in Australia. As this recognition continues to grow from a political and social perspective, the approach to ART pre-implantation practices may be further accommodated.

A *Positive Recognition and its Impact on Voluntary Assisted Dying*

The AHRC released an issues paper on euthanasia in 2016 prior to the implementation of VAD legislation.[210] In this paper, the AHRC summarised the process of euthanasia as follows:

> Euthanasia is sought not only by those *suffering excruciating pain*, but for other reasons such as changes in *quality of life* resulting from catastrophic physical injury and psychological factors associated with incurable diseases.[211]

This formed the subject of a significant ethical justification within the beneficence principle, namely that VAD is the compassionate and merciful response to pain, suffering and indignity.[212] These emphasised components are also reflected in passive euthanasia practices as well as the eligibility criteria for VAD requiring 'suffering which the person considers intolerable'.[213]

[208] National Health and Medical Research Council (n 82) 48–52 [8.13]–[8.17].

[209] Savulescu et al (n 94) 478.

[210] Australian Human Rights Commission (n 6).

[211] Ibid 3 (emphasis added).

[212] Senate Standing Committee on Legal and Constitutional Affairs, Parliament of Australia, *Rights of the Terminally Ill (Euthanasia Laws Repeal) Bill 2008* (Report, June 2008) 34.

[213] *Voluntary Assisted Dying Act 2022* (NSW) s 16(1)(d)(iii); *Voluntary Assisted Dying Act 2021* (Qld) s 10(1)(a)(iii); *Voluntary Assisted Dying Act 2021* (SA) s 26(1)(d)(iv); *End-of-Life*

In certain circumstances, these same considerations have provided reasoning to Courts for passive euthanasia in countries where active euthanasia is prohibited. This was the approach of the UK High Court in *Great Osmond Street Hospital v Yates* [2017].[214] In this case, the Court exercised its child welfare jurisdiction to withdraw the life support of an 11-month-old who had been suffering from a rare genetic condition.[215] In making this determination, the court gave extensive consideration to the best interests of the child involved.[216] The best interests of the child were said to not only extend to medical treatment but also included emotional welfare and pleasure, pain, and suffering.[217] The Court determined that it was not in the child's best interests to continue life sustaining practices when the act of doing so did not provide adequate quality of life.[218]

As previously mentioned, the significant increase in public support was an important factor in the expansion of the pain and suffering justification.[219] Most recently, a reported 76% of Australians support the principle that a person experiencing unrelievable suffering who asks to die should be allowed to receive the assistance of a doctor to do so.[220] In comparison, the first Australian public attitude poll about VAD in 1962 reported only 47% of respondents in favour of the practice.[221] By 1978 support for VAD had increased to 67% of respondents.[222] The increase in support from 1962 to 2021 indicates a growing positive recognition of pain and suffering in circumstances where quality of life is diminished.

Choices (Voluntary Assisted Dying) Act 2021 (Tas) s 6(2); *Voluntary Assisted Dying Act 2017* (Vic) s 9(1)(d)(iv); *Voluntary Assisted Dying Act 2019* (WA) s 16(1)(c)(iii).

214 *Great Ormond Street Hospital v Yates* [2017] EWCH 1909 (Fam); Dominic Wilkinson and Julian Savulescu, *Ethics, Conflict and Medical Treatment for Children: From disagreement to dissensus* (Elsevier, 1st edition, 2018) ch 1.

215 Ibid 1.

216 Ibid 8.

217 Ibid 8–9.

218 Ibid 10, 13.

219 Kresin et al (n 77) 7; Braun (n 10) 10–12.

220 The Australia Institute, *Polling – Voluntary assisted dying and the territories* (Report, April 2021) 3.

221 Kresin et al (n 77) 4–5.

222 Ibid.

The consistent public support for active euthanasia is an important indicator on how the pain and suffering justification can be expanded and used for other pre-emptive healthcare practices. This was evident in the legal and ethical analysis for PGT which showed significant considerations to pain and suffering to justify a similarly contentious practice.

B *The Pain and Suffering Justification for Genome Editing*

The development of CRISPR/Cas9, has expanded ARTs ability to edit human genes.[223] This technology could be used to treat childhood and adult diseases, make genetic changes to a human embryo to create heritable changes passed on to future children.[224] Despite these potential benefits, GGE practices are currently restricted by legislation which imposes an imprisonment penalty on anyone who makes heritable alterations to the genome of a human cell.[225]

However, as discussed above, many previously contentious or prohibited practices — including VAD and PGT — are now considered ethically justifiable, prompting successful implementations of legislation and ethical regulations.[226] This justification centres around the importance of a practice to alleviate or remove a person's pain and suffering.[227] In applying this expanded principle of pain and suffering to GGE, there is a possibility the practice could be effectively regulated under a similar framework.

A regulated approach allowing for therapeutic uses of GGE has seen growing public support. A global social media survey reported that 59% of respondents

[223] Liang (n 2) 363–6.

[224] Segers (n 102) 2056–7.

[225] *Prohibition of Human Cloning for Reproduction Act 2002* (Cth) s 15.

[226] *Voluntary Assisted Dying Act 2022* (NSW); *Voluntary Assisted Dying Act 2021* (Qld); *Voluntary Assisted Dying Act 2021* (SA); *End-of-Life Choices (Voluntary Assisted Dying) Act 2021* (Tas); *Voluntary Assisted Dying Act 2017* (Vic); *Voluntary Assisted Dying Act 2019* (WA); *Assisted Reproductive Technology Act 2007* (NSW); *Assisted Reproductive Treatment Act 1988* (SA); *Assisted Reproductive Treatment Act 2008* (Vic); *Human Reproductive Technology Act 1991* (WA); National Health and Medical Research Council (n 82).

[227] *Voluntary Assisted Dying Act 2022* (NSW) s 16(1)(d)(iii); *Voluntary Assisted Dying Act 2021* (Qld) s 10(1)(a)(iii); *Voluntary Assisted Dying Act 2021* (SA) s 26(1)(d)(iv); *End-of-Life Choices (Voluntary Assisted Dying) Act 2021* (Tas) s 6(2); *Voluntary Assisted Dying Act 2017* (Vic) s 9(1)(d)(iv); *Voluntary Assisted Dying Act 2019* (WA) s 16(1)(c)(iii); National Health and Medical Research Council (n 82) 48–52 [8.13]–[8.17].

agreed to the application of human genome editing to cure life-threatening diseases in children and adults.[228]

Professor Dianne Nicol from the Centre for Law and Genetics at the University of Tasmania conducted a citizens' jury to discuss the circumstances human gene editing should be permitted.[229] The citizens' jury were presented with information about the technology from experts in the field and also on the ethical, legal and social issues associated with the technology.[230] The majority of the citizens' jury recommended that human gene editing should be:[231]

- Only used to alleviate human suffering, improve quality of life, and reduce childhood mortality.
- Regulated with regular reviews that include stakeholder and community input.
- Made available equitably to those most in need, with their informed consent.
- Researched to identify and assess the risks and benefits to society and individuals.

This indicates a clear public support for the therapeutic applications of GGE which focus strongly on the potential for the technique to alleviate pain and suffering and improve quality of life. In combination with the previously conducted ethical analysis, GGE has the potential to achieve current standards for ethical acceptability as used for other ARTs.

Therefore, if regulations were to be modelled after the approach to PGT[232] — permitting therapeutic and prohibiting non-therapeutic applications — it is likely the practice would be seen as ethically acceptable, garnering social and legal support for these applications through the expanded pain and suffering justification.

[228] Tristan McCaughey et al, 'A Global Social Media Survey of Attitudes to Human Genome Editing' (2016) 18(5) *Cell Stem Cell* 569, 569–571.

[229] 'Is human gene editing good for our health? A citizens' jury speaks', *Australian Government Department of Health and Aged Care* (News, 10 March 2023) <https://www.health.gov.au/news/mrff-is-human-gene-editing-good-for-our-health-a-citizens-jury-speaks>.

[230] Ibid.

[231] Ibid.

[232] National Health and Medical Research Council (n 82) 48–52 [8.13]–[8.17].

The caveat to these technologies is their unknown implications — what effect heritable changes to the human genome or germ cells could have on future generations, and whether these technologies could be abused to allow non-therapeutic changes or enhancement to human genomes.[233] When summarised in this way, the fears associated with GGE are similar to those when implementing legislation and regulations for VAD and PGT. Notably, the risks and concerns associated with VAD and PGT did not result in a moratorium on these practices, they were instead carefully regulated. This same approach could be taken to GGE.[234]

V CONCLUSION

This article sought to determine whether the recently expanded recognition of pain and suffering as an ethical justification for voluntary assisted dying in Australia would also permit for the expansion of assisted reproductive techniques to include pre-implantation embryonic practices.

Recognition of pain and suffering forms the baseline for the VAD legislative framework in Australia.[235] An analysis of the beneficence and non-malfeasance principles indicated that these concepts are no longer viewed in the strictest sense of administering life sustaining measures to remove pain and suffering. The expansion of these principles, combined with the significance of patient autonomy constituted the ethical justification for VAD in Australia.[236] Though the expansion of this concept to consider pain and suffering was a consistent theme in the justification of VAD in Australia, its significance has yet to be recognised when concerned with genome editing practices.

In the context of assisted reproduction, Australian regulations, despite making consistent references to pain and suffering considerations in regulating PGT,[237] have yet to consider the applicability of this justification to GGE. Genome editing techniques have the potential to alleviate the pain and suffering caused

[233] Snelling (n 165) 3.

[234] Emilia Niemiec and Heidi Carmen Howard, 'Ethical issues related to research on genome editing in human embryos' (2020) 18 *Computational and Structural Biotechnology Journal* 887, 889–890.

[235] Senate Standing Committee on Legal and Constitutional Affairs, Parliament of Australia, *Rights of the Terminally Ill (Euthanasia Laws Repeal) Bill 2008* (Report, June 2008) 34.

[236] Braun (n 10) 9–14; Australian Human Rights Commission (n 6) 35–8.

[237] National Health and Medical Research Council (n 82) 48–52 [8.13]–[8.17].

by many genetic diseases and therefore benefit millions worldwide.[238] If associated ethical issues were to be addressed through selective legislation to prevent abuse and premature use of the technology, therapeutic applications of GGE are likely to be considered ethically justifiable under the recent expansion of the beneficence and non-malfeasance principles to provide considerable recognition to pain and suffering.[239]

[238] Cavaliere (n 150) 218; Savulescu et al (n 94) 477; Segers (n 102) 2058.

[239] Savulescu et al (n 94) 478.