



Minister of Health and Associate Minister of Health

End of Life Choice Act 2019: Terms of Reference for the Review

28 August 2024

These documents have been proactively released by the Ministry of Health on behalf of the Minister of Health, Hon Dr Shane Reti and the Associate Minister of Health, Hon David Seymour.

Title of Cabinet paper:

- Agreeing terms of reference for the review of the End of Life Choice Act 2019

Titles of minutes:

- End of Life Choice Act 2019: Terms of Reference for the Review (CAB-24-MIN-0252)
- End of Life Choice Act 2019: Terms of Reference for the Review (SOU-24-MIN-0067)

Titles of briefings:

- Terms of reference for the statutory review of the End of Life Choice Act 2019 – H2023033040 (19 December 2023)
- Terms of reference for the statutory review of the End of Life Choice Act 2019 – H2023033040 (29 February 2024)
- Draft Cabinet paper for agreeing terms of reference for the review of the End of Life Choice Act 2019 – H2024040628 (3 May 2024)
- Revised Cabinet paper agreeing terms of reference for the review of the End of Life Choice Act 2019 – H2024043081 (31 May 2024)
- Agreeing terms of reference for the review of the End-of-Life Choice Act 2019: Cabinet paper for lodging – H2024044126 (19 June 2024)
- Review of the End of Life Choice Act 2019: Confirming the review approach, timelines and details for the online process canvassing public opinion on the Act – H2024045571 (4 July 2024).

Some parts of this information release would not be appropriate to release and, if requested, would be withheld under the Official Information Act 1982 (the Act). Where this is the case, the relevant sections of the Act that would apply have been identified. Where information has been withheld, no public interest has been identified that would outweigh the reasons for withholding it.

Key to redaction code/s:

- Out of scope
- S 9(2)(a) to protect the privacy of natural persons.
- S 9(2)(g)(i) to maintain the effective conduct of public affairs through the free and frank expression of opinions by or between or to Ministers and officers and employees of any public service agency.
- S 9(2)(h) to maintain legal professional privilege.



Cabinet

Minute of Decision

This document contains information for the New Zealand Cabinet. It must be treated in confidence and handled in accordance with any security classification, or other endorsement. The information can only be released, including under the Official Information Act 1982, by persons with the appropriate authority.

End of Life Choice Act 2019: Terms of Reference for the Review

Portfolio Health / Associate Health (Hon David Seymour)

On 8 July 2024, Cabinet:

- 1 **noted** that under section 30 of the End of Life Choice Act 2019 (the Act), the Ministry of Health is required to undertake a review of the operation of the Act, to be completed in November 2024;
- 2 **noted** that the coalition agreement between the New Zealand National Party and the ACT Party includes a commitment to ‘agree the terms of reference for the statutory requirement to review the Act following consultation between the Parties, with any potential future changes to be progressed by way of a member’s bill, recognising this is a conscience issue’;
- 3 **agreed** that the review will take place in two parallel streams:
 - 3.1 a review of the operation of the Act, which will be conducted by the Ministry of Health and informed by targeted engagement with relevant stakeholders; and
 - 3.2 an online process, administered by the Ministry of Health, to canvass public opinion on the Act. This canvassing will include, but not be limited to, suggested changes and improvements that can be made to the Act, and concerns around the functioning of the Act or objections to the Act;
- 4 **noted** that the ACT Party considers that the scope of section 30 of the current legislation is wide enough to include consideration of matters such as expanding eligibility settings, but accepts the agreed scope of and approach to the 2024 review due to the urgency of beginning work on the review;
- 5 **agreed** that the Government will make no changes to the Act following the review, noting that the coalition agreement between the New Zealand National Party and the ACT Party states that ‘any potential future changes to be progressed by way of a member’s bill, recognising this is a conscience issue’;
- 6 **noted** that the review process is expected to be completed and reported back in November 2024;
- 7 **noted** that separate reports will be provided from each review stream to the Minister of Health who will table these in Parliament so that individual parties can decide whether to pick up and progress changes recommended by officials or raised through public feedback, through private members’ bills;

- 8 **agreed** to the terms of reference for the review of the Act, attached as Appendix A to the submission under CAB-24-SUB-0252;
- 9 **noted** that the Minister of Health and the Associate Minister of Health (Hon David Seymour) will agree details for the online process to gather public feedback, including timings and the prompts for the public to respond to;
- 10 **authorised** the Minister of Health to make any minor or technical changes to the terms of reference prior to publication, in line with the decisions under CAB-24-MIN-0252.

Rachel Hayward
Secretary of the Cabinet

PROACTIVELY RELEASED

In Confidence

Office of the Minister of Health
Office of the Associate Minister of Health (Pharmac)
Cabinet Social Outcomes Committee

Agreeing terms of reference for the review of the End of Life Choice Act 2019

Proposal

- 1 This paper seeks Cabinet's agreement to the approach to be taken and terms of reference for the statutory review of the End of Life Choice Act 2019 (the Act).

Relation to government priorities

- 2 This paper fulfils a commitment made under the coalition agreement between the New Zealand National Party and the ACT Party, to 'agree the terms of reference for the statutory requirement to review the End of Life Choice Act 2019 following consultation between the Parties, with any potential future changes to be progressed by way of a member's bill, recognising this is a conscience issue'.
- 3 Under the Act, the Ministry of Health | Manatū Hauora is required to review the operation of the Act within three years of it coming into force, and then every five years after that.

Executive Summary

- 4 Under section 30 of the End of Life Choice Act 2019 (the Act), the Ministry of Health | Manatū Hauora (the Ministry) is required to review the operation of the Act during 2024.
- 5 The coalition agreement between the New Zealand National Party and the ACT Party includes a commitment to agree the terms of reference for the requirement to review the Act, following consultation between the Parties.
- 6 During discussions on the review, the ACT Party have expressed a desire for the public to have the opportunity to provide their views on matters that go beyond the scope of the current legislation, such as considering options for expanding the eligibility settings to enable more people to access assisted dying in New Zealand.
- 7 To address these interests, we are proposing to progress the review in two parallel streams:

- 7.1 a review of the operation of the End of Life Choice Act 2019, which will be conducted by the Ministry of Health and informed by targeted engagement with relevant stakeholders, and
 - 7.2 an online process, administered by the Ministry of Health, which will canvass public opinion on what changes could be made to the End of Life Choice Act 2019.
- 8 The review of the operation of the Act will consider whether the legislation as written is operating effectively and achieving its intended purposes. This review would take a targeted approach to engagement focused on individuals and organisations with a role under the Act, or particular expertise relevant to assisted dying.
- 9 Alongside this, there will be a separate process where individuals and organisations can provide their views on the Act through an online portal. This will include but will not be limited to, suggested changes and improvements that can be made to the Act, and concerns around the functioning of the Act or objections to the Act. The feedback that is received through the portal will be summarised in a report, which will accompany advice from the Ministry of Health.
- 10 Reports from the review are expected to be provided to the Minister of Health in November 2024, who will table these in parliament. Individual parties can then decide whether to pick up and progress any changes through private members' bills.
- 11 We are seeking agreement to this two-stream approach to the review, and to the terms of reference for the review, which are attached at **Appendix A**.

Background

- 12 The End of Life Choice Act 2019 is the law that makes assisted dying legal in New Zealand. The Act came into force on 7 November 2021, following a public referendum held alongside the 2020 General Election. The Act is administered by the Ministry of Health | Manatū Hauora (the Ministry).
- 13 The Act sets out the legal framework that allows people to have choice in how they end their lives. This includes strict eligibility criteria and processes, safeguards to protect patients and practitioners, and it sets out the administrative bodies that oversee and monitor the provision of assisted dying.
- 14 Assisted dying in New Zealand is provided by a small number of medical and nurse practitioners as part of the Assisted Dying Service – Ngā Ratonga Mate Whakaahuru, which is operated by Health New Zealand | Te Whatu Ora.

The Ministry is required to undertake a review of the Act during 2024

- 15 The legislation requires that the operation of the Act must be reviewed within three years of it coming into force, and every five years after that.

- 16 The coalition agreement between our Parties, the New Zealand National Party and the ACT Party, includes a commitment to ‘agree the terms of reference for the statutory requirement to review the End of Life Choice Act 2019 following consultation between the Parties, with any potential future changes to be progressed by way of a member’s bill, recognising this is a conscience issue’.

We are proposing to progress the review through two parallel streams

- 17 To meet the requirements of the Act, the Ministry needs to undertake a review of the Act to be completed in November 2024, which considers how the current Act is operating and whether changes may be needed. The Act Party has signalled a desire for individuals and organisations to have the opportunity to provide their views on matters that go beyond the scope of the current legislation, such as considering options for expanding the eligibility settings to enable more people to access assisted dying in New Zealand.
- 18 To address these interests, we are proposing to progress the review in two parallel streams:
- 18.1 a review of the operation of the End of Life Choice Act 2019, which will be conducted by the Ministry of Health and informed by targeted engagement with relevant stakeholders, and
 - 18.2 an online process, administered by the Ministry of Health, which will canvass public opinion on what changes could be made to the End of Life Choice Act 2019.
- 19 At the conclusion of the review, reports from both of these streams would be provided to the Minister of Health and tabled in parliament. The Government will not make changes to the Act following the review. As agreed by the government parties, findings will be treated as a conscience issue. Individual parties will decide whether to pick up and progress changes through private members’ bills.

Reviewing the operation of the Act

- 20 The Ministry of Health will undertake a review of the operation of the current legislation. This will consider whether the legislation as written and agreed by parliament is operating effectively and achieving its intended purposes, which are to:
- 20.1 give persons who have a terminal illness and who meet certain criteria the option of lawfully requesting medical assistance to end their lives
 - 20.2 establish a lawful process for assisting eligible persons who exercise that option
 - 20.3 provide for safeguards to ensure that assisted dying is only provided to those who are eligible, who actively seek and consent to it, and that this consent is provided without pressure from others.

- 21 The scope of this review will include considering whether changes are needed to address:
- 21.1 the meaning and interpretation of rules or settings in the Act
 - 21.2 the effectiveness of mechanisms in the Act, such as those intended to support access and provide safeguards
 - 21.3 how the Act supports the administration of assisted dying
 - 21.4 the roles and responsibilities of those involved
 - 21.5 alignment of the Act with other pieces of legislation and the wider health system.
- 22 Given that this stream of the review will be focused on the operation of the Act, rather than matters involving assisted dying more broadly, the Ministry will take a targeted approach to engagement, seeking input from:
- 22.1 organisations and individuals that are directly referenced in the Act, or that have a role directly related to the Act
 - 22.2 organisations and individuals that are directly involved in the provision of assisted dying, or that regulate or represent workforces that are
 - 22.3 organisations and individuals with particular knowledge or expertise relevant to the operation of the Act.
- 23 The review will welcome input from those who have had experience with the Assisted Dying Service. The public communications on the review will include an invitation for anyone who has sought or is seeking assisted dying, and family and whānau members of those who have been through the process, to contact the Ministry to share their feedback or insights.

Canvassing public opinion on what changes could be made to the End of Life Choice Act

- 24 Minister Seymour and I recognise that assisted dying is an issue on which there are a range of strong views, including from people who have written to us expressing a strong desire for their views to be heard as part of the review.
- 25 To address this, we propose a second stream of work that will run in parallel to the review of the operation of the Act outlined above. This will provide an opportunity for any individuals and organisations with views on the Act to share those views via an online portal which will be administered by the Ministry.
- 26 The portal will be open for a fixed period of time where individuals and organisations can share their views in response to a set of prompts. These prompts will invite participants to indicate what changes they believe could be made to the current legislation, and their reasons for this. Feedback may include but would not be limited to, suggested changes and improvements

that can be made to the Act, and concerns around the functioning of the Act or objections to the Act.

- 27 Minister Seymour and I will agree details related to this in coming weeks including when the portal will be open, and the prompts used to elicit feedback.
- 28 The feedback that is received through the portal will be summarised and provided in a report to accompany advice from the Ministry.
- 29 The Ministry will not seek to address views shared through the portal as part of its review, as the intent of this process is to allow the public to have their views captured and presented for parties to consider alongside the advice from officials.
- 30 This will be an online-only process and will not include any in-person meetings or forums. This is a pragmatic approach reflecting the need to manage what could be a significant amount of feedback in a timely and cost-effective way.

Agreeing the terms of reference for the review

- 31 We are seeking Cabinet agreement to this two-stream approach to the review, and agreement of the terms of reference for the review, which are attached at **Appendix A** and reflect the process outlined above.

Cost-of-living Implications

- 32 There are no cost-of-living implications resulting from the proposals in this paper.

Financial Implications

- 33 The Ministry has advised that the review of the operation of the Act can be completed within baseline funding.
- 34 The process to gather public feedback via an online portal is expected to have an additional fiscal impact which was not budgeted for in the policy work programme for 2024/2025. To manage this pressure without seeking additional funding the Minister of Health will work with the Ministry on reprioritising or rephasing the policy work programme over the year to accommodate this work within existing resources.

Legislative Implications

- 35 There are no legislative implications resulting from the proposals in this paper, however the review of the operation of the Act will make recommendations for legislative change.

Impact Analysis

- 36 Regulatory impact analysis requirements do not apply to this paper. A Climate Implications of Policy Assessment (CIPA) is not required for the proposals in this paper.

Population Implications

- 37 The Ministry collects information about the demographics of applicants to the Assisted Dying Service, including gender and ethnicity data, which is collected based on health sector standards and protocols.
- 38 Over the period of 1 April 2022 to 31 March 2023, there were 807 new formal applications for assisted dying, 111 people were still in the process of assessment or in preparation for assisted dying, and 328 people had an assisted death.
- 39 There are no population implications as a direct result of this paper. However, particular population groups are likely to have an interest in providing feedback on the operation of the Act, and changes that they believe could be made to it. This is expected to include older people, Māori, Pacific peoples, ethnic communities and disabled people.
- 40 As part of work to design the online portal, the Ministry will consider how to address the needs of those who may face barriers to accessing the portal.

Human Rights

- 41 In a previous report on the consistency of the End of Life Choice Bill with the New Zealand Bill of Rights Act 1990, it was found that the Bill appeared to be inconsistent with section 19(1) (freedom from discrimination) of the Bill of Rights Act in respect of age. Given that considering changes to eligibility is out of scope for the review of the operation of the Act, changes to the age of eligibility for assisted dying will not be in scope for that part of the review. However, members of the public may comment on this when they provide feedback through the online portal.
- 42 More broadly, a range of rights are relevant to assisted dying which may be raised through the online portal. These may include, for example, the right not to be deprived of life, the right to freedom of thought, conscience and religion, the right to freedom from discrimination, and the rights of minorities.
- 43 New Zealand's legal obligations under the International Covenant on Civil and Political Rights and the United Nations Convention on the Rights of Persons with Disabilities are also relevant (particularly the principle of 'respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons', and Article 10 – Right to Life).

Use of External Resources

- 44 The development of the proposals in this paper has not used any external resources.

Consultation

- 45 The following agencies were consulted on this paper: The Ministry of Justice, Department of Corrections, Health New Zealand | Te Whatu Ora, New Zealand Police, Department of Internal Affairs, Ministry of Business, Innovation and Employment, Whaikaha – Ministry of Disabled People, Te Puni Kōkiri, Ministry for Pacific Peoples, and the Accident Compensation Corporation. The Department of the Prime Minister and Cabinet was informed.

Communications

- 46 We plan to release the terms of reference for the review on the Ministry of Health website once they have been agreed by Cabinet, along with other supporting communications about the review.

Proactive Release

- 47 We intend to proactively release this Cabinet paper within 30 days of Cabinet's decision.

Recommendations

The Minister of Health and Associate Minister of Health recommend that the Committee:

- 1 **note** that under section 30 of the End of Life Choice Act 2019, the Ministry of Health is required to undertake a review of the operation of the End of Life Choice Act 2019 to be completed in November 2024;
- 2 **note** that the coalition agreement between the New Zealand National Party and the ACT Party includes a commitment to 'agree the terms of reference for the statutory requirement to review the End of Life Choice Act 2019 following consultation between the Parties, with any potential future changes to be progressed by way of a member's bill, recognising this is a conscience issue';
- 3 **agree** that the review will take place in two parallel streams:
 - 3.1 a review of the operation of the End of Life Choice Act 2019, which will be conducted by the Ministry of Health and informed by targeted engagement with relevant stakeholders, and
 - 3.2 an online process, administered by the Ministry of Health, to canvas public opinion on the End of Life Choice Act 2019. This canvassing will include but not be limited to, suggested changes and improvements that can be made to the Act, and concerns around the functioning of the Act or objections to the Act;
- 4 **agree** that the Government will make no changes to the End of Life Choice Act 2019 following the review, noting that the coalition agreement between the New Zealand National Party and the ACT Party states that "any potential

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future changes to be progressed by way of a member's bill, recognising this is a conscience issue";

- 5 **note** that the review process is expected to be completed and reported back in November 2024;
- 6 **note** that separate reports will be provided from each stream to the Minister of Health who will table these in parliament so that individual parties can decide whether to pick up and progress changes recommended by officials or raised through public feedback, through private members' bills;
- 7 **agree** to the attached terms of reference for the review of the End of Life Choice Act 2019 (**Appendix A**);
- 8 **note** that the Minister of Health and Associate Minister of Health will agree details for the online process to gather public feedback, including timings and the prompts for the public to respond to;
- 9 **agree** that any minor or technical changes to the terms of reference can be made by the Minister of Health prior to publication.

Authorised for lodgement

Hon Shane Reti
Minister of Health

Hon David Seymour
Associate Minister of Health

Appendix A

Terms of reference for the review of the End of Life Choice Act 2019

The End of Life Choice Act 2019 (the Act) is the law that makes assisted dying¹ legal in New Zealand. It came into force on 7 November 2021, and is administered by the Ministry of Health | Manatū Hauora (the Ministry).

The Act sets out the legal framework for assisted dying, including eligibility criteria, processes, safeguards to protect patients and practitioners, and the establishment of administrative bodies to oversee and monitor the provision of assisted dying.

Requirement to review the Act

The Ministry of Health is required to review the operation of the Act within three years of it coming into force, and every five years after that. As such, the Ministry is required to undertake a review of the operation of the Act to be completed in November 2024.

The coalition agreement between the New Zealand National Party and the ACT Party includes a commitment to 'agree the terms of reference for the statutory requirement to review the End of Life Choice Act 2019 following consultation between the Parties, with any potential future changes to be progressed by way of a member's bill, recognising this is a conscience issue'.

Scope and approach to the review

The statutory review of the Act will be progressed through two parallel streams:

- a review of the operation of the End of Life Choice Act, to be informed by targeted engagement, and
- an online process canvassing public opinion on what changes could be made to the End of Life Choice Act.

The respective scopes and engagement approaches of these streams are set out below.

Review of the operation of the Act

The Ministry will consider whether the legislation as written is operating effectively and achieving its intended purposes. The purposes of the Act are to:

- give persons who have a terminal illness and who meet certain criteria the option of lawfully requesting medical assistance to end their lives
- establish a lawful process for assisting eligible persons who exercise that option

¹ In the Act, 'assisted dying' means an eligible person's medical or nurse practitioner giving them medication to relieve their suffering by bringing on death; or the taking of medication by the eligible person to relieve their suffering by bringing on death.

- provide for safeguards to ensure that assisted dying is only provided to those who are eligible, who actively seek and consent to it, and that this consent is provided without pressure from others.

In considering how well the Act is achieving its purposes, the Ministry will consider whether changes may be needed to:

- increase clarity around the meaning and interpretation of rules or settings in the Act
- improve the effectiveness of mechanisms in the Act, such as those intended to address issues of access and safety
- support effective administration of assisted dying
- provide clarity around the roles and responsibilities of those involved, and
- improve alignment of the Act with other relevant pieces of legislation, and the wider health system (including the principles of the Pae Ora (Healthy Futures) Act 2022).

To inform the review of the operation of the Act, officials from the Ministry of Health will undertake targeted engagement with:

- organisations and individuals that are directly referenced in the Act, or that have a role directly related to the Act
- organisations and individuals that are directly involved in the provision of assisted dying, or that regulate or represent workforces that are
- organisations and individuals with particular knowledge or expertise relevant to the operation of the Act.

Feedback is also welcome from those with experience of the service, and from the families and whānau of those who have received an assisted death.

This process will gather expert insight on how the Act is currently operating, particularly for those who work within or close to the scope of the legislation.

Canvassing public opinion on changes to the Act

The Government recognises that assisted dying is an issue on which there are a range of strong views, and that many individuals and organisations have expressed a desire to share their views on the Act.

To capture these views, a parallel process will take place alongside the review referenced above, which will see an online portal established where individuals and organisations can share their views or feedback on the changes they believe could be made to the End of Life Choice Act.

The portal will include prompts for people to respond to when providing feedback, but organisations and individuals will be free to provide feedback on any aspect of the Act. This may include but would not be limited to, suggested changes and improvements that can be made to the Act, and concerns around the functioning of the Act or objections to the Act.

This will be an online-only process and will not include any in-person meetings or forums.

The feedback that is received through the portal will be summarised in a report, and will not include recommendations.

Outputs from the review

The review will produce two reports which will be provided to the Minister of Health in November 2024:

- A report from the Ministry of Health outlining findings from the review of the operation of the Act, and noting recommended changes to the Act.
- An accompanying report summarising the public feedback received through the online portal on the Act.

These reports will be tabled in parliament. The Government will not make changes to the End of Life Choice Act 2019 following the review. Individual parties can decide whether they wish to pick up and progress changes through private members' bills.

Roles and responsibilities

The Ministry of Health will undertake the review of the operation of the Act, and administer the process to canvass public opinion on the Act.

All reporting on the review will be to the Minister of Health, as the Minister responsible for the review.



Cabinet

Minute of Decision

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End of Life Choice Act 2019: Terms of Reference for the Review

Portfolios **Health / Associate Health (Hon David Seymour)**

On 1 July 2024, following reference from the Cabinet Social Outcomes Committee, Cabinet **deferred** consideration of the submission *End of Life Choice Act 2019: Terms of Reference for the Review* [CAB-24-SUB-0235] until Cabinet on 8 July 2024.

Rachel Hayward
Secretary of the Cabinet



Cabinet Social Outcomes Committee

Minute of Decision

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End of Life Choice Act 2019: Terms of Reference for the Review

Portfolio Health / Associate Health (Hon David Seymour)

On 26 June 2024, the Cabinet Social Outcomes Committee **referred** the submission under SOU-24-SUB-0067 to Cabinet on 1 July 2024 for further consideration.

Janine Harvey
Committee Secretary

Present:

Rt Hon Christopher Luxon
Rt Hon Winston Peters
Hon David Seymour
Hon Nicola Willis (Chair)
Hon Chris Bishop
Hon Dr Shane Reti
Hon Erica Stanford
Hon Louise Upston
Hon Matt Doocey
Hon Melissa Lee
Hon Nicole McKee
Hon Casey Costello
Hon Penny Simmonds
Hon Chris Penk

Officials present from:

Office of the Prime Minister
Officials Committee for SOU