

26 September 2024

## Manatū Hauora

Tēnā koutou katoa,

### Review of the End of Life Choice Act 2019

Te Whare Piki Ora o Māhutonga - the Royal Australasian College of Surgeons (RACS) is the leading advocate for surgical standards, professionalism and surgical education in Aotearoa New Zealand and Australia. RACS is a not-for-profit organisation representing more than 7000 surgeons and 1300 surgical trainees and International Medical Graduates (IMGs) across Aotearoa New Zealand and Australia. RACS also supports healthcare and surgical education in the Asia-Pacific region and is a substantial funder of surgical research.

RACS is the accredited training provider in nine surgical specialties - Cardiothoracic Surgery, General Surgery, Neurosurgery, Orthopaedic Surgery, Otolaryngology Head and Neck Surgery, Paediatric Surgery, Plastic and Reconstructive Surgery, Urology and Vascular Surgery. Surgeons are required by RACS and Te Kaunihera Rata o Aotearoa - Medical Council of Aotearoa (MCNZ) to continue with surgical education and review of their practice throughout their surgical careers.

We welcome the opportunity to review the End of Life Choice Act 2019 (the Act).

In summary, we would like to see the review address the following key points:

- A. The eligibility requirement to be a person who “suffers from a terminal illness that is likely to end their life within 6 months” is problematic for several reasons. It is difficult for a doctor to predict and prognose death so precisely. The requirement excludes patients who will survive longer than 6 months but have a very poor quality of life. Excluding people of advanced age is ageist. The conditions for eligibility should be widened to focus on poor quality of life and/or ongoing pain/suffering resulting from a condition that is irreversible.
- B. Patients should be enabled to make informed choices about the end of their life. The Act does not allow doctors to discuss the option of assisted dying unless raised first by the patient. This restriction inequitably limits access to assisted dying to people with high health literacy. It also breaches the principles of informed consent as outlined in the HDC Code 1996 and by MCNZ in its statement for doctors regarding informed consent.
- C. The Act emphasises the individual person and their choice without consideration of involvement of whānau in such choices. We encourage the Ministry to actively seek a range of Māori voices in the Review.
- D. There is no provision in the Act to enable people to request assisted dying in an Advanced Directive when they are still competent.

Each of these points is explored in more detail as follows. The contents of this submission were also provided through your online survey that closed today.



**A. Access to assisted dying - eligibility requirements for a person to receive assisted dying**

1. Section 5(1)(c) requires that an eligible person “suffers from a terminal illness that is likely to end the person’s life within 6 months”.
2. This excludes people with long term but devastating illnesses, such as neurological conditions. It means the person who will survive longer than 6 months but have a very poor quality of life is not able to access assisted dying as an option.
3. It is also very difficult to predict and prognose death as a doctor.
4. Section 5(2)(c) excludes people of advanced age from accessing assisted dying.
5. This is ageist. If a person is of good cognitive capacity, being of advanced age should not exclude them from being able to access assisted dying.
6. There is no definition of advanced age leaving this terminology open to interpretation.
7. The conditions for eligibility should be widened to remove time, terminal illness and advanced age as eligibility conditions and to focus on people with a poor quality of life and/or ongoing pain/suffering as a result of their condition which is irreversible.

**B. Access to assisted dying – discussion must not be initiated by health practitioner**

8. Section 10(1) and (2) require doctors not “initiate any discussion with the person that, in substance, is about assisted dying under this Act”.
9. Effectively “gagging” healthcare professions from mentioning the option of assisted dying enables inequity. Only patients with a high health literacy and an awareness of their right to access assisted dying can utilise this option, even if the treating doctor considers it to be in the best interest of the patient to consider.
10. Doctors are not able to discharge their duty to fully inform patients about options.
11. The principles of informed consent include informing patients and their whanāu of all their options moving forward.
12. As outlined in the Health and Disability Commissioner (Code of Health and Disability Services Consumers’ Rights) Regulations 1996 (HDC Code 1996) <sup>1</sup> three rights together form the elements of informed consent. These are: the right to effective communication (Right 5); the right to be fully informed (Right 6); and the right to consent freely given by a competent person (Right 7).
13. Within the MCNZ statement for doctors regarding informed consent<sup>2</sup>; the third principle is:  
“You must give your patient the information they need to help them make a fully-informed decision. Share information that is relevant to them, in a way they understand, and allow reasonable time for the patient to make their decision. Think about whether there is anything else you can do to make it easier for your patient to consider the different options and make a fully informed decision. Cover the options available including those that you may not be able to provide yourself.”

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<sup>1</sup> Health and Disability Commissioner (Code of Health and Disability Services Consumers’ Rights) Regulations 1996. [www.legislation.govt.nz/regulation/public/1996/0078/latest/whole.html](http://www.legislation.govt.nz/regulation/public/1996/0078/latest/whole.html)

<sup>2</sup> Te Kaunihera Rata o Aotearoa | Medical Council of New Zealand. Informed Consent: Helping patients make informed decisions about their care [Internet]. 2021 [cited 2022 Aug 10]. Available from: <https://www.mcnz.org.nz/assets/standards/79e1482703/Statement-on-informedconsent.pdf>.

### **C. Access to assisted dying – inequity of access**

14. See comments above about preferencing those people who have a high level of health literacy, and disadvantaging people of advanced age.
15. From the official assisted dying report,<sup>3</sup> demographics of those accessing the assisted dying process from April 2022 to March 2023:
  - 81% NZ European/Pākehā, 5% Māori, 0.62% Pacifica
  - 55% were women/wāhine
  - 58% were 65-84 years, 18% 85+ years
  - 68% had a diagnosis of cancer, 76% were receiving palliative care.
  - Of the 807 applicants, 328 had an assisted death during that time period.
16. It is possible this shows inequity of access, as the 2023 demographics for Aotearoa population are 68% Pākehā, 18% Māori and 9% Pacifica. It is also possible there are different attitudes to assisted dying between different ethnic groups. We would be interested to see the Review identify and consider any research on this issue.
17. It is difficult to comment on delivery as the demographic breakdown is not provided for those who complete the assisted dying process.
18. It is concerning there is no reference to Māori or to te Tiriti o Waitangi in the Act. A comprehensive article by Paula Lee<sup>4</sup> addresses the absence of te Tiriti, lack of Māori input into the co-design and delivery of assisted dying, and lack of partnership, participation and protection. A concern raised is that the Act has an emphasis on the individual and the choice of the individual, a very Western world view that doesn't fit with the importance in Te Ao Māori of whanāu and of the collective view.
19. We encourage greater involvement of Māori voices in the consideration of the review of the Act and would welcome a te Tiriti clause.

### **D. No provision for an Advance Directive to include assisted dying provisions**

21. It is of concern that 48 people who had previously been eligible for the assisted dying program lost their competence to proceed when previously they had been competent and expressed a wish to access assisted dying.
22. We would like to see a provision within the Act to enable people to request assisted dying in an Advance Directive when they are competent and may express a wish to access assisted dying if they lose competence and have a poor quality of life.

We would be pleased to discuss our submission as part of your targeted engagement with health sector organisations and are happy for it to be published as you progress the Review.

Nāku iti noa, nā

**Ros Pochin FRACS**  
**Chair, Aotearoa New Zealand National Committee**

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<sup>3</sup> Registrar (Assisted Dying) annual report to the Minister of Health / Assisted Dying Service = Ngā Ratonga Mate Whakaahuru -New Zealand. Assisted Dying Service Ngā Ratonga Mate Whakaahuru Wellington, New Zealand - Ministry of Health, 2023

<sup>4</sup> Lee P. Mōku anō ēnei rā: The End of Life Choice Act and its Compliance with Te Tiriti o Waitangi. Te Tai Haruru: Journal of Māori and Indigenous Issues. 2020; 7: 144-162.