MANATŪ HAUORA
MINISTRY OF HEALTH

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7 June 2024

s 9(2)(a)

[redacted] [redacted]
Ref: H2024041217

Tēnā koe s 9(2)(a)

Response to your request for official information

Thank you for your request under the Official Information Act 1982 (the Act) to the Ministry of Health – Manatū Hauora (the Ministry) on 9 May 2024 for information regarding the End of Life Choice Act 2019 and assisted dying. You requested:

> *"I would like to request any information pertaining to the practice and policy associated with assisted dying under the End of Life Choice Act 2019.*
> *I am especially interested in information relating to the degree of capacity required by someone accessing assisted dying in terms of s 6 of the Act."*

I have identified 12 documents within the scope of your request. These documents are itemised in Appendix 1 of this letter, and copies of the documents are enclosed. The table in Appendix 1 outlines the grounds under which I have decided to withhold information. Where information is withheld, this is noted in the document itself. I have considered the countervailing public interest in release in making this decision and consider that it does not outweigh the need to withhold at this time.

Other information related to your request, including the Cabinet paper titled *Implementing the End of Life Choice Act and providing for assisted dying services,* is available on the Ministry website here: www.health.govt.nz/about-ministry/information-releases/release-ministerial-decision-making-documents/end-life-choice-act-implementation-cabinet-papers-and-minutes.

I trust this information fulfils your request. If you wish to discuss any aspect of your request with us, including this decision, please feel free to contact the OIA Services Team on: oiagr@health.govt.nz.

Under section 28(3) of the Act, you have the right to ask the Ombudsman to review any decisions made under this request. The Ombudsman may be contacted by email at: info@ombudsman.parliament.nz or by calling 0800 802 602.

Please note that this response, with your personal details removed, may be published on the Manatū Hauora website at: www.health.govt.nz/about-ministry/information-releases/responses-official-information-act-requests.

Nāku noa, nā

Emma Prestidge
Group Manager, Family and Community Health Policy
Strategy Policy and Legislation | Te Pou Rautaki

Appendix 1: List of documents for release

#	Date	Document details	Decision on release
1	25 January 2021	Briefing: End of Life Choice Act: Implementing a system to provide assisted dying services H20202124	Released with some information withheld under section 9(2)(a) of the Act to protect the privacy of natural persons.
2	25 February 2021	Briefing: End of Life Choice Act: Determining an approach to provide for assisted dying services HR20210216	
3	8 April 2021	Briefing: End of Life Choice Act – Providing Medicines for Assisted Dying 20210278	Released with some information withheld under the following sections of the Act: • 9(2)(a); and • 9(2)(h) to maintain legal professional privilege.
4	19 April 2021	Briefing: End of Life Choice Act – Funding and related decisions to provide for assisted dying services 20210680	Released with some information withheld under section 9(2)(a) of the Act.
5	7 May 2021	Briefing: End of Life Choice Act: Safeguards for Assisted Dying HR20210746	
6	7 May 2021	Briefing: End of Life Choice Act Draft Cabinet paper for Ministerial consultation HR20211017	
7	21 May 2021	Briefing: End of Life Choice Act: Confirming the mechanism to fund assisted dying services HR20210996	
8	18 June 2021	Briefing: End of Life Choice Act: Interactions with Other Systems HR20210844	
9	26 July 2021	Briefing: End of Life Choice Act: Regulation Paper for Ministerial Consultation HR20211091	
10	16 August 2021	Briefing: End of Life Choice Act: Finalising funding settings for assisted dying services HR20211920	
11	20 September 2021	Briefing - End of Life Choice Act: Approval of assisted dying services notice HR20211945	
12	26 November 2021	Briefing: End of Life Choice Act: Data collection, monitoring, and research on assisted dying HR20211867	

Document 1

Briefing

End of Life Choice Act: Implementing a system to provide assisted dying services

Date due to MO:	N/A	**Action required by:**	25 January 2021
Security level:	IN CONFIDENCE	**Health Report number:**	20202124
To:	Hon Andrew Little, Minister of Health		

Contact for telephone discussion

Name	Position	Telephone
Dr Ashley Bloomfield	Director-General of Health	s (9)(2)(a) [redacted]
Clare Perry	Acting Deputy Director-General, Health System Improvement and Innovation	s (9)(2)(a) [redacted]
Caroline Flora	Acting Deputy Director-General, System Strategy and Policy	s (9)(2)(a) [redacted]

Minister's office to complete:

☐ Approved

☐ Needs change

☐ See Minister's Notes

☐ Decline

☐ Seen

☐ Withdrawn

☐ Noted

☐ Overtaken by events

Comment:

End of Life Choice Act: Implementing a system to provide assisted dying services

Purpose of report

1. This briefing outlines the work that the Ministry of Health has undertaken to implement the End of Life Choice Act 2019 (the Act) and establish a system to provide assisted dying services.
2. It outlines how we plan to support you to make a series of decisions on the design of this system, and some design principles that will inform the way we approach this work.
3. This briefing is revised to take into account some comments that you provided to us on a previous version.

Summary

4. Following the recent referendum the Ministry of Health has begun work to implement a system to provide assisted dying from 7 November 2021, in line with the Act. Assisted dying will be an entirely new service within the health and disability system.
5. Work to implement the Act is underway, and involves managing a number of complex and sensitive elements, including wide ranging views on assisted dying among different parts of the health and disability system, and uncertainty on key points like how many New Zealanders may want to seek assisted dying.
6. The Ministry has set itself the following objectives for what needs to be delivered from 7 November 2021:
    a. the provision of a service by suitably qualified medical practitioners that allows people to seek assisted dying
    b. the implementation of administrative systems and professional guidance to support and inform this service, which have been developed based on stakeholder engagement
    c. the establishment of the three statutory entities set out in the Act to oversee and support the provision of assisted dying
    d. the provision of public information about the Act and how people can exercise the choices and rights that it provides
    e. the introduction of any regulations required to support the administration and operation of assisted dying in New Zealand.
7. Our approach to progressing work to achieve these objectives involves:
    a. developing detailed planning - we expect to brief you on our key tasks, timeframes and sequencing in early 2021
    b. strong governance - we are establishing a project governance group to oversee the implementation which includes internal and external experts with a range of perspectives

  c. active engagement with the sector throughout implementation – we expect to brief you on a proposed approach for stakeholder engagement in early 2021.

8. There are also a range of policy and practical issues that will need to be addressed. These include answering questions such as how assisted dying services should be funded, who should be responsible for delivering services, and how and where services should be provided. We will provide you with a series of briefings seeking your decision on these and other issues, starting in January 2021. Many of these decisions will be interconnected.

9. We have identified some design principles, which will inform the way we approach this work, and help to ensure that we develop a service that fits the New Zealand context, which involve:

  a. giving effect to our obligations under Te Tiriti o Waitangi, including considering the interests and needs of Māori

  b. ensuring equity, which involves inclusiveness for all communities and equity of access to services

  c. providing services that are effective and have robust accountability and safety measures

  d. providing good value for health and disability system resources

  e. ensuring consistency with health and disability system strategies.

10. We will ensure future briefings incorporate analysis which considers these in implementation decisions.

11. At your request, we will discuss the implementation work with representatives of the Act Party as we progress. We are currently making arrangements for an initial meeting with Brooke van Velden (the ACT Party representative on matters related to the End of Life Choice Act) this month. We will include further engagement in our stakeholder planning, and provide you with updates on this engagement through weekly reports.

Recommendations

We recommend you:

a. **Note** that the Ministry is required to implement the End of Life Choice Act 2019 and establish an assisted dying service by 7 November 2021.

b. **Note** that the Ministry has set itself the following objectives for what needs to be delivered from this date:

  i. the provision of a service by suitably qualified medical practitioners that allows people to seek assisted dying

  ii. the implementation of administrative systems and professional guidance to support and inform this service, which have been developed based on stakeholder engagement

  iii. the establishment of the three statutory entities set out in the Act to oversee and support the provision of assisted dying

   iv. the provision of public information about the Act and how people can exercise the choices and rights that it provides
   v. the introduction of any regulations required to support the administration and operation of assisted dying in New Zealand.

c. **Note** that work to progress these objectives is underway, and that our approach to ensuring success involves:
   i. developing detailed planning
   ii. strong governance, including internal and external experts with a range of perspectives
   iii. active engagement with the sector throughout implementation.

d. **Note** that implementing a system to allow for assisted dying will involve addressing a range of policy and practical issues, including answering questions like: how assisted dying services should be funded, who should be responsible for delivering services, and how and where services should be provided.

e. **Note** that we will provide you with further briefings on this work from January 2021 covering:
   i. a series of policy and practical decisions
   ii. details on our implementation planning and timeframes
   iii. a proposed approach for stakeholder engagement.

f. **Note** that the following design principles should inform the way we develop assisted dying services, to:
   i. give effect to our obligations under Te Tiriti o Waitangi
   ii. ensure equity, which involves inclusiveness for all communities and equity of access to services
   iii. provide services that are effective and have robust accountability and safety measures
   iv. provide good value for health and disability system resources
   v. ensure consistency with health and disability system strategies.

g. **note** that at your request we will discuss the implementation work with representatives of the Act Party as it proceeds, and that we are currently planning an initial meeting with Brooke van Velden this month.

h. **Agree** to forward a copy of this briefing to the Associate Ministers of Health for their information. **Yes/No**

Dr Ashley Bloomfield
Director-General of Health
Date:

Hon Andrew Little
Minister of Health
Date:

End of Life Choice Act: Implementing a system to provide assisted dying services

Background

12. The End of Life Choice Act 2019 (the Act) received Royal assent on 16 November 2019, with enactment contingent on a public referendum. This was held alongside the 2020 General Election with 65.1% of voters in favour.

13. The Ministry of Health is responsible for administering the Act. Following the referendum result the Ministry has until 7 November 2021 to implement a system that allows for the provision of assisted dying for eligible people. Further detail on the content of the Act is provided in Appendix One.

Work to implement the Act is underway

14. The Ministry did some tentative planning for the implementation of the Act prior to the referendum result, though this was limited to preparations that would allow us to respond to both possible results. Following the referendum result we have accelerated our activity, with the recruitment of an implementation team and further planning work.

15. Assisted dying has never existed in New Zealand and will be an entirely new service within the health and disability system. Implementing a system to provide assisted dying services will involve managing a number of complex and sensitive elements, including:

   a. a wide range of views on assisted dying among different parts of the health and disability system, and among those who have an interest in the establishment of an assisted dying service

   b. uncertainty about a number of key elements, including how many New Zealanders may want to seek assisted dying, and how many medical practitioners may be willing to provide assisted dying services

   c. competing pressures for resources from other priorities/projects in the health and disability system.

Our objectives for 7 November 2021

16. The Act requires that a system is in place from 7 November 2021 that allows for the provision of assisted dying to eligible people. This system also needs to meet other requirements in the Act, including the establishment of statutory entities.

17. We expect that an initial system will be in place by this date in a limited manner, reflecting some of the uncertainties noted above, and allowing it to be further developed over time, as the health system learns and adjusts, and New Zealand society becomes more familiar with assisted dying as a concept.

18. For example, on day one there is not likely to be nationwide access to health practitioners in all regions trained and willing to participate in assisted dying, meaning people may need to travel for services. The number and location of health practitioners qualified and willing to provide assisted dying will be a key determinant of where

services can be provided, and it may be desirable to cluster these people together so they can support each other.

19. The Ministry is committed to ensuring that a system is place from 7 November that addresses all of the requirements of the Act, and has set itself the following objectives for what needs to be delivered from this date:

    a. the provision of a service by suitably qualified medical practitioners that allows people to seek assisted dying

    b. the implementation of administrative systems and professional guidance to support and inform this service, which have been developed based on stakeholder engagement

    c. the establishment of the three statutory entities (two committees and a registrar role) set out in the Act to oversee and support the provision of assisted dying

    d. the provision of public information about the Act and how people can exercise the choices and rights that it provides

    e. the introduction of any regulations required to support the administration and operation of assisted dying in New Zealand.

20. To ensure that we succeed in meeting these objectives, our approach to progressing this work involves detailed planning, establishing strong governance, and active engagement with the health sector throughout implementation.

Detailed implementation planning is being developed

21. Detailed implementation planning is well underway, and is expected to cover:

    a. stakeholder engagement and communications

    b. providing advice for decisions on a range of policy settings (see paragraph 32 below)

    c. the design of assisted dying services

    d. identifying and appropriating funding for assisted dying services

    e. establishing statutory entities and making appointments to them

    f. developing forms, systems and processes to support assisted dying services

    g. developing standards of care, guidance and training for health/medical practitioners who will be involved in assisted dying services

    h. developing information for the public regarding assisted dying services

    i. implementation of initial care pathways and models of care.

22. We expect to brief you on our implementation planning including timeframes and sequencing in early 2021.

Governance will be provided by a group of internal and external experts

23. To ensure effective implementation we are establishing a project governance group to oversee the implementation process. This group will be composed of internal and external members. Our planned governance structure for this work is summarised in Appendix Two.

24. Internal members of the group will include the Chief Medical Officer and Chief Nursing Officer, while external members will include Māori representation, and a representative from a clinical college.

25. Our objective is that this group should include individuals with expertise in the provision and governance of health services, along with people who can provide the perspective of key population and sector groups.

The Ministry will engage with the sector throughout implementation

26. Ensuring that we address the needs and interests of key stakeholders will be essential to the success of the implementation. Key stakeholders for this work include:

    a. the health and disability sector, including professional colleges

    b. iwi and Hapori Māori

    c. people who may be eligible for assisted dying

    d. broader sector groups such as the Privacy Commissioner and the Human Rights Commissioner.

27. We have already commenced engagement with some parts of the health and disability sector – primarily through routine channels such as regular meetings. Some of the key stakeholders the Ministry has spoken with so far include: District Health Board (DHB) Chief Executives, DHB Chief Medical Officers, the New Zealand Medical Council and the Nursing Council. We plan to engage with other sector bodies on an ongoing basis to provide updates on the work and to ensure that we understand their needs.

28. We are currently developing an engagement approach that has wide reach across the sector, with key stakeholders represented through advisory groups and other channels.

29. There were high levels of engagement with the End of Life Choice Bill at Select Committee, with approximately 37,200 unique submissions from individuals and organisations. Our engagement approach will not revisit matters which were relevant to the drafting of the Act, focusing instead on service design and delivery.

30. We expect to brief you on a proposed approach for stakeholder engagement in early 2021.

Funding will be sought through Budget 2021

31. As the provision of assisted dying will be a new function for the health and disability system, we plan on submitting a bid for some initial funding as part of Budget 2021/22. There is uncertainty currently about costs for the delivery of assisted dying services, along with other cost elements (such as the statutory bodies, medicines, IT systems, training etc) which will be influenced by policy and design decisions.

32. We will provide you with further updates on this bid as part of the process for Budget 2021.

Decisions will be required from you on a range of policy and practical issues

33. The implementation of a system to allow for assisted dying will involve addressing a range of policy and practical issues. Some key questions to be answered include:

    a. **How assisted dying services should be funded –** eg, whether funding should be provided entirely from government, or through some form of mixed model, and whether government funding should be provided centrally or through local entities such as DHBs or contracted providers.

b. **Who should be responsible for delivering services** – eg, whether services should be delivered by public and/or private providers, by local organisations (eg DHBs) or contracted providers, through a central service or some form of mixed model.

c. **How and where services should be provided** – eg, what the geographic spread of services should be, and through what organisations/entities New Zealanders should be able to request assisted dying.

d. **How workforce demands should be addressed** – eg, which practitioners should be involved in the system, how conscientious objection should be managed, including in situations when groups of practitioners or organisations want to conscientiously object (rather than just individuals), and what training and support should be provided to those involved in the system.

e. **How life-ending medicines will be managed** – eg, how these should be chosen, procured and who should be responsible for managing them.

f. **How statutory bodies should operate** – eg, when and how these should be established, the specific scope of their roles (beyond what is already set out in legislation) and how they should interact with each other.

g. **How an assisted dying service should be designed** – eg, how different stakeholders should be engaged, and how equity and Te Tiriti o Waitangi considerations should be addressed.

h. **What regulatory framework may be required** – eg, what regulations may be needed to provide a robust, transparent and accountable system.

34. We plan to provide you with a series of briefings to seek your decision on these and other issues from January 2021. Many of these decisions will be interconnected.

Design principles will help us plan this work

35. In order to establish an assisted dying service that is suitable for the New Zealand context, we consider that it will be useful to have some design principles that inform the way we approach this work.

36. We have identified following design principles which will inform our approach to this work:

a. **Giving effect to our obligations under Te Tiriti o Waitangi, including considering the interests and needs of Māori** – This involves using Te Tiriti o Waitangi principles set out in the Stage One Wai 2575 report[1] to inform how we work with Māori on the implementation of the Act. There are diverse views within Te Ao Māori about assisted dying, with some Māori in support of whānau choice and others questioning how assisted dying sits within tikanga, with concerns that it prioritises individual choice over whānau-oriented values. Direct engagement with

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[1] Hauora: Report on Stage One of the Health Services and Outcomes Kaupapa Inquiry

Māori is expected on detailed elements of service design (eg, how services can be provided in a way that addresses the needs of whānau).

b. **Ensuring equity, which involves inclusiveness for all communities and equity of access to services** - In the context of establishing assisted dying services, equity primarily relates to positive and negative access considerations where:
    i. no group of people should experience issues that prevent them from accessing assisted dying services when they would otherwise be eligible, and
    ii. no group of people should be accessing assisted dying services at a rate which is disproportionately high, as this could imply an upstream issue, such as disproportionate terminal illness, or a lack of healthcare access.

c. **Providing services that are effective and have robust accountability and safety measures** - In the context of assisted dying, service effectiveness is about both:
    i. the accuracy with which eligibility is determined, and people are assisted to die (eg, with a minimum of suffering), and
    ii. how well the system provides safeguards to ensure that people who are ineligible or who are unable to make a free choice are not assisted to die.

d. **Providing good value for health and disability system resources** - As kaitiaki of the health and disability system, the Ministry should ensure that any resource allocated to an assisted dying service is providing the outcomes we intend.

e. **Ensuring consistency with health and disability system strategies** - An assisted dying service needs to fit within the wider health and disability system, which means that it should align with the direction for the health and disability system which is set out in strategies including:
    i. He Korowai Oranga (the Māori Health Strategy)
    ii. Whakamaua: Māori Health Action Plan 2020-2025
    iii. Ola Manuia (the Pacific Health and Wellbeing Action Plan)
    iv. The New Zealand Disability Strategy.

Risks

37. While we are currently in the formative stages of risk identification, it is apparent that the key risk factors related to this work will include:

a. the potential for parts of the health and disability system (notably medical practitioners) to refuse to be involved in assisted dying

b. competing pressures for resources from other priorities/projects in the health and disability system

c. the potential for concerns about inadequate or insufficient engagement with stakeholders, given the short timeframe between the referendum confirming the Act and the service being implemented.

38. We also note that as the Act was a member's bill, amendments may be needed as part of the implementation to ensure the Act functions as intended. There has already been interest from other organisations about amending the Act to resolve some potential

legislative issues. We are working through whether this needs to occur and will advise you as necessary.

39. There is likely to be large amounts of correspondence and interest in this work and we will need to manage this interest while also maintaining timeframes.

40. The fact New Zealand has never had assisted dying before, along with the strong views from sections of public in favour and against assisted dying means that litigation in relation to assisted dying services is almost certain. There has already been litigation in relation to the Act, with a declaratory judgment sought by Hospice NZ prior to the public referendum result.

41. These risks will be built on in our implementation plan, which will set out management strategies for these and other risks that we identify.

Next steps

42. We will provide you with further briefings on this work from January 2021 covering:

   a. a range of policy and practical decisions

   b. details on our implementation planning and timeframes

   c. a proposed approach for stakeholder engagement.

ENDS.

Appendix One: End of Life Choice Act Content

The Act includes, in brief:

a. ***Processes:*** for establishing eligibility of a person for assisted dying which involves at least two medical practitioners, and in some cases if capacity of the person to make the decision is not clear, a psychiatrist, as well as a Registrar to oversee and facilitate processes; and for delivering medication to end the life of an eligible person who wishes to do so.

b. ***Safeguards*:** including conscientious objection provisions for health practitioners; requirement that a health practitioner cannot raise assisted dying - the interested person must raise the topic first; allowance for the person to change their mind at any time; requirement for the attending medical practitioner to consult with health practitioners regularly in contact with the person and family members approved by the person; and a requirement to stop processes if pressure is suspected.

c. ***Establishment of administrative bodies***: the Registrar who will support processes; the Support and Consultation for End of Life in New Zealand (SCENZ) group which maintains a list of health practitioners who are willing to participate in assisted dying, and provides other kinds of support including standards of care for the administration of medicines in assisted dying; and a Review Committee who will review instances of assisted dying which are provided to them by the Registrar.

d. ***Powers:*** for the Minister of Health to appoint a Review Committee who will consider assisted dying reports and report annually about instances of assisted dying; and for the Director-General of Health to appoint the SCENZ group, to approve the required forms to support the functioning of the Act, and to nominate a Ministry employee as the Registrar.

In the Act**, 'assisted dying' means**:

- An eligible person's doctor 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.

There are strict criteria in the Act on **who is eligible** for assisted dying. To be eligible, a person must meet all of the following criteria:

- be aged 18 years or over
- be a citizen or permanent resident of New Zealand
- suffer from a terminal illness that is likely to end their life within six months
- be in an advanced state of irreversible decline in physical capability
- experience unbearable suffering that cannot be relieved in a manner that the person considers tolerable
- be able to make an informed decision about assisted dying.

Both the doctor treating the person and a second – independent – doctor must agree that the person is eligible for assisted dying. If either doctor is unsure of the person's ability to make an informed decision, a psychiatrist must also assess the person to confirm their eligibility.

A person will **not be eligible** for assisted dying if the only reason they give is that they:

- are suffering from a mental disorder or mental illness
- have a disability of any kind
- are of advanced age.

A person cannot use an 'advance directive' to request assisted dying. An advance directive is a statement signed by a person setting out ahead of time what treatment they want or do not want to receive in the future.

Welfare guardians do not have any power to make decisions or take actions under the Act.

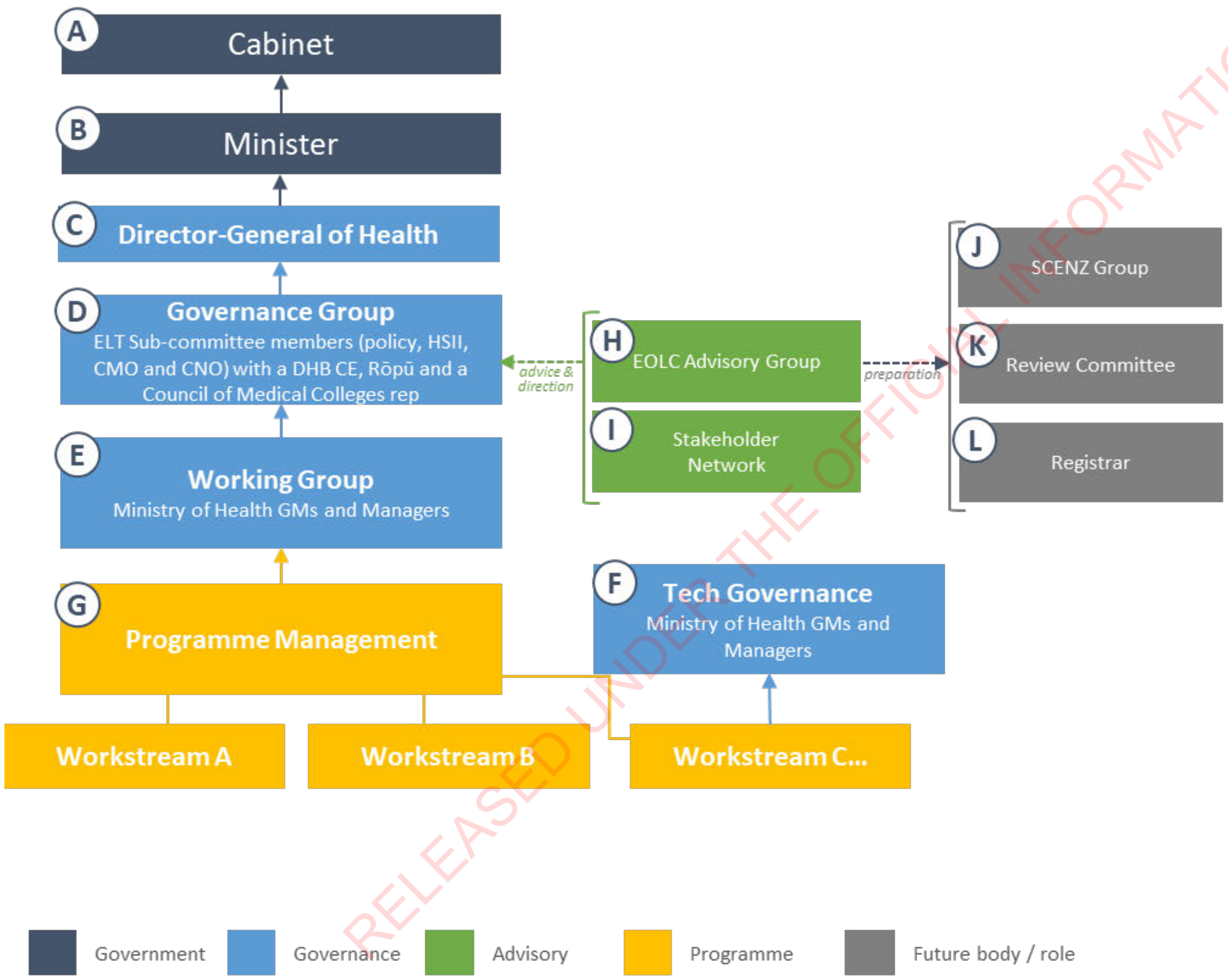
There are some practices which people may conflate with assisted dying that are not covered by the Act, for example:

- End of life care and palliative care services.
- The withdrawal of treatment by a medical practitioner at the patient's request, or because the treatment is medically futile, is lawful and generally considered ethical. This is not assisted dying. Section 11 of the New Zealand Bill of Rights Act 1990 (BORA) provides that everyone has the right to refuse to undergo any medical treatment.
- Medication given for pain relief with the primary aim of relieving patient distress is lawful and ethically acceptable, even when it may have the secondary effect of shortening life. This is also not assisted dying.

Document 1

Appendix Two: Ministry internal Governance Structure

Governance and advisory framework



A Cabinet

B Minister

C Director-General of Health

D **Governance Group**
ELT Sub-committee members (policy, HSII, CMO and CNO) with a DHB CE, Rōpū and a Council of Medical Colleges rep

E **Working Group**
Ministry of Health GMs and Managers

G **Programme Management**

Workstream A

Workstream B

Workstream C...

F **Tech Governance**
Ministry of Health GMs and Managers

H EOLC Advisory Group

I Stakeholder Network

advice & direction

preparation

J SCENZ Group

K Review Committee

L Registrar

⬛ Government 🟦 Governance 🟩 Advisory 🟨 Programme ⬜ Future body / role

A: Cabinet; B: Minister
Approval of policy settings; funding decisions.

C: Director-General of Health; D: Governance Group
Programme decision making; strategic risk and issue management; overall programme direction.

E: Working Group
Operational risk and issue management; Design Authority for service design; review and advice on options before presentation to Governance Group.

F: Technology Governance
Technology assurance, including: architecture Design Authority; security; privacy.

G: Programme Management
Support and co-ordination.

H: EOLC Advisory Group Health sector advice and direction including advising on and preparing for the establishment of new bodies and roles.

I: Stakeholder Network
Broad stakeholder network who are kept informed about service design and programme progress.

J: SCENZ Group
Support and Consultation for End of Life in New Zealand (SCENZ) Group established through the End of Life Choice (EOLC) Act 2019.

K: Review Committee
Review Committee established through the EOLC Act 2019.

L: Registrar
Registrar Role established through the EOLC Choice Act 2019.

Document 2

MINISTRY OF HEALTH
MANATŪ HAUORA

Briefing

End of Life Choice Act: Determining an approach to provide for assisted dying services

Date due to MO:	25 February 2021	**Action required by:**	4 March 2021
Security level:	IN CONFIDENCE	**Health Report number:**	HR20210216
To:	Hon Andrew Little, Minister of Health		

Contact for telephone discussion

Name	Position	Telephone
Dr Ashley Bloomfield	Director-General of Health	s (9)(2)(a) [redacted]
Clare Perry	Acting Deputy Director-General, Health System Improvement and Innovation	s (9)(2)(a) [redacted]
Caroline Flora	Acting Deputy Director-General, System Strategy and Policy	s (9)(2)(a) [redacted]

Minister's office to complete:

☐ Approved
☐ Needs change
☐ See Minister's Notes

☐ Decline
☐ Seen
☐ Withdrawn

☐ Noted
☐ Overtaken by events

Comment:

Document 2

End of Life Choice Act: Determining an approach to provide for assisted dying services

Security level:	IN CONFIDENCE	**Date:**	25 February 2021
To:	Hon Andrew Little, Minister of Health		

Purpose of report

1. This report seeks a decision about whether the Government should take active steps to ensure the provision of assisted dying services, and if so, which of the two high-level approaches identified should be taken.

Summary

2. The End of Life Choice Act 2019 (the Act) is silent on which organisations should provide assisted dying and whether the Government should take steps to ensure the provision of assisted dying services, such as publicly funding services or being directly involved in their delivery.

3. The Government could opt to take a 'hands off' approach with individual medical practitioners determining whether they provide services. This would not support our design principles of equity and choice, with access to assisted dying depending on whether there are willing medical practitioners in a particular area and whether people are able to travel and pay for services.

4. We expect the Government will want to take steps to ensure that people will have access to assisted dying services in line with other publicly funded health services. We are seeking your decision to confirm this.

5. We have developed a Budget bid that seeks $46 million of funding over four years which includes costs associated with implementing the Act, and a contingency for funding assisted dying services.

6. To help us determine what is needed from assisted dying services, we have examined the interests of different groups that will be involved with assisted dying including people seeking assisted dying, their families/whānau, medical practitioners and organisations that employ them.

7. The most critical factor that will determine the availability of assisted dying services is the number of medical practitioners who are willing to be involved. Some practitioners are known to oppose assisted dying while many of those who may support assisted dying in principle may be reluctant to provide services in practice. We are currently undertaking a survey of medical and nurse practitioners, psychiatrists and pharmacists to understand the views of this workforce, with results expected in March 2021.

8. An effective system to provide for assisted dying should make assisted dying accessible and equitable, provide choice and control to those seeking assisted dying, and support and maintain the wellbeing of those who provide assisted dying.

9. We have identified two approaches the Government could use to provide for assisted dying services in New Zealand, and note some key points below.

Approach One - Support any medical practitioners who are suitably qualified and willing to provide assisted dying, by providing funding for assisted dying services on a fee-for-service basis, along with some funding to district health boards (DHBs) to recognise the cost of any provision by staff within their services. The Ministry of Health (the Ministry) would be responsible for administering funding and have some oversight of provision.	Addresses access by maximising the number of medical practitioners who can provide funded services. Encourages choice by enabling any suitable medical practitioners to provide funded services, including smaller providers. Access and choice may be limited if there are areas with few willing medical practitioners. May reduce pressure on individual medical practitioners and give them more choice, but could also make establishing support networks more complex. A fee-for-service approach could attract criticism that assisted dying is receiving special or more generous treatment than palliative care.
Approach Two – Make DHBs responsible for ensuring that a level of assisted dying service provision is available across New Zealand, and provide additional funding to provide for assisted dying services. DHBs would be responsible for administering funding for assisted dying services and determining where and how services are provided.	Addresses access by providing a minimum level of provision through DHBs in a similar manner to other health services. Limited choice as people either need to use funded services provided by DHBs or pay to access non-DHB funded provider. Dependant on how DHBs decide to provide for services. Access may vary depending on whether services are provided locally, regionally, or nationally. The need to support practitioners may encourage DHBs to provide services from one or more central 'hub' locations rather than across different areas. Potentially allows assisted dying to be connected with the other care that people already receive, though DHBs may want to keep assisted dying at arms-length from other activities.

10. While there are arguments to be made for both approaches, we recommend adopting Approach One as this is more likely to result in the successful provision of assisted dying services in the short term, with options to revisit and change the approach in future as services becomes operational and we become more familiar with the complexities of providing assisted dying.

11. The approach that is chosen will determine the subsequent decisions to be made about how this will be applied, including the type and level of funding for services, whether there should be conditions attached to funding and what accountability arrangements should apply. We plan to provide you with a briefing on these decisions in March 2021.

12. Given the sensitivity associated with assisted dying, and the absence of an explicit direction in the Act for the provision of services, you may want to consider whether a Cabinet paper should be developed to seek or confirm decisions on the approach to be taken. We can provide you with further advice on this through the weekly update.

Recommendations

We recommend you:

a) **Agree** that the Government should take active steps to ensure that assisted dying services are available to people from 7 November 2021 **Yes/No**

b) **Note** that we have developed a Budget bid seeking $46 million over four years, including $21 million for costs associated with implementing the End of Life Choice Act, and $25 million as a contingency to meet the cost of funding assisted dying services

c) **Indicate** which approach should be taken to provide for assisted dying services

- **Approach One** - Support any medical practitioners who are suitably qualified and willing to provide assisted dying, by funding assisted dying services on a fee-for-service basis, and provide additional funding for DHBs to recognise the cost of service provision by their staff **(recommended)** **Yes/No**
- **Approach Two** - Make DHBs responsible for ensuring that a level of assisted dying service provision is available across New Zealand, and provide additional funding to provide for assisted dying services **Yes/No**

d) **Note** that when a preferred approach is chosen, we will provide you with further advice on subsequent decisions including funding, clinical governance and accountability settings, with a briefing planned for March 2021

e) **Note** that these decisions will help to determine the cost of assisted dying services, which is currently represented by the $25 million contingency in the Budget bid

f) **Note** that given the sensitivity associated with assisted dying, and the absence of an explicit direction in the End of Life Choice Act for the provision of services, you may want to consider whether decisions on providing for assisted dying services should be sought or confirmed by Cabinet

g) **Indicate** whether you would like to receive advice on developing a Cabinet paper to seek or confirm decisions on assisted dying services, including possible timeframes **Yes/No**

Dr Ashley Bloomfield
Director-General of Health
Ministry of Health
Date:

Hon Andrew Little
Minister of Health
Date:

End of Life Choice Act: Determining an approach to provide for assisted dying services

Work is proceeding on elements that are required to enable assisted dying

1. In our previous briefing to you *End of Life Choice Act: Implementing a system to provide assisted dying services* [HR20202124] we outlined the structural elements that we need to deliver from 7 November 2021 to give effect to the End of Life Choice Act 2019 (the Act).

2. These include developing administrative systems and professional guidance, the establishment of two statutory entities and a new role to oversee and support the provision of assisted dying, and developing public information and advice.

3. Work is well under way on these and we plan to provide you with a briefing detailing our implementation plan and stakeholder engagement approach in early March 2021.

This briefing focuses on whether and how assisted dying services should be provided for by the Government

4. While the Act requires the establishment of the structural elements referenced above, it is silent on which organisations/entities should actually provide assisted dying, and whether the Government should take steps to ensure the provision of assisted dying services[1].

5. There is a decision to be made about whether the Government should:

   a. take active steps to ensure that a certain level of assisted dying services are available to people from 7 November 2021

   b. take a 'hands off' approach to service provision – with the health and disability system and individual medical practitioners determining whether/what services are provided.

6. Appendix A provides a summary description of assisted dying services.

A 'hands off' approach would have implications for equity and choice

7. Without government action to ensure that services are provided, the decision about whether to provide assisted dying services would fall to individual medical practitioners and the organisations for which they work.

8. It is difficult to predict exactly what would happen in this situation, but we suspect that a small number of medical practitioners may be willing to provide assisted dying as a

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[1] As a comparison, the Contraception, Sterilisation, and Abortion Act 1977 which provides the legislative framework for providing abortion services, explicitly requires the Minister of Health to take reasonable steps to ensure the availability of abortion and related counselling services throughout New Zealand when entering into Crown Funding Agreements.

private service to people. This could create a *de facto* private market for assisted dying services. Costs might be covered through a combination of private fees and charitable donations. Some medical practitioners might also be willing to meet costs themselves.

9. District health boards (DHBs) are unlikely to provide for assisted dying services under this scenario. DHBs can consider the need for assisted dying alongside other health needs in their planning, but competing priorities for funding and the complexities associated with assisted dying mean that this would likely be regarded as a low priority.

10. This approach would not support our design principles around equity and choice[2]. Access to assisted dying would depend on whether there are willing medical practitioners and suitable facilities in a particular area, whether people can travel to access them, and whether people are able to pay for services or fundraise to meet costs.

We expect the Government will want to act to ensure that assisted dying services are available in an equitable manner, and have prepared a Budget bid accordingly

11. We have assumed that the Government will want to take active steps to ensure that people will have access to assisted dying services, in line with other health services. We are seeking your agreement on this.

12. We have developed a Budget bid that seeks $46 million of funding over four years. This includes:

    a. $21 million for costs associated with implementing the Act, including IT system development, the establishment and operation of the statutory entities and workforce development and training

    b. $25 million as a contingency to meet the cost of funding assisted dying services to eligible people.

13. The actual cost of assisted dying services will depend on the approach that is taken to providing services, decisions about how services are funded, and the level of demand for services.

14. Demand is highly uncertain given that assisted dying has not been provided in New Zealand before, and is further complicated by the subjective nature of some of the eligibility criteria (eg, what is considered 'unbearable pain and suffering' will vary depending on the individual).

15. We think that assisted dying could account for up to one percent of all deaths in New Zealand. This would equate to around 946 applications for assisted dying, and up to 338 deaths as a result of assisted dying per year[3].

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[2] These were outlined in our previous briefing and include: giving effect to our obligations under Te Tiriti o Waitangi, ensuring equity (which involves inclusiveness for all communities and equity of access to services), providing services that are effective and have robust accountability and safety measures, providing good value for health and disability system resources and ensuring consistency with health and disability system strategies.

[3] Overseas jurisdictions, including Victoria, Oregon and Canada, have shown assisted dying rates accounting for between 0.3 percent and 2 percent of all deaths.

16. The difference between the number of applications and assisted deaths reflects the fact that a large proportion of those who apply for assisted dying in other jurisdictions do not end up using the service. This results from people applying to give themselves the option of assisted dying, but ultimately deciding not to use it. There may also be situations where people die more quickly than they expect to or where they are found to be ineligible.

We have examined what we know or can infer about the different groups involved with assisted dying to determine an appropriate approach

17. To help us consider what is needed from assisted dying services, we have examined the potential interests of different groups who will be involved with assisted dying. Notably:

    a. people seeking assisted dying

    b. families/whānau of people seeking assisted dying

    c. medical practitioners and nurse practitioners

    d. organisations that provide health care, end of life care, and employ or work with medical practitioners.

18. This is based on information about assisted dying in overseas jurisdictions, publicly expressed views by particular groups, select committee submissions on the End of Life Choice Bill, and general information about health care provision in the New Zealand context.

The situations of people seeking assisted dying will vary

19. Only a small proportion of New Zealanders will meet the criteria to quality for assisted dying[4], only some of these people will apply to access assisted dying, and only a proportion of this cohort will ultimately be assisted to die. As noted previously, we think that up to 950 applications could be made for assisted dying each year, resulting in up to 338 deaths as a result of assisted dying.

20. The majority of those seeking assisted dying are likely to be suffering from cancer, though people may also seek assisted dying where they suffer from other conditions including neurodegenerative, cardiac and respiratory conditions.

21. The criteria to access assisted dying mean that people who do apply are likely to be physically impaired, and may be limited in what they can do, such as having difficulty completing basic tasks, or being limited in their ability to travel long distances due to care needs. These people are likely to already be receiving medical care to manage their

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[4] To be eligible, a person must: be aged 18 years or over, be a citizen or permanent resident of New Zealand, suffer from a terminal illness that is likely to end their life within 6 months, be in an advanced state of irreversible decline in physical capability, experience unbearable suffering that cannot be relieved in a manner that the person considers tolerable, and be able to make an informed decision about assisted dying.

condition and/or reduce their suffering. While people may be physically impaired, to be eligible they also need to be able to make an informed decision about assisted dying.

22. The settings where people spend their final months, weeks and days depend on their condition, care needs, and other circumstances. As some people get closer to the end of their life they may be moved to aged residential care, hospice and/or hospital to provide for their care needs. Others can remain in their home if they have the right supports around them. A large proportion of those who die from cancer are supported to die at home.

23. There is likely to be a preference from many of those seeking assisted dying to be supported to die at home. This reflects both experiences from overseas jurisdictions, as well as the high importance that New Zealanders place on concepts of home and whenua.

24. Dying at home won't be an option for some people. This may be due to medical reasons, such as being unable to travel, because they are living in an aged residential care that doesn't allow for assisted dying, or because their home is not a suitable place to spend their final days.

The families/whānau of people seeking assisted dying will need support

25. Supporting a family or whānau member who has a terminal illness places significant pressure on family members who may have a number of support needs including information, financial support, respite care, and support responding to a range of emotional responses (eg, anger, resentment, denial, anxiety, depression, guilt and grief).

26. The prospect of a terminally ill family member seeking assisted dying will add to this pressure, and complicate support needs. The needs of a family/whānau supporting someone seeking assisted dying may include the following.

   a. Having information about all elements of the process, including how they can be involved (eg, being with the person when they die, what to do if they are concerned about whether the person is capable of making this decision).

   b. Emotional support including counselling, hui and conflict resolution – there may be division within families between those who support a decision to seek assisted dying and those who oppose it.

   c. Cultural and spiritual support – such as addressing the health of the individual in the context of the health of the whānau, and support to observe and uphold tikanga Māori.

   d. Support related to care of the family member after death.

27. While family can be a significant source of support to people at the end of their lives, family members can also create significant challenges. Some family members may seek to actively prevent someone from seeking assisted dying where they strongly disagree with it. There is also the potential for family members (and others) to seek to coerce someone who is terminally ill to seek assisted dying where they would not do so otherwise. Coercion is prohibited under the Act.

28. Both of these behaviours create challenges for medical practitioners and other health workers involved in someone's care. They will need to be alert to these situations and

supported to make what will sometimes be difficult decisions that may involve them challenging the expectations of family members.

The availability of willing medical practitioners is critical to providing for assisted dying

29. Medical practitioners who agree to provide assisted dying services will be the central workforce for providing assisted dying, as most of the process set out in the Act is driven by them.

30. The number of medical practitioners who are willing to provide assisted dying services will impact on where services are provided, how accessible they are, and the extent to which people are able to exercise choice. The fewer medical practitioners there are who are willing to provide assisted dying, the greater the pressures are likely to be on those who are willing – eg, more people seeking assisted dying per practitioner.

31. Only a small proportion of medical practitioners are likely to be willing to participate in assisted dying, as a large proportion of medical practitioners are known to hold objections to assisted dying.

32. Many of those who support the availability of assisted dying in principle may be cautious about committing to provide assisted dying in practice. This may reflect concerns about:

    a. direct hostility from members of the community – eg, having their practices boycotted or attacked by those who oppose assisted dying

    b. indirect hostility and stigma – eg, being viewed negatively by patients, or shunned by professional colleagues

    c. the psychological and emotional pressures involved in providing assisted dying

    d. the additional scrutiny of their clinical practice associated with assisted dying.

33. Medical practitioners may also be cautious about being involved because assisted dying is new, or because they don't consider that sufficient guidance, training or other support has been provided.

34. Government decisions about how assisted dying services are to be funded, provided and supported are likely to have some influence on the number of medical practitioners who are willing and able to provide assisted dying services.

35. We expect that those who do agree to participate are likely to be a mixture of general practitioners and specialists in areas including oncology, neurology, and palliative medicine.

36. Among medical practitioners there are some smaller groups that will be particularly critical to the availability of assisted dying services for some people. For example:

    a. **Psychiatrists**, who will play a critical role determining whether or not people are competent to request assisted dying in situations where the attending medical practitioner and/or the independent medical practitioner are uncertain. Psychiatrists are a limited workforce, and if few psychiatrists are willing to participate, then access to assisted dying may be reduced for some people.

    b. Although all health professionals have obligations to be responsive to the needs of Māori, **practitioners who identify as Māori**, and practitioners from other ethnic groups are also a key group, as they are well placed to provide culturally responsive services, and support their colleagues to provide assisted dying in a way that addresses the cultural needs of particular groups.

c. **Nurse practitioners** will also have a role in assisted dying services. Nurse practitioners will not be involved in determining eligibility for assisted dying, but once someone has been found eligible, and has decided on a date/time to die, attending nurse practitioners can prescribe life-ending medication, provide or administer the medication, and be available to the person until they die. Nurse practitioners are more likely to work in rural areas and in underserved communities.

37. We are currently undertaking a survey of medical practitioners, psychiatrists, nurse practitioners and pharmacists to understand the current views of these workforces, and what areas they are interested in hearing about as implementation progresses. Results are expected in March 2021.

The way organisations respond to assisted dying will also have an impact on services

38. In New Zealand palliative and end of life care is provided in a number of settings, including hospitals, aged residential care, hospices, and in the community (at home). During the final days, weeks and years of a person's life, a care pathway may see someone receive care in one setting or move between settings depending on their needs.

39. The way that the organisations responsible for care in these settings respond to assisted dying will have an impact on where and how people can access assisted dying services.

40. The Act is silent on the role of organisations in assisted dying, meaning that non-government organisations are not required to provide assisted dying services if they do not want to.

41. A number of organisations that operate or represent hospices have publicly stated that they oppose and will not provide assisted dying, including Hospice New Zealand[5]. Some umbrella organisations representing aged care providers have also stated that they will not provide for, or allow assisted dying in their facilities.

42. There is some uncertainty around whether organisations who object to assisted dying can prohibit any willing medical practitioners or other staff who work for them from facilitating assisted dying. Legal advice is that an organisation can prohibit staff from providing assisted dying services within their facilities, but cannot prevent staff from providing services in other settings when they are not employed or contracted by the organisation.

43. Many organisations may try to take a 'neutral' position to assisted dying. This might involve allowing staff to participate (eg, to perform assessments and provide advice), while avoiding doing anything that might be viewed as actively supporting assisted dying (eg, limiting whether/where people can be supported to die within facilities).

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[5] Hospice New Zealand also sought a declaratory judgement from the High Court in September 2020 to confirm that non-government organisations cannot be required to provide for assisted dying services.

44. Decisions by organisations will have an impact on the care pathways that some people can receive. For example: people who seek or may want to seek assisted dying may not be able to receive care in facilities run by an organisation that prohibits assisted dying, such as hospices, or may need to be transferred to other services if they want to receive assisted dying.

45. Regardless of the position taken by organisations, they will need to ensure that their staff can meet the requirement under the End of Life Choice Act to refer people seeking assisted dying to Support and Consultation for End of Life in New Zealand (SCENZ).

46. DHBs are subject to different requirements from other health care organisations, as they are funded directly by the Government to plan and provide health care services. DHBs can be required to provide specific health services.

We have examined what an effective system to provide for assisted dying needs to do

47. We have determined what an effective system to provide for assisted dying needs to do, based on what we know about the interests of different groups, the design of systems overseas, and our design principles for this work, including Te Tiriti o Waitangi considerations.

48. An effective system to provide for assisted dying is one that:

   a. makes assisted dying accessible and equitable by:

      i. ensuring clear and accessible information is available for people wanting to know about assisted dying, and their families, and that this can be accessed easily

      ii. allowing applications to be made and for people to receive services in a variety of different settings, and close to where they live, or possibly even at home (avoiding the need for significant travel where possible)

      iii. ensuring that cost is not a barrier to accessing services

      iv. ensuring that the service is provided in a timely manner (to limit uncertainty and suffering), subject to the requirement for appropriate safeguards

      v. ensuring that processes after death are straightforward, respectful, and do not hinder normal grieving processes and cultural considerations.

   b. ensures that the process to provide assisted dying is safe by:

      i. incorporating safeguards to actively detect coercion, and situations where people may be incapable of making an informed decision

      ii. making assessments that are supported by robust clinical guidance, and including processes to ensure the competence of decision makers and the rigor of decision-making processes

      iii. providing good public information on the operation of the system (transparency)

      iv. ensuring that all decisions to assist someone to die are subject to some form of review (accountability)

c. provides choice and control to those seeking assisted dying, and supports their whānau to be involved as appropriate by:
    i. allowing people to access services and be assisted to die in a setting of their choice (where this is possible)
    ii. allowing people to make decisions about how and when they want to be assisted to die
    iii. allowing for whānau to be involved in decisions where this is appropriate (where the person seeking assisted dying agrees)
    iv. allowing people to receive services that are culturally responsive to them, and those who are supporting them.

d. supports and maintains the wellbeing of those who provide assisted dying by:
    i. providing good training and clinical support to health professionals
    ii. ensuring they are aware of the practices they need to follow to keep themselves safe, and are well-trained to do so
    iii. providing emotional, psychological and cultural support.

49. Some of these points are already addressed through the process set out in the Act (eg, provisions to provide safeguards and allowing people to choose when and how they want to be assisted to die). Others will depend on how assisted dying services are provided.

50. There are also some natural tensions between some of these that will need to be navigated. For example:

a. there is a tension between the desire for assisted dying processes to be provided in a timely manner and the need to ensure that appropriate safeguards are applied

b. there is a tension between a desire for services to be accessible for people in all areas, and the need to ensure that medical practitioners have good access to clinical support, which may be more challenging if services are provided in remote areas.

We have identified two approaches the Government could take to provide for assisted dying services

51. We have identified two high level approaches that the Government could use to provide for assisted dying services in New Zealand.

52. The first approach would involve supporting any medical practitioners who are suitably qualified and willing to provide assisted dying, by providing funding for assisted dying services on a fee-for-service basis, along with some central support in partnership with SCENZ.

53. Under this approach the Ministry of Health (the Ministry) would be responsible for administering funding for assisted dying services, and have some oversight of provision. Funding would also be provided to DHBs to recognise the cost of any provision by staff within their services who may want to provide services.

54. This approach has some similarities to the way maternity services are currently funded, allowing people to choose the provider and setting where they receive services, with the costs funded directly by the Ministry.

55. The second approach would involve making DHBs responsible for ensuring that a level of assisted dying service provision is available. DHBs would be provided with additional population-based funding to provide for assisted dying services, and assisted dying would be added to the Service Coverage Schedule which sets out services that DHBs are required to plan and provide for.

56. Under this approach, DHBs would be responsible for administering funding for assisted dying services, determining the locations and settings where services are provided, whether/how assisted dying services are integrated with other care, and the capacity of services.

57. The second approach reflects the way most health services are currently funded, including other end of life and palliative care services.

58. We considered a third approach, which would involve the Ministry contracting non-government organisations or private providers to deliver assisted dying services. However, we do not believe this would be viable. The relatively small scale of demand for assisted dying combined with sensitivities related to assisted dying in the health sector mean that there are unlikely to be organisations that would be willing to enter into such arrangements. There are also some provisions in the Act that could complicate the provision of services by contracted providers[6].

We have compared the approaches based on how they could support an effective system

59. The table below sets out how the two approaches compare in terms of supporting accessibility and equity, choice and control, and the wellbeing of those providing assisted dying. It also notes some specific benefits and issues associated with each approach.

Approach One - Support any medical practitioners who are suitably qualified and willing to provide assisted dying, by providing funding for assisted dying services on a fee-for-service basis, along with some funding to DHBs to recognise the cost of any provision by staff within their services. The Ministry would be responsible for administering funding and have some oversight of provision	**Approach Two** – Make DHBs responsible for ensuring that a level of assisted dying service provision is available across New Zealand, and provide additional funding to provide for assisted dying services. DHBs would be responsible for administering funding for assisted dying services and determining where and how services are provided.

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[6] These include a provision that prohibits organisations from providing employment or other benefits to staff that are conditional on them providing assisted dying services.

What it means for access and equity	Seeks to address access by maximising the number of medical practitioners who can provide funded services – any suitable practitioner can receive funding for providing services. Potential for people to be able to access service in a range of geographic areas, and settings, though access may be limited if there are areas with no/few willing practitioners. Potentially removes cost as a barrier for all people, whether they receive assisted dying services through public or private health services.	Seeks to address access by seeking to ensure a minimum level of provision across New Zealand through DHBs. Potential for people to be able to access services in a range of geographic areas, but this depends on how DHBs decide to provide for services. Access to services may vary in different areas depending on whether they are provided locally, regionally, or nationally[7]. Potentially removes cost as a barrier for people who receive services from DHBs.
What it means for choice and control	Encourages choice by enabling any suitable practitioners to provide funded services, including those working for smaller and culturally responsive providers. People can choose to receive a funded service from any willing practitioner, including their regular medical practitioner if the practitioner is willing and able. Choice may be limited if there are few willing practitioners in a particular area. Choice may be influenced by the level of funding that is available – eg, whether funding supports practitioners to travel to deliver services.	More limited choice as people either need to use funded services provided by DHBs or pay to access services from any non-DHB funded practitioner/provider. Whether or not people can receive a funded service from their regular medical practitioner will depend on whether this practitioner is part of a DHB's assisted dying service. Choice may be influenced by the level of funding that is available – eg, whether DHB funding supports practitioners to travel to deliver services.

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[7] The way DHBs provide abortion services illustrates how access to services can vary. While DHBs are required to provide for abortion services, access depends on the level of provision in a region. For example: people in Counties Manukau and the West Coast need to travel outside their DHB region as services are provided regionally rather than locally, while others can access local services within their DHB region.

What it means for supporting workforce wellbeing	May reduce pressure on individual medical practitioners by allowing demand for services to be spread across more people. Provides flexibility for medical practitioners to make case-by-case decisions about when and who they are willing to provide assisted dying services to (eg, existing patients). May make establishing and maintaining support networks more complex if practitioners are widely spread out or working in remote areas.	Support systems and networks can be developed within DHBs, including potentially using existing structures and processes. The need to support practitioners may encourage DHBs to provide services from one or more central 'hub' locations where there they can establish communities of willing practitioners, rather than across a range of different areas.
Other potential benefits	Potentially supports organic growth and innovation of assisted dying services, as it creates a level playing field in terms of receiving funding – assisted dying services are funded regardless of the size of an organisation or how many people they provide assisted dying services to. Involves using an existing mechanism (Section 88 notices under the New Zealand Public Health and Disability Act 2000) and payment systems that are already established within the Ministry.	Potentially allows assisted dying to be connected with the other care that people already receive through DHBs. However, DHBs may want to keep assisted dying provision at arms-length from their other activities given strong views among parts of the communities they serve, and the legal requirement to allow their staff to conscientiously object to being involved.
Other considerations	Organisations that employ medical practitioners (including DHBs) would need to make decisions about whether/how they will allow willing staff to participate (eg, by allowing them to conduct assessments as part of their normal practice). A fee-for-service approach to funding may attract criticism that assisted dying is receiving special or more generous treatment compared to palliative care, depending on the nature of	Potential for those who oppose assisted dying to seek to limit any provision through protest. There is also some additional risk of legal challenges to planning and funding decisions by DHBs based around the adequacy of community consultation. Implementation by DHBs may be complicated by the relatively limited timeframe before services are required, and how this fits with

	funding provided. Palliative care is partly funded by Government with some components (eg, grief and bereavement services) typically funded through charitable donations.	the timing of their annual planning processes.

60. We have not compared the approaches in terms of how they support safety because safeguards for assisted dying (set out in legislation and through professional requirements) would apply equally under both approaches. We plan to provide you with some specific advice on safeguards in a future briefing.

Approach One is likely to provide for the greatest degree of access to services and choice

61. Assuming that there is a desire for the Government to take steps to ensure the provision of assisted dying services, we recommend adopting Approach One, providing funding for assisted dying services on a fee-for-service basis, along with some funding to DHBs to recognise the cost of any provision by staff within their services.

62. While there are arguments to be made for both approaches, we consider that Approach One is more likely to result in the successful provision of assisted dying services because it:

    a. has the greatest potential to support access and choice for people seeking assisted dying services

    b. provides a high level of flexibility for medical practitioners who choose to be involved

    c. will allow the many uncertainties associated with providing assisted dying services, such as unknown levels of demand for services, to be monitored and responded to centrally.

63. Providing for assisted dying services this way also provides options to revisit and change the approach in future as services become operational and we become more familiar with the complexities of providing assisted dying. Future decisions could be made in light of other decisions taken as part of the government response to the Health and Disability System Review and any decisions taken on the palliative care system.

64. The key issue with this approach is the potential for gaps in access in areas where there may not be willing medical practitioners available. This issue applies equally to Approach Two as it is unlikely that services would be established by DHBs in areas where there are not willing medical practitioners to provide them. The result is that some people may need to travel longer distances than others to access services.

The approach that is chosen will determine the further decisions to be made

65. Once an approach has been chosen, there will be subsequent decisions to be made to determine exactly how this will be applied. The exact decisions will depend on the approach chosen, but they will involve determining funding, clinical governance and accountability settings, including:

    a. the volumes and levels of service that should be funded

b. whether funding should vary to recognise the needs of different groups (eg, culturally responsive services for Māori), or different levels of service (eg, costs to provide services in more remote areas)

c. whether funding should include ancillary services that are not directly connected to assisted dying, such as counselling and bereavement support

d. whether other potential sources of funding and targeting mechanisms such as co-payments and income tests should apply

e. the extent to which funding is required to support centralised training and co-ordination of services

f. whether there should be requirements or conditions attached to funding, and what these should cover

g. what clinical governance may be required to oversee service provision

h. the mechanisms to be used and the level of direction to be provided to and by the Ministry and DHBs.

66. These decisions will help to determine the cost of assisted dying services, which is currently represented by the $25 million contingency in the Budget bid referenced previously.

The approach that is chosen will also influence how the Crown engages with Māori on service design

67. As part of our work on assisted dying we have examined what the key Te Tiriti o Waitangi considerations are related to assisted dying, from a Crown perspective.

68. In summary these involve:

a. Tino rangatiratanga - Māori being able to self-determine their involvement with assisted dying and the way in which they are involved (including collective decision-making with whānau). The Act focuses on decision making by individuals, but there is scope to consider how whānau can be supported to participate in decision making where the person seeking assisted dying agrees.

b. Options - Māori being able to receive assisted dying services that address their cultural needs including supporting tikanga Māori, the involvement of Rongoā practitioners, and ritenga Māori.

c. Equity – assisted dying services are equally accessible to Māori in terms of location, time to access services, and connection to existing health services accessed by Māori. Services provided to Māori and non-Māori need to be of equal quality.

d. Active protection – Māori being protected from harm, including addressing risks related to coercion, and taking steps to address the risk of Māori being overrepresented among those seeking assisted dying because their medical conditions (eg, cancer) are diagnosed later, or not treated equally, or because of difficulties accessing palliative care and support.

e. Partnership - Māori being involved in the design, delivery and monitoring of assisted dying services.

69. Both approaches to providing for assisted dying services will allow these points to be considered and addressed in future aspects of design (eg, by developing guidelines to

encourage the involvement of whānau wherever possible, and considering whether funding should be used in a way that seeks to support culturally responsive services).

70. The approach that is chosen will determine whether responsibility for engaging with Māori on the design, delivery, and ongoing monitoring of assisted dying services sits with the Ministry (Approach One) or DHBs (Approach Two).

Outcomes from assisted dying may be influenced by the accessibility and effectiveness of palliative care

71. There is a complex relationship between assisted dying and palliative care, with varying and often strongly held views of assisted dying among those who are involved in providing palliative care.

72. Assisted dying may be viewed as an alternative to palliative care, though the extent to which it is considered a direct alternative will vary depending on whether someone believes that palliative care can mitigate suffering before death. Some people who seek assisted dying may already be receiving palliative care.

73. Regardless of the position people take on this relationship, there is agreement that:

    a. everyone who seeks assisted dying should be made aware of the support that is available to them through palliative care – the Act requires that people seeking assisted dying understand their other options for end-of-life care

    b. no one should seek assisted dying simply because they are unable to access palliative care, or cannot access a level of care that they believe would alleviate their suffering.

74. Concerns have been expressed that particular groups who have more difficulty accessing palliative care, including Māori, might be more likely to request assisted dying because they are unable to receive sufficient palliative care.

75. In a report that we provided to you in November 2020 *Improving the sustainability and equity of palliative care* [HR20202063] we noted that while there are good quality palliative care services available in New Zealand, there is currently no clear national picture of delivery capacity and quality, and that user experience varies with underlying equity issues.

76. It is estimated that palliative care services are needed by 24,000 people in New Zealand, but may be overlooking up to 11,000 people (including up to 1,600 Māori). This is primarily due to services having a 'cancer-centric' focus.

77. We note that in other jurisdictions where assisted dying has been introduced, this has often been accompanied by an additional investment into palliative care, as a way to improve access and quality of services and address the concern referenced above.

78. A briefing that provides an update of the palliative care work programme including initial advice on investment options to improve palliative care in the short term is planned for March 2021.

Equity

79. In the context of assisted dying, ensuring equity means addressing:

    a. equity of access – ensuring that no group will experience issues that prevent them from accessing assisted dying services when they would otherwise be eligible

    b. equity of service level – ensuring that assisted dying services provided to different groups are equally effective in addressing the needs of those seeking assisted dying and their whānau

    c. equity of outcome – ensuring that particular groups are not over or underrepresented among those who receive assisted dying because of inequities in healthcare (eg, due to unequal access to treatment or palliative care).

80. We have sought to ensure that all of these dimensions of equity are considered and addressed in our work, by making equity one of our design principles.

81. Consideration of equity in this briefing has included:

    a. using equity as a key criterion to assess the potential approaches to provide for assisted dying services

    b. identifying key Te Tiriti o Waitangi considerations related to assisted dying which include equity

    c. noting the connection between inequities in access to palliative care and the potential for this to impact on outcomes from assisted dying – with further work planned to address this.

Next steps

82. A decision is sought about whether the Government should take active steps to ensure that assisted dying services are available, and if so, which of the two approaches outlined in this paper should be used.

83. We can meet with you to discuss this further and provide further information if needed.

84. When an approach is agreed we will provide you with a further briefing on the subsequent decisions that are required to determine how this will be applied. This will help to determine the level of funding that is required to provide for assisted dying services as part of Budget 2021.

85. Given the sensitivity associated with assisted dying, and the absence of an explicit direction in the Act for the provision of services, you may want to consider whether decisions on providing for assisted dying services should be sought or confirmed by Cabinet.

86. We could develop a Cabinet paper that would focus solely on the high-level approach to be taken (the decisions sought in this briefing) or include decisions on funding and accountability settings as well (to be provided in a subsequent briefing). We could provide you with further advice on this including potential timings through the weekly update.

87. In addition to advice on providing for assisted dying services, we are also preparing advice that will cover:

a. Our implementation plan and stakeholder engagement approach – briefing to be provided in early March 2021

b. Legal and regulatory issues related to assisted dying – briefing to be provided by the end of March 2021

c. Safeguards related to assisted dying – to be provided in April 2021.

Appendix A – Different components of the assisted dying process, based on the End of Life Choice Act

When we refer to assisted dying services, we include the following activities:

- The initial consultation between a person and an attending medical practitioner where a request is made for assisted dying and an application is completed
- The first assessment by the attending medical practitioner to determine whether a person is eligible for assisted dying
- The second assessment by an independent medical practitioner to determine whether a person is eligible for assisted dying
- An assessment to be provided by a psychiatrist to determine whether a person is competent to request assisted dying (if this has not been established to the satisfaction of the attending and/or independent medical practitioner)
- Actions to allow a person who is eligible for assisted dying to determine when this will occur and the method to be used
- The administration of assisted dying by a medical practitioner or nurse practitioner, including remaining until the person has died.
- Any post-death support that needs to be provided.

This reflects the steps set out in the End of Life Choice Act, which involve the following process.

Request made for assisted dying

Person who wants assisted dying informs an attending medical practitioner.

If the medical practitioner has a conscientious objection to providing assisted dying they must let the person know that they can contact the SCENZ Group for the name and contact details of a replacement medical practitioner.

The attending medical practitioner (or replacement medical practitioner) must:

- explain the prognosis for the person's terminal illness, the irreversible nature of assisted dying, and the anticipated impacts of assisted dying
- communicate by any means with the person about the person's wish at intervals determined by the progress of the person's terminal illness
- ensure that the person understands their other options for end-of-life care
- ensure that the person knows that they can decide at any time before the administration of the medication not to receive the medication
- encourage the person to discuss their wish with others such as family, friends, and counsellors
- ensure that the person knows that they are not obliged to discuss their wish with anyone
- ensure that the person has had the opportunity to discuss their wish with those whom they choose
- do their best to ensure that the person expresses their wish free from pressure from any other person by conferring with other health practitioners who are in regular contact with the person and conferring with members of the person's family approved by the person
- record the actions they have taken.

The attending medical practitioner and person seeking assisted dying (or a representative if they can't write) fill in a form confirming the request for assisted dying and the form is sent to the registrar.

First opinion to be given by attending medical practitioner

Medical practitioner undertakes assessment to determine whether the person is eligible for assisted dying. This includes determining whether the person:

- suffers from a terminal illness that is likely to end their life within six months
- is in an advanced state of irreversible decline in physical capability
- is experiencing unbearable suffering that cannot be relieved in a manner that the person considers tolerable, and
- is competent to make an informed decision about assisted dying.

This assessment is likely to require discussion with the person (e.g. about their level of pain and suffering), and depending on the practitioner's knowledge of the person they may also need to conduct additional examinations, seek additional specialist diagnosis/testing and review clinical notes from specialists.

While doing the assessment the practitioner will also be vigilant for any signs of coercion.

Once the assessment has been made a form is sent to the registrar.

Second opinion sought from an independent medical practitioner

Independent medical practitioner identified by SCENZ Group undertakes an assessment to determine whether the person is eligible for assisted dying. This includes determining whether the person:

- suffers from a terminal illness that is likely to end their life within six months
- is in an advanced state of irreversible decline in physical capability
- is experiencing unbearable suffering that cannot be relieved in a manner that the person considers tolerable, and
- is competent to make an informed decision about assisted dying.

This assessment will require discussion with the person (eg, about their level of pain and suffering), examination of the person, along with the review of relevant clinical notes from specialists.

While doing the assessment the practitioner will also be vigilant for any signs of coercion.

Once the assessment has been made a form is sent to the registrar.

Third opinion given by psychiatrist *(if required)*

A third opinion is sought from a psychiatrist identified by the SCENZ Group if the person's competence to request assisted dying has not been established to the satisfaction of one or both of the medical practitioners.

Once the assessment has been made a form is sent to the registrar.

Person eligible for assisted dying determines when this will occur and method for receiving life-ending medication

If the person is found to be eligible for assisted dying, the attending medical practitioner must:

- advise the person that they are eligible for assisted dying
- discuss with the person the progress of the person's terminal illness
- discuss with the person the likely timing for the administration of the medication
- give the person a form to complete by choosing the date and time for the administration of the medication
- advise the person that at any time after completing the approved form the person may decide not to receive the medication, or to receive the medication at a time on a later date that is not more than 6 months after the date initially chosen for the administration of the medication
- advise the person about the methods for the administration of the medication
- ask the person to choose one of the methods
- send the form to the registrar

- make provisional arrangements for the administration of the medication on the chosen day and time.

At least 48 hours before the chosen time for the administration of the medication, the attending medical practitioner, or an attending nurse practitioner, must:

- write the appropriate prescription for the eligible person
- advise the Registrar of the method and date and time chosen for the administration of the medication.

Administration of assisted dying

At the chosen time for the administration of the medication, the attending medical practitioner, or an attending nurse practitioner, must ask the eligible person if they:

- choose to receive the medication at that time, or
- not to receive the medication at that time, but to receive the medication at a time on a later date that is not more than 6 months after the date initially chosen for the administration of the medication, or
- not to receive the medication at that time, and to rescind their request to exercise the option of assisted dying.

If the eligible person chooses to receive the medication, the attending medical practitioner, or the attending nurse practitioner, must provide and/or administer the medication.

The attending medical practitioner, or the attending nurse practitioner, must be available to the eligible person until the person dies, or arrange for another medical practitioner or attending nurse practitioner to be available to the person until the person dies.

Within 14 working days of a person's death as a result of the administration of medication the attending medical practitioner, or the attending nurse practitioner who provided or administered the medication must send the Registrar a report.

The Registrar must send the report to the Review Committee.

Document 3

MINISTRY OF HEALTH
MANATŪ HAUORA

Briefing

End of Life Choice Act – Providing Medicines for Assisted Dying

Date due to MO:	8 April 2021	**Action required by:**	22 April 2021
Security level:	IN CONFIDENCE	**Health Report number:**	20210278
To:	Hon Andrew Little, Minister of Health		

Contact for telephone discussion

Name	Position	Telephone
Dr Ashley Bloomfield	Director-General of Health	s (9)(2)(a)
Caroline Flora	Group Manager Family and Community Policy, System Strategy and Policy	s (9)(2)(a)
Olivia Payne	Senior Solicitor, Corporate Services	s (9)(2)(a)

Minister's office to complete:

☐ Approved
☐ Needs change
☐ See Minister's Notes

☐ Decline
☐ Seen
☐ Withdrawn

☐ Noted
☐ Overtaken by events

Comment:

End of Life Choice Act – Providing Medicines for Assisted Dying

Security level:	IN CONFIDENCE	**Date:**	8 April 2021
To:	Hon Andrew Little, Minister of Health		

Purpose of report

1. This report advises you on issues that have been identified related to the regulation of medications to be used for assisted dying under the End of Life Choice Act 2019 (the EOLC Act).

Summary

2. Clarity about the legal basis upon which medicines will be prescribed and supplied to patients seeking an assisted death will be important to ensure that health practitioners can feel confident providing assisted dying services.

3. The EOLC Act refers to the supply and administration of "medications" for assisted dying, and it is apparent that Parliament's intention was that medications for assisted dying should be regulated as medicines under the Medicines Act 1981. However, we consider that the regulatory status of medicines for assisted dying could be clearer.

4. The Medicines Act 1981 (the Medicines Act) defines medicines by reference to the concept of "therapeutic purpose". The legal definition of this term in the Medicines Act is broad enough to encompass medicines provided for the purposes of assisted dying services. This is because these medicines influence a physiological process and are provided to alleviate suffering from the underlying terminal condition. On this basis, the Ministry of Health (the Ministry) considers that all proposed medications to enable assisted dying are regulated under the Medicines Act. However, the term "therapeutic purpose" may cause some uncertainty for health practitioners.

5. To avoid doubt, regulations could be made under the Medicines Act to clarify that medications provided under the EOLC Act are medicines under the Medicines Act, as they affect a physiological process and relieve suffering caused by a terminal illness. This is consistent with advice previously provided by officials to the Select Committee considering the End of Life Choice Bill and would be consistent with the approach taken in the Abortion Legislation Act 2020.

6. Making regulations would take approximately two to three months to complete and is not expected to affect the successful implementation of the EOLC Act. If you choose to proceed with this option, regulations would be made under section 105 of the Medicines Act and would involve a minor and technical amendment. As such, we recommend that you would not need to consult with any organisations or entities, as there are no persons likely to be substantially affected by this regulation.

7. We are also working to respond to some other issues that have been identified involving the interface between the EOLC Act and the Medicines Act.

8. One issue involves the need for the Support and Consultation for End of Life in New Zealand (SCENZ) group to be able to provide guidance and practical assistance to health practitioners, including information about appropriate medications for use as part of assisted dying. This needs to occur to support practitioners, while ensuring that this guidance does not constitute advertising, which is prohibited under section 20 of the Medicines Act. We plan to address this by placing limits on how information is accessed about specific medications for assisted deaths, so that this is only available to participating practitioners. This will also support public safety.

9. A second issue involves some uncertainty about who makes decisions about the medicine to be used. Under the Medicines Act (and also the Health Practitioners Competence Assurance Act 2003 and Health and Disability Commission Code of Patient's Rights), a prescriber is responsible for a prescribing choice, while the EOLC Act states that the person seeking assisted dying should choose which method is used (which would influence the medications to be used). In most cases we expect that an eligible person would take on advice from a medical practitioner when making their decision, but it is conceivable that there may be cases where the practitioner and patient disagree. This issue will be managed through the provision of guidance to practitioners.

10. The Ministry is also considering other operational matters for how medicines will be provided for assisted dying including when prescriptions will need to be written, filled, and destroyed and who will hold and manage medicines before they are administered.

11. There is significant work underway to progress the Therapeutic Products Bill which will ultimately repeal and replace the Medicines Act and is expected to address a number of the issues raised in this report in the medium term. We provided you with advice on the Therapeutic Products Bill on 14 December 2020 [HR 20202242 refers].

Document 3

Recommendations

We recommend you:

a) **Note** that to implement the End of Life Choice Act 2019 we need a willing workforce and providing greater clarity about the legal status of medicines is expected to facilitate this.

b) **Note** that the Ministry is comfortable that the Medicines Act 1981 would regulate medicines for assisted dying, but there is an opportunity to provide certainty that this is the case, and greater clarity that prescribers are enabled to be supplied and to provide medicines for assisted dying as part of the care and treatment of a patient.

c) **Agree** to make a regulation under the Medicines Act 1981, that improves clarity for both matters by affirming that medicines for assisted dying are to be considered medicines under the Medicines Act, and that they will treat eligible people by alleviating suffering that is intolerable to them (recommended). **Yes/No**

OR

Agree to proceed implementation of the End of Life Choice Act 2019 without making a regulation under the Medicines Act 1981. **Yes/No**

d) **Agree** to authorise the Ministry to instruct Parliamentary Counsel Office to draft a regulation to give effect to the decision in (c). **Yes/No**

e) **Agree** to proceed with making a regulation (if agreed in (c)) without consultation, as this is a minor and technical amendment and there are no persons likely to be substantially affected by the regulation. **Yes/No**

f) **Note** that the SCENZ group's statutory role enables them to provide guidance about medicines for assisted dying, but that we plan to restrict access to this information to reduce the risk of this being viewed as advertising, and to ensure public safety.

g) **Note** that there is an implied difference in decisionmaker between the Medicines Act 1981 and End of Life Choice Act 2019 about which medicines to use, which is unlikely to be an issue in most assisted dying cases but could create legal uncertainty, which will be managed through the provision of guidance to practitioners.

Maree Roberts
Deputy Director-General
System Strategy and Policy
Date:

Hon Andrew Little
Minister of Health
Date:

End of Life Choice Act – Providing Medicines for Assisted Dying

Context

1. The End of Life Choice Act 2019 (EOLC Act) originated as a member's Bill which passed through select committee and other parliamentary processes and received Royal assent in November 2019. The Ministry of Health (the Ministry) supported the select committee by providing advice on matters that were of interest to members.
2. We interpret that the intent of Parliament was that medicines used for assisted dying would be managed by existing medicines regulatory schemes within New Zealand. Medicines in New Zealand, including their supply and prescribing, are controlled by the Medicines Act 1981 (the Medicines Act) and associated regulations.

Therapeutic Products Bill

3. There is significant work underway to progress the Therapeutic Products Bill which will repeal and replace the Medicines Act 1981. The Medicines Act is outdated and has not adequately kept pace with technological change. Some of the examples outlined in this report about the interaction of the Medicines Act with the EOLC Act can be viewed as further examples of this.
4. In the longer term the Therapeutic Products Bill will address a number of the issues raised in this report as part of a modern and comprehensive regulatory scheme for therapeutic products. The Ministry is continuing to progress policy necessary to finalise the Bill, with a view to introducing it to Parliament in late 2021 or early 2022. The advice in this report therefore reflects measures necessary in the shorter term to support the EOLC Act when it comes into effect on 7 November 2021.

New pieces of legislation often have areas open to interpretation

5. The EOLC Act is new for the health and disability sector, and it is likely there will be some uncertainty regarding some aspects of it. Many practitioners and organisations will be looking to the Ministry of Health or the statutory bodies under the Act for clarity. We will ensure that, as far as possible, guidance from the Support and Consultation for End of Life in New Zealand (SCENZ) group supports the sector, although some areas will remain inevitably open to interpretation.
6. The implementation of the EOLC Act relies upon there being sufficient workforce to provide it. We have an interest in ensuring that medical practitioners are as comfortable as possible about their legal ability to provide assisted dying services to ensure there are medical practitioners willing to provide it.
7. A transition period where some areas of new legislation are not completely clear is not a novel situation. We need to strike a balance between providing surety for the workforce to support their involvement in the assisted dying service and allowing the natural clarification of new legislation to play out.

Matters about medicines for assisted dying that could be clarified

The regulatory status of medicines for assisted dying could be clearer

8. The EOLC Act enables assisted dying by specifying four methods for medicines to be administered or provided to an eligible person (section 19(2)). The EOLC Act does not specify anything about the supply or regulation of those medicines. However, the EOLC Act:
    a. uses terminology consistent with the medicines regulatory regime in New Zealand;
    b. amends other legislation to position the assisted dying service within the health and disability system; and
    c. appoints suitable professionals to roles where providing and prescribing medicines will be a required part of the assisted dying process.

9. We believe it was the intent of Parliament that the EOLC Act would rely on existing legislation and regulatory structures to govern the supply and use of medicines in assisted dying.

10. The Medicines Act defines medicines as substances used for a therapeutic purpose. Therapeutic purposes include influencing a physiological process, which we consider that medicines for assisted dying will do. We therefore consider that medicines for assisted dying are regulated by the existing legislation.

11. However, some medical practitioners may not feel this is sufficiently clear. Officials' advice to select committee was that regulations could be made under the Medicines Act during implementation to clarify that medications used for assisted dying are medicines as defined by the Medicines Act. The EOLC Act did not make this regulation.

12. Legal advice is that making a regulation that clarifies that assisted dying medications are medicines under the Medicines Act may assist to insulate practitioners from allegations that they have committed a crime against the Crimes Act 1961 section 200 – poisoning with intent. While it is unlikely that an offence is committed given the clear statutory intent that medications are able to be lawfully provided under the End of Life Choice Act 2019, this clarification is still considered desirable to reassure practitioners that they can lawfully prescribe assisted dying medicines in the same manner that they prescribe other medicines.

13. Comparable legislation (the Abortion Legislation Act 2020) amended the Medicines Regulations 1984 to explicitly state that substances used to terminate a pregnancy are medicines (see Appendix One). This creates certainty that all legal instruments that govern other medicines also govern medicines used for abortions. Legal advice is that consistency reduces the likelihood that those opposed to assisted dying could try to challenge the implementation of assisted dying by arguing that the absence of a clarifying provision similar to that in the Abortion Legislation Act 2020 means that medicines are not able to be lawfully prescribed for assisted dying, as otherwise a similar amendment would have been made.

We could also increase certainty for prescribers about providing assisted dying medicines

14. Prescribing off-label and unapproved medicines will be necessary to provide assisted dying as it is very unlikely medicines will be approved specifically for providing assisted dying. This places increased responsibility on prescribers.

15. A foundation of the medicines regulatory scheme involves the evaluation of the safety, quality and efficacy of medicines and their consent to market through the New Zealand Medicines and Medical Devices Safety Authority (Medsafe). Most often it is pharmaceutical companies that apply to Medsafe for consent to market in New Zealand, providing information on aspects such as the intended uses and dosage, as well as manufacturing data.

16. An application for medicines approval includes information that demonstrates the medicine meets New Zealand and internationally recognised standards for quality, safety and efficacy. Medsafe reviews this information and makes a recommendation to the Minister of Health as to whether the medicine is approvable, or otherwise.

17. Once a medicine is approved by Medsafe any authorised prescriber can provide it under section 25 *of the Medicines Act* to patients for their care, even if the use they are providing it for a purpose that was not part of the approval. This arrangement is referred to as 'off-label prescribing' and is common practice. For example, many medicines prescribed to children are 'off label' because clinical trials have not included children and the applicant has not applied for medicines approval for that age group.

18. Any medicine that is not approved by Medsafe (an unapproved medicine) can still be supplied to medical practitioners for treatment of a patient under their care pursuant to section 29 of the Medicines Act. Only medical practitioners can be supplied unapproved medicines for the treatment of a patient under their care.

19. Medsafe have advised that it is unlikely medicines used for providing assisted dying in New Zealand will be approved for this use. It is very unlikely a pharmaceutical company would apply for medicines to be used for assisted dying due to reputational risk, and the likelihood that demand in New Zealand will be limited to a small group of eligible people.

20. The Ministry has reviewed information about medicines used in other jurisdictions where assisted dying is legal. We have assessed suitability of these medicines alongside their availability within New Zealand and the administration methods required by the EOLC Act. We identified a number of medicines that are suitable for use in combination to bring about an assisted death by either intravenous, or oral administration and have determined which are likely to be most clinically suitable (to bring about death in the most straightforward manner with as little difficulty as possible). Some of those medicines are unapproved, and the others would be off-label for this use. The next steps are to discuss the sourcing of these medicines with PHARMAC, and we have begun to do so.

21. All the medicines we have identified as potentially suitable for assisted dying will need to be prescribed off-label or as unapproved medicines. Prescribers have increased legal and clinical responsibilities when providing off-label or unapproved medicines.

22. There needs to be a robust informed consent process when prescribing off-label or unapproved medicines. This includes a requirement that the prescriber advises the person that the medicine is not approved for the use it is being provided, or that it is unapproved and therefore the safety, effectiveness and quality cannot be guaranteed.

23. When authorised prescribers provide off-label medicines, including medical practitioners prescribing unapproved medicines, it is based upon their own clinical judgement that the medicine is required for treatment of a patient; and the practitioner is legally and clinically responsible for the decision they make. If authorised prescribers are not sufficiently certain that the medicine fits the definitions of the decisions they are enabled to make under the

Medicines Act, there is a risk that they will not do so. If practitioners do not feel comfortable that they have a lawful basis to prescribe under the Medicines Act, access to assisted dying will be reduced.

24. We have considered whether the Ministry could apply for approval of medicines for assisted dying with Medsafe to resolve this matter. We do not advise this, as this would muddy the relationship between the Ministry and Medsafe as an independent regulator, as well as provide a controversial precedent for the Ministry ensuring medicines for a certain purpose are considered for approval. The degree of benefit that this kind of resolution would provide is marginal as prescribing is already possible.

Given the responsibility on prescribers, improving clarity about the legal situation could be beneficial

25. The EOLC Act intends to provide medicines for assisted dying to alleviate unbearable suffering that an eligible person does not find tolerable. We interpret that:
    a. authorised prescribers are enabled to prescribe medicines off-label to care for eligible people by fulfilling their request to receive assisted dying (section 25 of the Medicines Act), and
    b. only medical practitioners can be supplied unapproved medicines for treatment of patients in providing assisted dying (section 29 of the Medicines Act).[1]

26. These sections of the Medicines Act rely on the terms “care” and “treatment” of patients. We consider that greater clarity for prescribers and suppliers of medicines about their legal ability to provide medicines for assisted dying can be achieved by clarifying that medications under the EOLC Act are medicines for the care or treatment of patients.

27. Improving clarity would provide more surety for prescribers and reduce risk that some choose not to be involved due to legal uncertainties. Unless this is clarified, practitioners might be concerned that they could be committing an offence, such as poisoning with intent under section 200 of the Crimes Act 1961. While the Ministry considers that no such offence arises, a short regulation to clarify that these are medicines that are able to be prescribed lawfully, not poisons, would potentially provide practitioners with greater certainty and confidence.

Options for providing further clarity

28. The Ministry considers that there is only a small risk that proceeding with implementation without clarifying the status of assisted dying medicines will result in challenge or confusion.

29. We can, and intend to, provide guidance to practitioners to improve clarity about the EOLC Act and the assisted dying service. However, that guidance would not be as authoritative as a regulation and may be less effective in alleviating practitioner concerns.

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[1] **Nurse practitioners cannot be supplied unapproved medicines as they are not medical practitioners who are the only prescribers permitted to be supplied under this section of the Medicines Act. Similar to the matters we previously advised you in your weekly report on 4 March 2021, this will also affect the ability of nurse practitioners to practically provide assisted dying without the involvement of a medical practitioner.**

30. However, we consider there would be benefit in taking a similar approach to that taken with the Abortion Legislation Act 2020, to provide ultimate clarity about this issue through the development of simple regulations. With your approval, we would make a regulation under the Medicines Act (section 103(1)(i)) that outlines that medicines for assisted dying are medicines under the Medicines Act as they are used to treat an eligible person by alleviating suffering. This would improve clarity for both matters.

31. Making a regulation would require work between the Ministry of Health and Parliamentary Counsel Office to draft the regulation, and require you to consult with parties likely to be affected. At this stage, given the regulation is intended to merely clarify the application of the Medicines Act 1981 is as intended by Parliament, we consider that there will be few, if any, parties who are affected and would need to be consulted with.

32. As this is a minor and technical change, we recommend that Parliamentary Counsel Office be instructed on the basis of this briefing if you agree to a regulation being made.

33. If this process is followed, we estimate that making regulations under the Medicines Act would take approximately two - three months, and this would not affect our overall implementation timeframe.

34. If we receive decisions from you by 22 April 2021, we propose the following timeframe for making the regulation:

Timeframe	**Activity**
22 April – 3 May	Making drafting instructions
3 May – 17 May	Parliamentary Counsel Office draft the regulation
17 May – 7 June	Consultation of the draft regulation (*Advice – consultation is not necessary given this is a minor technical amendment. If you agree not to consult this would bring timeframes forward*)
17 June	Lodging Cabinet Paper
Before end July	Regulation made by Governor-General

The Ministry is managing some matters about medicines for assisted dying

Guidance about medicines for assisted dying needs to be provided by the SCENZ group

35. Assisted dying will be a new field of clinical practice for health practitioners in New Zealand, and they will need clear guidance, training, and support about how to provide assisted dying. It is likely that practitioners want support to include guidance about which medicines should be used and in which doses. In the recent workforce survey for End of Life Choice, many respondents indicated they were concerned about the efficacy of drugs that will be used, and that they want information and reassurance that there will be safe and effective sedation/analgesia at time of death.

36. The practicalities of ensuring sufficient supply of medicines for assisted dying, and for practitioners to have clinical oversight of their practice, also makes it desirable to have a clear shared understanding among practitioners of which medicines to use. Without provision of suitable clinical information, it is unlikely that practitioners will be comfortable providing assisted dying as a new area of practice.

37. The responsibilities of the SCENZ group under the EOLC Act imply that they are intended by Parliament to be the source of information for practitioners about medicines for assisted dying. The Act outlines that the SCENZ group will prepare standards of care, advise on the required medical and legal procedures, and provide practical assistance if requested.

38. However, we consider that the information about medicines for assisted dying should be provided in a tightly controlled way to ensure safety for the public, in a similar basis as the restrictions on publishing information about suicide. This could be done through arrangements like requiring medical practitioners to be registered on the list of willing practitioners administered by the SCENZ group before they are provided information about medicines, for example.

s 9(2)(h)

[redacted]

There is an implied difference between the two Acts about who makes decisions

42. The Medicines Act gives prescribers the ability to prescribe medicines and to determine what is clinically appropriate. A prescriber is responsible for their prescribing choice. Regardless of whether the authorised prescriber uses approved or unapproved medicines, they must provide care of an adequate professional and ethical standard as described in the Code of Health and Disability Consumers' Rights. Supply of an unapproved medicine or an approved medicine for an unapproved use requires patient consent and must comply with the Code of Health and Disability Services Consumers' Rights.

43. Under the EOLC Act the eligible person is advised about the four methods for assisted dying and asked to choose one of them. Each method for assisted dying is likely to require different medicines, so this may imply that the patient makes the choice about medicines rather than the medical practitioner.

44. Officials' advice to Select Committee was to remove explicit reference to the four methods for delivery of medicines from the EOLC Bill. This was because:

    a. depending on the circumstance, some of the options may not be clinically suitable

    b. the Code of Health Consumers' Rights requires practitioners to discuss clinically suitable options to meet the patient's rights to informed consent

    c. the SCENZ group is required to provide advice about administration of medicines

    d. removal would future-proof the legislation if there were new or emerging technologies

    e. the person's clinical circumstances may change quickly and the process laid out in the EOLC Act makes it hard to quickly change the method if needed.

45. We believe that for most cases of assisted dying an eligible person would consider the medical practitioner's clinical advice in choosing which method for assisted dying is most suitable for them. However, there may be cases where the eligible person is adamant they want to take a method of assisted dying that the medical practitioner considers clinically unsuitable, or where there are no appropriate medicines available.

46. In those cases, it is unlikely the medical practitioner would act contrary to their clinical judgement; prescribing the required medicines for that method of assisted dying would be refused by the practitioner. s 9(2)(h) [redacted]

47. We consider this to be a real risk, but one that is unlikely to be common. We can provide medical practitioners with guidance that supports them to have discussions with eligible people about their choice between the four methods of assisted dying provided by the EOLC Act, to increase the likelihood that the individual's choice aligns with the practitioner's clinical judgement.

48. There are no relevant regulatory powers under either Act that could provide clarity in this case. The only way to entirely resolve it would be to amend section 19 of the EOLC Act, which we do not recommend due to implementation timeframes. You may wish to resolve this upon review of the Act.

Other matters about medicines for assisted dying

49. Some other matters about provision of medicines for assisted dying that the Ministry is working through and we expect can be addressed operationally include:

    a. what information will need to be provided in prescriptions for assisted dying

    b. when prescriptions will need to be written, filled, and destroyed (given the potential for people to defer the date of their assisted death for up to six months)

    c. who will hold and manage medicines before they are administered to provide the assisted dying service

d. how prescriptions and unused medicines will be disposed of.

50. We are currently exploring other areas where regulations may need to be made for any other matters and will provide you with advice on this as required. If other regulations need to be made, we will include those for consideration in the same Cabinet paper as any decision taken to make regulations under the Medicines Act.

Equity

51. Equitable access to assisted dying services could be obstructed if the available workforce is reduced due to uncertainty (or perceived uncertainty) about legal matters related to medications.

52. The quality of assisted dying services that different people receive will depend on practitioners having clear guidance and confidence to prescribe the most appropriate medicines for an eligible person in each instance.

53. There are equitable access implications for any eligible people seeking assisted dying who have strong views about which method of assisted dying they would choose that differ from a medical practitioner's clinical view. This could also have implications under the options principle of Te Tiriti o Waitangi which outlines that Māori should be able to choose kaupapa Māori services. The service could operate contrary to this principle if one method were considered by Māori to be more appropriate for them based on tikanga or other cultural considerations, yet prescribers decline to provide it based on dispute about the clinical suitability.

54. Given there are some aspects of the EOLC Act and its interaction with the Medicines Act that are open to interpretation, there is risk of inequities arising through any differing practices and understandings of how a medical practitioner should provide assisted dying. We will seek to address this as far as possible through guidance.

Risk rating for the implementation project

55. The project to implement the EOLC Act by 7 November 2021 remains on track for successful delivery with the mitigations discussed in this report in place.

56. If you choose not to make regulations as recommended, this will not affect the ability to establish a service, but it may have implications on the number of medical practitioners who are willing to provide the service.

Next steps

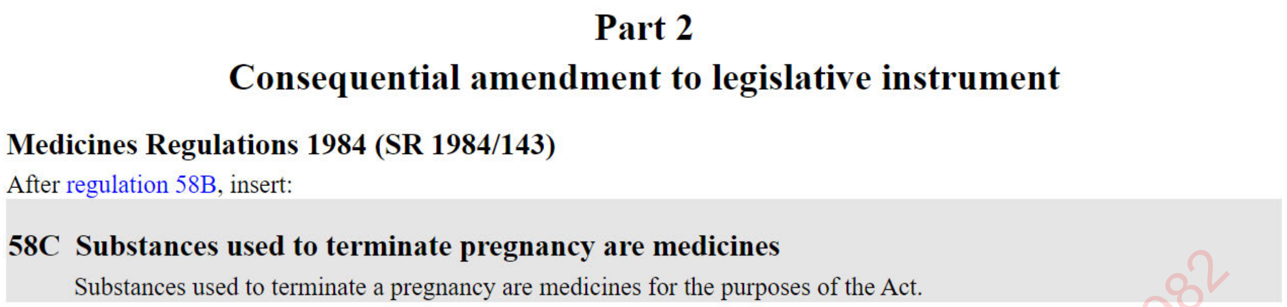
57. The Ministry will progress decisions you take on these matters and provide you further advice as needed. We will also continue to keep you updated about implementation of the EOLC Act, and any further issues identified or raised with us.

58. You can expect briefings about funding mechanisms and safeguards for assisted dying before the end of April.

ENDS.

Document 3

Appendix One: Abortion Legislation Act 2020.



Part 2

Consequential amendment to legislative instrument

Medicines Regulations 1984 (SR 1984/143)

After regulation 58B, insert:

58C Substances used to terminate pregnancy are medicines

Substances used to terminate a pregnancy are medicines for the purposes of the Act.

Document 4

MINISTRY OF HEALTH
MANATŪ HAUORA

Briefing

Date due to MO:	19 April 2021	**Action required by:**	26 April 2021
Security level:	IN CONFIDENCE	**Health Report number:**	20210680
To:	Hon Andrew Little, Minister of Health		

Contact for telephone discussion

Name	Position	Telephone
Dr Ashley Bloomfield	Director-General of Health	s (9)(2)(a)
Clare Perry	Deputy Director-General, Health System Improvement and Innovation	s (9)(2)(a)
Caroline Flora	Group Manager, Family and Community Policy, System Strategy and Policy	s (9)(2)(a)

Minister’s office to complete:

☐ Approved	☐ Decline	☐ Noted
☐ Needs change	☐ Seen	☐ Overtaken by events
☐ See Minister’s Notes	☐ Withdrawn	

Comment:

Document 4

End of Life Choice Act – Funding and related decisions to provide for assisted dying services

Security level:	IN CONFIDENCE	**Date:**	19 April 2021
To:	Hon Andrew Little, Minister of Health		

Purpose of report

1. You previously agreed to provide for assisted dying services by funding practitioners to deliver services on a fee-for-service basis [HR20210216 refers]. This report seeks decisions about how this approach will be applied, including which activities are funded.

Summary

2. In funding assisted dying services there is a need to strike a balance between funding a service that is accessible and supports equity, while also ensuring that funding settings are not out of step with funding settings for other health and disability services. To strike this balance we have applied the following principles when considering how assisted dying services should be funded:
    a. only additional costs directly associated with assisted dying should be addressed by funding;
    b. funding should, to the extent possible, be provided using approaches/mechanisms that are used to fund services in other parts of the health and disability system (rather than creating something completely new);
    c. where there are needs related to assisted dying that are the same or similar to needs for people receiving care in other parts of the health and disability system, existing services should be used to address these wherever possible.

3. The largest cost to be met associated with assisted dying will be the time required from the attending practitioner and a nurse practitioner (if one is involved). We are proposing that practitioners should be funded using a modular funding approach, where they can be funded for the specific services they provide.

4. Each module would have a fixed price, which will be determined by the Ministry of Health (the Ministry) and informed by advice from an independent organisation. A final decision will take into account the amount of funding that is available, and potential effects if the price is set too high or too low.

5. We also propose providing an allowance to address travel costs incurred by practitioners. This will support more equitable access to assisted dying and potentially increased choice, by allowing people to receive services at home or in their local area where they live in more remote areas, do not have access to willing practitioners nearby,

or are unable to travel due to health or other limitations. We recommend the allowance will be calculated on a fixed price model and whereby practitioners would be paid a fixed price for the travel costs they have incurred within half a day of travel, with the option to obtain an additional allowance should travel times exceed half a day.

6. We also recommend that practitioners should be prevented from charging their own co-payments as a condition of receiving government funding.

7. We considered whether funding should be provided to address some other potential costs but are advising against providing specific funding:

   a. to reduce existing co-payments and travel costs for patients – this would involve addressing costs that are not directly associated with providing assisted dying per se (eg the co-payment for visiting a general practitioner or nurse practitioner to initiate a discussion about accessing the assisted dying service), and treating people who access assisted dying differently from patients who access other health services;

   b. to enable separate or additional service component for kaupapa Māori services, as there is an underlying expectation that funding for services is provided on the basis that provision will be culturally responsive. Future models of assisted dying services for Māori could be considered alongside similar developments in palliative care as we consider it important that these services are developed at a similar pace, thereby lessening the risk of making assisted dying seem more accessible than palliative care [HR20210701 and HR20202063 refer].

   c. for a dedicated counselling and bereavement support services – as the Government already funds bereavement support for the families of people who have died, and the number of deaths resulting from assisted dying is expected to be low (1% or fewer of total deaths) meaning any additional demand for existing services may be negligible;

   d. for services provided by staff directly employed by district health boards (DHBs) – as the additional costs involved for DHBs will be very small relative to the Crown funding they already receive.

8. We acknowledge that there are many unknowns associated with providing assisted dying and we will closely monitor services from November to see whether there are any additional costs that might need to be addressed, and whether prices reflect the real cost of providing services.

9. We have considered what requirements should apply to practitioners who receive funding for providing assisted dying services, and have concluded that a good approach would be to make funding conditional on meeting a set of service standards that will be developed with the sector over the coming months. We will also require practitioners to have done training and demonstrated learning prior to providing these services.

10. Following your decisions on this briefing we will determine the best mechanism to provide modular funding for assisted dying services, and work to implement these services. We will provide you with regular updates on this work, including activities to determine prices, though your weekly update. The recommendations in this briefing will also form part of a wider Cabinet Paper which you are scheduled to take to the Social Wellbeing Committee in June 2021.

Recommendations

We recommend you:

a) **Note** that you previously agreed to provide for assisted dying services by funding suitably qualified practitioners to deliver services on a fee-for-service basis, and that decisions are now sought on how this approach will be applied [HR20210216 refers].

b) **Agree** that practitioners should be funded using a set of core modules that practitioners can claim when they deliver services which will be based on: **Yes / No**

- supporting the application process and providing the first assessment
- providing the second (independent) assessment
- providing a third assessment (if required to determine a person's competence to request assisted dying)
- confirming a person's eligibility and the supply and administration of assisted dying medications.

c) **Agree** that the level of funding (price) to be provided under each module should be a fixed amount, and that price setting will be informed by an analysis by an independent provider, with the Ministry making the final decision as to the price. **Yes / No**

d) **Agree** that the Ministry should provide an allowance for travel costs incurred by practitioners to allow people to receive services at home or in their local area where they: **Yes / No**

- live in remote areas
- do not have access to willing practitioners nearby, or
- are unable to travel due to medical or other limitations.

e) **Agree** that an allowance should be provided to meet travel costs incurred by practitioners, which will be calculated on a fixed price model and whereby practitioners would be paid a fixed price for the travel costs they have incurred within half a day of travel, with the option to obtain an additional allowance should travel times exceed half a day. **Yes / No**

f) **Agree** that, although the Ministry will closely monitor services from November to see whether there are any additional costs, we are presently advising against funding for: **Yes / No**

- reducing existing co-payments and travel costs for patients
- separate or additional modules for kaupapa Maori services
- dedicated counselling and bereavement support for affected families and whanau
- for services provided by staff directly employed by DHBs

g) **Agree** that conditions for practitioners to receive funding should reflect service standards which will be developed with the sector over coming months. **Yes / No**

h) **Agree** that practitioners should be prevented from charging their own co-payments as a condition of receiving government funding. **Yes / No**

i) **Note** that we will provide you with further advice later this year about what specific medicines and equipment will be employed to deliver assisted dying, and how the costs associated with this might be met.

j) **Note** that following your decisions on this briefing we will provide you with further updates on work to determine an appropriate price for services, and the progress of the Budget 2021 bid through the weekly update.

k) **Note** that the decisions in this paper and in a set of other related papers will be included in a Cabinet Paper which will be submitted in June 2021.

Maree Roberts
Deputy Director-General
System Strategy and Policy
Date:

Hon Andrew Little

Minister of Health
Date

End of Life Choice Act – Funding and related decisions to provide for assisted dying services

Background

1. We previously provided you with a briefing *End of Life Choice Act: Determining an approach to provide for assisted dying services* which sets out two possible approaches to providing for assisted dying services in New Zealand [HR20210216].
2. You agreed that the Government should take steps to ensure that assisted dying services are available to people from 7 November 2021, and that an approach should be taken that involves funding assisted dying services on a fee-for-service basis.
3. The benefits of this approach include supporting access to services by maximising the number of practitioners[1] who can provide funded services, providing a high level of flexibility for practitioners who choose to be involved, and allowing the many uncertainties associated with providing assisted dying services to be actively monitored and responded to centrally.
4. Following these decisions, this paper seeks decisions about how this approach will be applied. This includes determining which activities should be funded and what accountability requirements should be attached to funding.

Decisions on funding for assisted dying must take account of wider settings in the health and disability system

5. Assisted dying will be a new service within the health and disability system. In developing advice on funding assisted dying services, we have been mindful of the need to balance service comprehensiveness against overall alignment with the way services are funded in the wider health and disability system.
6. An approach that does not appropriately address the costs associated with providing assisted dying could deter practitioners from participating, resulting in reduced access and equity, while an approach that is viewed as comprehensive when compared with other services (eg, palliative care) could. There is also a risk that assisted dying could become the preferable choice for people who may have otherwise chosen access to palliative care.
7. In funding assisted dying services there is a need to strike a balance between funding a service that is accessible and supports equity, while also ensuring that funding settings are not out of step with funding for other health and disability services. To strike this

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[1] This briefing uses the term "practitioners" instead of "medical practitioners". This is because although most of the services provided under the EOLC Act will be performed by a medical practitioner, there is also provision under the modular funding system we are proposing for nurses to claim for the provision of these services as well. Once the new Act comes into force, we will closely monitor who claims for these services.

balance we have applied the following principles when considering how assisted dying services should be funded:

a. only additional costs directly associated with assisted dying should be addressed by funding

b. funding should, to the extent possible, be provided using approaches/mechanisms that are used to fund services in other parts of the health and disability system (rather than creating something completely new)

c. where there are needs related to assisted dying that are the same or similar to needs for people receiving care in other parts of the health and disability system, existing services should be used to address these wherever possible

8. As part of our work to implement the End of Life Choice Act we plan to work with representatives from the Health and Disability Sector to develop a set of service standards for the delivery of assisted dying.

9. These standards will reflect:

a. the legal requirements set out in the End of Life Choice Act

b. good clinical practice for the delivery of health services generally

c. wider health and disability system requirements including the Code of Health and Disability Services Consumers' Rights.

The main cost associated with providing assisted dying services will be practitioner time

10. Based on experiences in overseas jurisdictions, the largest cost to be met associated with assisted dying will be the time required from the attending practitioner and nurse practitioner (if one is involved).

11. The provision of assisted dying will require sufficient time for the attending practitioner to do the following:

a. build a relationship with the person, and develop an understanding of them and their situation – in many cases an attending practitioner will not have provided care to someone prior to them seeking assisted dying

b. understand the person’s medical status, including determining or confirming their prognosis, and their options for end of life care

c. support the person to make an application for assisted dying, including providing them with all of the required information and confirming that they understand it

d. encourage them to discuss their decision with their family/whānau and provide information to family/whānau as needed

e. confirm that the person is not being pressured to apply, which will include discussion with the person, other practitioners involved in their care, and members of the person’s family (if they agree)

f. assess the person to determine whether they are eligible for assisted dying, which involves working through the various criteria

g. confirm that assessments have also been completed by an independent practitioner and a psychiatrist (if required), and determine with the person when, where and how they will be assisted to die

h. provide assisted dying itself (to be done by the attending practitioner or a nurse practitioner operating under their supervision), which includes:

    i. prescribing and obtaining suitable medications

    ii. preparing the person, and setting up equipment (eg, establishing IV lines, laying out medications, etc)

    iii. providing information and support to family/whānau members and others who attend (eg, making sure they understand what will happen, and confirming post-death arrangements)

    iv. administering or supervising the administration of the medications

    v. monitoring the person while they die, and confirming the death.

i. record all of the actions they have taken at each stage of the process and completing all of the required forms for the registrar of assisted dying as appointed under section 27 of the Act (the number of forms required will vary, depending on the process).

12. Time will also be required from practitioners who provide independent assessments and psychiatrists where they are asked to assess a person's competence to make an informed decision.

We propose to fund assisted dying services using modular funding

13. We propose to fund practitioners using a modular funding approach, where practitioners can be funded for the specific services they provide. This would be similar to the way primary maternity services are currently funded.

14. Although yet to be confirmed, it is likely that the modular funding approach we have identified will consist of four modules covering the core services that are provided:

a. supporting the application process and providing the first assessment – to be claimed by the attending practitioner

b. providing the second assessment – to be claimed by the independent practitioner

c. providing a third assessment (if required to determine a person's competence to request assisted dying) – to be claimed by a practitioner who is a qualified psychiatrist

d. confirming a person's eligibility and the supply and administration of assisted dying medications and care – to be claimed by the attending practitioner.

15. A more detailed description of these potential modules is provided in Appendix A.

16. Using a modular approach will enable any suitable practitioners to provide funded services, including smaller providers. It should also mean that the government will only pay for modules that are delivered to each patient. For example: where patients apply and are assessed, but are not found to be eligible, only the costs associated with supporting someone to apply and be assessed will be funded.

17. Under this approach funding may sometimes be received for service elements that are not delivered in certain situations. For example: where someone wants to be assisted to die but changes their mind on or before the day. In these cases it would not be reasonable to limit or decline funding as practitioners may have already incurred costs associated with providing these services (eg, cancelling other activities and setting aside time to provide assisted dying).

We propose setting a fixed price for each module

18. A key consideration in providing modular funding is the level of funding (price) to pay a practitioner for each module that is delivered, and whether this should be a fixed amount, or vary according to particular costs or circumstances related to delivery.

19. The amount of time that will be required to provide assisted dying services will be different in every case, because of variables including:

    a. the medical conditions that patients have – eg, how close to death they may be, and the level of complexity involved in determining if they are eligible

    b. the varying circumstances in which assisted dying is sought – eg, where they live, whether they seek assisted dying at home, in aged-residential care or hospital, a marae, and whether they may need to be moved between settings for assisted dying to take place

    c. the level of involvement from family/whānau and other support people

    d. particular cultural needs, including actions that need to be taken to enable important cultural or ceremonial processes to take place.

20. Setting variable rates of funding can make this more responsive to individual circumstances, however this also makes designing and administering funding significantly more complex, and usually results in a claiming process that is more compliance heavy. Setting variable rates of funding can also create conflict between different parts of the health sector as it raises questions about funding parity (or the lack of it) between practitioners working in different settings (eg, funding rates for general practitioners versus specialists).

21. Because no two situations where people seek assisted dying will be the same, we believe it would be preferable to set a single fixed price for each module. While this may be viewed as less responsive, it will make the modules relatively simple for practitioners to understand and claim for.

22. In setting a single price for each module, the government would acknowledge that the exact time and cost involved in providing assisted dying services will be different in every case, but that this funding is provided to cover the substantive costs associated with providing assisted dying.

23. The extent to which this approach is accepted by practitioners will largely depend on the price that is set for each module.

We propose using independent analysis to help determine a suitable price for the modules

24. Pricing health services is complex and can be subject to significant scrutiny from sector groups with an interest in the outcome. Because assisted dying has never been provided in New Zealand before, there is limited information on which to set a price.

25. We propose to engage an independent provider to develop a costing methodology and advise on suggested pricing for each module. Receiving advice from an independent provider may help to address potential concerns from the sector about the Ministry setting prices too low and provide an independent perspective on how pricing is determined, given the limited information that is available.

26. A final decision on prices would be made by the Ministry, taking into account the independent advice, as well as:

    a. the amount of funding that is available – we will provide you with updates on the progress of the Budget bid through the weekly update

    b. the need to avoid setting a price that is too low – as this could create a barrier to practitioners providing services

    c. avoiding setting a price that may be seen as too high or out of step with other health services – as this could be viewed as creating an incentive for assisted dying and /or could form the basis for parity claims from other parts of the sector, e.g. for travel costs.

27. If you agree, we will provide you with updates on price setting work through the weekly report.

We also propose to provide an allowance for travel costs incurred by practitioners

28. In our previous advice, we noted that there is likely to be a preference from many of those seeking assisted dying to be supported to die at home (or in other community locations such as marae) if this is possible. This has been the experience overseas where practitioners often travel to a person's home or another location (such as an aged care facility)[2] to administer assisted dying.

29. Providing an allowance for travel costs incurred by practitioners would support more equitable access to assisted dying and potentially increase choice, by allowing people to receive services at home or in their local area where:

    a. they live in more remote areas

    b. they do not have access to suitably qualified practitioners nearby, or

    c. they are unable to travel due to medical or other limitations.

30. Allowances that recognise the cost of travel for practitioners are provided in other parts of the health and disability system, where access to services in the community is seen as important (eg, work done by community support workers and maternity carers).

31. We propose to provide an allowance that will allow practitioners involved in assisted dying to receive some funding where they need to travel to support the application process, conduct assessments, or provide assisted dying. The travel allowance would only cover direct costs associated with travel, such as vehicle hire, fuel costs and flights. The cost of time to travel would be built into the modular prices that are set for services.

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[2] Medical practitioners do not travel to assist patients to die in some jurisdictions (such as Victoria) where medication is provided directly to patients to administer without direct medical assistance or supervision.

32. We have identified three approaches that could be taken to addressing travel costs, based on mechanisms that already exist in other parts of the health and disability system.

Option	**Benefits**	**Limitations**
Option 1 – Introduce a mileage rate (58.5 cents per km) based on rate provided to community support workers, and allow reimbursement for costs where air travel is required.	Provides a contribution to the cost of actual travel costs, with more paid to practitioners who have to travel further. Not limited based on why travel is required	Involves some compliance (recording travel distance) though this is common in other parts of the health and disability system. More time-consuming to administer and mean that costs are met after they have been incurred.
Option 2 – Provide a fixed allowance to recognise the travel costs of practitioners who are required to travel to provide these services. This is the approach taken in the Primary Maternity Services Notice. The specific amount would need to be calculated but could be provided based on up to half a day of travel. Different amounts could also be established based on whether the location is semi-rural, rural or remote-rural zones (in the same manner as allowances for maternity carers).	Simple to claim and administer (based on address for service). Practitioner is able to be paid for their travel costs in advance.	Fixed allowance may over or under compensate depending on how it compares with actual costs in each case. The option is not particularly flexible to exceptions.
Option 3 – Fixed allowance, with option for a 'top up' travel allowance if practitioners have to travel more than half a day. This option would be a hybrid of Options 1 and 2. All practitioners would be reimbursed for the costs of travelling within a half day, with an additional allowance calculated for any	Paying the fixed allowance would still be simple to claim and administer, although the additional allowance may require additional resource. More flexibility for practitioners to be paid a reasonable rate should they have to travel a	Slightly more difficult for the Ministry to administer in comparison to Option 2. May involve some compliance from practitioners (recording travel distance).

Option	Benefits	Limitations
travel costs in excess of this time.	considerable distance from their practice to a remote location to deliver a service.	

33. Although Option 1 would enable practitioners to be reimbursed for the actual travel they have undertaken to provide a service, the administrative costs could impose a significant burden on the Ministry and mean costs are only covered after they have been incurred. Option 2 would prove much simpler for the Ministry to implement and would enable practitioners to receive funding for their intended travel at the outset, although it would disadvantage those who have to travel more than half a day to deliver a service.

34. We recommend Option 3 where practitioners would be paid a fixed price for the travel costs that are incurred within half a day, with the option to obtain an additional allowance should travel times exceed half a day. This may be more difficult for the Ministry to administer than Option 2, but the number of practitioners who will be required to travel more than half a day is likely to be small.

We do not propose introducing additional measures to address existing co-payments or travel costs for patients

35. There will be costs for people seeking assisted dying, associated with co-payments to see a general practitioner (eg, when they attend an initial appointment to make an application for assisted dying), and travel to access services where they cannot be provided locally.

36. While it would be possible to take specific steps to reduce or remove these costs, this would involve addressing costs that are not directly associated with providing assisted dying per se, and treating people who access assisted dying differently from patients who access other health services.

37. We recently provided you with advice on co-payments in palliative care where we sought your direction on whether you wish us to pursue work on individual financial barriers to palliative care [HR 20210701 refers]. Not meeting these costs in assisted dying could see people seeking assisted dying needing to meet co-payments and travel costs in the same manner as people accessing other health services.

38. People who seek assisted dying may be able to receive some limited assistance from existing mechanisms in the health and disability system, including:

    a. the National Travel Assistance Scheme which provides some financial assistance to people for whom the cost of travel is a barrier to accessing treatment – though this is subject to a lot of restrictions which mean people seeking assisted dying will often be ineligible[3]

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[3] The NTA is subject to eligibility rules based on age and financial need (whether someone has a Community Services Card), and generally does not cover costs associated with accessing primary care services or private referrals or treatments.

   b. lower cost primary care visits for people who have a Community Services Card – an adult with a card will not pay more than $19.50 for a standard visit with a practitioner.

We propose that modular funding should incorporate addressing the cultural needs of Māori and other groups

39. As part of our work on assisted dying we have examined what the key Te Tiriti o Waitangi considerations are related to assisted dying, from a Crown perspective, and how these can be addressed.

40. A number of these have implications for how assisted dying services are provided to Māori, including:

   a. the need for practitioners to enable whānau to participate when the decision to apply for assisted dying is being made, and to observe and uphold tikanga Māori when assisted dying is being administered

   b. allowing for the involvement of Rongoā practitioners, kaumatua, and ritenga Māori.

41. We have considered whether specific funding should be provided to enable culturally responsive services to be provided to Māori. Some of these culturally specific practices could include:

   a. the provision of specific Māori traditional medicine by Rongoā practitioners

   b. the provision of service on a Marae

   c. travel expenses of whānau, or Māori who wish to travel to their marae.

42. On balance, we consider that specific funding is not required to enable culturally responsive services to be provided to Māori, as this would be out-of-step with the approach taken in the wider health and disability system (including palliative care), where there is an underlying expectation that funding for services is provided on the basis that provision will be culturally responsive (addressing the specific cultural needs of Māori and other groups). We do not wish to bring about a situation whereby assisted dying may be perceived to be a more attractive or accessible option than palliative care. We have provided you with some recent advice on future directions in the palliative care system [HR20210701 and HR20202063 refer] where it was noted that there is room to grow both assisted dying and palliative care services to be more responsive to the needs and aspirations of Māori.

43. We also note that the Ministry currently funds services to address the specific health needs of Māori, including providers of Rongoā (providers of traditional Māori medicine), that could potentially be drawn on by Māori and seeking assisted dying and their whānau. However, providers of these services would need to be practitioners in order to claim for the individual modules.

44. There may also be the potential for Kaiārahi (navigators) at Whānau Ora to work with and support Māori and their whānau with cultural needs in the case of an assisted death although this is likely to require additional resources and funding for kaiārahi.

45. We propose that modular funding should incorporate an expectation of culturally responsive provision, in line with the approach taken in other parts of the health system.

46. This would be supported by:

   a. the fee-for-service funding approach, which will allow any willing practitioners to be funded, including those who work in Māori health services, or other settings where Māori are served

   b. training and guidance for practitioners on culturally responsive practice in the context of assisted dying, including the development of a training module that deals with cultural safety in broad terms enabling practitioners to work with local iwi and hapū to ensure that a service is provided correctly to Māori in accordance with local protocols

   c. monitoring of outcomes from assisted dying, including how Māori and other cultural groups respond, and whether there are inequities in access, service quality or outcomes that need to be addressed.

47. However, we plan to closely monitor services from November to see whether any additional costs might have to be met to provide these cultural services, and whether prices reflect the real cost of providing services.

We do not recommend funding specific counselling and bereavement support

48. The need for services does not end when someone has died. The government funds bereavement support for the families of people who have died as ongoing grief can have significant consequences if left unaddressed (eg, resulting in poorer health outcomes, employment and housing instability, and mental illness). Consideration could be given to funding bereavement support services for the families of people who are assisted to die – by extending existing services, or making new provision for the funding of new services.

49. However, as the number of deaths by assisted dying per year is likely to be low, we do not recommend that specific additional funding be provided in the short term as the existing provision of support services are likely to be sufficient.

We recommend preventing practitioners from charging co-payments if they receive government funding

50. Preventing the charging of co-payments (by making this a condition of receiving government funding) could prevent a potential barrier to access for some people. However, this might limit the types of services people can receive depending on the level of government funding that is provided. For example: if there were no specific funding to recognise transport costs and practitioners could not charge a co-payment to meet this cost, they may be unwilling to travel long distances to provide services in more isolated areas.

51. On balance, we recommend preventing practitioners from charging co-payments if they receive government funding, as a way to support access and equity. This would not prevent practitioners from providing entirely privately funded services at whatever price they deem appropriate, however we consider the emergence of a private market to be unlikely, especially initially.

Providing support for DHBs

52. The fee-for-service approach set out in the paper will allow practitioners to provide assisted dying services, and claim for costs where they:

a. spend all or part of their time in private practice, or working for non-government organisations, or

b. work in primary practice (whether or not they receive funding from a DHB through a PHO).

53. However, this will not cover the cost of any services provided by practitioners who are employed directly by DHBs (eg, specialists working full-time delivering services in a DHB-run hospital).

54. We have considered whether some additional funding should be provided to DHBs to recognise the cost of any services provided by these practitioners as part of their work. However, the amounts involved would be very small compared to the Crown funding they receive each year. This reflects both the small number of people who are likely to seek assisted dying, and the spread of these cases across the health system.

55. If half of those who seek assisted dying only receive services through staff employed directly by DHBs, this would equate to around $3.3 million of additional cost every financial year, which would be split across the 20 DHBs. Given this, we do not propose to provide specific funding to DHBs for assisted dying, with any associated costs to be met from general Crown funding.

Equity

56. In the context of assisted dying, ensuring equity means addressing:

a. equity of access – ensuring that no group will experience issues that prevent them from accessing assisted dying services when they would otherwise be eligible

b. equity of service level – ensuring that assisted dying services provided to different groups are equally effective in addressing the needs of those seeking assisted dying and their whānau

c. equity of outcome – ensuring that particular groups are not over or underrepresented among those who receive assisted dying because of inequities in healthcare (eg, due to unequal access to treatment or palliative care).

57. We have sought to ensure that all of these dimensions of equity are considered and addressed in our work, by making equity one of our design principles.

58. Consideration of equity in the development of this briefing has included considering how the funding of assisted dying services will align with funding for services across the health and disability system. This involves striking a balance between:

a. needing to address the costs of providing assisted dying to support access - by meeting reasonable costs for practitioners, and supporting them to travel, and

b. avoiding funding assisted dying in a way that would put it out of step with funding for other health services.

Next steps

59. Following your decisions on this briefing we will determine the best mechanism to provide modular funding for assisted dying services, and work to implement this.

60. We are still working to determine exactly which medicines and equipment will be needed to deliver assisted dying, and how the costs associated with these will be met. We will provide you with further advice on this in due course.

61. We will provide you with further updates on work to determine an appropriate price for services, and the progress of the Budget bid through the weekly update.

ENDS.

Appendix A – General description of core modules to be funded for assisted dying services

Module	What services are included?	Who can claim it?
Application process and first assessment	Attending practitioner supports person to apply, including: • explaining the prognosis for the person's terminal illness, the irreversible nature of assisted dying, and the anticipated impacts of assisted dying • communicating by any means with the person about the person's wish at intervals determined by the progress of the person's terminal illness • ensuring that the person understands their other options for end-of-life care • ensuring that the person knows that they can decide at any time before the administration of the medication not to receive the medication • encouraging the person to discuss their wish with others such as family/whānau, friends, and counsellors, and ensure that the person has had the opportunity to discuss their wish with those whom they choose • do their best to ensure that the person expresses their wish free from pressure from any other person, by conferring with other health practitioners who are in regular contact with the person and conferring with members of the person's family approved by the person • confirming the request for assisted dying (by completing a form with the person) • recording the actions they have taken. Attending practitioner undertakes assessment to determine whether the person is eligible for assisted dying. This includes determining whether the person: • suffers from a terminal illness that is likely to end their life within six months • is in an advanced state of irreversible decline in physical capability	Attending practitioner or their representative

	• is experiencing unbearable suffering that cannot be relieved in a manner that the person considers tolerable, and • is competent to make an informed decision about assisted dying. Once the assessment has been made a form is sent to the registrar of assisted dying (as appointed under section 27 of the EOLC Act).	
Second assessment	Independent practitioner identified by the Support and Consultation for End of Life in New Zealand (SCENZ) Group undertakes an assessment to determine whether the person is eligible for assisted dying. This includes determining whether the person: • suffers from a terminal illness that is likely to end their life within six months • is in an advanced state of irreversible decline in physical capability • is experiencing unbearable suffering that cannot be relieved in a manner that the person considers tolerable, and • is competent to make an informed decision about assisted dying. While doing the assessment the practitioner will be vigilant for any signs of coercion. Once the assessment has been made a form is sent to the registrar of assisted dying.	Independent practitioner or their representative
Third assessment (if required	A third opinion is sought from a practitioner who is a qualified psychiatrist if the person's competence to request assisted dying has not been established to the satisfaction of one or both of the practitioners. Someone is deemed to be competent to make an informed decision if they can: • understand information about the nature of assisted dying that is relevant to the decision • retain that information to the extent necessary to make the decision • use or weigh that information as part of the process of making the decision • communicate that decision in some way. Once the assessment has been made a form is sent to the registrar of assisted dying.	practitioner who is a qualified psychiatrist, or their representative

Confirmation of eligibility and administration of assisted dying	Attending practitioner confirms that the person is eligible for assisted dying (on the basis of previous assessments), and: • advises the person that they are eligible for assisted dying • discusses with the person the progress of their terminal illness • discusses with the person the likely timing for the administration of the medication • gives the person a form to complete to choose the date and time for the administration of the medication • advises the person that at any time after completing the approved form the person may decide not to receive the medication, or to receive the medication at a time on a later date that is not more than 6 months after the date initially chosen for the administration of the medication • advises the person about the methods for the administration of the medication • asks the person to choose one of the methods • sends the form to the registrar of assisted dying • makes provisional arrangements for the administration of the medication on the chosen day and time. At least 48 hours before the chosen time for the administration of the medication, the attending practitioner, or an attending nurse practitioner writes the appropriate prescription for the eligible person, advises the registrar of assisted dying of the method and date and time chosen for the administration of the medication. At the chosen time the attending practitioner, or an attending nurse practitioner will ask the eligible person if they: • choose to receive the medication at that time, or • not to receive the medication at that time, but to receive the medication at a time on a later date that is not more than 6 months	Attending practitioner or their representative

	after the date initially chosen for the administration of the medication, or - not to receive the medication at that time, and to rescind their request to exercise the option of assisted dying. If the eligible person chooses to receive the medication, the attending practitioner, or the attending nurse practitioner, must provide and/or administer the medication. The attending practitioner, or the attending nurse practitioner, must be available to the eligible person until the person dies, or arrange for another practitioner or attending nurse practitioner to be available to the person until the person dies. Within 14 working days of a person's death as a result of the administration of medication the attending practitioner, or the attending nurse practitioner who provided or administered the medication must send the registrar of assisted dying a report.	

Document 5

MINISTRY OF
HEALTH
MANATŪ HAUORA

Briefing

End of Life Choice Act: Safeguards for Assisted Dying

Date due to MO:	7 May 2021	**Action required by:**	N/A
Security level:	IN CONFIDENCE	**Health Report number:**	20210746
To:	Hon Andrew Little, Minister of Health		

Contact for telephone discussion

Name	Position	Telephone
Dr Ashley Bloomfield	Director-General of Health	s (9)(2)(a)
Clare Perry	Deputy Director-General, Health System Improvement and Innovation	s (9)(2)(a)
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Minister's office to complete:

☐ Approved
☐ Needs change
☐ See Minister's Notes

☐ Decline
☐ Seen
☐ Withdrawn

☐ Noted
☐ Overtaken by events

Comment:

Document 5

End of Life Choice Act: Safeguards for Assisted Dying

Security level: IN CONFIDENCE **Date:** 7 May 2021

To: Hon Andrew Little, Minister of Health

Purpose of report

1. This report provides you with information on the safeguards that will apply to the provision of assisted dying services. It outlines particular areas that are likely to attract attention from stakeholders, and discusses some questions that are not directly addressed by the End of Life Choice Act (EOLC Act).
2. This report discloses all relevant information.

Summary

3. For the purpose of this briefing, safeguards are legal provisions, professional requirements, and other structures intended to protect patients, practitioners, and the general public in the delivery of health care.
4. The EOLC Act provides a number of explicit safeguards for the provision of assisted dying services. Key safeguards in the EOLC Act involve the assessment of a person's competence, protections against suspected coercion, and the right of practitioners to not participate in the process where they conscientiously object. These safeguards differ from the usual protections associated with most health services to address the specific risks associated with assisted dying.
5. Except where the EOLC Act deliberately overrides existing legislation, it is intended to be consistent with standard health legislation and professional requirements that apply to the provision of all health and disability services. These requirements form a wider set of safeguards for assisted dying, including requirements related to professional competence and patient rights.
6. We have considered whether some of these safeguards could be strengthened, such as training requirements for practitioners involved in assisted dying services. The Ministry of Health (the Ministry) is preparing some specific training for practitioners intending to provide assisted dying.
7. There is a risk that safeguards could, either on their own or collectively, create barriers to access for individuals who meet the criteria to access assisted dying services. Equitable access is a key consideration in the implementation activities that the Ministry is responsible for.
8. The implementation of assisted dying should be viewed as one component of wider work to improve palliative and end of life care in New Zealand. Work that is underway to

address inequitable access to palliative care will identify actions that would further strengthen the safeguards for assisted dying.

Recommendations

We recommend you:

a) **Note** that the EOLC Act provides a number of explicit safeguards, including assessment of a person's competence, protections against suspected coercion, and the right of practitioners to not participate in the process where they conscientiously object

b) **Note** that given the sensitivity associated with assisted dying, we are providing you with visibility of the various safeguards that will apply to these services, listed in the appendices to this report

c) **Note** that other health legislation and professional requirements constitute a wider set of safeguards for the provision of assisted dying services

d) **Note** the Ministry is preparing specific training for practitioners intending to provide assisted dying services

e) **Note** that there is a risk that safeguards for assisted dying may create barriers to access for individuals who meet the criteria to access these services

f) **Note** that safeguards for assisted dying would be strengthened by actions to address wider health system barriers, particularly actions aimed at addressing inequitable access to palliative care

Maree Roberts	Hon Andrew Little
Deputy Director-General, System Strategy & Policy	**Minister of Health**
Ministry of Health	
Date:	Date:

End of Life Choice Act: Safeguards for Assisted Dying

Assisted dying services require clear safeguards

1. This paper describes the safeguards that will apply to assisted dying (based on the EOLC Act and wider protections), and discusses:
    - several key safeguards that are likely to attract most attention from stakeholders
    - other areas that we are considering that are not directly addressed by the Act.
2. While some safeguards apply to general health services, assisted dying requires specific safeguards not associated with other health services. This is because there are no opportunities to rectify a situation if someone is assisted to die when they should not have been.
3. There is a balance to be struck in providing for safeguards, between protecting people and limiting potential barriers that might prevent eligible individuals from accessing assisted dying. There are likely to be different views among stakeholders about exactly where this balance should lie.

Safeguards are legal provisions and other structures intended to protect patients, health practitioners, and the general public

4. For the purpose of this briefing, safeguards are legal provisions, professional requirements, and any other structures intended to protect patients, practitioners, and the general public.
5. Safeguards seek to protect those seeking assisted dying (patients), by:
    - providing the service only to those who meet eligibility criteria and make their decision free of coercion
    - ensuring assisted dying is only provided by suitably skilled and competent practitioners
    - ensuring robust processes are in place to ensure services are high quality and include appropriate support for people and practitioners
    - ensuring that people are not subject to negative consequences as a result of seeking assisted dying (eg, criminal prosecution, financial penalties, etc.).
6. Safeguards also protect those providing assisted dying (practitioners) by:
    - ensuring practitioners are not subject to criminal or civil prosecution as a result of providing assisted dying
    - ensuring practitioners are not required to provide assisted dying services where they have a conscientious objection.

9. Safeguards also seek to address the interests of the general public, by ensuring that provision of assisted dying is transparent and accountable, while also protecting sensitive information and the privacy of those involved with assisted dying.

10. A summary of all the safeguards in the EOLC Act is provided in Appendix 1.

Safeguards are provided in the End of Life Choice Act and other legislation

Safeguards in the End of Life Choice Act

11. Except where the EOLC Act deliberately overrides existing legislation, assisted dying needs to be consistent with settings in wider health legislation, professional practices and guidelines that apply to the general provision of health and disability services.

12. The two key pieces of legislation are:

- **Health Practitioners Competence Assurance Act 2003 (HPCAA)** – this seeks to protect the health and safety of members of the public by providing mechanisms to ensure that health practitioners are competent and fit to practise their professions.
- **Health and Disability Commissioner Act 1994** – this seeks to promote and protect the rights of health consumers and disability services consumers by facilitating fair, simple, speedy, and efficient resolution of complaints relating to infringements of those rights.

13. The protections provided by these are outlined in Appendix 2.

14. Professional standards and guidelines for health practitioners are developed by the relevant responsible authorities. For example, the Medical Council is the authority responsible for regulating medical practitioners, and therefore sets the appropriate standards for how doctors practise medicine.

15. The standards, codes of conduct and guidance issued by responsible authorities continue to be relevant for the provision of assisted dying services. In particular, guidance about informed consent, assessing capacity, and providing culturally safe care all continue to remain relevant to the provision of assisted dying, just like any other health service. We expect that responsible authorities and health employers will provide opportunities for training to support practitioners to understand their roles and responsibilities in relation to the provision of assisted dying services.

16. The Ministry is taking on responsibility for ensuring the health workforce has access to appropriate training, given that assisted dying will be a new health service in the New Zealand context. The Ministry will work to provide multi-disciplinary training and resources to help practitioners upskill as is appropriate to their chosen level of involvement in the provision of assisted dying services. We updated you on this in the weekly report, on 15 April 2021.

Accountability mechanisms provided by the Act reinforce the safeguards in place

17. The EOLC Act establishes the following entities to support and oversee the assisted dying process:

   a. **Support and Consultation for End of Life in New Zealand (SCENZ)** Group, to be appointed by the Director-General of Health, that will serve as the central source of information for medical practitioners and patients with regard to assisted dying, including maintaining a list of medical practitioners willing to provide assisted dying, and developing standards of care for assisted dying.

b. The end-of-life **Review Committee**, to be appointed by the responsible Minister, that will monitor assisted death reports and check their compliance with the requirements of the EOLC Act.

c. The **Registrar** for assisted dying, a role to be established within the Ministry, that will be responsible for keeping records of all documentation related to the assisted dying process, producing annual reports, and referring any complaints on to relevant authorities.

18. SCENZ and the Review Committee both provide quality improvement mechanisms, supported by the Registrar's role in collating and monitoring data. This means these entities would be appropriate bodies to review how safeguards for assisted dying are working in practice, and the information they collect and report on will enable the Ministry to advise the Government on any areas that may require strengthening.

Some safeguards are likely to attract greater public attention, due to the nature of assisted dying

19. After examining submissions from the select committee process on the End of Life Choice Bill, feedback from recent engagements with stakeholders, and experiences in overseas jurisdictions, we have identified several safeguards where we believe there is likely to be the greatest attention from those with an interest in assisted dying. These are discussed in detail below.

Determining competence to make an informed decision

20. A person is only eligible for assisted dying if they are found competent to make an informed decision about assisted dying, as well as meeting the other criteria. In the Act, competence means that the person is able to:

a. understand information about the nature of assisted dying that is relevant to the decision; and

b. retain that information to the extent necessary to make the decision; and

c. use or weigh that information as part of the process of making the decision; and

d. communicate the decision in some way.

21. The test for assessing a person's capacity to make decisions about accessing assisted dying services is aligned with other assessments of people's decision-making capacity that practitioners are required to make for the provision of other health services.

22. The main difference is that the EOLC Act removes the presumption of competence that would apply for other health services, where patients are assumed to be competent to make a decision unless they are found to be otherwise.

23. A number of resources exist to help practitioners determine competence, including an online toolkit to assist health practitioners in assessing capacity. The content is consistent with the requirements of the EOLC Act.[1]

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[1] **Douglass A., Young G., and McMillan J. "A Toolkit for Assessing Capacity." New Zealand Law Foundation (May 2019). Available at: http://www.barristerschambers.co.nz/mcap/ur_1.html.**

Application of this test of competence in situations involving potentially complicating factors

24. For other health services, rights 7(3) and 7(4) of the Code of Health and Disability Services Consumers' Rights (the Code) provide that:

    a. a person with diminished competence has the right to make informed choices and give informed consent to the extent appropriate to his or her level of competence

    b. services can be provided to a person who is not competent to give informed consent and no other person is entitled to give consent on their behalf, where certain other requirements have been met.

25. The EOLC Act expressly overrides these rights in the Code as a safeguard for those who may have conditions that affect their ability to give informed consent to assisted dying. Access to assisted dying is only permitted if the person requesting it meets the criteria for competence under the Act.

26. Whether a person is competent to make an informed decision about assisted dying or not is a legal test based on an underlying clinical assessment.

27. Some candidates for assisted dying may have intellectual disabilities, other cognitive impairments, mental health conditions, and/or similar factors that may complicate an assessment of their competence to make a decision about assisted dying. These factors do not absolutely determine whether or not a person is competent to make an informed decision about assisted dying. Rather, it depends on whether a person has the specific abilities and support needed to make that particular decision, meaning they can understand information given, retain it, weight it, and communicate it.

28. Use of a supported decision-making process[2] may play a role in assisting people to understand their options, and would not prevent them from being eligible for assisted dying if competence is established. However, the attending medical practitioner would likely need to work closely with those supporting the person to ensure the person is free from pressure.

29. Right 5 of the Code, the right to effective communication, provides that health practitioners must communicate in a form, language and manner that enables the consumer to understand the information provided. This includes the right to a competent interpreter where necessary and reasonably practicable. Where a person is unable to physically write, the EOLC Act explicitly permits their representative to sign the confirmation of the request on their behalf and at their request in the presence of the attending medical practitioner, provided the representative meets certain criteria.

30. In practice, a mental illness or cognitive impairment suggests that careful consideration of that person's capacity is required for the purposes of assisted dying. There is a further protection as the EOLC Act requires a psychiatrist's assessment if either of the two medical practitioners involved in assessing someone's competence to make an informed decision about assisted dying are unsure. In some situations the assessment of a

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[2] **Supported decision-making aims to ensure people with cognitive impairments get appropriate support to understand and consider decisions, in order to make the decision themselves. It is considered best practice under Article 12 of the United Nations Convention on the Rights of Persons with Disabilities.**

person's competence may need to be delayed to allow for treatment of conditions that may impair competence.

31. Existing guidance for practitioners covers situations where a person has a medical condition that may impair their capacity, and this will inform the specific guidance that the Ministry is developing for practitioners who will provide assisted dying services.

How the competence test applies later in the process

32. The EOLC Act requires that, at the time a person has chosen to die, the attending health practitioner must ask the person if they choose to receive the medication then, or later (within 6 months), or to rescind their request for assisted dying. It is not explicit in the Act whether a re-assessment of that person's competence needs to take place. However, the requirement for the practitioner to ask the person whether they wish to take the medication would be meaningless if a competent decision was not also required at that point. Therefore it is clearly the statutory intent that the person must be competent to make an informed decision at that stage.

33. In addition, the provisions of the Act relating to the procedures at the time of death relate to an "eligible person". The definition of "eligible person" under the Act requires that the person must be competent to make an informed decision about assisted dying. If at any stage a person is not competent, then they are no longer eligible, and the provisions of the Act do not apply.

34. This would not necessitate the need for a second opinion as is required for the eligibility assessment, and is unlikely to be an onerous process, as health practitioners are frequently required to make decisions about whether a person is competent in the course of their practice. However, it may be appropriate in some circumstances to seek a second opinion.

35. For other health services where a person lacks capacity, someone such as a welfare guardian can make a decision on a person's behalf or their prior expression of their wishes may stand, if they have an advance directive in place.

36. Both of these options are explicitly prohibited by the EOLC Act. This means there is a risk that a person who has opted for assisted dying may lose that option if they are assessed as no longer competent later in the process. This reflects Parliament's intent that assisted dying should not be provided to a person who lacks competence.

37. There may be some circumstances where it is difficult to assess a person's competence at the time of administration of medication, for example because they are heavily medicated in order to manage their pain. Because the EOLC Act does not allow clinicians to presume that a person is competent, they will need to assess whether the person is actually competent at that point in time. This reinforces the need for clinicians to have access to guidance that is specific to the competence assessment in the assisted dying process.

What constitutes rescinding a decision?

38. People who have previously requested assisted dying are free to rescind their decision to receive assisted dying at any stage in the process. This must be recorded by the relevant health practitioner on an approved form to be sent to the Registrar, and any prescription for medication to assist the person to die must be immediately destroyed by the health

practitioner (the actual medicine would need to be securely returned to the pharmacy for destruction). If at any subsequent time the person decides they do want to receive assisted dying, they must start the process again by making a new request.

39. The EOLC Act states that a person who wishes to rescind their request to receive assisted dying must communicate that wish to the relevant health practitioner. Their wish can be rescinded orally, in writing, or by gesture. No particular form of words is required to rescind the original request. There may be some situations where it is difficult to interpret whether a person is expressing their wish to rescind their decision. However, the fact that no particular form of words is required to express such a wish, as well as the implicit requirement for practitioners to be assessing the person's competence at the stage of confirming their decision, means health practitioners will take a cautious approach.

Suspected coercion

40. There are several provisions in the Act to safeguard against the possibility of someone being coerced to seek assisted dying, by requiring the relevant health practitioners to:

   a. not initiate any discussion about assisted dying with a person they are providing a health service to, unless the discussion is at the person's request

   b. do their best to ensure that the person expresses their wish free from pressure from any other person by conferring with other health practitioners who are in regular contact with the person, and conferring with members of the person's family (if approved by the person)

   c. take no further action under the Act to provide assisted dying to a person if they suspect on reasonable grounds that the person is not expressing their wish free from pressure from any other person.

41. The attending medical practitioner must also discuss the person's choice of assisted dying with them at intervals determined by the progress of the person's terminal illness, ensure the person understands their other options for end of life care, and that the person knows they can change their mind at any time. These requirements provide opportunities for the attending medical practitioner to understand the context in which the person is choosing the option of assisted dying, and whether there are any signs of pressure from other people to make that choice.

How coercion is defined in the context of assisted dying

42. In the EOLC Act, coercion is defined as "pressure from any other person". A health practitioner is not required to provide evidence of pressure in order to stop the provision of assisted dying to a person. Instead, the requirement is that they have a suspicion on reasonable grounds. This means the assessment is partially subjective (forming a suspicion) and partially objective (must be on reasonable grounds).

43. There are many situations where it is likely to be difficult to assess whether a person's wish to receive assisted dying is their own decision, or may be a product of direct or indirect pressure from others. For example, a person may say that they "no longer want to be a burden" on their loved ones as a reason for exercising the option of assisted dying. In practice, this means practitioners should explore the patient's situation to understand the context in which they are expressing preference for assisted dying over

other options, and what they mean by "being a burden". It would be reasonable to expect a practitioner to refer a person on to a provider (such as their GP) that would be well-placed to arrange social supports and other appropriate services to alleviate that burden.

44. The requirements outlined in the EOLC Act support practitioners to canvas a wide range of issues with the person relating to the person's condition and care options. These conversations are likely to provide the information practitioners need to make a holistic assessment of whether the person is choosing assisted dying free from pressure from others.

45. To support the Te Tiriti principle of Māori self-determination, the systems and processes for assisted dying need to ensure that practitioners are supported to identify their potential cultural biases that may influence their view of coercion. Although the EOLC Act requires that the person ultimately makes the decision for themselves, the Act also recognises the role of the person's family, whānau and friends in discussing their wishes and supporting them to come to a decision. Cultural safety training and other workforce development activities will play an important role in supporting practitioners to ensure that collective decision-making is not misinterpreted as coercion.

46. Other jurisdictions have developed guidance to support practitioners to identify potential signs of coercion, and similar guidance will likely be developed for the New Zealand context.

How far should practitioners be expected to go to 'do their best' to detect coercion?

47. The attending medical practitioner is required to 'do their best' to ensure the person is expressing their wish free from pressure from others. This means they must actively consider the possibility of coercion, ask questions to explore whether it is a factor in a person's request for assisted dying, and ensure they meet the requirements to confer with other health practitioners and the person's family (if approved by the person) as outlined in the EOLC Act.

48. Although other professionals, such as social workers, psychologists, and lawyers, could play a valuable role in detecting potential coercion, the EOLC Act only requires medical practitioners to confer with other health practitioners and the person's family in order to assess potential coercion.

49. Parliament debated a Supplementary Order Paper (SOP) that proposed establishing an Independent Panel of Practitioners to review and approve each request for assisted dying.[3] The Panel would have been required to include lawyers, social workers, elder abuse experts, and other appropriate experts (as determined by the Minister of Justice). Because Parliament ultimately did not agree to this SOP, it can be inferred that Parliament's intent is for the assessment of coercion to be strictly a responsibility of the medical practitioners, in terms of legal requirements under the Act.

50. Although the attending medical practitioner may wish to consult other relevant professions for the purposes of detecting coercion, this should only be initiated with the informed consent of the person.

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[3] **Supplementary Order Paper 2019 (302) End of Life Choice Bill (269-2)**

Arrangements are in place to prevent further applications if coercion is detected

51. The EOLC Act requires that the attending medical practitioner or attending nurse practitioner must stop the process if they suspect a person wishing to receive assisted dying is being pressured to do so by another person. This also triggers requirements for the practitioner to inform the person that they are taking no further action to assist them to receive assisted dying, and to complete a form to notify the Registrar of the actions they have taken.

52. The Registrar is required by the Act to maintain a register that will include all approved forms required as part of the assisted dying process, including forms to record that no further action is being taken due to suspected coercion. However, the Act does not require any further action to be taken by any person in relation to suspected pressure once the relevant health practitioner has sent the form to the Registrar. Furthermore, the Act does not specify that the finding of coercion makes a person ineligible to re-apply to receive assisted dying. This means there is a risk that someone who is being pressured to receive assisted dying could 'shop around' for a different practitioner and recommence the process.

53. At this time, the requirements outlined in the EOLC Act may guard against the possibility of 'shopping around' practitioners. If a person were to restart the process with a different practitioner, that practitioner is then legally obliged to read the person's medical files and confer with other health practitioners who are in regular contact with the person. This would likely alert the practitioner to any previous requests for assisted dying that may have been refused or halted for any reason. However, this is not guaranteed, as medical files may lack necessary information and a person can refuse to consent to share this information.

54. Although previously having the process halted does not make a person ineligible to re-apply for assisted dying, this information would need to be taken into account in the new assessment of whether there is coercion, by both the attending medical practitioner and the independent medical practitioner.

55. Since the Registrar holds all the approved forms relating to the assisted dying process, they would be in a position to check whether any new confirmed requests are associated with a previous request that has been halted due to suspected coercion. The Act requires the Registrar to consult the Privacy Commissioner before establishing the register and at regular intervals while maintaining it. The Ministry will consult with the Privacy Commissioner to test the boundaries of the Registrar's ability to do so, and then consider whether it is possible to notify practitioners that they are assisting a person who was previously refused further assistance due to suspected coercion.

Safeguards against potential pressure on the person to not receive assisted dying services

56. Different people will have differing views on assisted dying, particularly when those close to them choose to receive assisted dying. The EOLC Act requires the attending medical practitioner to encourage the person making the request for assisted dying to discuss their wish with others such as family, friends, and counsellors, as well as ensuring the person knows they are under no obligation to discuss their wish with anyone. Those who do request assisted dying may have supportive friends and family, however there are also likely to be situations where a person's family actively encourage them not to go

through with assisted dying. There may also be situations where a person chooses not to tell their family, meaning their family only finds out about the person's decision to receive assisted dying after the fact, which may result in formal complaints.

57. The EOLC Act sets out a process that gives an eligible person the right to make the decision to access assisted dying as an individual, in the context of a patient-clinician relationship. The Act provides the eligible person with protection from coercion in both directions, by giving clinicians tools to stop the process when pressure to receive assisted dying is suspected, as well as by explicitly providing that the person is under no obligation to discuss their wish with anyone other than the attending medical practitioner.

Conscientious objection

58. A health practitioner is not under any obligation to assist anyone who wishes to exercise the option of receiving assisted dying if they have a conscientious objection to providing that assistance. They must provide patients with information about SCENZ if the patient has asked, but are not required to do anything further. Medical practitioners who conscientiously object to providing assisted dying are additionally required to inform the person of their conscientious objection. They are also required to advise patients of their right to ask the SCENZ Group for the name and contact details of a replacement medical practitioner. The replacement medical practitioner then becomes the 'attending medical practitioner' for the remainder of the process.

59. The EOLC Act has protections for those who conscientiously object to providing assisted dying services. The Act prohibits an employer from disadvantaging an employee or prospective employee because they conscientiously object to providing assisted dying. Employers are also prohibited from privileging an employee or prospective employee based on their willingness to provide assisted dying services.

What must health practitioners do to meet the legal requirement of advising a patient of their rights?

60. The EOLC Act requirement to advise patients of their right to ask the SCENZ Group for the contact details of a replacement medical practitioner is similar to the limitation on conscientious objection rights for reproductive health services. In this area, the HPCAA and the Contraception, Sterilisation and Abortion Act 1977 both require that health practitioners who object on the ground of conscience to providing reproductive health services must inform the person who requests the service of their conscientious objection and how to access the contact details of the closest provider of the requested service.

61. In 2020, prior to the referendum on the EOLC Act, Hospice New Zealand applied to the High Court for declarations intended to clarify the scope of the conscientious objection rights provided by the Act. The High Court observed that the right to conscientiously object has its usual meaning in medical practice, so it applies to situations where a health practitioner has a deeply-felt belief that it is wrong for them to provide the assistance sought for personal, moral reasons, internal to them.

62. The New Zealand Medical Association's position statement on conscientious objection[4] notes that a practitioner with a conscientious objection should:

- inform the patient of their objection, preferably in advance or as soon as practicable
- inform the patient that they have the right to see another doctor and ensure the patient has sufficient information to enable them to exercise that right
- take whatever steps are necessary to ensure the patient's timely access to care is not impeded
- continue to treat the patient with dignity and respect, even if the doctor objects to the treatment or procedure the patient is seeking, and
- continue to provide other care to the patient, if the patient wishes.

Safeguards for when someone is declined assisted dying

63. Those who have expressed a wish to access assisted dying, yet are declined due to the safeguards in place, are likely to require support following the decision.

64. Practitioners would understand how to approach these conversations with sensitivity as part of general good clinical practice.

65. The EOLC Act does not set out an explicit mechanism for someone to seek a review of a decision to decline them access to assisted dying. However, judicial review could be one mechanism that would allow people to challenge whether the law was followed in parts of the process outlined in the EOLC Act, including the process of determining their eligibility. Judicial review proceedings may not be the most appropriate mechanism to challenge denial of access to assisted dying given the expense and time required. Although it is unlikely that a court would look closely at matters of clinical judgement,[5] such as a medical practitioner's assessment of prognosis, a court may review whether the practitioner has correctly applied the statutory criteria.

66. When the Registrar receives complaints about health practitioners' conduct relating to assisted dying, they are required to refer the complaint to the Health and Disability Commissioner (HDC), the appropriate responsible authority, or the New Zealand Police, depending on which party has the appropriate jurisdiction to examine the complaint. The roles of HDC and responsible authorities are outlined in Appendix 2. These bodies do not provide a 'review' mechanism as such, but are empowered to examine complaints relating to the quality of service provided (HDC) and professional and clinical conduct of health practitioners (both HDC and responsible authorities).

67. The desirability of a specific review mechanism for access to assisted dying could be addressed as part of the review of the operation of the Act that is required within 3 years of commencement.

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[4] New Zealand Medical Association (2019), "Objection on the Grounds of Freedom of Conscience (Conscientious Objection). Available at: https://assets-global.website-files.com/5e332a62c703f653182faf47/5e332a62c703f657a92fdb57_Objection-on-the-grounds-of-freedom-of-conscience-FINAL_December-2019.pdf

[5] Ron Paterson "Access to Health Care" in Peter Skegg and Ron Paterson (eds) *Health Law in New Zealand* (Thomson Reuters, Wellington, 2015) 67 at 87.

We are considering wider safeguards beyond the End of Life Choice Act

Further work is underway to ensure suitable clinical safeguards are in place

68. Work is underway to ensure practitioners are supported with clinical safeguards to support clinical practice and decision-making. For example, these safeguards would include arrangements for the provision of 'backup' medication that a health practitioner could use if the planned medication is not sufficiently effective.

69. SCENZ will have the mandate to prepare standards of care and advice on the required medical and legal procedures in relation to the administration of medication for assisted dying.

70. Detailed clinical advice relating to assisted dying will be tightly managed for public safety reasons, with access likely to be restricted to practitioners who are registered with SCENZ.

Suitability of practitioners

71. We have considered whether it would be appropriate to place any additional requirements on practitioners to be considered suitable to provide assisted dying services, beyond the existing requirements outlined in the EOLC and the HPCAA.

72. The HPCAA requires that health practitioners perform only those health services that are within their scope of practice as specified by the responsible authority for their profession. Nothing in the EOLC Act overrides this.

73. The Medical and Nursing Councils have indicated that they do not intend to establish specific scopes of practice for assisted dying. This means that any health practitioners who meet the criteria outlined in the EOLC Act would be able to provide the service as long as they are competent to do so. In practice, being 'competent' involves having relevant training and experience.

74. Only a small proportion of medical practitioners are likely to be willing to participate in assisted dying, as a large proportion of medical practitioners are known to hold objections to assisted dying. Introducing requirements for any qualifications, training or experience beyond what is required by the EOLC Act may reduce the pool of potential practitioners who are qualified and willing to provide assisted dying. However, requiring the workforce to be suitably qualified is critically important for ensuring the quality and safety of services.

Specific training for practitioners will be a further safeguard

75. There will be a clear expectation that practitioners complete training that is relevant to their role in the provision of assisted dying services. Completion of relevant training is a way for practitioners to demonstrate they are competent to provide the service. Although the Ministry does not have a statutory avenue to mandate training requirements, we intend to make the completion of specified training a minimum standard for involvement in service delivery through conditions for claiming funding, the Standards of Care, and other operational arrangements.

76. The Ministry expects that all organisations employing practitioners who intend to provide assisted dying services will provide opportunities for training about their roles

and responsibilities. This training could include training that the Ministry is developing, as well as other internally sourced resources.

77. The Ministry is developing an online training module to promote health practitioners' understanding of their legal obligations under the EOLC Act, and what the Act generally means for them and their patients. This training is intended for all practitioners whether or not they have a formal role under the EOLC Act. The module will be another safeguard for practitioners, and is intended to facilitate access to the information they need as part of their general obligations to keep their professional knowledge up to date.

Witnesses at time of death

78. Unlike other jurisdictions like Victoria (Australia), there is no requirement in the EOLC Act for observers or witnesses to be present at the time of death.

79. Having a witness present would be a potential avenue for practitioners to protect themselves, by having someone who can confirm that the practitioner has met their legal responsibilities.

80. Existing guidance for general health services relating to the presence of observers is that the patient's consent should be obtained prior to the consultation, and this would be particularly important for the administration of medication for assisted dying.

81. The guidance for practitioners will recommend that they have a witness present and outline the appropriate process, noting that a witness is not a requirement and would require the patient's consent.

82. The death reporting requirements outlined in the EOLC Act apply to each assisted death that takes place. In addition to the name of the medical practitioner or nurse practitioner who was available to the person until the person died, the names of any other health practitioners who were present must be provided to the Registrar. The names of any witnesses who are not health practitioners do not need to be provided to the Registrar. Information about any other witnesses that were present (e.g. a lawyer) may be relevant and useful in the event that a complaint is made, however it is not within the Registrar's function to routinely collect this information.

Whether remote delivery can be part of the assisted dying process

83. The EOLC Act requires that the application for assisted dying is confirmed in person, as the attending medical practitioner must be present when the application is signed by the person seeking assisted dying or their representative.

84. For other parts of the process, the Act includes a reference to the medical practitioner needing to "personally communicate by any means (for example, by telephone or electronic communication) with the person about the person's wish at intervals determined by the progress of person's terminal illness". Without an explicit requirement for either the person or the medical practitioner to be in the same room, this could be read as allowing for these interactions to be conducted remotely.

85. Practitioners need to take care that using remote delivery of any elements of the assisted dying process does not reduce their ability to fulfil their legal obligations. It may be appropriate for telehealth to be used for some elements of the process to support access to assisted dying, for example by reducing the need to travel for an assessment.

However, this would carry a risk of reducing the information that the practitioner needs to perform the assessment and fulfil their legal obligations such as doing their best to detect coercion, such as non-verbal cues. This means the range of circumstances where remote delivery may be appropriate is likely to be narrow. Existing guidance for practitioners on the appropriate use of telehealth could be built on to support practitioners to determine where it could be safely used for some parts of the assisted dying process. For example, it could involve the attending medical practitioner remotely collaborating with a local health practitioner who could be in the same location as the person.

86. On 25 April 2021, you agreed that it would be appropriate to provide a specific travel allowance to compensate health practitioners for any travel required to provide assisted dying services [HR20210680 refers]. This travel allowance is likely to reduce the potential need to consider remote delivery for some parts of the process.

Te Tiriti o Waitangi considerations

87. The consistency of assisted dying service provision with the Crown's Te Tiriti o Waitangi obligations depends largely on implementation decisions, particularly how information and guidance will consider the specific needs of Māori.

Tino Rangatiratanga

88. As the EOLC Act protects the right of health practitioners to conscientiously object to providing assisted dying services, Māori health providers and practitioners are able to self-determine their involvement with assisted dying.

89. The EOLC Act makes it clear that the attending medical practitioner should encourage the person to take the opportunity to discuss their wishes with others. Guidance will be developed for medical practitioners around how they can provide services in a culturally responsive way, including ways to encourage and support the involvement of whānau in the assisted dying process.

Options

90. The EOLC Act ensure that everyone accessing assisted dying is aware of their choice to opt out at any stage. Training and guidance will also support practitioners and providers to provide services in a culturally responsive way, for instance by ensuring they check their own cultural biases in assessing competence and potential coercion.

Equity

91. Alternatives to assisted dying services needs to be equally accessible to Māori, in particular high quality palliative care. This is addressed in the equity section below in paragraphs 97-99.

Active protection

92. The purpose of safeguards is to ensure active protection is a key consideration across all aspects of the provision of assisted dying, for example by considering how arrangements will ensure the cultural safety of assisted dying services.

93. The accountability processes set out in the EOLC Act support the establishment of monitoring and reporting processes. These will contribute to review of the profile of those accessing assisted dying, to check whether Māori are under or overrepresented in a way that suggests some safeguards need to be strengthened.

94. As implementation activities progress, there will be other opportunities to consider wider safeguards that uphold the principle of active protection. For example, active protection could extend to arrangements that would ensure the cultural safety of assisted dying services, as well as appropriate support for family and whānau members of the person accessing assisted dying.

Partnership

95. Māori involvement in the design, delivery, monitoring, and review of assisted dying services is necessary to ensure the safeguards in place are working for Māori. This is a key consideration across the range of implementation activities underway.

Equity

96. The need for specific safeguards in the provision of assisted dying services should be balanced with the need to limit potential barriers that could prevent eligible individuals from accessing assisted dying. There may be implications for equitable access to assisted dying, depending on the way some safeguards are implemented. Equity is a key consideration in the Ministry's implementation activities, for example the development of standards and guidance the SCENZ Group will provide to practitioners.

Action to address wider health system barriers would contribute to adequate safeguards for assisted dying

97. The EOLC Act requires that someone seeking assisted dying must be provided with information to enable an informed decision, including other options for end-of-life care.

98. Palliative care aims to optimise quality of life until death, as well as providing support to family, whānau and other caregivers. It could be provided alongside assisted dying, or as an alternative. In New Zealand, palliative care is provided across a range of settings and access to a particular setting (eg. hospice) and/or model of care may vary depending on the DHB's arrangements for that region. Inequitable access to palliative care may have implications for how people weigh up their options for end-of-life care. Failure to address inequities in the palliative care system could create an ongoing risk that some people do not perceive palliative care as an alternative option to assisted dying for them. Other countries that have introduced assisted dying services have consistently bolstered palliative care funding and service delivery.

99. On 30 March 2021 we provided you with an update on our policy work to address sustainability and equity issues in palliative care, and are due to provide you with final advice in June [HR20210701 refers]. We are considering options for palliative care in light of your decisions on assisted dying and on wider health and disability system reforms, including the compatibility of funding models for both types of services to avoid any possibility that assisted dying is viewed as more accessible than palliative care.

Next steps

100. We are developing a Cabinet paper with an overview of the implementation activities and the planned approach to provide for assisted dying services. [HR20210680 refers].

ENDS.

Appendix 1: Summary of safeguards in the End of Life Choice Act 2019

1. The following is a summary of the explicit safeguards that are provided within the EOLC Act.

Safeguards to protect those seeking assisted dying

Eligibility criteria

2. The EOLC Act sets out criteria that must be met in order for a person to qualify for assisted dying. The Act explicitly states that a person cannot be eligible if that person is only suffering from any form of mental disorder or mental illness, or has a disability of any kind or is of advanced age.

3. Patients must meet all of the following criteria to qualify:

   a. be aged 18 years or over

   b. be a citizen or permanent resident of New Zealand

   c. suffer from a terminal illness that is likely to end their life within 6 months

   d. be in an advanced state of irreversible decline in physical capability

   e. experience unbearable suffering that cannot be relieved in a manner that the person considers tolerable

   f. be able to make an informed decision about assisted dying.

Second opinion

4. The Act requires that a patient be assessed against the eligibility criteria by two medical practitioners (including one deemed to be 'independent').

Requiring competence to make the decision

5. The person who is applying must be found competent to make an informed choice about assisted dying by two medical practitioners or a psychiatrist (if one or both of the practitioners cannot make this determination).

6. Someone is deemed to be competent to make an informed decision if they can:

   a. understand information about the nature of assisted dying that is relevant to the decision (comprehension)

   b. retain that information to the extent necessary to make the decision (recall/memory)

   c. use or weigh that information as part of the process of making the decision (reasoning)

   d. communicate that decision in some way.

Require informed decision making

7. Someone seeking assisted dying must be provided with information by the attending medical practitioner to enable them to make an informed decision, including:

   a. the prognosis for the person's terminal illness

   b. the irreversible nature of assisted dying and the anticipated impacts of assisted dying

   c. their other options for end-of-life care.

Non-initiation

8. This requirement means that health practitioners cannot in the course of providing a service initiate any discussion with a person about assisted dying or make any suggestion to the person that the person exercise the option of receiving assisted dying.

Suspected coercion

9. The attending medical practitioner must 'do their best' to ensure someone seeking assisted dying is doing so free from pressure from any other person, including a requirement to confer with other health practitioners who are in regular contact with the person (with or without their consent) and with members of the person's family (if the person approves). Any actions taken must be recorded.

10. The attending medical or nurse practitioner must cease all action to assist someone to receive assisted dying (and report this to registrar) if at any time during the process they suspect 'on reasonable grounds' that a person who has expressed the wish to receive assisted dying is not expressing their wish free from pressure from any other person.

Use of advanced directives and decisions by welfare guardians is prohibited

11. People seeking assisted dying must personally make the decision and have capacity at the time assisted dying is sought.

Regular check-ins to confirm decision

12. Over the course the person's illness and throughout the application process the practitioner must advise the person that at any time the person may decide not to receive the medication, or to receive the medication at a time on a later date that is not more than 6 months after the date initially chosen for the administration of the medication.

13. The person has the right to rescind their decision to seek assisted dying at any time, and no further action can be taken if this occurs.

Confirm decision on day medication is provided

14. The practitioner must confirm with the patient that their decision has not changed, and that they wish to receive the medication so that they can die.

Person signing for an applicant must not benefit from their death

15. If someone needs to sign the application for assisted dying on behalf of another person (when the person cannot physically write), they must declare that they do not stand to benefit from the person's death.

Immunity from criminal liability

16. Someone who seeks assisted dying (section 37(3)) is immune from criminal liability.

Use of force to prevent assisted dying is not justified

17. The justified use of force defence, to prevent suicide or in self-defence, is not justified to prevent someone from seeking assisted dying (section 37(4)).

Offences for practitioners who do not comply with requirements

18. A medical practitioner, nurse practitioner, or psychiatrist commits an offence if they wilfully fail to comply with any requirement of the EOLC Act. Conviction of an offences carries a prison term of up to three months, or a fine of up to $10,000 or a combination of both.

19. There are also offences for practitioners, and other persons who complete, or partly complete forms for others without their consent, or alter or destroy partially completed forms without consent. Conviction of an offences carries a prison term of up to three months, or a fine of up to $10,000 or a combination of both.

20. If the Registrar receives a complaint about the appropriateness of the conduct of any health practitioner, they must refer the complaint to:

    a. the Health and Disability Commissioner, if it appears that the complaint alleges that the conduct of the health practitioner is, or appears to be, in breach of the Code of Health and Disability Services Consumers' Rights

    b. the appropriate authority, if it appears that the complaint relates to a health practitioner's competence, fitness to practise, or conduct

    c. the New Zealand Police.

Destruction of prescriptions that are no longer required

21. If an attending medical practitioner, or nurse practitioner holds a prescription and the medication is no longer required, they must immediately destroy the prescription.

Effect of assisted dying on contracts

22. A person who dies as a result of assisted dying is, for the purposes of any life insurance contract, or any other contract taken to have died from the terminal illness they suffered.

Safeguards to protect those providing assisted dying

Conscientious objection

23. A practitioner is not obliged to assist someone to exercise assisted dying if they have a conscientious objection to providing that assistance to the person – this overrides any legal obligation that might otherwise apply.

Immunity from criminal liability

24. Practitioners are not liable for aiding and abetting suicide 37(1), or any other liability under the Crimes Act, for the death of someone who seeks assisted dying, whether the death was the result of an action (e.g. administration of medication) or inaction (e.g. not seeking to revive someone who is dying) by that person.

Immunity from civil liability

25. Practitioners are immune from civil liability if they act in good faith (and believing on reasonable grounds) to assist someone to die, whether the death was the result of an action or inaction by that person.

Safeguards to protect the interests of the general public and the ongoing provision of assisted dying

Annual reporting

26. The Registrar must provide an annual report to the Minister and House of Representatives on the total number of assisted deaths (including a summary of the methods used), the number of complaints received about any breaches of the EOLC Act and how those complaints were dealt with, and any other matters deemed appropriate.

Restrictions on making public details of assisted dying deaths

27. Certain details of assisted dying deaths cannot be broadcast, including the method by which medication was administered, the place where the medication was administered, the name of the person who administered the medication or their employer.

Review committee

28. The committee must consider the reports sent to it and report to the Registrar whether it considers that the information contained in each report shows satisfactory compliance with the requirements of the EOLC Act.

29. The committee can direct the Registrar to follow up on any information contained in an assisted death report that the Committee considers does not show satisfactory compliance with the requirements of the Act.

Appendix 2: Protections provided by the Health Practitioners Competence Assurance Act 2003 and the Health and Disability Commissioner Act 1994

Health Practitioners Competence Assurance Act 2003 (HPCAA)

1. The HPCAA:
    a. establishes responsible authorities for the various professions involved in the health system (e.g. medical council, nursing council, etc). Responsible authorities prescribe scopes of practice for their professions, set standards of competence, prescribe necessary qualifications, register practitioners and issue annual practising certificates.
    b. establishes professional conduct committees that investigate complaints made to responsible authorities. These committees can investigate individual practitioners' competence and conduct, as well as their compliance with the competence and scope requirements set by the responsible authorities.
    c. provides for the Health Practitioners Disciplinary Tribunal (the Tribunal) that hears and determines more serious cases against health practitioners. Professional committees can bring charges against practitioners to be heard by the Tribunal. Additionally, following an investigation by the Health and Disability Commissioner that has demonstrated that there has been a serious breach of the Code of Health and Disability Service Consumers' Rights, the Director of Proceedings may bring charges before the Tribunal.
2. Responsible authorities and professional conduct committees consider complaints about practitioners received from the Health and Disability Commissioner, employers of practitioners and other practitioners. They do not hear complaints from consumers or complaints made on the consumer's behalf in the first instance as they authorities must first refer any complaints they receive from or on behalf of consumers to the Health and Disability Commissioner for investigation.
3. At the conclusion of a review of a practitioner's competence, if it has reason to believe a practitioner fails to meet the required standard of competence, a responsible authority must order the practitioner to:
    a. undertake a competence programme
    b. have conditions imposed on their scope of practice
    c. sit an examination or take an assessment
    d. be counselled or assisted, and
    e. if there are reasonable grounds for believing that the health practitioner poses a risk of serious harm to the public by practising below the required standard of competence, or the practitioner fails to satisfy the requirements of a competence programme, the committee may suspend the practitioner until the Tribunal hears the case.

The role of the Health Practitioners' Disciplinary Tribunal

4. The principal function of the Health Practitioners' Disciplinary Tribunal (Tribunal] is to hear and determine disciplinary charges against health practitioners laid by the Director

of Proceedings following an investigation by the Health and Disability Commissioner, or referred to it by a professional conduct committee.

5. The proceedings before the Tribunal are civil proceedings. The party prosecuting the civil charge before the Tribunal is required to prove it to the civil standard of the balance of probabilities. The Tribunal has stronger powers available to it than the conduct committees and considers more serious misconduct. The Tribunal can make orders when:

   a. the practitioner has been guilty of professional misconduct because of any act or omission that, in the judgment of the Tribunal, amounts to malpractice or negligence in relation to the scope of practice in respect of which the practitioner was registered at the time that the conduct occurred; or

   b. the practitioner has been guilty of professional misconduct because of any act or omission that, in the judgment of the Tribunal, has brought or was likely to bring discredit to the profession that the health practitioner practised at the time that the conduct occurred; or

   c. the practitioner has been convicted of an offence that reflects adversely on his or her fitness to practise (these are offences which are subject to a period of 3 months or more, or involve breaches of certain listed statutes which are particularly relevant to practitioner practice, such as the Misuse of Drugs Act, the Burial and Cremation Act and others); or

   d. the practitioner has practised his or her profession while not holding a current practising certificate; or

   e. the practitioner has performed a health service that forms part of a scope of practice of the profession in respect of which he or she is or was registered without being permitted to perform that service by his or her scope of practice; or

   f. the practitioner has failed to observe any conditions included in the practitioner's scope of practice; or

   g. the practitioner has breached an order of the Tribunal.

6. The Tribunal can make one or more findings of professional or other misconduct – accordingly, a practitioner can be found in breach of one or more of the charges listed above.

7. Orders that are able to be made are:

   a. an order that the practitioner's registration be cancelled

   b. an order that the practitioner's registration be suspended for a period not exceeding three years

   c. an order that, for a period of up to three years, that the practitioner only practise in accordance with conditions as to employment, supervision, or otherwise specified in the order

   d. an order that the practitioner be censured

   e. an order that the practitioner pay a fine not exceeding $30,000.00

   f. an order that the practitioner pay part or all of the costs and expenses of any investigation of the Health and Disability Commissioner, any inquiry by a

Professional Conduct Committee relating to the subject-matter of the charge, the prosecution by the Director of Proceedings or the Professional Conduct Committee, and the Tribunal's hearing.

Health and Disability Commissioner Act 1994

8. The Health And Disability Commissioner (HDC) is a New Zealand Crown entity responsible for promoting and protecting the rights of health and disability services consumers. Some of the key functions of the HDC are to:
   a. act as the initial recipient of complaints from consumers and consumer representatives about health care providers and disability services providers, and to ensure that each complaint is appropriately dealt with
   b. investigate, on complaint or on the Commissioner's own initiative, any action that is or appears to be in breach of the Code of Health and Disability Services Consumers' Rights 1996
   c. refer complaints or investigations on the Commissioner's own initiative to the Director of Proceedings, an officer established under the Health and Disability Commissioner Act for the purpose of deciding whether or not any further action should be taken in respect of any such breach or alleged breach
   d. make recommendations to any appropriate person or authority in relation to the means by which complaints involving alleged breaches of the Code may be resolved and further breaches avoided.

9. The Commissioner has jurisdiction to receive and investigate complaints in relation to any health service or disability service.

10. The Code of Health and Disability Services Consumers' Rights (the Code) establishes the rights of consumers, and the obligations and duties of providers to comply with the Code when receiving health and disability services. The Code is a regulation under the Health and Disability Commissioner Act and provides for the following rights:
    a. Right 1 - Right to be treated with respect
    b. Right 2 - Right to freedom from discrimination, coercion, harassment, and exploitation
    c. Right 3 - Right to dignity and independence
    d. Right 4 - Right to services of an appropriate standard
    e. Right 5 - Right to effective communication
    f. Right 6 - Right to be fully informed
    g. Right 7 - Right to make an informed choice and give informed consent
    h. Right 8 - Right to support
    i. Right 9 - Rights in respect of teaching or research
    j. Right 10 - Right to complain.

11. A provider is not in breach of the Code if the provider has taken reasonable actions in the circumstances to give effect to the rights and comply with the duties in the Code. The onus is on the provider to prove it took reasonable actions.

12. The Code provides that "nothing in this Code shall require a provider to act in breach of any duty or obligation imposed by any enactment or prevents a provider doing an act authorised by any enactment". Accordingly, the provisions of the End of Life Choice Bill would take precedence over the Code if there was any conflict.

13. Any person may complain orally or in writing to an advocate or to the Commissioner alleging that any action of a health care provider or a disability services provider is or appears to be in breach of the Code. This includes not only consumers, but also their families and other support people, and other third parties such as concerned staff members in a health or disability service.

14. The Health and Disability Commission (HDC) can investigate after an individual's death in relation to the care provided to that individual up until their death.

There is no limitation period for complaints to the Health and Disability Commissioner

15. A complaint can be made at any time and often there will be an extended period between when the care is provided and when the harm becomes apparent.

16. During an investigation, the HDC may consider oral evidence obtained during interviews with witnesses and parties, and documentary evidence such as correspondence, clinical notes, policy and practice manuals, and any other relevant evidence such as labelled medication containers. Where the quality of care is an issue, HDC will obtain independent expert advice from a peer of the provider with knowledge of, and experience in, the matters under investigation.

17. After an investigation, recommendations may be made to the provider, the appropriate authority (for example, a registration body), the Director-General of Health (the Ministry of Health), or any other person or organisation HDC thinks fit, including professional colleges, district health boards, ACC, and consumer and provider groups. Recommendations to providers vary from case to case, but may include a written apology to the consumer, undertaking specific training; and implementing and reviewing systems to prevent further breaches of the Code.

18. In any case where, after deciding to investigate the action of a health care provider or a disability services provider, it appears to the Commissioner that the investigation directly concerns a health practitioner, the Commissioner must promptly give notice of the investigation to the appropriate authority.

19. The HDC cannot award damages, institute fines or take disciplinary action against practitioners. Where an investigation suggests that there may be concerns about the competence of a registered health practitioner, HDC may recommend to the registration authority (for example, the Medical Council for a doctor) that it consider whether a review of the practitioner's competence is warranted.

20. In a small number of cases, the Commissioner may refer the matter to the Director of Proceedings, to consider whether to bring disciplinary and/or other proceedings. The Director of Proceedings is a role established under the HDC Act that is independent of the Commissioner.

21. The Director of Proceedings can issue proceedings against a provider who is a regulated health practitioner by bringing a disciplinary charge in the Health Practitioners Disciplinary Tribunal. The Director of Proceedings may also commence proceedings before the Human Rights Review Tribunal. This would generally be when the provider is

not a practitioner regulated under the HPCA Act or relates to a wider entity rather than an individual practitioner.

22. If a proceeding brought by the Director of Proceedings is successful, the Human Rights Review Tribunal may take any, or a combination of, the following actions:

    a. issue a Declaration that the Code has been breached

    b. order that the provider cease engaging in the offending conduct

    c. order compensatory damages be paid by the provider

    d. order exemplary damages be paid by the provider

    e. order that any loss or damage is redressed by the provider

    f. order any other relief as the Tribunal sees fit.

Briefing

End of Life Choice Act: Draft Cabinet paper for Ministerial consultation

Date due to MO:	7 May 2021	**Action required by:**	21 May 2021
Security level:	IN CONFIDENCE	**Health Report number:**	HR20211017
To:	Hon Andrew Little, Minister of Health		

Contact for telephone discussion

Name	Position	Telephone
Dr Ashley Bloomfield	Director-General of Health	s (9)(2)(a) [redacted]
Clare Perry	Deputy Director-General, Health System Improvement and Innovation	s (9)(2)(a) [redacted]
Caroline Flora	Group Manager, Family and Community Health Policy	s (9)(2)(a) [redacted]

Minister's office to complete:

☐ Approved
☐ Needs change
☐ See Minister's Notes

☐ Decline
☐ Seen
☐ Withdrawn

☐ Noted
☐ Overtaken by events

Comment:

Document 6

End of Life Choice Act: Draft Cabinet paper for Ministerial consultation

Security level:	IN CONFIDENCE	**Date:**	7 May 2021
To:	Hon Andrew Little, Minister of Health		

Purpose of report

1. This briefing provides a draft Cabinet paper for Ministerial consultation and talking points to support your engagement with your colleagues. The paper updates Cabinet on the implementation of the End of Life Choice Act 2019 (the Act) and seeks Cabinet's endorsement for an approach to provide for assisted dying services.
2. This report discloses all relevant information.

Summary

1. We have previously provided you with information on the implementation of the End of Life Choice Act (the Act), and sought decisions on how provision should be made for assisted dying services.
2. We are now providing you with a draft Cabinet paper for Ministerial consultation which:
    a. provides Cabinet with an overview of how the Act is being implemented
    b. seeks Cabinet's agreement to an approach to provide for and fund assisted dying services that reflects your previous decisions.
3. In addition to these decisions, the paper also seeks Cabinet's agreement to an approach that will see the Ministry of Health (the Ministry) directly purchase the medications and equipment required for assisted dying.
4. We consider that the direct purchase of medications by the Ministry is the best approach for addressing a number of complexities associated with obtaining products for use with assisted dying, including the current unavailability of some products in New Zealand.
5. The cost of these products would be met using funding set aside for the provision of assisted dying services as part of Budget 2021. We will provide you with further information on arrangements for the procurement and funding of assisted dying medicines and equipment in your Weekly Report.
6. We recommend that Ministerial consultation takes place from 10-21 May, and have provided some talking points to support your engagement with your colleagues. We plan to provide a final version of the paper on 1 June, to be lodged by 3 June, for consideration by the Cabinet Social Wellbeing Committee on 9 June.

Recommendations

We recommend you:

a) **Note** that this briefing provides a draft Cabinet paper for Ministerial consultation which:

- provides an overview of how the End of Life Choice Act 2019 is being implemented to enable the availability of assisted dying from 7 November 2021
- seeks Cabinet's endorsement of an approach to provide for and fund assisted dying services which reflects your previous decisions

b) **Note** that part of the approach set out in the Cabinet paper will see the Ministry of Health directly purchase medications and equipment required for assisted dying, as direct purchase will enable the Ministry to address a range of complexities associated with accessing and funding these

c) **Agree** that the Ministry of Health should directly procure and fund the medications and equipment required for assisted dying **Yes / No**

d) **Note** that we plan to provide you with further information on arrangements for the procurement, funding, and provision of assisted dying medicines and equipment in your Weekly Report

e) **Agree** to circulate the draft Cabinet paper for Ministerial consultation **Yes / No**

f) **Note** that in addition to the Cabinet paper we have also provided some talking points to assist you in discussions with your colleagues

f) **Note** that we plan to provide you with a final version of the paper on 1 June, which can be lodged on 3 June for consideration by the Cabinet Social Wellbeing Committee on 9 June.

Maree Roberts
Deputy Director-General
System Strategy and Policy
Date:

Hon Andrew Little
Minister of Health
Date:

End of Life Choice Act: Draft Cabinet paper for Ministerial consultation

Background

7. Over recent months we have provided you with information on the implementation of the End of Life Choice Act 2019 (the Act). We have also sought and received decisions from you on how assisted dying services should be made available.

8. You have agreed that:

   a. the Government should take active steps to ensure that assisted dying services are available to people from 7 November 2021

   b. this should be done by supporting any medical practitioners who are suitably qualified and willing to provide assisted dying, by funding assisted dying services on a fee-for-service basis [HR20210216 refers]

   c. practitioners should be funded using a set of modules that they can claim when they provide parts of the assisted dying process

   d. an allowance should be provided for travel costs incurred by practitioners to allow people to receive services at home or in their local area, including in situations where they live in remote areas and/or do not have access to willing practitioners nearby, or are unable to travel due to medical or other limitations

   e. conditions for practitioners to receive funding should include:

      i. meeting service standards which will be developed with the sector over coming months

      ii. preventing practitioners from charging their own co-payments to prevent these from becoming a barrier to access [HR20210680 refers].

9. Following discussions with your office we have developed a draft Cabinet paper which:

   a. provides Cabinet with an overview of how the Act is being implemented

   b. seeks Cabinet's agreement to an approach to provide for and fund assisted dying services that reflects your previous decisions.

We propose that the Ministry will procure and fund medications to ensure effective products are available

10. In addition to your previous decisions, the Cabinet paper also seeks agreement to an approach that will see the Ministry of Health (the Ministry) directly purchase medications and equipment required for assisted dying.

11. A range of medicines will be needed to enable the effective administration of assisted dying by a medical practitioner or nurse practitioner. The medicines and equipment required will vary, depending on the medical condition of the person, and the method they choose. The Act provides for patients to choose to take life-ending medicine orally

or intravenously, and to decide whether this will be administered by the practitioner, or triggered by the patient.

12. There are a range of complexities associated with procuring and funding medications for assisted dying in New Zealand, including that:
    a. some of the products required for oral administration are not currently available in New Zealand and will need to be 'compounded' (turned into a powder at a compounding pharmacy) before they can be used
    b. products required for intravenous medications are available in New Zealand, but are currently only funded by PHARMAC for other purposes (not assisted dying)
    c. the availability of some medications may be limited or change over time if manufacturers or other jurisdictions take steps to prevent products from being supplied or exported to enable assisted dying
    d. the volume of medicines required will be very small (reflecting the small number of people expected to seek assisted dying), but will need to be available in short timeframes when they are needed.

13. We have concluded that the best approach to procuring and funding medicines and equipment for assisted dying will be to have the Ministry purchase these directly from manufacturers, wholesalers and compounding pharmacies. We have consulted with PHARMAC and they are supportive of this approach.

14. The cost of these products would be met using funding set aside for the provision of assisted dying services as part of Budget 2021. Further work will need to be done on costs, but these are expected to be small given the low volumes involved.

15. Our goal is to have an arrangement where practitioners can be provided with a single kit that contains all the medicines and supplies needed to cover the different administration methods. This will include ensuring that there is a backup option that can be used in the unlikely event that a medication does not end someone's life as expected.

16. We plan to provide you with further information on arrangements for the procurement, funding, and provision of assisted dying medicines and equipment in your Weekly Report.

The paper can be considered by Cabinet in June following Ministerial consultation

17. The table below summarises the steps involved to get the paper to the Cabinet Social Wellbeing Committee (SWC) on 9 June.

18. There is some scope to extend these dates if additional time is needed for Ministerial consultation. However, we recommend getting Cabinet decisions before the end of June 2021 so that there is sufficient time for the Ministry to give effect to these decisions.

Action	Date
Draft version of Cabinet paper provided for Ministerial consultation	7 May
Ministerial consultation period	10 – 21 May
Final version of Cabinet paper provided to Minister's office for review and lodging	1 June
Cabinet paper lodged for consideration by SWC	3 June
Cabinet paper considered by SWC Committee	9 June
Cabinet paper decisions confirmed by Cabinet	14 June

19. In addition to the Cabinet paper we have also provided some talking points to assist you in discussions with your colleagues.

We have received feedback on the paper from other agencies

20. The draft paper has been shared with the following agencies: Ministry of Justice, Police, Department of Corrections, Accident Compensation Corporation, Ministry of Social Development, Te Puni Kokiri, Ministry for Pacific Peoples, Office for Disability Issues, the Treasury, and the Department of Prime Minister and Cabinet.

21. The most substantive piece of feedback came from Treasury, which was concerned that Cabinet is being asked to agree to fund assisted dying services via a national fee-for-service approach when Ministers have not been presented with other options, and the cost of this approach is yet to be determined (because prices have not yet been set).

22. We have proposed (and Treasury has agreed) to an approach that involves:

    a. including an appendix with the paper that outlines the options that were considered to provide for assisted dying services, the criteria that were used to assess these, and why a national fee-for-service based approach was chosen

    b. getting Cabinet to agree the planned approach to provide for assisted dying services through this paper

    c. getting Cabinet to agree that you and the Minister of Finance (Joint Ministers) will agree final funding settings once work on these has been completed.

23. We expect these funding settings would include:

    a. a schedule of prices for the funding modules that practitioners can claim when they provide assisted dying services

    b. settings for a travel allowance that will be provided to practitioners

    c. specific arrangements for the purchase of medicines and equipment needed for assisted dying.

24. This advice would also include an estimate of the expected costs of providing assisted dying based on these settings, and any required financial recommendations for the drawdown of funding set aside for assisted dying as part of Budget 2021.

25. Feedback from other agencies has mostly involved detailed questions about exactly how assisted dying will be implemented which that paper does not seek to address (eg, how some of the safeguards will protect particular groups), and whether particular interest groups have been engaged (eg, disability organisations).

26. We are providing further information to agencies to address their questions and updating our engagement plan to make sure we are talking to, or have plans to talk to, the stakeholders they have identified.

Equity

27. The Cabinet paper and proposals contained within it have been developed with a view to supporting equity in access, service level, and outcomes. Measures taken to address these dimensions of equity include making equity one of our design principles, and using equity as a key criterion when selecting the best approach to provide for assisted dying services.

Next steps

28. After we receive feedback from Ministerial consultation we will incorporate this into the Cabinet paper and provide a final version to your office on 1 June 2021.

ENDS.

Document 7

Briefing

End of Life Choice Act: Confirming the mechanism to fund assisted dying services

Date due to MO:	21 May 2021	**Action required by:**	3 June 2021
Security level:	IN CONFIDENCE	**Health Report number:**	20210996
To:	Hon Andrew Little, Minister of Health		

Contact for telephone discussion

Name	Position	Telephone
Clare Perry	Deputy Director-General, Health System Innovation and Improvement	s (9)(2)(a) [redacted]
Caroline Flora	Group Manager, Family and Community Health Policy, System Strategy and Policy	s (9)(2)(a) [redacted]
Dr Ashley Bloomfield	Director-General of Health	s (9)(2)(a) [redacted]

Minister's office to complete:

☐ Approved

☐ Needs change

☐ See Minister's Notes

☐ Decline

☐ Seen

☐ Withdrawn

☐ Noted

☐ Overtaken by events

Comment:

End of Life Choice Act: Confirming the mechanism to fund assisted dying services

Security level:	IN CONFIDENCE	**Date:**	21 May 2021
To:	Hon Andrew Little, Minister of Health		

Purpose of report

1. This report seeks your agreement to use a section 88 notice as the mechanism to pay health practitioners for providing assisted dying services and sets out our planned approach to develop the notice over coming months, including sector consultation. This report discloses all relevant information and implications.

Summary

2. You have previously agreed that funding to support provision of assisted dying services will be made available, and that funding will be provided on a fee-for-service basis to individual practitioners, be based on service modules, and provided at a fixed price determined by the Ministry [HR20210216 refers].

3. The Ministry's preparations for implementation of an assisted dying service includes workforce planning to ensure there is a sufficient workforce to provide services across New Zealand in an equitable manner, from 7 November 2021. The funding mechanism selected to provide the service needs to be accessible for any suitably qualified and willing practitioner, regardless of whether they are employed in a public health organisation, private practice, or non-government organisation.

4. We recommend that a notice made under section 88 of the New Zealand Public Health and Disability Act 2000 (section 88 notice) is the funding mechanism used for assisted dying services, for the immediate implementation stage and medium term.

5. Section 88 notices are a form of tertiary legislation that can be made and amended by the Minister of Health. A section 88 notice needs to be approved by the Minister and then published in the New Zealand *Gazette* before it comes into effect.

6. Section 88 notices can allow provision of funding to any willing health practitioner suitably qualified to provide assisted dying in one overarching arrangement and can have some flexibility built in to support the development of the service at the outset. This is also the mechanism we are most certain can be put in place before 7 November 2021.

7. In the longer term when the service is established and health system reforms have occurred, it may be favourable to review the funding mechanism. While a section 88 notice is a good mechanism to support the establishment of assisted dying services, we anticipate there will be review of the implementation and development in the two years

after establishment. This will allow for further evolution of the funding mechanism if required.

8. If you agree to this as the funding mechanism, the section 88 notice will outline the decisions you have already taken about the approach to funding the assisted dying service [HR20210680 refers]. This includes that:

   a. practitioners must be suitably qualified

   b. additional co-payments cannot be charged if funding is claimed under the notice

   c. practitioners providing assisted dying while practicing under DHB employment cannot receive payment through the section 88 notice

   d. payment will be based on service modules and there will be travel assistance

   e. the price of each module will be fixed and, in the first instance, determined by the Ministry of Health after receiving independent advice.

9. There is no statutory requirement to consult in relation to the development of a section 88 notice. However, with your agreement, we plan to consult with key sector organisations to develop the details of the notice that are not already determined by your decisions.

10. We intend for consultation to be over a period of three weeks, to commence after Cabinet decisions on assisted dying services are made and any information has been made public. Consultation would be facilitated by a draft notice that lays out the terms and conditions for payment and other matters we would intend to address directly through the notice, to understand the sectors views.

11. The draft notice will also refer to a price schedule which sets the price for each module of the service, and service specifications that outline the expectations for providing the service. These will be separate documents, included by reference in the section 88 notice, which will provide flexibility to update the service specifications as the new service evolves.

12. To reassure the sector that we will not neglect to review prices in future, we also plan to include rules about reviewing prices in the notice and keep the price schedule as included by reference to support relevant updates after review. Payment revisions will be subject to Budget processes.

13. We intend to consult the draft versions of the service specifications and the section 88 notice at the same time, with input from the sector to the development of both. Consultation on prices to be included in the schedule will be separate, as it will be facilitated by an independent provider that will advise the Ministry on price, however we will ensure both consultation processes are aligned, and sector groups can engage in both.

14. There are risks to consulting the section 88 notice and service specifications with the sector, including that the sector may not support the approach taken to providing funding, and that this could lead to public criticism and/or fewer practitioners being willing to provide the service.

15. We will address these risks by carefully managing consultation with the sector, pre-empting and responding to concerns about the notice based on previous experience and being clear about which aspects of the notice are already agreed upon and which

aspects are open to consultation. We are also aware that the sector is likely to be interested in other matters beyond the notice. We will continue to engage closely with the sector on other implementation matters outside of the notice, consistent with our approach to engagement so far.

16. After consultation is completed (with your approval) we would report back to you summarising what we have heard from the sector, and how we propose the notice is crafted considering their feedback. If you are satisfied with the notice you can then issue it by publishing it in the Gazette. We intend to have a final version of the notice for you to publish in August.

17. Funding for supply and preparation of assisted dying medicines will be addressed separately as the arrangements for medicines will not be suitably addressed by service provision funding. The Ministry will provide you with updates through your weekly report on proposed funding and procurement arrangements for assisted dying medicines and preparation of medicines.

Recommendations

We recommend you:

a) **Note** your previous decisions to fund assisted dying services on a fee-for-service basis [HR20210216 refers], and your further decisions that payment should be based on service modules [HR20210680 refers].

b) **Note** that the key considerations for the most appropriate funding mechanism are supporting equitable access by allowing for participation of all willing qualified health practitioners, and ensuring funding is available when the Act comes into force on 7 November 2021.

c) **Note** that a notice made under section 88 of the New Zealand Public Health and Disability Act 2000 is the mechanism the Ministry considers is the most suitable to fulfil these requirements.

d) **Agree** that a notice under section 88 of the New Zealand Public Health and Disability Act 2000 should be the funding mechanism at the outset of the assisted dying service. **Yes/No**

e) **Note** that while it is not required by law, we recommend undertaking targeted consultation with health sector representatives on the formation of the section 88 notice as this mechanism is distrusted by some parts of the sector.

f) **Note** that the Ministry proposes that the section 88 notice includes by reference service specifications and a price schedule, to support flexibility as the service develops. An independent provider will advise the Ministry on price and consult the sector about this.

g) **Agree** that officials will conduct consultation with key health sector representatives on a draft section 88 notice and service specifications for a period of three weeks, to commence after Cabinet decisions on assisted dying services are made. **Yes/No**

h) **Agree** that for the purpose of consultation, the draft section 88 notice will include: **Yes/No**

  - i) the administrative information required to facilitate payment
  - ii) terms and conditions of payment, including providing specified information about the service
  - iii) that practitioners must have completed specified training
  - iv) a requirement to adhere to a service specification
  - v) an outline of each of the core service modules
  - vi) reference to a price schedule that will determine payment rates for the modules covered by the notice
  - vii) rules about how prices will be reviewed in future
  - viii) a requirement to comply with obligations under Te Tiriti o Waitangi
  - ix) other standard, legally required clauses.

i) **Note** that with your agreement to recommendation g, the Ministry will report back on sector consultation and advise you of any changes recommended to the content of the section 88 notice, or to the service specifications, as well as provide you with the price schedule to support your decision to issue the notice in the *Gazette*.

j) **Note** that all matters relating to provision of medicines for assisted dying will be carried out separately and we will be updating you on this through your weekly report.

Maree Roberts	Hon Andrew Little
Deputy Director-General	**Minister of Health**
System Strategy and Policy	Date:
Date:	

End of Life Choice Act: Confirming the mechanism to fund assisted dying services

Background

18. Over recent months we have sought and received decisions from you on how assisted dying services should be made available, and you have agreed that:

   a. the Government should take active steps to ensure that assisted dying services are available to people from 7 November 2021

   b. this should be done by supporting any medical practitioners who are suitably qualified and willing to provide assisted dying, by funding assisted dying services on a fee-for-service basis [HR20210216 refers]

   c. practitioners should be funded using a set of modules that they can claim when they provide parts of the assisted dying process

   d. an allowance should be provided for travel costs incurred by practitioners to allow people to receive services at home or in their local area, including in situations where they live in remote areas and/or do not have access to willing practitioners nearby, or are unable to travel due to medical or other limitations

   e. conditions for practitioners to receive funding should include:

      i. meeting service standards that will be developed with the sector over coming months

      ii. preventing practitioners from charging their own co-payments to prevent these from becoming a barrier to access [HR20210680 refers].

Work underway

19. Following these decisions, work is underway on components that will determine how practitioners receive funding for assisted dying. We also have work underway to determine how the service is provided. These components are interrelated (also see Figure One) and include:

   a. the mechanism that will be used to fund practitioners who are not employed by district health boards (DHBs) (the focus of this briefing)

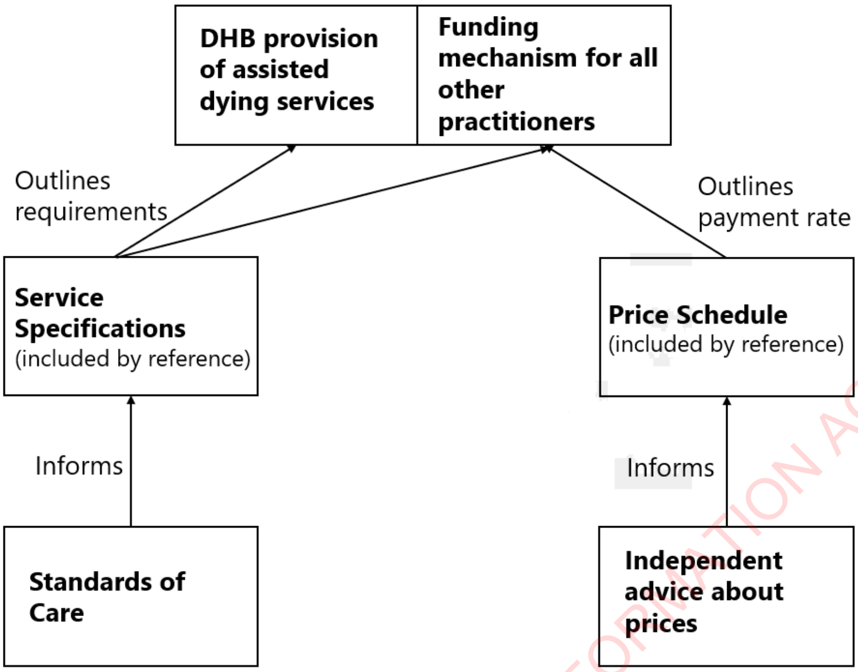
   b. the levels of funding that those practitioners can claim for completing parts of the assisted dying process – procuring independent advice to inform a price schedule

   c. how DHBs will make provision for willing members of their staff to provide assisted dying services as part of DHB services

   d. standards of care outlined by SCENZ which will also apply to all practitioners and inform the service specifications

   e. the service specifications that will outline the requirements for providing the service and apply to all health practitioners providing the service (relevant to this briefing).

Figure 1: relationships of work underway.



20. The levels of funding (prices) that practitioners not working under DHB employment can claim will be determined by the Ministry after it receives independent advice on an appropriate costing methodology. The Ministry is currently negotiating with an independent provider with expertise in providing cost estimates for this advice and we anticipate receiving this in July.

21. We expect to provide you with a copy of the report of the independent provider and a recommended schedule of prices in August 2021.

22. We are working to support DHBs to make arrangements to enable staff members who are willing to provide assisted dying services to do so, if asked. Such DHB staff may work in areas where assisted dying is likely to be raised by patients (e.g. oncology). These staff are already paid by DHBs, but DHBs may need to:

    a. fund travel costs and make arrangements for practitioners to provide services in patients' homes or other community settings

    b. make arrangements to allow assisted dying to take place within DHB-run facilities where needed (e.g. policies for how this is managed within facilities when required)

23. The Ministry is currently working to determine which of the available mechanisms should be used to require this (eg, a service coverage schedule variation, a letter of expectations, etc). We will report to you separately on this matter.

24. Standards of care are required to be developed and approved by the Support and Consultation for End of Life in New Zealand (SCENZ) group and will inform clinical practice. The Ministry is currently working to establish this group and to support the development of standards of care. We anticipate the SCENZ group will be in place in early July.

25. Service specifications stipulate what the services are to be delivered and how they should be delivered (eg, the service, standards, measures). They will be drafted by the Ministry in consultation with clinical experts and informed by the standards of care made by the SCENZ group.

26. We intend for draft service specifications to be consulted with the sector at the same time as consulting on the funding mechanism. We will update you on the progress of the service specifications development through your weekly report.

27. Prices may also need to be altered from time to time to reflect the costs of delivering the service and it is desirable that they be available in separate schedule on our website to easily update them (although any cost difference would be subject to Budget approval processes). We have taken this approach before in the Hearing Aid Services Notice 2018.

Selecting a mechanism to fund practitioners who provide assisted dying services

28. The health and disability system includes a number of mechanisms that can be used to fund services, depending on whether these are delivered locally, regionally or nationally, whether services are provided in a single setting or variety of settings, and which workforces are involved.

29. In determining an appropriate mechanism to fund practitioners for assisted dying we have been mindful of the need for a mechanism to:

    a. enable individual practitioners to opt-in to provide services and claim funding

    b. allow funding to be accessed on an equal basis by practitioners working in a range of settings including public and private healthcare, in primary care and other settings

    c. provide some flexibility in the requirements it imposes on practitioners, and allow for these to be amended via a simple, transparent process (recognising that assisted dying is a new area and amendments may be required over time)

    d. align with (or at least avoid conflicting with) expected changes that will take place through the Government's health and disability system reforms, including any changes to the way that palliative care services are commissioned.

30. The funding mechanism also needs to support the aims of the implementation of the End of Life Choice Act 2019 (EOLC Act) by ensuring:

    a. equitable access for eligible people

    b. as many suitable qualified practitioners who are willing to provide assisted dying services can do so without undue difficulty, to ensure there is a willing and able workforce to provide the service

    c. a safe, quality and consistent service

    d. culturally safe and appropriate service provision, in-line with our obligations under Te Tiriti o Waitangi

    e. funding to support these elements is in place by 7 November 2021.

31. We examined four potential mechanisms to provide funding to practitioners (a comparison of these is provided in Appendix 1):

a. **a notice made under section 88 of the New Zealand Public Health and Disability Act 2000 (NZPHD Act) via the *Gazette*** (a section 88 notice) to facilitate funding for all suitable health practitioners not practicing under the employment of DHBs. This is the Ministry's preferred option. Section 88 notices are a form of tertiary legislation that can be made and amended by the Minister of Health. A section 88 notice needs to be approved by the Minister and then published in the New Zealand *Gazette* before it comes into effect

b. **a mixed model which would involve varying the existing service agreement with primary care providers (and possibly others) and also making a section 88 notice for all other willing practitioners not covered by the agreement(s) –** service agreements are made under section 5 of the New Zealand Public Health and Disability Act 2000. We would need to vary the agreement(s) to include assisted dying services. This would be by varying the primary healthcare organisation service agreement (PHOSA) negotiated with PSAAP (and any other agreements), and also making a notice to cover practitioners not in primary care.

c. **making a new service agreement** similar to PHOSA, however that would encompass all qualified health practitioners and be specific to assisted dying services

d. **offering standard contracts** for all willing qualified health practitioners.

We recommend using a section 88 notice as the payment mechanism for assisted dying services

32. On balance we believe that a section 88 notice is the best mechanism to provide funding to practitioners who provide assisted dying services because it can:

    a. facilitate payment to any suitable practitioner who has opted-in without needing to make separate arrangements for different settings

    b. be designed to provide the flexibility necessary to support a new and developing service while maintaining consistent arrangements for all practitioners providing the service – by allowing for service specifications and a price schedule to be updated in a uniform manner and without onerous processes as the service develops

    c. be an enduring arrangement while health and disability system reforms are underway

    d. be made before 7 November 2021.

33. A section 88 notice made under the NZPHD Act will make payments available to any health practitioner who meets the terms and conditions of the notice. To support the involvement of practitioners in the assisted dying service, the notice should not require any onerous reporting from the practitioners providing the service but should capture the core requirements of the assisted dying service.

34. The section 88 funding mechanism is used in the maternity sector and involves participants (eg, midwives) claiming payment from the Ministry for a service delivered under the notice. Section 88 notices are also used to fund the provision of hearing aids, breast prostheses, funded family care, and other patient benefits and subsidies.

35. There is no specific format for a section 88 notice meaning it can provide flexibility in how funding is set up, and allows national coverage, across different workforces and providers within a single notice.

36. A section 88 notice must be approved by the Minister of Health, and can by amended by the Minister, though changes with financial implications require funding approval through the Budget process.

Process for issuing a section 88 notice

37. A section 88 notice is a form of tertiary legislation which comes into effect when approved by the Minister and published in the New Zealand Gazette.

38. There is no statutory requirement to negotiate or consult a section 88 notice with the health sector. While this can be a benefit to get a mechanism in place quickly, it also means that section 88 notices are not always viewed positively by practitioners and their parent organisation, especially as notices do not necessitate a negotiation process whereas other funding mechanisms do.

39. To address this, we are proposing to undertake a three-week focussed consultation process with representatives of the health sector. This will be an opportunity to request feedback from on the notice, respond to any concerns and socialise the approach to ensure it is supported.

40. We are proposing for that consultation on the notice also incorporates consulting on service specifications at the same time, as they will be of interest to the sector, and while we don't plan to incorporate their requirements in the notice itself, they will be included by reference.

41. We also plan to align consultation so that the independent provider that will advise the Ministry about suitable price will be consulting separately, but in a way that means the sector can also engage in this process, as it also relates to the funding mechanism.

42. At the conclusion of all consultation and advice, the Ministry will report back to you on what we have heard from sector consultation, on the independent advice about price. We will provide you with our recommendations for the content of the notice, the service specifications and price schedule before you make your decision to issue the notice.

43. Sector consultation will include key groups representing the interests of practitioners, such as: General Practice New Zealand, the Royal New Zealand College of General Practitioners, the Royal New Zealand College of Psychiatrists, Nurse Practitioners New Zealand, College of Nurses Aotearoa, New Zealand Medical Association, Primary Health Alliance, New Zealand Nurses Organisation and other relevant groups.

44. The timeframes to proceed with consultation (assuming receiving your approval of this course of action on 2 June, and Cabinet decisions on 14 June) are as follows:

Drafting of the section 88 notice	To be concluded in June
Drafting the service specifications	To be concluded in July
Draft section 88 notice and service specifications circulated to sector groups for feedback	Late June (or once Cabinet decisions have been taken) - for a period of three weeks.
Last day for feedback from sector groups	Early-mid July
Report to Minister of Health with recommendations from consultation on the notice and service specifications, with price schedule, independent pricing advice, and proposed section 88 notice attached.	Early August
Any feedback from Minister of Health taken into account and a final version of section 88 notice provided.	August
The Minister of Health makes the section 88 notice by publishing it in the New Zealand *Gazette*.	Late August
The Ministry progresses implementing and testing the section 88 notice in administrative systems.	September – November

Draft notice for consultation

45. Some aspects of the draft section 88 notice will outline the decisions you have already taken on the approach to funding the assisted dying service rather than new aspects for your consideration. These aspects will be communicated to the sector rather than consulted. This includes that:

    a. practitioners must be suitably qualified

    b. specifying that additional co-payments cannot be charged if funding is claimed under the notice

    c. practitioners providing assisted dying while practicing under DHB employment cannot receive payment through the section 88 notice

    d. payment will be based on service modules and there will be travel assistance

    e. the price of each module will be fixed and, in the first instance, determined by the Ministry of Health after receiving independent advice.

46. In order to keep the section 88 notice simple and straightforward to implement across the health sector, and to support involvement of all willing and qualified practitioners, the content of the section 88 notice should focus on the terms and conditions of payment, and not on quality standards in the notice itself.

47. We intend to share the content of the draft notice with health sector representatives to discuss and test the approach with them. The content of the draft notice which we would request sector feedback on includes:

   a. the administrative information required to facilitate payment through a buyer-created invoice scheme
   b. terms and conditions of payment, including providing specified information about the service
   c. that practitioners must have completed specified training
   d. a requirement to adhere to a service specification that will be drafted and consulted with the sector at a later date
   e. an outline of each of the core service modules
   f. reference to a price schedule that will determine payment rates for the modules covered by the notice. The schedule will be made by the Ministry after an independent assessment of fair price is completed
   g. rules about how prices will be reviewed in future
   h. a requirement to comply with equity and cultural competency considerations
   i. other standard legally required clauses.

48. At the conclusion of the consultation period we will report back to you on the views the sector representatives shared about this content, and any recommended changes in light of consultation.

Service specifications for consultation

49. The service specification for assisted dying services will be included by reference in the draft section 88 notice and require practitioners' compliance with the specifications in order to be funded. The draft service specifications will include the requirements for providing a culturally safe and responsive service and be informed by the standards of care developed by SCENZ.

50. Service specifications may need to be changed in future to reflect the detail of what practitioners must do to deliver assisted dying services, especially in the early inception and as it develops. This is a simpler process when the specifications are included only by reference in the notice, because altering them does not require redrafting the notice and then publishing it in the *Gazette* each time. We intend to discuss this with the sector.

51. Consultation with the sector about the draft notice will also include consulting about the draft service specifications, as they are referenced in and interact with the notice.

Risk

52. While overall we believe that there is clear benefit to consulting on the section 88 notice with the sector, there are also risks. The risks include that:

    a. the sector may not support the approach taken to providing funding, and that could lead to public criticism and/or fewer practitioners being willing to provide the service

    b. the sector organisations engaged with may not be fully representative of the views of willing health practitioners

    c. public knowledge of the consultation leads to criticism from those parties who are not consulted.

53. We will manage these risks by clearly defining the scope of the consultation on the section 88 notice, by pre-empting concerns of the sector and being prepared to address these concerns (eg, by designing a flexible notice which addresses some of the adverse experiences in other examples of section 88 notices) and by informing the sector about the opportunities to engage on the other aspects of the funding, service specification work, and other aspects of service design.

54. We are also aware feedback is likely to go beyond the content of the notice and service specifications, and we intend to consider that feedback as it relates to other workstreams of the implementation of the End of Life Choice Act.

Equity

55. Equitable service provision is a core consideration of the implementation of assisted dying services and is best supported by ensuring all willing and qualified practitioners can be funded to provide assisted dying services if they wish to. The section 88 notice funding mechanism recommended in this report is the best option to rapidly support equitable access in establishing an assisted dying service.

56. The section 88 notice and other documents which lay out the requirements for being funded to provide the assisted dying service will also support equity by ensuring that the service is flexible and able to respond to needs of people accessing the service, as well as being culturally responsive.

Next steps

57. With your agreement, the Ministry will draft a section 88 notice that we will then consult on with representatives of the health sector. After consultation we will report back to you with the views of the sector and any proposed changes to the notice. We will then work to issue the notice in the *Gazette*. This is expected to conclude before the end of August.

58. We plan to provide you with further information on arrangements for the procurement, funding, and provision of assisted dying medicines and equipment, and later about the development of service specifications in your Weekly Report.

ENDS.

Document 7

Appendix 1: Comparing possible mechanisms to fund practitioners for providing assisted dying services

Mechanism:	**Section 88 notices**	**Mixed Model**	**A new service agreement encompassing all suitable practitioners**	**Standard Contracts.**
Mechanism involves: Criteria:	– making tertiary legislation which facilitates funding for all suitable health practitioners not practicing under the employment of DHBs.	- varying the existing service agreement with primary care providers (and possibly others) and also making a section 88 notice for all other willing practitioners not covered by that agreement.	– drafting and negotiating a new service agreement encompassing all suitably qualified practitioners.	– drafting and agreeing contracts with every willing and suitably qualified practitioner
Level of complexity and confidence that this can be in place and operating by 7 November 2021	Yes – the timeframes for making a notice is within the control of the Ministry and while it doesn't require consultation, we could do so to ensure support for the mechanism.	Maybe – Amendments to service agreements would require negotiation and agreement with representative organisations. Involves both negotiating amendments to existing service agreements and developing a separate S88 notice to cover practitioners not captured by existing agreements.	Unlikely – Requires the negotiation of an entirely new service agreement that covers different practitioner groups. This would require negotiation and agreement with a wide range of representative organisations. Reaching agreement is likely to be very difficult in the required timeframe.	Maybe – organising contracts for individual practitioners would be administratively burdensome and may not be practicable in the required timeframe. It is likely only some contracts would be in place in November, with patchy availability until good coverage can be achieved.
Mechanism enables individual practitioners to opt-in to provide services and claim funding	Yes – a notice can cover all practitioners and allow any to opt-in and receive funding.	Yes – different practitioner groups can be covered but would require multiple mechanisms (amendments to existing service agreements and a S88 notice to cover those not included in service agreements).	Yes – a new agreement can allow different practitioner groups to be covered.	Yes - would require each practitioner to have a contract.

Mechanism:	**Section 88 notices**	**Mixed Model**	**A new service agreement encompassing all suitable practitioners**	**Standard Contracts.**
Mechanism allows funding to be accessed on an equal basis by practitioners working in a range of settings including public and private healthcare, in primary care and other settings	Yes – a single notice can cover all practitioners regardless of setting.	Yes – though there may be some variation in the terms/conditions included in amended service agreements vs the S88 notice.	Yes - if a single agreement can be negotiated.	Yes – though the administration related to individual contacts might be viewed as a barrier by some practitioners.
Mechanism provides some flexibility in the requirements it imposes on practitioners, allowing for these to be amended easily (as assisted dying is a new area and requirements may require some amendments over time)	Yes – the service specification and price schedule can be referred to and put in separate documents so that they can be amended without changing the notice itself.	Limited – many changes like funding adjustments would require renegotiating service agreements, although service specifications may be varied more easily.	Limited – many changes would require renegotiating the agreement, although service specifications may be varied more easily.	No – changes like funding would require renegotiating every contract, although service specifications may be varied more easily.

Mechanism:	Section 88 notices	Mixed Model	A new service agreement encompassing all suitable practitioners	Standard Contracts.
Mechanism aligns with (or at least avoid conflicting with) expected changes that will take place through the Government's health and disability system reforms	Yes – use of a notice would see services managed by the Ministry in line with other national services, which can be transferred to Health NZ at a later date without the need to change the mechanism as part of health reforms.	Uncertain – the future status of service agreements across parts of the health workforce (eg, primary care) is still to be determined. Using service agreements may require changes at a later date as part of health reforms.	Possibly – a new service agreement could be created to avoid the need for revision during health reforms.	Yes – contracts would be unaffected, and can be transferred to Health NZ at a later date without the need to change these as part of health reforms.

Document 8

MINISTRY OF
HEALTH
MANATŪ HAUORA

Briefing

End of Life Choice Act: Interactions with other systems

Date due to MO:	18 June 2021	**Action required by:**	22 June 2021
Security level:	IN CONFIDENCE	**Health Report number:**	20210844
To:	Hon Andrew Little, Minister of Health		

Contact for telephone discussion

Name	Position	Telephone
Dr Ashley Bloomfield	Director-General of Health	s (9)(2)(a)
Clare Perry	Deputy Director-General, Health System Improvement and Innovation	s (9)(2)(a)
Caroline Flora	Group Manager, Family and Community Health Policy, System Strategy and Policy	s (9)(2)(a)

Minister's office to complete:

☐ Approved
☐ Needs change
☐ See Minister's Notes

☐ Decline
☐ Seen
☐ Withdrawn

☐ Noted
☐ Overtaken by events

Comment:

End of Life Choice Act: Interactions with other systems

Security level:	IN CONFIDENCE	**Date:**	18 June 2021
To:	Hon Andrew Little, Minister of Health		

Purpose of report

1. This report provides you with information about how the End of Life Choice Act 2019 (the Act) interacts with the work of other government agencies, and how any interactions between the Act and other agencies will be resolved.
2. This report discloses all relevant information and implications.

Summary

3. The Act, which comes into force on 7 November 2021, will have implications for the work and the systems employed by other Government agencies, including the Ministry of Justice, New Zealand Police, the Department of Corrections, the Department of Internal Affairs, the Ministry of Social Development, as well as the Office of the Privacy Commissioner and the Health and Disability Commission.
4. This briefing provides you with an overview of how the processes within the Act will interact with the work of other agencies, including changes to the reporting of deaths by assisted dying. Key interactions are:
    a. changes to the way that a death is reported after an assisted death has occurred;
    b. a new type of medical certificate of cause of death;
    c. annual reporting on complaints of assisted dying; and
    d. potential complaints about an assisted dying service to the Coroner, the Registrar (assisted dying), and New Zealand Police.
5. The paper provides a summary of the interactions that could arise once the Act comes into force, especially in relation to any assisted dying deaths that may be reported to the Coroner, assisted deaths in Corrections facilities, and the reporting of offences.
6. The Ministry has already discussed all of the interactions in this paper with the relevant agencies and we are supporting them to implement solutions, where required, before the Act comes into force. Where immediate solutions are not necessary, the Ministry will continue to actively monitor the impact of the Act once it comes into force, and work with the relevant agencies to address these interactions.

7. This paper is provided to give you visibility of interactions with other Government agencies and provide you with information on the work that is happening so that you can answer any questions from your colleagues.

Recommendations

We recommend you:

a) **Note** that the End of Life Choice Act 2019 will affect the work of other government agencies, and that the Ministry is working with these individual agencies on the resolution of these interactions.

b) **Share** this briefing with your Ministerial colleagues – the Minister of Justice, the Minister of Corrections, the Minister of Police, the Minister of Internal Affairs, the Minister for Social Development and the Attorney-General – to inform them of the effect the End of Life Choice Act 2019 will have on their portfolios and the work underway in order to ensure a smooth implementation across agencies. **Yes/No**

Maree Roberts
Deputy Director-General
System Strategy and Policy
Date:

Hon Andrew Little
Minister of Health
Date:

End of Life Choice Act: Interactions with other systems

Context

1. The implementation of the End of Life Choice Act 2019 (the Act) is underway and on track to be delivered when it comes into force on 7 November 2021. This briefing provides you with an overview of how the processes within the Act will affect the work of other agencies.

2. We have discussed the interactions mentioned in this briefing with the relevant agencies to ensure they are properly prepared and aware of what influence the Act will have on their day-to-day work once it comes into force.

3. In preparing this briefing, we have consulted with the Ministry of Justice, New Zealand Police, the Department of Corrections, the Department of Internal Affairs, the Ministry of Social Development, the Accident Compensation Corporation, as well as Crown Law, the Office of the Privacy Commissioner and the Health and Disability Commission.

4. You may want to consider sharing this briefing with your Ministerial colleagues – the Minister of Justice, the Minister of Corrections, the Minister of Police, the Minister of Internal Affairs, the Minister for Social Development and the Attorney-General. This will inform them of the effect the Act will have on their portfolios and the work underway in order to ensure a smooth implementation across agencies.

5. This briefing groups the interactions relating to the implementation of the Act into three categories:

   a. routine interactions with other systems which *will* arise from the implementation of the Act;

   b. potential interactions with other systems or agencies that *may* arise from the implementation of the Act; and

   c. other interactions.

Routine interactions with other systems

Death reporting processes

6. The Act has prescribed four changes to the way a death is reported after an assisted death has occurred. These are:

   a. a new requirement for the attending practitioner to report by submitting a prescribed form to the Registrar (assisted dying) (the Registrar) about the death by assisted dying, including specifics about the method and any problems and/or difficulties that occurred in the administration of the medication;

   b. a new type of medical certificate of cause of death specific to assisted dying which has been created through an amendment to the Burial and Cremation Act 1964;

   c. the Births, Deaths, Marriages, and Relationships Registration (Prescribed Information) Regulations 1995 which prescribe the content of the death certificate issued by the Department of Internal Affairs (DIA) have been amended to include records of the terminal illness that made the person eligible for assisted dying, and the fact that the death was by assisted dying; and

d. change to the process for approving a cremation.

Submission of report by prescribed form

7. The Act establishes a Review Committee that must scrutinise every death by assisted dying that occurs in New Zealand. The attending practitioner must provide an assisted death report by a prescribed form to the Registrar who in turn is required to refer that report to the Committee. The Committee then determines whether the assisted death report shows satisfactory compliance with the requirements of the Act and reports that back to the Registrar.

8. The new requirement for an attending practitioner to submit an assisted death report to the Registrar is a simple matter that is being addressed through implementation work within the Ministry of Health (the Ministry), specifically the development of prescribed forms to be approved by the Director-General of Health. We will also address this matter in guidance and training for practitioners.

9. The next steps if the report is not found to show satisfactory compliance are not clearly laid out in the Act. Although, the Committee can require the Registrar to follow up on any information contained in the report, which does not show satisfactory compliance.

10. We have had discussions with New Zealand Police (Police), Ministry of Justice and Crown Law about the kinds of matters that might constitute referral for criminal investigation. This is covered in the criminal complaints section later in this briefing in more detail (see paragraphs 36-39).

New type of medical certificate of cause of death

11. All deaths that occur in New Zealand must be registered with DIA. The Act introduces a new type of medical certificate of cause of death specific to an assisted death, and the Ministry will oversee the training of practitioners in the implementation of this new certificate.

12. The medical certificate of cause of death information is currently provided to DIA through existing protocols and data channels, in accordance with the Births, Deaths, Marriages, and Relationships Registration (Prescribed Information) Regulations 1995. It will be necessary for the Ministry to ensure the information about assisted dying contained in the medical certificate of cause of death is also shared securely.

13. The requirements of the death certificate will also be altered to include record of the death being through assisted dying, and of the terminal illness that made the person eligible. Therefore, it will be necessary for the data flow from the Ministry death documents database to be modified so that it will support that change without the need for additional systems to be created.

14. We have discussed this change to systems with DIA, and they understand the requirement to alter existing processes. We foresee that the changes should be dealt with between our two agencies without any issue.

Change to the process for approving a cremation

15. The Cremation Regulations 1973 amends the "Certificate of Medical Practitioner or Nurse Practitioner" (or Form B) which is completed by a medical or nurse practitioner if a body is requested to be cremated. The amendments to Form B require the practitioner to include mention of the assisted death. The completed Form B is then submitted to medical referees who are employed by crematorium authorities to conduct an approval process before a body can be cremated. The Burial and Cremation Act 1964, its associated regulations, and approval process are administered by the Ministry. We will be engaging with crematorium authorities to inform them of this amendment and how the Act will affect their work.

16. We have already briefed the Associate Minister of Health, the Hon Dr Ayesha Verrall, on the work underway within the Ministry to examine the future state of the Burial and Cremation Act 1964 [HR 20210798 refers]. Over the long term, future changes to the Burial and Cremation Act may also require changes to the Act's operating procedures.

Annual reporting on complaints about assisted dying

17. Other agencies must annually provide information to the Registrar about any complaints that they have received about breaches of the Act and how they were dealt with. The agencies affected by this requirement are Police, the Health and Disability Commission, and the responsible authorities (Medical Council, Nursing Council, and Pharmacy Council).

18. We are working with these agencies to ensure that they are aware of this requirement and will come to an agreed process for annual reporting when the Act comes into force.

Consultation with the Office of the Privacy Commissioner

19. The Privacy Commissioner notes there will be considerable information flows required across the health and justice sectors to give effect to the Act. Health information that is collected, used, held and disclosed by health agencies is governed by the Health Information Privacy Code 2020 (HIPC) which takes the place of the information privacy principles in the Privacy Act 2020. Any new information sharing procedures that may be introduced as a result of the Act will need to take proper account of the HIPC.

20. We have engaged with the Office of the Privacy Commissioner to discuss this and other privacy concerns under the Act and how the privacy of people seeking assisted dying, their whānau, and that of the practitioners providing assisted dying, can be supported, among other matters.

21. Before the Registrar establishes the register of approved forms, Review Committee reports and reports to the Minister under s 27(2) they are required to consult with the Privacy Commissioner.

22. The Ministry has confirmed to the Office of the Privacy Commissioner that our understanding of the term "health information" in the Health Act 1956 includes information about assisted dying services provided under the Act, and therefore could lawfully be shared using existing mechanisms. The Office of the Privacy Commissioner has also indicated that the definition of "health information" in the HIPC is broad

enough to incorporate information about assisted dying services under the Act. Therefore, no amendment to the HIPC is necessary.

Managing complaints about assisted dying services

23. A key area where assisted dying interacts with other agencies is in the investigation and management of complaints. Most of these interactions concern complaints of criminal wrongdoing or the competency of practitioners that may result from an assisted dying service.

Complaints to the Registrar

24. In s 27(4) of the Act it is implied that the Registrar will be able to receive complaints about matters relating to an assisted dying service. The Registrar is then required by the Act to refer those complaints to either Police, the Health and Disability Commissioner, the relevant responsible authority, or to respond to the complainant and explain why the complaint was not referred onward.

25. The role of the Registrar under the Act is unique in the sense that people can send complaints directly to the Registrar. In most cases for people receiving health and disability services, people are generally advised to lodge their complaint about a health service with the health provider or practitioner in the first instance, and/or with the Health and Disability Commissioner who is responsible for promoting and protecting the rights of consumers as set out in the Code of Health and Disability Services Consumers' Rights. The Commissioner is empowered to investigate complaints under the Health and Disability Commissioner Act 1994. (The Registrar does not have any investigative powers.)

26. To ensure alignment with other complaints processes for health and disability services, whilst implementing the Act we plan to make contact information and the Registrar's complaints process available so people can lodge complaints easily and directly, but also provide information about the Health and Disability Commissioner at the same time so that it is clear that the Health and Disability Commission complaints process can also be followed.

Complaints about Practitioners

27. Section 27(4) of the Act enables the Registrar to forward any complaints about the conduct of practitioners to the Health and Disability Commissioner if it appears that the conduct of the practitioner appears to be in breach of the Code of Health and Disability Services Consumers' Rights, or to the "appropriate authority" if it appears the complaint relates to a practitioners competence and fitness.

28. Consequently, the Health and Disability Commissioner is likely to be the primary recipient of complaints about concerns people have about the service they are receiving in the provision of assisted dying, or in respect of conscientious objection.

29. Complaints about a practitioner's competence and fitness are likely to be referred to the Medical, Nursing or Pharmacy Councils who are the registering authorities which medical, nurse and pharmacy practitioners are required to be registered with in order to practice in New Zealand.

30. The kinds of complaints these responsible authorities deal with (under the Health Practitioner Competence Assurance Act 2003) relate to the professional and clinical conduct of the medical or nurse practitioner. A serious complaint could result in suspension of registration, special conditions for practice such as supervision, or deregistration. These authorities can undertake their own investigation as required, but they can also refer any such complaints to the Health and Disability Commissioner to take such action as they think fit.

31. Engagement with the Health and Disability Commission has been ongoing since early this year. We are continuing to work closely with the Health and Disability Commission to ensure they are well linked into the implementation of the Act.

Coronial inquiry

32. The Act amends the Burial and Cremation Act 1964 to direct that the attending medical or nurse practitioner must issue a certificate giving the cause of death immediately after the person's death by assisted dying. It is also specified that a certificate should not be issued if the Coroner has decided to open an inquiry under the Coroner's Act 2006.

33. We have discussed this provision with officials at the Ministry of Justice and we are of the view that there are no foreseeable circumstances where a coronial inquiry could already be underway when an assisted death is carried out (including in the period immediately after, during which the medical certificate of cause of death is required to be issued). Therefore, in every case of an assisted death, a medical certificate of cause of death will be issued by the attending practitioner.

34. However, it is possible that a complaint of a serious nature could arise after the assisted death has occurred. In those cases, a medical certificate of cause of death will already have been issued and the Coroner will not become aware of the death through referral by a practitioner.

35. As a result, other means of reporting the death to Coroners will be utilised. This could be, for example, a complaint being made with Police about the death which could then be referred to the Coroner, a direct appeal made to the Solicitor-General to request that an inquiry is opened, or a High Court ruling instructing that an inquiry should be opened.

Criminal complaints

36. Sections 37 and 38 of the Act provide immunity for practitioners from criminal and civil liability, providing that the provisions of the Act are complied with. However, it is possible that some instances of assisted dying could lead to a situation where complaints of a criminal nature are raised by friends and family of the deceased, attending practitioners or other members of the public.

37. The Act includes offences specific to providing assisted dying in s 39. These include offences for:

  a. medical practitioners, nurse practitioners or psychiatrists wilfully failing to comply with the requirements of the Act;

  b. a person who completes or partially completes a form under the Act for someone else without that person's consent; and

c. a person who destroys or partially destroys a completed or partially completed form without the consent of the person who completed it.

38. Anyone who is convicted of these offences is liable to a $10,000 fine and/or imprisonment for a term not exceeding three months.

39. In addition to these offences, it is our view that the requirement of the provision in s 37 that a person must be acting "in good faith and believing on reasonable grounds that a person wishes to exercise the option of receiving assisted dying" in order to be immune from criminal liability could be challenged in some cases. This would mean that some offences under the Crimes Act 1961 could be relevant and considered by Police for prosecution. These are the kinds of cases we consider are likely to be referred to the Coroner after an assisted death has occurred.

Planned approach: Coronial and criminal pathways

40. As the Act introduces a medical procedure which has never been used in New Zealand before, it is not certain how and in what circumstances a specific instance of assisted dying could lead to a complaint of criminal misconduct. However, we have met with Police and the Ministry of Justice to discuss possible pathways. We agree that Police are inevitably going to receive public complaints about an assisted dying process, either directly or on referral from, for example, the Registrar. Likewise, the majority of any complaints made directly to the Coroner are likely to be referred to Police, as they are the Coroner's investigative arm.

41. Our agencies also agree that, in accordance with s 27(4) of the Act, the Registrar will have oversight of all complaints related to assisted dying. Police will notify the Registrar of every individual complaint they receive in relation to assisted dying, and (as required) ask the Registrar to organise assistance from the Ministry of Health in the investigation of individual cases. Likewise, any complaint the Registrar may receive will be recorded and referred to Police for investigation where appropriate.

42. If Police decide that a complaint amounts to criminal offending, they may choose to prosecute. However, if Police are of the view that the case amounts to a complaint about the competency of an individual practitioner, they will advise the Registrar accordingly. The Registrar would then have the option of forwarding that evidence to the Health and Disability Commissioner or the relevant Medical, Nursing or Pharmacy Councils for investigation. The Police could also conclude there is insufficient evidence to substantiate any accusation of wrongdoing and advise the Registrar accordingly.

43. The Director-General of Health has written to the Chief Coroner about this planned approach and we will continue to work with the Coroner's Office should any challenges arise from the implementation of the Act.

Other interactions

Assisted dying in Corrections facilities

44. A person in a Corrections facility may wish to seek assisted dying as there is nothing in the Act that prohibits it. Corrections advises that anyone in prison who is eligible for assisted dying may also have the option to apply for compassionate release, due to the underlying terminal illness, which can be granted by the Parole Board. If an application for assisted dying is made while someone is in prison, they would likely be eligible for

compassionate release to a suitable place for the assisted death to occur (eg, their home, hospice care, marae or a hospital).

45. There may also be cases where a person requests to die in prison. This may occur if someone has been in prison for a long time and has no whānau or support networks outside of prison.

46. In a situation where assisted dying is requested by someone in prison, Corrections will consider all options to provide the most humane environment for the assisted dying to take place. Corrections will continue to develop operational practices and processes to manage requests for assisted dying.

47. Corrections notes it is standard practice under s 13(2) of the Coroners Act 2006 for any death in a Corrections facility to be referred to the Coroner. However, the Act amends section 13(2) of the Coroners Act so that a death in custody as a result of assisted dying is not automatically referred. However, if the Coroner is referred a death where the person died using assisted dying in custody then the Coroner would have to open an investigation. In addition, s 183 of the Corrections Act requires a prison manager to immediately report a death in custody to a constable. We do not consider this will create an issue as Corrections can inform Police that the death was a result of assisted dying.

Māori in Corrections facilities

48. Māori are disproportionally represented in the prison population. We will continue to discuss the Act's implementation with Corrections to determine an approach that encompasses Corrections' strategy *Hōkai Rangi*, Whakamaua: Māori Health Action Plan and the development of a kaupapa Māori model of care within Corrections.

Government financial assistance

49. We have consulted with the Ministry of Social Development (MSD) regarding whether there would be any strong interactions between the Act and MSD financial assistance. MSD does not anticipate any major difficulties in this regard.

50. If an MSD client chooses to consider an assisted death, this would not directly affect any eligibility to a main benefit or New Zealand Superannuation/Veteran's Pension. For example, clients may be eligible for the Supported Living Payment on the grounds of a terminal illness if they are not expected to live for more than two years. This would not be affected by the provisions of the Act.

51. Supplementary assistance, where eligibility is not dependent on how long a person has left to live, is also unlikely to be affected by the Act. The Disability Allowance would still be covered as a client must have either a disability that is likely to last at least six months or have a life expectancy of less than six months because of a terminal illness. Eligibility for the Accommodation Supplement is not restricted to a timeframe. Temporary Additional Support may be granted for a maximum period of 13 weeks (and regranted or cut shorter, as appropriate).

52. The main changes for when a client dies relate to people who have a partner included on a benefit - if the client considering assisted dying is in hospital or residential care, the partner's income could change depending on the situation. For instance, if a client receiving the Supported Living Payment (SLP) is in hospital for more than 13 weeks, the client would have their rate of SLP reduced to the hospital rate of $46.56 net (as at 1

April 2021), while the partner's rate increases to a single rate of benefit and they also become eligible for Special Disability Allowance

53. There is also the Terminal Benefit which, contrary to its name, is not a benefit in itself but a transitional arrangement where there is provision for the surviving partner to continue getting the deceased partner's rate of benefit (including extra help payments like the Accommodation Supplement) for 28 days following the date of death.

ACC and disentitlement

54. You have received a copy of the briefing that the Ministry for Business, Innovation and Employment and the Accident Compensation Corporation provided to their Minister about an interaction between the Act and their legislation, the Accident Compensation Act 2001 (the AC Act) where s 119 disentitles persons and their spouses/dependants from certain entitlements where a personal injury is wilfully self-inflicted or involves suicide.

55. The Ministry of Health supports the approach outlined in the briefing on interactions between the AC Act and the End of Life Choice Act, which is to apply an operational approach (an interpretation of s 119) that will ensure that no one is financially disadvantaged through a loss of entitlement to accident compensation as a result of choosing an assisted death.

56. We also agree with the report's comment that it would be desirable to address any ambiguity about the relationship between s 119 of the AC Act and the End of Life Choice Act by amending one of these pieces of legislation at some point in the future. We note that the responsible Minister has signalled that a change could be made to the AC Act as part of a planned amendment Bill to provide additional clarity, and the Ministry of Health is happy to provide support to enable such a change at that time.

57. We have also examined other legislation to identify whether there may be any other unintended interactions with the Act, but we have not identified any other issues in this regard.

Health and Safety

58. We have considered whether the requirements of the Act involve any novel health and safety concerns that require consultation with expert authorities. We have concluded that the risks involved are similar to those in other health and disability services. Therefore, we will address any matters of health and safety as required within our implementation work.

Equity

59. Any implications that the Act may have for the systems and policies of other agencies must be balanced with the need to limit potential barriers that could prevent eligible individuals from accessing assisted dying. In the context of assisted dying, ensuring equity means addressing:

   a. equity of access – ensuring that no group will experience challenges that prevent them from accessing assisted dying services when they would otherwise be eligible;

b. equity of service level – ensuring that assisted dying services provided to different groups are equally effective in addressing the needs of those seeking assisted dying and their whanau; and

c. equity of outcome – ensuring that particular groups are not over or underrepresented among those who receive assisted dying because of inequities in healthcare (eg, due to unequal access to treatment or palliative care).

60. We have sought to ensure that all of these dimensions of equity are considered and addressed in our work, by making equity one of our design principles.

Provision of information

61. Many of the matters which involve interactions with other systems relate to complaints and reporting processes. These processes need to occur consistently and seamlessly to ensure that all people seeking assisted dying or affected by the assisted dying service in some way receive equitable quality services, and treatment of complaints and concerns. Having well-understood processes to interact with these other systems is a high priority in the way we implement alongside other agencies.

62. Matters relating to the equity of access to information, as well as wider understanding of the Act is culturally sensitive and may require different pathways for ethnic minorities in New Zealand society, including Māori and Pasifika. We have already provided you with a briefing [HR20210680 refers] which sets out how we are proposing to accommodate the cultural needs of Māori and other ethnic groups in the assisted dying process.

Next steps

63. The Ministry will continue to work with the agencies as outlined in this briefing and will provide you updates on these activities as necessary through the weekly report.

ENDS.

Document 9

MINISTRY OF HEALTH
MANATŪ HAUORA

Health Report

End of Life Choice Act: Regulation Paper for Ministerial Consultation

Date due to MO:	26 July 2021	**Action required by:**	2 August 2021
Security level:	IN CONFIDENCE	**Health Report number:**	20211091
To:	Hon Andrew Little, Minister of Health		

Contact for telephone discussion

Name	Position	Telephone
Dr Ashley Bloomfield	Director-General of Health	s (9)(2)(a) [redacted]
Caroline Flora	Group Manager, Family and Community Policy, System Strategy and Policy	s (9)(2)(a) [redacted]

Minister's office to complete:

☐ Approved
☐ Needs change
☐ See Minister's Notes

☐ Decline
☐ Seen
☐ Withdrawn

☐ Noted
☐ Overtaken by events

Comment:

Action for Private Secretaries

Return the signed report to the Ministry of Health by 13 August 2021, with any feedback from Ministerial consultation.

Date dispatched to MO:

End of Life Choice Act: Regulation Paper for Ministerial Consultation

Security level:	IN CONFIDENCE	**Date:**	26 July 2021
To:	Hon Andrew Little, Minister of Health		

Purpose of report

1. This report provides you with a Cabinet paper for the Cabinet Legislation Committee and seeks your agreement to conduct Ministerial consultation. The paper seeks approval to amend the Medicines Regulations 1984 to clarify that medications prescribed for an assisted dying service are "medicines" for the purposes of the Medicines Act 1981.

Summary

2. The End of Life Choice Act 2019 (the Act) received Royal assent in November 2019 and will come into force on 7 November 2021. The Act is new for the health and disability sector, and it is likely there will be some uncertainty from the health and disability sector about how it will operate.
3. We previously advised you about an opportunity to clarify a potential issue about the status of medicines used in an assisted dying service [HR20210278 refers]. Although Parliament intended that medications for an assisted dying service under the Act should be regulated as medicines under the Medicines Act 1981, there may be some uncertainty within the medical, nursing, and pharmacy professions that this is the case.
4. When the Act was being considered by Parliament, officials advised Select Committee that regulations could be made under the Medicines Act 1981 to clarify that medications used for assisted dying are medicines as defined by the Medicines Act 1981.
5. The Regulations proposed by the attached Cabinet paper amend the Medicines Regulations 1984 to clarify that medicines used in an assisted dying service are medicines for the purpose of the Medicines Act 1981.
6. You are now invited to conduct Ministerial consultation on the draft Cabinet paper ahead of lodging the paper on 19 August 2021 for consideration by Cabinet Legislation Committee on 26 August 2021. We have provided you with talking points (Appendix One) for the Committee meeting and to support your office during Ministerial consultation.
7. The proposed timeframes for providing this to Cabinet Legislation Committee is detailed below:

Ministerial consultation	2 – 13 August
Briefing to request lodging	17 August
Lodging of Cabinet paper	19 August
Cabinet Legislation Committee	26 August

Recommendations

The Ministry recommends that you:

a) **agree** to conduct Ministerial consultation on the attached draft Cabinet paper from 2 August to 13 August 2021 **Yes/No**

b) **note** that the Ministry plans to lodge the attached paper with the Cabinet Office on 19 August 2021 for consideration by Cabinet Legislative Committee on 26 August 2021

c) **note** that talking points are attached to support Ministerial consultation

Maree Roberts	Hon Andrew Little
Deputy Director General	**Minister of Health**
System Strategy and Policy	Date:

Appendix One: Talking points for End of Life Choice Act: Regulation Paper for Consideration by Cabinet Legislation Committee

- The End of Life Choice Act 2019 (the Act) received Royal assent in November 2019. Assisted dying will be lawful from 7 November 2021. The Act is new for the health and disability sector, and it is likely that there will be some uncertainty from the health and disability sector about how it will operate.
- Earlier this year, the Ministry of Health informed me there is an opportunity to clarify the potential issue about the status of medicines employed in an assisted dying service. The Medicines Act 1981 defines medicines as substances used for a therapeutic purpose. Therapeutic purposes include influencing a physiological process, and although I agree this is what medicines in an assisted dying service will achieve, some health practitioners may not feel this is sufficiently clear.
- I believe it is important to provide clarity that the medicines which are used for assisted dying are subject to the same conditions and requirements that apply to other medicines under the Medicines Act 1981.
- Improving clarity would provide reassurance for health practitioners and reduce the risk that some may choose not to be involved due to perceived legal uncertainties.
- A regulation has been drafted under section 105 of the Medicines Act 1981 to amend the Medicines Regulations 1984 to clarify the status of these medications.
- I intend to make this regulation with the support of the Cabinet Legislation Committee.

Document 10

Briefing

End of Life Choice Act: Finalising funding settings for assisted dying services

Date due to MO:	16 August 2021	**Action required by:**	23 August 2021
Security level:	IN CONFIDENCE	**Health Report number:**	HR20211645
To:	Hon Andrew Little, Minister of Health		

Contact for telephone discussion

Name	Position	Telephone
Clare Perry	Deputy Director-General, Health System Improvement and Innovation	s (9)(2)(a) [redacted]
Caroline Flora	Associate Deputy Director-General, System Strategy and Policy	s (9)(2)(a) [redacted]
Dr Ashley Bloomfield	Director-General of Health	s (9)(2)(a) [redacted]

Minister's office to complete:

☐ Approved	☐ Decline	☐ Noted
☐ Needs change	☐ Seen	☐ Overtaken by events
☐ See Minister's Notes	☐ Withdrawn	

Comment:

Document 10

End of Life Choice Act: Finalising funding settings for assisted dying services

Security level:	IN CONFIDENCE	**Date:**	16 August 2021
To:	Hon Andrew Little, Minister of Health		

Purpose of report

1 This report seeks your agreement to final funding settings for assisted dying following:

  a. feedback from health sector organisations on the draft Assisted Dying Services Notice 2021 to be made under section 88 of the New Zealand Public Health and Disability Act 2000 (the Notice)

  b. independent advice from Sapere on a pricing approach, and

  c. work to operationalise a care pathway for assisted dying.

2 This report discloses all relevant information and implications.

Summary

3 Cabinet previously agreed that the Government will take steps to ensure that assisted dying services are available to eligible people from 7 November 2021, and that funding would be provided to any suitable practitioners who are willing, on a fee-for-service basis (excluding those directly employed by District Health Boards (DHBs)) [CAB-21-MIN-0241 refers].

4 We have recently consulted with sector organisations on the content of a draft notice to fund assisted dying, undertaken design work on the care pathway for people seeking assisted dying, and commissioned and received independent advice from Sapere on pricing assisted dying services.

5 We are now seeking your agreement to detailed settings for funding assisted dying services, which involve:

  a. **providing funding through five standard modules** which reflect the assisted dying process as laid out in the End of Life Choice Act 2019 (the Act), with a fixed price to be paid for each module, based on an estimate of the number of hours involved and an hourly rate provided by Sapere.

  b. **an additional two-hour fixed allowance** which can be claimed alongside modules one and four in situations where clinical, social or cultural considerations mean that delivering these modules takes longer than a standard delivery.

6 The proposed hours and prices for these modules are:

	Standard hours	Additional payment for complex cases (if needed)	Value of modules
Module one - Application and first opinion of eligibility	3 hours	2 hours	$724.80 $1,208.00 (complex cases)
Module two - Independent assessment of eligibility	2.5 hours		$604.00
Module three - Competency assessment by a psychiatrist (if necessary)	4 hours		$1,544.16
Module four - Decision about eligibility or ineligibility and follow-up	1.5 hours	2 hours	$362.40 $845.60 (complex cases)
Module five- Prescribing and administration of medicines	4.5 hours		$1,087.20
Total	15.5 hours	Up to 19.5 hours	$4,322.56 (up to $5,288.96 for complex cases)

7 We also propose to provide funding for:

- **a supervisor fee** for an attending medical practitioner to provide instruction to an attending nurse practitioner when they administer medicines for assisted dying, which reflects that the Act does not allow nurse practitioners to undertake this role without instruction from an attending medical practitioner. We propose a rate of payment that is 50 percent of the price of module five.
- **the cost of obtaining clinical notes** from a person's normal general practitioner, who will need to collate and provide them so the eligibility assessment can be completed. We propose a standard fee of $231.25, in line with ACC rates.
- **an optional payment to allow another health practitioner to support** an attending medical practitioner when they are providing the final part of the process for the first time. This person might be an experienced colleague, or a nurse from their practice. We propose a rate of payment that is 50 percent of the price of module five. This is not necessary for nurse practitioners providing the service for the first time as they will have instruction from an attending medical practitioner.

8 We propose that the travel allowance should compensate for actual costs of travel. This allowance would pay reasonable and actual costs on invoice.

9 We also propose that partial payment can be made for practitioner(s) scheduled to complete module five in cases where there is little or no notice of cancellation or rescheduling.

10 We propose that the pricing of payments made under the Notice are reviewed every two years with advice provided to the Minister of Health to ensure pricing continues to reflect the cost of providing the service.

11 A full overview of the funding settings proposed in this paper are provided in Appendix Two.

12 Following your decisions on these funding settings we will provide advice to you and the Minister of Finance (Joint Ministers) on the subsequent financial decisions that need to be made, and finalise an Assisted Dying Services Notice 2021 for your approval.

Recommendations

We recommend you:

a) **Note** that we are seeking your agreement to detailed settings for a notice to be made under Section 88 of the New Zealand Public Health and Disability Act 2000 to fund health practitioners to provide assisted dying services, following:

- recent consultation with sector organisations – a summary of feedback received is attached as Appendix One and will be shared with these organisations
- independent advice on from Sapere on pricing assisted dying services, and
- work on the care pathway for people seeking assisted dying.

c) **Agree** that the Notice includes five core modules to compensate non-DHB health practitioners for providing the service, with time allowances of: **Yes/No**

Module	Includes compensation for:	Time allowance:
One	The attending medical practitioner completing the application and first opinion of eligibility	3 hours
Two	The independent medical practitioner completing the second opinion of eligibility	2.5 hours
Three	A psychiatrist completing a competency assessment (if necessary)	4 hours
Four	The attending medical practitioner providing the decision about eligibility or ineligibility	1.5 hours
five	Prescribing and administration of medicines (by either an attending medical practitioner or nurse practitioner)	4.5 hours
Total	(If entire process occurs)	15.5 hours

d) **Agree** that an additional payment based on two additional hours is available for both modules one and four, claimable in situations where clinical, social or cultural considerations mean that delivering these modules takes longer than a standard delivery. **Yes/No**

e) **Agree** that the rates of payment used to determine the value of the modules for delivering assisted dying services will be:

- for medical practitioners - $241.60 per hour **Yes/No**
- for psychiatrists - $386.04 per hour **Yes/No**
- for nurse practitioners - $241.60 per hour. **Yes/No**

f) **Agree** that the following additional payments are available for:

- compensating the costs of obtaining clinical notes from a person's GP if they are not the attending medical practitioner, at a standard fee of $231.25 **Yes/No**
- a supervisor's fee of 50 percent of the cost of module five to be paid to an attending medical practitioner providing instruction to an attending nurse practitioner, which reflects that the Act does not allow nurse practitioners to undertake this role without instruction. **Yes/No**
- an optional peer support fee of 50 percent of the cost of module five to pay for peer support from another health practitioner, if the attending medical practitioner chooses this at the first time they administer medicines. **Yes/No**

g) **Note** that optional peer support will not be available to nurse practitioners as they will have instruction from an attending medical practitioner which provides equivalent support.

h) **Agree** that the Notice also includes a travel allowance which reimburses reasonable and actual costs upon invoice, including: **Yes/No**

- non-motor vehicle travel costs such as flights
- private motor vehicle travel costs for travel above 20km at the same rate as Disability Support Services (for in-between travel)
- pays a practitioner 50 percent of the hourly rate of payment for the time to travel
- accommodation and meal costs, in exceptional cases where overnight stays are necessary to provide the service.

i) **Agree** that a partial payment is made for module five, and any applicable supervisors' fee or optional peer support fee in cases where a change to the planned date of administering medicines happens: **Yes/No**

- within three working days of the planned date, a partial payment of 20 percent of the usual fee, and any non-refundable travel costs is made
- on the planned date, a partial payment of 50 percent of the usual fee, and any non-refundable travel costs is made.

j) **Agree** that a review of the pricing in the Notice will occur every two years to allow for the pricing to reflect the cost of providing services. **Yes/No**

k) **Note** that once you have confirmed these funding settings, the Ministry will:

- provide advice to you and the Minister of Finance (Joint Ministers) at the beginning of September on the subsequent financial decisions that need to be made
- finalise the Notice and provide it to you in mid-September for your approval.

Clare Perry	Hon Andrew Little
Deputy Director-General	**Minister of Health**
Health System Innovation and Improvement	Date:
Date:	

End of Life Choice Act: Finalising funding settings for assisted dying services

Cabinet previously agreed an approach to providing assisted dying services and you also made some decisions

1 In June, Cabinet considered a paper on the approach for providing for assisted dying services and agreed that:

   a. the Government will take steps to ensure that assisted dying services are available to eligible people from 7 November 2021, in line with other health services, and

   b. the Government will take a national approach to funding and providing for assisted dying services, which will involve allowing any suitable individual practitioner who is willing, to receive funding for providing assisted dying services, on a fee-for-service basis (excluding those directly employed by DHBs) [CAB-21-MIN-0241 refers].

2 Cabinet also noted that:

   a. fee-for-service funding will allow individual practitioners to claim for funding when they complete parts of the assisted dying process and will include an allowance for travel costs

   b. practitioners who provide funded assisted dying services will be prohibited from charging co-payments, to prevent these from becoming a barrier to access [CAB-21-MIN-0241 refers].

3 You have previously agreed that funding will be provided to willing practitioners using a modular approach and paid using a notice made under section 88 of the New Zealand Public Health and Disability Act 2000. Using this notice will enable a flexible approach that ensures as many practitioners as possible can provide the service and support equitable access for eligible people [HR20210996 refers].

We have done further work on the funding design, including sector consultation, and are now seeking your agreement to detailed settings

4. We have recently:

   a. consulted with key sector organisations about the draft content of the notice, and an associated draft service specification, over a three-week period

   b. commissioned and received independent advice on from Sapere on pricing assisted dying services

   c. undertaken design work on the care pathway for people seeking assisted dying.

5 As a result of these insights we have developed detailed settings that we propose to use to fund practitioners to provide assisted dying, and we are now seeking your agreement to these.

Sector feedback on the notice has been generally supportive, with some suggestions made, and clarifications sought

6 Consultation on the draft Notice and service description occurred over a three-week period in July 2021 with 37 health sector organisations invited. Consultation involved two online Q&A sessions and a questionnaire which covered various elements of the approach. Approximately 27 representatives attended the online meetings, although some may have represented the same organisation. We received eight submissions in response to the questionnaire.

7 A full summary of the feedback received from the submissions is provided in Appendix One. We plan to share this with the organisations who participated.

8 The feedback from the health sector organisations was mainly supportive of the use of the Notice to provide funding for willing and suitable practitioners to provide the service. Many comments reflected that the sector understands the importance of providing the flexibility necessary to support equitable access to assisted dying services across New Zealand.

9 The detailed feedback we received was mainly about clarifying and testing the scope of the funding modules and querying what would happen if practitioners only partially complete certain modules. Additionally, some submitters provided technical suggestions on wording in the Notice and service description.

10 There were several suggestions that the Notice should include funding for additional elements which are discussed later in this paper.

11 The involvement of nurse practitioners was queried, with the New Zealand Nurses Organisation asking why nurse practitioners would not be able to claim modules which don’t relate to the administration of medicines. This reflects the way the Act is drafted, and we have previously briefed you on this issue through your weekly report.

Proposed settings for funding assisted dying services

12 The following sections step through the settings we are proposing for the funding of assisted dying services. In some cases, these vary from previous advice we provided to you earlier in the year [HR20210680 and HR20210996 refers], reflecting changes in our thinking including in response to feedback from the sector, independent advice on pricing and ongoing operational planning.

13 In identifying these settings, we have kept in mind the design principles for the assisted dying work, which include:

a. giving effect to our obligations under Te Tiriti o Waitangi, including considering the interests and needs of Māori

b. ensuring equity, which involves inclusiveness for all communities and equity of access to services

c. providing services that are effective and have robust accountability and safety measures

d. providing good value for health and disability system resources

e. ensuring consistency with health and disability system strategies [HR20202124 refers].

14 We have also considered factors raised with you in previous briefings about how we approach funding for assisted dying services [HR20210216 and HR20210680 refer], including:

  a. making use of systems, structures and settings that already exist in the health and disability system, rather than funding duplicate solutions

  b. balancing the need to ensure health practitioners are compensated fairly and not disincentivised from providing assisted dying services, while also avoiding funding at a level that might be seen to incentivise assisted dying or be out of step with other parts of the health system

  c. ensuring that the funding mechanism is straightforward to understand and to administer, especially as this is a new service, and we may need to adjust settings as we learn

  d. incorporating an understanding of international experiences and any comparable situations in the New Zealand health and disability system.

15 As previously noted, willing practitioners who are employed by DHBs will be supported to provide assisted dying services through their DHB employment rather than modules funded through the Notice. Where practitioners split their time between DHB funded services and private services, they will be able to choose the setting which they provide services in. The Ministry is working with DHBs to ensure staff are supported.

16 Appendix Two provides an overview of the funding settings we are proposing.

We propose to fund assisted dying using five standard modules, with an additional allowance available in certain modules to take account of complex cases

We propose that the Notice will split funding into five modules…

17 The draft Notice that was provided to the sector for consultation split funding into five modules, which map against the process laid out in the Act:

  a. **Module one – Application and first opinion** - to be completed by the Attending Medical Practitioner (AMP)

  b. **Module two – Independent second opinion** - to be completed by an Independent Medical Practitioner (IMP)

  c. **Module three – Competency assessment** - to be completed by a psychiatrist (if required)

  d. **Module four – Confirm eligibility and make arrangements for administration, or confirm ineligibility and arrange support/handover** – to be completed by the AMP

  e. **Module five – Prescribing and administration of medicines** – to be completed by the AMP or an Attending Nurse Practitioner (ANP) operating under their supervision.

18 We propose to retain this standard structure, as this seems to work well, and a number of stakeholders have commented that structuring funding in this way makes sense.

...and each module will have a specific time allocated, to determine the suitable level of funding

19 The next step after confirming the number of modules is to establish a reasonable amount of time to base the price of each module on.

20 Estimating the time required for each module is inherently difficult, given potential variations in scenarios for people seeking assisted dying services and the fact that this service has not been provided in New Zealand before.

21 We have proposed a standard set of hours that the price of each of the modules will be based on, drawing from both the independent advice we received from Sapere, and our own internal work to map out the process and care pathway.

We also propose that there should be additional payments for complex cases

22 We also consider that the modules should include some flexibility in payment rates to recognise that some cases may be particularly complex and may require more time at certain points of the process. This complexity may be caused by clinical, social or cultural considerations.

23 There are Te Tiriti o Waitangi and equity considerations in ensuring that the assisted dying service can be responsive enough to support individual needs, which in some cases may place requirements on an attending practitioner's time that go above and beyond what might be considered normal. However, systems that involve complex payment rates, or have some burden of proof to access a higher payment rate to support people with greater needs can also have inequitable impacts, as complexity itself can become a barrier.

We propose that provision of assisted dying services should be funded up to 19.5 hours

24 Table One references the advice Sapere provided (with both a 'minimum' and 'average' number of hours), and the hours we propose to use.

Table One: Proposed hours for each module

	Minimum (Sapere advice)	**Average (Sapere advice)**	**Proposed standard hours**	**Proposed additional payment for extra hours in complex cases (if needed)**
Module one	3 hours	5 hours	3 hours	2 hours
Module two	2 hours	4 hours	2.5 hours	
Module three	2 hours	4 hours	4 hours	
Module four	1 hour	1.5 hours	1.5 hours	2 hours
Module five	4.5 hours	5 hours	4.5 hours	
Total	12.5	19.5	15.5 hours	Up to 19.5 hours

25 Sapere noted that it may take longer for practitioners to provide parts of the process initially as they get used to it and recommends setting payment rates for modules using the 'minimum' hours suggested in their advice, with provision for extra hours to compensated

for if needed. Sapere suggests that these times can be reviewed in the future to see if it is possible to set fixed rates, which may be closer to the 'average' figures they have provided

26 Our rationale for the proposed numbers of hours for each module are:

a. **Module one** – a standard rate based on three hours reflects advice from Sapere and the fact that this module involves both the application process and first assessment. The addition of an extra fixed payment (based on two hours) for complex cases recognises that this part of the process could take longer in some cases, including where significant engagement with whānau is involved.

b. **Module two** – a standard rate based on two and a half hours reflects the fact that an independent medical practitioner will be assessing someone they are not familiar with and takes into account time required to review clinical notes and any other relevant information.

c. **Module three** – a standard rate based on four hours reflects feedback from psychiatrists that this is likely to be a complex assessment and that two hours would not be sufficient, and seeks to address concerns that there may be a shortage of willing psychiatrists if funding is seen as insufficient.

d. **Module four** – a standard rate based on one and a half hours reflects the time needed in module four to either let someone know they are eligible and make arrangements for the time, place and method for assisted dying, or inform someone that they are ineligible and link them back to their general practitioner and/or other services to support them. The addition of an extra fixed payment (based on two hours) for complex cases recognises that in some cases these conversations and arrangements might be complex where large numbers of whānau need to be involved and/or circumstances change. We see appropriately resourcing this module as an important factor in fulfilling our active protection obligation under Te Tiriti o Waitangi to ensure both eligible and ineligible people and their whānau are well-supported.

e. **Module five** – a standard rate based on four and a half hours reflects feedback from a range of sources including other jurisdictions that this part of the process is likely to take half a day, along with time needed to write prescriptions and make arrangements a few days beforehand.

27 Feedback from sector consultation included comments that we should consider the time necessary to support whānau in the process. This aligns with our consideration of Te Tiriti principles to support the collective decision-making and whānau involvement necessary to support eligible Māori to access assisted dying services in a culturally appropriate way and safe way. We consider that the core modules allow time to speak with whānau and explain the process, and the additional payments for modules one and four will support any more complex circumstances.

Hourly rates of payment

28 The value of each module will be determined by the hours it is based on, and the hourly rate of payment that is used.

29 We have considered what the rate of payment should be for medical practitioners, psychiatrists and nurse practitioners for providing the services under the Act. The rates of payment we propose to use are:

a. **for medical practitioners** - $241.60 per hour. This was recommended by Sapere based on the Multi-Employer Collective Agreement. We propose to use this rate for all medical practitioners (eg, general practitioners and specialists) given that the work involved will be equivalent

b. **for psychiatrists** - $386.04 per hour. This was recommended by Sapere based on the ACC rate of payment. We propose to pay a competitive rate, acknowledging that a shortage of available psychiatrists is a significant risk to the functioning of the assisted dying service

c. **for nurse practitioners** - $241.60 per hour for delivering module five. This reflects the fact that in administrating medicines for assisted dying nurse practitioners will be doing the same or very similar work to attending medical practitioners.

30 The value of each module is summarised in the table below based on the hours and rates proposed.

Table Two: Proposed hourly rates of payment

	Standard hours	**Additional payment for extra hours in complex cases (if needed)**	**Value of modules**
Module one	3 hours	2 hours	$724.80 $1,208.00 (complex cases)
Module two	2.5 hours		$604.00
Module three	4 hours		$1,544.16
Module four	1.5 hours	2 hours	$362.40 $845.60 (complex cases)
Module five	4.5 hours		$1,087.20
Total	15.5 hours	19.5 hours	$4,322.56 (up to $5,288.96 for complex cases)

Fee to supervise attending nurse practitioners

31 The Act specifies that where nurse practitioners administer medicines for assisted dying (module five) they must do so under the instruction of the attending medical practitioner.

32 Given this requirement on attending medical practitioners, we consider that it is fair to compensate them, although at a lesser amount, given that they will not be administering medicines and may not attend in person.

33 We propose that a separate payment of 50 percent of the usual rate of module five ($543.60) is made to attending medical practitioners who provide supervision under this circumstance.

Additional payments

34 Feedback from sector organisations on the draft Notice included a number of suggestions for other types of costs that could be funded, including:

a. the cost of obtaining clinical notes from someone's general practitioner

b. funding for another health practitioner to support to an attending medical practitioner when they are administering medicines for assisted dying

c. providing after-death care for whānau

d. compensating facilities where assisted dying takes place

e. paying for the initial appointment when someone first requests assisted dying.

Cost of obtaining clinical notes

35 Where the person who serves as the attending medical practitioner for someone seeking assisted dying is not that person's enrolled general practitioner, they may need to pay this person to provide relevant clinical notes to inform their assessment. There is precedent for this cost to be paid in the health sector, as this is something that happens when assessments are being made by health insurance companies, by ACC case managers, or by specialist services.

36 We propose that provision is made to pay this cost, using the rate paid by ACC ($185 per hour) for a standard time of 75 minutes – a standard payment totalling $231.25. If we do not provide this payment, attending medical practitioners may run into difficulty in obtaining clinical notes without compensating the GP themselves.

Funding another practitioner to provide support when administering medicines for assisted dying

37 We received feedback that one organisation was unsure whether the standard module funding approach "enabled a collective approach by practitioners to support culturally appropriate practice. Ie [sic], more than one being involved simultaneously." We have considered whether there should be an allowance for a second practitioner to support an attending medical practitioner in the final stage of the process.

38 The administration of medicines to end a life could be challenging for practitioners, on a clinical level, but also on an emotional, psychological or ethical level. While many practitioners may be comfortable providing this service alone, some may be more willing to participate in the assisted dying service if they know they can have a colleague with them who can provide clinical, emotional and moral support. There is no legislative requirement for such a role, though we note that nurse practitioners will have the support of attending medical practitioners who are required to provide supervision.

39 Given this is a new service and it will take some time to establish clinical practice, a payment for this kind of optional support could increase the availability of a confident and willing workforce. It may also build both the confidence of the attending medical practitioner in each case, and those who observe and provide support to them to then go on and provide the service themselves.

40 There is no direct precedent for this kind of support payment internationally, or within the New Zealand health and disability system. We note that even if a payment was not provided for this role, an attending medical practitioner could still take a colleague with them to

administer medicines if they wished, and arrange reimbursement from the fee these receive for delivering the module. These types of arrangements do happen in some cases overseas.

41 We think it is appropriate to strike a balance between supporting a confident workforce who are willing to provide the service, and while not wanting to fund a level of support that would go above and beyond what is provided in other parts of the health system.

42 We propose to fund a colleague to attend alongside a practitioner the first time they administer medicines for assisted dying, as a way to support the workforce. This would be optional and funded at a rate of 50 percent of module five. This person might be an experienced colleague, or a nurse from their practice.

Other suggestions

43 We do not propose to provide additional funding:

a. for after-death care for whānau - as the government already funds bereavement support for the families of people who have died, and the number of deaths by assisted dying per year is likely to be low.

b. to compensate facilities when assisted dying takes place there – as aged residential care providers and hospitals are already funded to manage the costs and needs related to people dying within a facility, and additional costs linked to the provision of assisted dying itself are specifically funded

c. for the initial appointment when someone first requests assisted dying – given that people may ask questions about assisted dying at any time, and from health practitioners in a range of contexts, it would not be practical to fund these conversations. Further, simply responding to a request for information from someone as part of a normal consultation is unlikely to impose additional costs on practitioners. Where more than information is required (and someone wants to apply) this process will be funded through module one.

Travel allowance

44 Facilitating travel is one of our key levers to support equitable access to the assisted dying service. The ability for practitioners to travel to provide the service also provides eligible people with an element of choice in where they choose to receive assisted dying.

45 We previously proposed that a travel allowance would be calculated on a fixed price model whereby practitioners would be paid a fixed price for the travel costs they have incurred within half a day of travel, with the option to obtain an additional allowance should travel times exceed half a day [HR20210680 refers].

46 However, while fixed amounts make sense from an administrative simplicity point of view, travel costs related to assisted dying could vary widely and we have had difficulty establishing fixed rates that we are confident would address reasonable costs for practitioners in most cases. There is significant uncertainty about when, how often and how far practitioners might need to travel to provide this service

47 Feedback from sector stakeholders and independent advice from Sapere has suggested that an approach based on actual costs would be more appropriate. We have taken their proposals and the feedback of the sector into account and now propose an allowance which is similar to the proposal by Sapere but, bases compensation amounts on health and

disability system rates. The proposed allowance is described in the table below, which also sets out what was recommended by Sapere.

Table 3: Proposed travel allowance settings

Element	Travel allowance settings proposed by Sapere	Travel allowance settings proposed by Ministry of Health
Private motor vehicle travel costs:	• distance under 20km not compensated • distance over 20km is reimbursed at the IRD travel rate (79 cents per kilometre).	• distance under 20km not compensated • distance over 20km is reimbursed at the Disability Support Services travel in-between travel rate (58.5 cents per kilometre).
Time to travel:	• if travel is required, then a minimum payment of one half-hour at half the applicable hourly rate would be paid regardless of distance • if total travel exceeds one half-hour then it will be paid at half the applicable hourly rate, rounded up to the nearest five-minute multiple.	• for the cost of time to travel more than 20km – paying practitioners for their time at 50 percent of the relevant hourly rate (pro rata).
Other mode of transport costs:	• if travel requires a mode of transport other than a private vehicle, then reimbursement will be based on "actual and reasonable" costs on submission of actual invoices.	• if travel requires a mode of transport other than a private vehicle, then reimbursement will be based on "actual and reasonable" costs on submission of actual invoices.
Incidentals:	• accommodation and meals will be reimbursed using ACC's rates and policy	• accommodation and meal costs will be reimbursed on submission in exceptional circumstances where overnight stays are required to provide the service.

Making partial payments

48 In previous advice we suggested that the full price of each module should be paid to practitioners regardless of how much of the module is completed, on the basis that it would not be reasonable to limit or decline funding as practitioners may have already incurred costs associated with providing these services (eg, cancelling other activities and setting time aside) [HR20210680 refers].

49 We also considered providing full payment for practitioners in cases where the person decides to cease the assisted dying process, on the basis that partial payments might create

a perception that practitioners would have an incentive to assist someone to die in order to receive a full payment.

50 However, after consultation with the sector, and receiving advice from Sapere we have reconsidered this position.

51 Partial payments are used in maternity services and other situations in the health sector. For example, a lead maternity carer (LMC) receives a partial payment if the pregnant person is cared for by DHB midwifery services for the birth, despite the LMC caring for the person for the duration of the pregnancy and intending to support the birth.

52 We see no need to provide for partial payments for modules one through four, as these will always be completed or very near completed in each case.

53 However, there is the potential for module five to be only partially completed – for example: where a time is set and the person dies, or changes their mind or reschedules before the day or on the day that the medicine was to be administered.

54 We propose to allow for partial payments of module five to address:

a. potential concerns about the incentive effect of paying practitioners for parts of a service that they do not deliver

b. an argument that paying for services that are not provided would be out of step with the way funding is provided for in other parts of the health system where partial payments are sometimes used.

55 An eligible person is entitled to delay or decline the service at any point in the process including on the planned day of delivery, and the planned date of administration of medicines is the point where it is most crucial that they can. Given that eligible people will have terminal illnesses and be in an advanced state of irreversible decline, it is also possible the person could die before administration of medicines for assisted dying.

56 If a change, delay or cancellation to the planned date for administering medicines occurs with sufficient notice, we expect that the practitioner(s) involved will be able to reschedule their time with little or no impact to clinical practice. In these cases, we would not make any payment to the practitioner.

57 We propose providing partial payment in cases where a change, delay or cancellation to the planned date for administering medicines occurs within three working days of the date, or on the date. In these cases, we consider there is likely to be some effect on the practitioner(s) ability to reschedule their time. We are proposing that if:

a. a change occurs within three working days of the planned date, the practitioner is paid 20 percent of the usual rate for module five

b. a change occurs on the planned date, the practitioner is paid 50 percent of the usual rate for module five.

Review of pricing

58 Where Notices have been used to fund other types of services there has been a concern from the sector that once prices are set there is no mechanism to review and adjust them over time.

59 With this in mind the draft Notice currently includes a provision stating that the Ministry will undertake a review of the prices it pays for assisted dying services once every two years and submit the results of this review to the Minister of Health.

60 We consider that including this provision in the final Notice is appropriate as it provides a mechanism through which prices paid through the notice can be reviewed, while allowing the Government of the day to determine whether such changes are appropriate given other priorities in the health system and any other considerations.

Equity

61 Equity of access is the main consideration in establishing the funding settings for assisted dying services. There are two aspects of this – location, and different access needs such as disability, language barriers, and differing cultural and social needs. We are comfortable that the travel allowance, along with time allowances in the standard funding modules work together to account for differing circumstances, and can address most location issues, and different access needs. This will ensure that people receive the same or similar service level, regardless of their needs.

62 For circumstances where the timeframes in the standard modules do not support more complex needs, we consider that the additional two-hour time that can be claimed in modules one and four will provide the support necessary.

63 The pre-established funding setting which means assisted dying services are available without cost to eligible people further supports equitable access.

64 As with previous briefings about the funding settings for assisted dying services, considerations of equity in the development of this briefing have included how the funding of assisted dying services will align with funding for services across the health and disability system. This involves striking a balance between:

a. needing to address the costs of providing assisted dying to support access by meeting reasonable costs for practitioners, and supporting them to travel, and

b. avoiding funding assisted dying in a way that would put it out of step with funding for other health services.

Next steps

65 Following your decisions on the funding settings we will:

a. provide advice to you and the Minister of Finance (Joint Ministers) at the beginning of September on the subsequent financial decisions that need to be made. In June 2021, Cabinet authorised Joint Ministers to approve final funding settings and the drawdown of contingency funding for the provision of assisted dying services [CAB-21-MIN-0241 refers]

b. finalise the Assisted Dying Services Notice 2021 and provide it to you in mid-September for your approval.

ENDS.

Appendix One: Summary of feedback from sector organisations on a draft of the Assisted Dying Services Notice 2021 and a draft service description

Consultation with the health sector

The Ministry of Health carried out consultation on the section 88 Notice (the Notice) with 37 key health organisations for a three-week period (6 to 27 July 2021). This was achieved through an online questionnaire and two online 'question and answer' sessions that were held on 15 and 19 July, with 27 participants. These online sessions included a short presentation to explain the scope of the Notice, why a section 88 Notice is being used, the planned approach to pricing, the role of the service description, and Te Tiriti o Waitangi considerations.

The questions discussed during the online sessions included the following subjects:

- funding arrangements that support Māori and Māori providers
- consideration for the involvement and care of the patient's family and whānau
- the aspects of end of life care covered by the section 88 Notice
- funding restrictions to District Health Boards (DHB)
- the voluntary participation of health practitioners to provide the service
- the services nurse practitioners can provide under the legislation.

Questions about other parts of the End of Life Choice Act, ethics, medications, or other aspects not directly related to the Notice and service specification were not answered in these online sessions.

Across the two 'question and 'answer' sessions, approximately 27 participants attended (though some accounts may have had more than one person participating).

We received written responses to the questionnaire from eight organisations:

- New Zealand Aged Care Association (NZACA)
- New Zealand Medical Association (NZMA)
- New Zealand Nurses Organisation (NZNO)
- New Zealand Society of Anaesthetists (NZSA)
- Royal New Zealand College of General Practitioners (RNZCGP)
- Royal Australian and New Zealand College of Psychiatrists (RANZCP)
- Tui Ora Ltd
- Whanganui Regional Health Network (WRHN)

Summary of sector feedback

Overall, the general response from organisations was supportive of the Notice. The questionnaire contained questions asking organisations to provide feedback on:

- the function of the Notice and service description, and the process for changing them;
- eligibility and entitlement requirements;
- actions/activities required from those providing each of the modules; and
- the process for practitioners to be paid.

For all questions, most of the organisations stated that these processes are clear. For instance, one organisation stated that 'the modular system for funding is clear and enables the different activities to be shared across the system.'

Some organisations did have reservations about there not being any co-payment options and assisted dying services in public facilities, or anywhere with full public funding, not being able to claim section 88 payments. Correspondingly, NZMA expressed that a drawback with this funding approach, which is also an issue with the section 88 maternity services Notice, 'is that fees are not negotiated, and any increases or adjustments are determined unilaterally by the Ministry.'

Most of the detailed feedback we received focused on clarifying and testing the scope of the different modules. Clarification was sought, for example, on the payment process for the actions of the attending medical practitioner throughout the modules, as well as what happens if practitioners only partially complete certain modules. Additionally, some submitters provided technical suggestions on wording in the Notice and service description.

The following sections outline some of the key points and strongly held views that were raised by sector organisations throughout the consultation period.

Organisations are interested in the role of District Health Boards in assisted dying

- This funding approach means that any practitioners who choose to provide this service outside of DHB employment can receive funding from the Notice. Practitioners employed by a DHB will be funded by the DHB, and the Ministry of Health is working to support DHBs with their role. There were a few responses that requested clarity on the eligibility for DHB employees or practitioners who work in both a public and private capacity, and whether there will be a difference in the funding for services provided.
- To ensure consistency across public and private services, RANZCP suggested that the service description clarifies the document's relevance to practitioners involved in assisted dying services as a DHB employee. This would highlight the need to engage with other materials when delivering the service, such as the End of Life Choice Act, Code of Conduct, Professional Guidance, and other requirements in the Health and Disability Act.

Additional funding options were raised

- Organisations thought that consideration should be given to the costs of after-death care and the management of after-death care in the context of rest homes, for instance, where carers may not wish to be involved. RANZCP stated that alternative options, namely palliative care, should be equally funded and equally available as assisted dying services.
- Tui Ora said it should be clarified that a practitioner is not funded for the initial consultation where the patient broaches the subject of assisted dying; they stated that any initial conversation in consultation (prior to module one) should at least be partly funded. NZNO also questioned whether this initial consultation not being funded is a barrier to accessing the service.
- NZMA proposed a module that enables funding for post assisted dying services, such as supporting the whānau of a person that has received assisted dying.
- NZACA also recommended a module to specifically support assisted dying within aged residential care facilities. NZACA expressed concerns about there being many duties that the aged residential care facility would potentially need to carry out at an additional cost to the facility. Facilities not receiving funding for such additional costs may not be in the financial position to support the assisted death.

Nurse practitioners' involvement in the service

- NZNO noted that Clinical Nurse Specialists and Registered nurses who may provide care to the patient have not been included as part of those who can claim funding during the assisted dying phase. They questioned why nurse practitioners are excluded from modules one-to-four, stating they should be able to be the second opinion in module two and should be included as practitioners delivering module four.
- This is a limitation we are aware of and is a feature of the current legislation. Our funding approach aligns with the legislation. The way the End of Life Choice Act is written means most of the work is done by medical practitioners, but administration of medicines can be done by either the medical practitioner or a nurse practitioner who is supervised by a medical practitioner.

Ensuring accessibility to assisted dying services is a priority

- We asked organisations whether this funding approach supports equitable access and outcomes for people seeking assisted dying. The majority answered 'yes', while some organisations questioned what would happen if the funding amount was insufficient for practitioners or the facilities supporting the patient, particularly for work that is both time and labour intensive.
- Equitable access to assisted dying services was highlighted as a key priority throughout the consultation process, especially considering both the small number of people in New Zealand estimated to use this service and the small number of practitioners (at least initially) that we anticipate will be willing to provide the service.
- There was support for the funding approach in terms of ensuring that access to assisted dying services should not depend on the region people live in, affording to pay for the services, and should not be restricted by social or cultural barriers.

Assisted dying services funding should support obligations under Te Tiriti o Waitangi

- We asked organisations whether this funding approach gives sufficient effect to obligations under Te Tiriti o Waitangi, and how this could be improved. This aligns with the view that assisted dying should be culturally supportive, but still reflect the funding of other existing health services and not conflict with other Government decisions.
- It is important to note that Te Tiriti o Waitangi is applicable to all New Zealanders, not just Māori. Organisations recognised that there are complex perspectives on whether assisted dying aligns with tikanga, and that the service will follow a Te Tiriti compliant approach to acknowledge this. It was also highlighted that Māori should be the ones to determine whether sufficient effect has been given to support tino rangatiratanga.
- Tui Ora stated that this funding approach may give some effect to Te Tiriti obligations only if:

  > 'there is an open and honest approach on the part of the Ministry to consider that the needs of Māori whānau may extend beyond the funding structure that recompenses a practitioner for work with a patient. Support should be provided to practitioners who are Māori and working in Māori organisations to provide culturally responsive services.'

- Tui Ora additionally expressed that the 'service design provides an excellent opportunity to model a Ministry response which attends closely to obligations and opportunities under Te Tiriti.'

Appropriate support and care for whānau is essential

- One organisation thought that it is unclear if the service enables a collective approach by practitioners to support culturally appropriate practice (i.e. more than one person being involved simultaneously).
- NZNO stated that the funding approach 'looks to the individual health practitioner and not the collective family, whānau, and wider medical practice looking after the patient.' NZNO also questioned what payments are available to support whānau and who needs to be present to support those looking at assisted dying.
- Organisations highlighted the importance of both small and large whānau groups being cared for in a culturally appropriate way. Some expressed concern that the proposed funding structure would underestimate the costs of the time needed for whānau to understand procedures. Correspondingly, RNZCGP considered that the 15 minute standard consultation time would likely need to be extended due to the magnitude of the decision and implications for whānau.
- Tui Ora stated that there should be an opportunity to make clearer for whānau what is and is not funded. They suggested that funding the delivery of culturally appropriate care for Māori should be considered, which could extend to financially supporting costs for Māori organisations to provide training and information hui for whānau around the assisted dying process.

Comments on funding practitioner travel costs

- We provided organisations with different examples of how payments for travel costs should be provided. Most organisations responded in favour of reimbursing for the actual costs of practitioners' travel by invoicing, booking on behalf, or similar.
- A few organisations found that the wide variation in the time needed to provide the service is ambiguous and has potential to substantially increase costs. WRHN noted that costs may be higher where districts do not have health practitioners participating in assisted dying services.
- Providing travel costs for this service when it is not available for most other GP services is not standard practice except in rural areas, and RANZCP would like to know more about why this is specified. RANZCP also sought clarification whether costs for travel over four hours cannot be claimed for modules one-to-four, for instance, if a psychiatrist was needed for a capacity assessment in module three and needed to do 'out of area travel'.

Other comments

- RANZCP raised concerns over implementation risks of assisted dying being a service as soon as 7 November 2021, particularly due to the existing strain on general practice care caused by impacts such as the health and disability system review response and Covid-19 testing and vaccinations.
- RNZCGP identified that documentation in module five 'needs to be robust due to the potential for assisted dying services to be under considerable public scrutiny.' They noted that the system will include an audit of the health practitioners record, but there is no expectation that they will be expected to review the quality of work undertaken.

Document 10

Appendix Two: Overall proposed funding settings for Assisted Dying Services Notice 2021

Module	Involves	Who can do it	Standard Payment rate	Possible additional payments
One – Application and first opinion of eligibility	• Supporting the person to complete an application form • Completing the first assessment of eligibility by reviewing clinical notes, speaking with the person • Contacting health practitioners in regular contact and whānau approved by the person	Attending Medical Practitioner	3 hours at $241.60 Total: $724.80	• Travel allowance • Additional 2 hours to support complex cases (Total $1,208 for complex cases) • Cost for providing notes (to be on-paid to enrolled GP) of $231.25
Two – Independent second opinion of eligibility	Completing the second assessment of eligibility by reviewing clinical notes and examining the person	Independent Medical Practitioner	2.5 hours at $241.60 Total: $604	• Travel allowance
Three – Competency assessment (if required)	Coming to an opinion about competency by reading the person's medical files and examining the person	Psychiatrist	4 hours at $386.04 Total: $1,544.16	• Travel allowance
Four – Confirming eligibility or ineligibility and making arrangements	Explaining the opinion of eligibility or ineligibility and either discussing planning the administration of medicines, or supporting the person to receive after-care (if ineligible)	Attending Medical Practitioner	1.5 hours at $241.60 Total: $362.40	• Travel allowance • Additional 2 hours to support complex cases (Total $845.60 for complex cases)
Five – Prescribing and administration of medicines	Making provisional arrangements for administration of medicines and writing the appropriate prescription. Administering the medicines.	Attending Medical Practitioner or an Attending Nurse Practitioner (under the instruction of an attending medical practitioner)	4.5 hours at $241.60 Total: $1,087.20	• Travel allowance • Partial payment if changed or cancelled at short notice • Supervisory module (50% of module - $543.60) • Optional peer support module (50% of module - $543.60)
Total (If all modules used)			**15.5 hours** **$4,322.56**	**19.5 hours + supervisor or optional peer support module:** **$5,288.96** (+ any travel allowances and any partial payments of module five)

Document 11

MINISTRY OF HEALTH
MANATŪ HAUORA

Briefing

End of Life Choice Act: Approval of the Assisted Dying Services Notice 2021

Date due to MO:	20 September 2021	**Action required by:**	27 September 2021
Security level:	IN CONFIDENCE	**Health Report number:**	20211945
To:	Hon Andrew Little, Minister of Health		

Contact for telephone discussion

Name	Position	Telephone
Clare Perry	Deputy Director-General, Health System Improvement and Innovation	s (9)(2)(a) [redacted]
Caroline Flora	Associate Deputy Director-General, System Strategy and Policy	s (9)(2)(a) [redacted]

Minister's office to complete:

☐ Approved

☐ Needs change

☐ See Minister's Notes

☐ Decline

☐ Seen

☐ Withdrawn

☐ Noted

☐ Overtaken by events

Comment:

End of Life Choice Act: Approval of the Assisted Dying Services Notice 2021

Security level:	IN CONFIDENCE	**Date:**	20 September 2021
To:	Hon Andrew Little, Minister of Health		

Purpose of report

1. This briefing seeks your approval of the Assisted Dying Services Notice 2021 (the Notice), to be made under section 88 of the New Zealand Public Health and Disability Act 2000.
2. This notice will allow the Ministry of Health to make payments to practitioners who provide assisted dying services when the End of Life Choice Act 2019 comes into effect on 7 November 2021.
3. This report discloses all relevant information.

Approval sought

4. The Assisted Dying Services Notice 2021 is provided for your approval, and reflects:
    a. previous decisions made by Cabinet to adopt an approach that will allow willing and qualified practitioners to receive funding for providing assisted dying services, on a fee-for-service basis (excluding those directly employed by DHBs) [CAB-21-0241 refers]; and
    b. previous decisions made by you on the funding settings that will apply to payments for practitioners, including the modules and prices to be used [HR20211645 refers].
5. In addition to the Notice, we have also attached a short overview, which summarises the structure and key content from the Notice.
6. The Notice is made under section 88 of the New Zealand Public Health and Disability Act 2000, which allows payments to be made by the Crown and/or District Health Boards for health services.
7. Approving the Notice will allow the Ministry of Health to make payments to practitioners who provide assisted dying services when the End of Life Choice Act comes into effect on 7 November 2021.

Funding medicines for assisted dying

8. The Notice does not cover pharmacists who dispense medication for assisted dying, as funding for these services is being arranged through a separate agreement between the Ministry and two DHBs.
9. Pharmacies in these DHBs will be responsible for sourcing and distributing kits containing the medicines and equipment required to administer assisted dying.

Managing travel costs

10. In your comments on HR20211645 you queried how the Ministry will manage travel costs, and in particular:
    a. whether there is a risk that a small number of practitioners may come to be viewed as specialists in relation to assisted dying, and may be sought by people across New Zealand over local practitioners
    b. whether/how the Ministry will prevent people from requesting practitioners from long distances away when there may be suitable practitioners available locally.

11. In most cases we expect that people seeking assisted dying will either approach a local medical practitioner in the first instance, or seek a referral from the SCENZ Group. Where a referral is sought, the secretariat for the SCENZ Group will seek to identify suitable practitioners who are located closer to the patient in the first instance.

12. The Notice sets out the requirements that providers must meet to submit a travel claim, including that claims must be accompanied by invoices and GST receipts, identify travel destinations that the practitioner has travelled from and to, and provide an explanation as to why the travel and/or overnight stay was necessary.

13. We will also seek to manage travel costs by:
    a. supporting as many practitioners as are willing to provide assisted dying services
    b. providing guidance to those making referrals to identify suitable practitioners who are located closer to the patient in the first instance
    c. supporting the use of virtual consultations where this is possible and appropriate
    d. using operational policy to enable case by case consideration of circumstances where there are high or unusual travel costs to ensure these are reasonable.

Next steps

14. In order for the Notice to be in place from 7 November it needs to be approved by you no later than 1 October 2021. Once you have approved the Notice, we will arrange for it to be published in the New Zealand Gazette, as this is a legal requirement for section 88 notices.

15. You will also need to table the notice in Parliament as soon as practicable after it has been approved.

16. We plan to publish the Notice on the Ministry of Health website, along with a user guide for practitioners wanting to access funding through the Notice.

17. We expect that publishing the Notice will attract some interest from stakeholders, who have been waiting to see what levels of funding will be available to those who provide assisted dying services. We are preparing communications materials to be used alongside the release of the Notice and will provide these to your office.

Recommendations

We recommend you:

a)	**Approve** the Assisted Dying Services Notice 2021 made under section 88 of the New Zealand Public Health and Disability Act 2000.	**Yes/No**
b)	**Agree** to arrange to table the Assisted Dying Services Notice 2021 in Parliament soon as practicable after it has been approved.	**Yes/No**

Clare Perry Deputy Director-General **Health System Improvement and Innovation** Date:	Hon Andrew Little **Minister of Health** Date:

ENDS.

Appendix One: Overview of the Assisted Dying Services Notice 2021

The Assisted Dying Services Notice 2021 is a legal instrument made under section 88 of the New Zealand Public Health and Disability Act 2000, and allows the Ministry of Health to make payments to medical and nurse practitioners for providing assisted dying services.

The Notice is organised in three parts, and two schedules.

Part A provides information about this notice, including:

- when it comes into effect – 7 November 2021
- its purpose – setting out terms and conditions on which practitioners will be funded for providing assisted dying services, and
- the objective of funding provided through the Notice, which is to fund practitioners to support equity of access to assisted dying services for eligible persons.

This part also includes a clause outlining situations where future changes to the Notice can be made without giving 12 weeks' notice, which is otherwise required for changes to notices. Changes may be made without providing notice where they reflect:

- any change of law or Crown direction
- any standards of care developed by the SCENZ Group
- any workforce standards and training requirements for assisted dying services required by the Ministry
- any increase to the prices paid for the provision of assisted dying services
- any data or reporting requirements the Ministry considers are necessary to administer and improve assisted dying services.

Part B contains most of the important information related to funding assisted dying services including:

- the eligibility criteria to claim funding
- the service standards that must be met to claim funding
- the scope of funding that can be claimed, and
- the modules and other costs that can be claimed for.

To be able to claim for assisted dying services under this notice, a health practitioner must be a medical practitioner, nurse practitioner, or psychiatrist, as defined in the End of Life Choice Act 2019, and must have completed the training requirements for assisted dying services.

To be funded a health practitioner must also deliver assisted dying services:

- in a prompt, efficient, professional, and ethical manner
- in a way that embraces, supports, and encourages a Māori worldview of health and provides high-quality, equitable services for Māori
- in a culturally appropriate manner that reflects the culture and values of the person being provided assisted dying services, and
- in accordance with:
    - the standards of care developed by the SCENZ Group
    - the requirements for reporting on assisted dying services
    - the requirements of the health practitioner's responsible authority, including requirements to act within the health practitioner's scope of practice
    - the standards of any professional college of which the health practitioner is a member
    - the requirements of the Code of Health and Disability Services Consumers' Rights, and
    - all relevant laws.

When requested by the Registrar (Assisted Dying), a health practitioner must also cooperate with, and provide information in relation to complaints received.

The Notice divides the assisted dying process set out under the End of Life Choice Act 2019 into five modules, that can be claimed by health practitioners depending on which parts of the process they provide.

Module One involves the attending medical practitioner:

- providing the relevant information and doing the relevant checks to enable someone to make a request for assisted dying - section 11(2)
- completing the relevant forms - sections 12(2) and (5)
- undertaking an assessment and providing a first opinion on eligibility - sections 13(2) and (3)
- requesting an opinion from an independent medical practitioner (and psychiatrist if required) - section 14(2) and section 15(2)

Module Two involves an independent medical practitioner:

- undertaking an assessment and providing a second opinion on eligibility - sections 14(3) and (4)
- requesting an opinion from a psychiatrist (if required) - section 15(2)

Module Three involves a psychiatrist undertaking an assessment and providing an opinion on the competence of the person to request assisted dying (if this is required) - sections 15(3) and (4).

Module Four involves the attending medical practitioner either:

- where the person is not eligible for assisted dying:
    - advising them that they are not eligible and completing the relevant form - sections 16(2) and (5)
    - if the attending medical practitioner is the person's usual medical practitioner, arranging for any required clinical care and other relevant support services where appropriate
    - if the attending medical practitioner is not the person's usual medical practitioner, providing a handover to the person’s usual medical practitioner, or another medical practitioner who can provide or arrange for any required clinical care and other relevant support services where appropriate
- where the person is eligible for assisted dying:
    - advising the person that they are eligible for assisted dying - sections 17(2) and (3)
    - discussing with the person the date and time for the administration of medication - section 18(2), and
    - making provisional arrangements for the administration of medication - sections 19(2)

Module Five involves the attending medical practitioner, or an attending nurse practitioner under the supervision of the attending medical practitioner:

- making arrangements at least 48 hours before the date to administer medications including completing the prescription – section 19(3)
- administering medications - sections 20(2) to (5)
- reporting the death to the Registrar - section 21(1).

A fixed amount is set for delivering each module (in the pricing schedule), and for modules one to four, this amount will be paid regardless of whether:

- a person is found to be eligible or ineligible as the result of an assessment
- the person decides not to receive any further assisted dying services
- the person dies before the administration of medication
- the health practitioner suspects the person is not expressing their wish free from pressure from any other person and ceases the service
- the health practitioner is no longer able to deliver assisted dying services due to incapacity, illness, or injury.

For module five, a partial payment can be made where:

- the need for administration of medications changes within three days of the planned date – in which case 20% of the normal payment can be received
- the need for administration of medications changes on the planned day – in which case 50% of the normal payment can be received.

Where the planned date for administration of the medication is changed and this is delivered at a later date, an attending medical practitioner and/or attending nurse practitioner can make a separate additional claim for Module 5.

In addition to these modules, practitioners can also receive:

- an additional payment if module one takes longer than three hours to deliver
- an additional payment if module four takes longer than one and a half hours to deliver
- an additional 50% of the fee for module five to pay an attending medical practitioner for their supervision, if this module is delivered by an attending nurse practitioner
- an optional payment for module five that allows another health practitioner to support an attending medical practitioner the first time they administer medication
- a fee to cover the cost of obtaining clinical notes, where these are required by an attending medical practitioner who is not the person's normal medical practitioner or nurse practitioner.

Health practitioners can also receive payment for travel costs where travel is necessary to deliver assisted dying services. Payments for travel costs can cover:

- private motor vehicle travel for distances over 20 kilometres in a return trip
- non-motor vehicle travel (such as flights)
- the health practitioner's time (paid at a rate set out in the pricing schedule)
- accommodation and meal costs in exceptional cases where overnight stays are necessary.

This part of the Notice also states that the Ministry of Health will undertake a review of the prices it pays for assisted dying services as set out in the Pricing Schedule once every two years. Decisions about whether to change prices will be made by the Minister of Health and Cabinet.

Part C sets out the general requirements that apply to a health practitioner who receives funding through the Notice.

Most of these requirements are standard, and apply to other types of funding provided through similar mechanisms. These include conditions covering:

- when the Ministry can suspend a practitioner's ability to claim funding under the Notice, and the process involved
- how payments will be provided by the Ministry, how any overpayments will be managed, and the need to advise the Ministry of any bankruptcy
- the conditions for payments to be withheld by the Ministry, and the ability for claims to be reconsidered
- arrangements for electronic claiming
- auditing arrangements, and the need to provide information when requested
- limitations on public statements and advertising
- dispute resolution processes
- uncontrollable events
- maintaining confidentiality.

In addition to these standard provisions, this section also includes conditions that health practitioners cannot claim for funding if they charge co-payments for their services, provide the service in their capacity as an employee of a District Health Board, or can have these costs met through any other government agency/funding.

The two schedules included at the back of the Notice are:

- a schedule providing definitions for key terms used in the Notice and some other technical details related to how it should be interpreted
- a pricing schedule that sets out the specific amounts of payment that can be made to health practitioners to deliver assisted dying services, along with other costs set out in Part B including travel.

Document 12

MINISTRY OF HEALTH
MANATŪ HAUORA

Briefing

End of Life Choice Act: Data collection, monitoring, and research on assisted dying

Date due to MO:	26 November 2021	**Action required by:**	10 December 2021
Security level:	IN CONFIDENCE	**Health Report number:**	HR20211867
To:	Hon Andrew Little, Minister of Health		

Contact for telephone discussion

Name	Position	Telephone
Steve Barnes	Group Manager, Family and Community Health Policy	[redacted]
Caroline Flora	Associate Deputy Director-General, System Strategy and Policy	[redacted]

Minister's office to complete:

☐ Approved

☐ Needs change

☐ See Minister's Notes

☐ Decline

☐ Seen

☐ Withdrawn

☐ Noted

☐ Overtaken by events

Comment:

End of Life Choice Act: Data collection, monitoring, and research on assisted dying

Security level:	IN CONFIDENCE	**Date:**	26 November 2021
To:	Hon Andrew Little, Minister of Health		

Purpose

1. This paper provides information on the data collection and monitoring that the Ministry plans to do on assisted dying. It also outlines the importance of research on assisted dying and seeks your direction on the extent to which the Ministry should actively commission research in this area.
2. This report discloses all relevant information and implications.

Summary

3. The introduction of assisted dying in Aotearoa has strong interest from, and wide implications for, health practitioners delivering the service, people going through the system and their whānau, and wider communities.
4. The Ministry plans to collect both quantitative and qualitative data and monitor assisted dying services to inform operational reporting and service improvement, provide accountability and transparency, and inform future policy decisions in this area. Further details on the data we plan to collect and monitor is in the appendices to this briefing.
5. As kaitiaki of the health and disability system, the Ministry also has a role in supporting evidence-based research on assisted dying in Aotearoa. This includes supporting Māori as Tiriti partners, enabling tino rangatiratanga, and using kaupapa Māori research approaches.
6. There is a need to develop a body of knowledge that informs both how assisted dying is provided in practice, and wider conversations and understandings about the social and cultural implications of assisted dying for Aotearoa. Supporting research is also important to encourage public confidence in, and acceptance of, assisted dying.
7. The Ministry currently supports research for other health services in a limited capacity and could support research on assisted dying in a similar way, by providing access to data, and supporting applications for contestable funding from sources like the Health Research Council.
8. There is an argument that the Ministry should take a more active role in commissioning research on the basis that this is an entirely new area for Aotearoa and an area of significant public interest. It could also be argued that the Ministry has a responsibility to make sure that research takes place to allow the health needs and interests of Māori to be understood and inform actions by Māori and the Crown in this area.

9. The Ministry's role in supporting research is expected to change as part of the health and disability system reforms, with the expectation that the Ministry will have a broader, more proactive, and strategic approach to research than it has done in the past.

10. We propose that the Ministry take an active role in funding and commissioning research, which is targeted to areas of knowledge that are directly relevant to the Ministry's role and responsibilities related to assisted dying.

11. If you agree, we will provide further advice in early 2022 on what a process to determine appropriate research areas/questions could look like, how this could be funded, and what decisions would need to be made to progress this.

Recommendations

We recommend you:

a) **Note** that the Ministry has plans to collect data and conduct monitoring and evaluation as part of our role in overseeing the provision of assisted dying, and further information on this is provided in the appendices

b) **Note** that the Ministry will provide you with high-level numbers from our operational monitoring dashboards via your weekly reports, and will provide more detailed information to your office on a monthly basis

c) **Note** a post-implementation evaluation will commence in November 2022, and will involve in-depth analysis of all available data, along with input from stakeholder groups involved in the assisted dying service

d) **Note** that the Ministry has a role in supporting research on assisted dying in Aotearoa and there is a need to develop a body of knowledge that informs how assisted dying is provided and addresses the needs and interests of Māori

e) **Note** that the Ministry will provide a supporting role in research on assisted dying at minimum, but that we consider that the Ministry should take an active role in commissioning research in some specific areas, recognising the unique complexities around assisted dying as a new service

f) **Agree** that the Ministry take an active role in funding and commissioning research on assisted dying, and that this should be targeted to areas that are directly relevant to the Ministry's role and responsibilities in this area **Yes/No**

g) **Note** that if you agree, we will provide further advice to you in early 2022 on what a process to determine appropriate research areas/questions could look like, and what decisions would need to be made to progress this.

Caroline Flora	Hon Andrew Little
Associate Deputy-Director General	**Minister of Health**
System Strategy and Policy	Date:
Date: 22/11/2021	

End of Life Choice Act: Data collection, monitoring, and research on assisted dying

The introduction of assisted dying will require a new body of knowledge

1. The introduction of assisted dying in Aotearoa has wide implications for health practitioners delivering the service, people going through the system and their whānau, and also for the wider community.

2. In implementing assisted dying in Aotearoa, we are drawing from the knowledge and experiences of other jurisdictions where assisted dying is provided, but there will be a need to develop a gradually building body of knowledge that is specific to Aotearoa.

3. This knowledge can inform how assisted dying is provided in practice, and wider conversations and understandings about the social and cultural implications of assisted dying for Aotearoa.

We plan to collect data, monitor, and evaluate assisted dying services

4. The Ministry has plans to collect detailed information and conduct monitoring as part of our role in overseeing the provision of assisted dying services. This information gathering and monitoring will reflect the Ministry's obligations to provide:

   - **operational reporting**: providing the information needed for the delivery of assisted dying services, including the case management of applications by the Registrar (assisted dying) and the assisted dying secretariat
   - **service monitoring and improvement**: ensuring early identification and management of service delivery issues, such as timeliness through the different assessment steps, workforce availability, and any issues with accessing medications
   - **accountability**: ensuring the service is operating as intended and providing for equity analysis across and between different population groups, which includes analysis addressing Māori interests and Te Tiriti obligations
   - **transparency**: meeting reporting requirements under the End of Life Choice Act 2019 (the Act), and providing stakeholders with information that is accurate and timely, supporting public confidence in the service
   - **information to inform future policy decision:** including future reviews of the system, and the legislation.

We will collect both quantitative and qualitative data

5. Collecting both quantitative and qualitative data will inform the Ministry's data analysis and reporting function. This will help us understand both how the assisted dying service is being provided, and how the service is experienced by people, their whānau, and those who provide the service.

6. While we are required to collect a substantial amount of quantitative data, we recognise that qualitative data is significant for understanding the context of each assisted death and gaining more information on what we can learn from people's experiences.

7. Detailed reporting may be limited in the early stages of the service, when the number of people using the service is low, to protect confidentiality.

8. The Ministry intends to collect ethnicity information of both the health practitioner providing assisted dying and the person seeking it, along with information on iwi affiliation, gender, and disability status. Collecting this information will enable equity analysis and allow Māori to monitor Crown obligations.

9. In identifying data to be collected on assisted dying, the Ministry used Māori data sovereignty principles and guidance from the Mana Ōrite Agreement between Statistics New Zealand and the Data Iwi Leaders Group of the National Iwi Chairs Forum.

10. A full list of the data we plan to collect on assisted dying services is provided in **Appendix One**.

We also have monitoring and evaluation arrangements for the assisted dying service

11. Regular monitoring and evaluation of the assisted dying service and the experience of providers/users is important to ensure the system meets and delivers on the expectations of whānau, communities, and health practitioners. Monitoring and evaluation is important to give people confidence in the assisted dying service.

12. For the first year of the assisted dying service, the Ministry intends to carry out three levels of monitoring for the service. These are:

    - regular internal monitoring to support ongoing service improvement
    - annual reporting by the Registrar to meet legislative requirements
    - a formal post-implementation evaluation to examine the service implementation.

13. Regular internal monitoring will include daily operational dashboards as well as weekly and monthly service monitoring. These will be used to support the case management function, identify and manage service delivery issues (eg, timeliness, workforce availability, medications issues, accessibility and equity), and will inform ongoing service improvement. We will provide you with regular updates via your weekly report on high level numbers from these dashboards and provide more detailed information to your office on a monthly basis.

14. The Act requires annual reporting on the total number of assisted deaths, number of complaints received (if any), and other matters relevant to the operation of the Act. We expect our reporting will likely go beyond this with additional reporting such as equity analysis across and between different groups and monitoring against Tiriti obligations (ie, achieving equitable health outcomes for Māori).

15. A post-implementation evaluation will commence in November 2022, and will involve in-depth analysis of all available data, along with input from stakeholder groups involved with the service. While this is not a legislative requirement, it is important for the Ministry to evaluate the implementation of the assisted dying service as part of its role as kaitiaki of the health and disability system. This evaluation is expected to evaluate how the service is functioning and what non-legislative changes and improvements may be needed. We will provide you with more information about the planned evaluation in 2022.

16. The Ministry will also review the operation of the Act no later than 7 November 2024 (three years after its commencement) and then at subsequent intervals of no more than five years, as required by the Act.

17. More information about the planned arrangements for monitoring and evaluation of assisted dying services are provided in **Appendix Two**.

The Ministry has a role in supporting research on assisted dying

18. In addition to collecting and reporting data on assisted dying, there will also be a need to develop a body of research in this area. There is strong interest from both researchers and wider community members in the implementation and operation of the assisted dying service in Aotearoa. Research will allow the many different dimensions related to assisted dying to be explored and understood in a way that is particularly relevant to Aotearoa.

19. As kaitiaki of the health and disability system, the Ministry has an interest in seeing and supporting the development of evidence-based research into assisted dying in Aotearoa. This interest is reflected in Tā Tātou Rautaki (the Ministry's five-year organisational strategy), where one of the six organisational capability objectives is that 'we will ensure data insights and evidence drive our decisions'.

20. Whakamaua (Māori Health Action Plan 2020-25) also includes a Ministry commitment to evidence and insights for Māori. The Ministry has a role in partnering with Māori and supporting the use of kaupapa Māori research approaches.

21. Quality research provides another source of information for the Ministry to monitor and evaluate how this new legislation and health service operates in Aotearoa and how assisted dying affects different communities. This will enable the Ministry and the wider health sector to learn, respond, and improve the way services are provided, both during the first year, but also over time.

22. The Crown also has an obligation as a Te Tiriti partner, to understand and address the needs and interests of Māori related to assisted dying. To uphold active protection and tino rangatiratanga, the Ministry needs to enable Māori partnership in research. Research conducted by, for, and about Māori will be important to understand how assisted dying impacts Māori, and what this means for the Crown as a Tiriti partner.

The Ministry is the subject of a Waitangi Tribunal claim related to research on assisted dying

23. In April 2021, a Waitangi Tribunal claim (Wai 3023) was made on the possible effects of the Act in relation to Māori suicide rates, particularly for rangatahi Māori. The claimant sought an urgent hearing, which was not granted, with the claim to be heard as part of the Health Services and Outcomes Kaupapa Inquiry (Wai 2575). The Ministry expects that the claim will be heard as part of part two, stage two of the Wai 2575 claim, which focuses on mental health (including suicide and self-harm).

24. The claim made is that the Crown has breached the principles of Te Tiriti by failing to commission new research and have proper regard to existing research on the impact that assisted dying will have on suicide rates for Māori, particularly for rangatahi Māori.

25. In its response to the request for an urgent hearing, the Ministry noted that:

- research on whether assisted dying services increase the prevalence of suicide has not been conducted in Aotearoa and the Ministry is not aware of any research that explores the effects of assisted dying services on indigenous suicide rates

- the reasons that people consider suicide are complex and informed by many different factors that can accumulate over a lifetime, making it difficult to attribute changes in suicide rates over time to any particular cause, including to the introduction of legislation around assisted dying services.

26. The Ministry has taken some actions to address wider elements of the claim in its work to implement assisted dying services. This has included:

- considering how we can address the particular needs and interests of Māori across all workstreams of the implementation programme, including (but not limited to) stakeholder engagement and public information, funding and accountability, standards of care and clinical guidance, service design, data collection, and reporting
- seeking advice from Māori experts on rangatahi suicide and the things they believe need to be considered in the design and implementation of assisted dying
- meeting with the claimant to understand their interests and concerns.

27. The Ministry acknowledges that it is important assisted dying services are implemented in a way that does not undermine suicide prevention efforts, and that supports whānau to respond appropriately to suicidal distress or behaviour. We agree it is important the Ministry supports research that examines how the provision of assisted dying could impact Māori, including Māori suicide rates.

The Ministry will support research on assisted dying...

28. The Ministry currently takes on a largely supporting role in research on other health issues, and this type of support will be provided for research on assisted dying as a minimum if no further measures are taken.

29. This supporting role will involve the Ministry, where appropriate:

- endorsing research applications by researchers for contestable funding from other bodies such as the Health Research Council (eg, by having the Chief Science Adviser writing letters of support)
- responding to requests for information and data collected by the Ministry about assisted dying to support research
- passing on requests for information/participation, such as requests for health practitioners to participate in research on their experiences.

30. Supporting researchers this way can support good relationships between them and the Ministry, while leaving individual researchers to determine what subjects are important or should be a priority to investigate around assisted dying.

...But it may be desirable for the Ministry to take on a more active role

31. The Ministry could go beyond simply supporting research and take a more active role in commissioning and funding some research on assisted dying.

32. Arguments for this include assisted dying being entirely new to Aotearoa. Assisted dying is a complex area on which philosophical, moral, religious, ethical, and clinical views are divided. This means the Government may have a responsibility to make sure that a body of quality research is developed to inform policy and practice in this area.

33. Taking a more active role would also support the Ministry to fulfil its Tiriti obligations, including by enabling Māori researchers to contribute to research as Tiriti partners. The Ministry has a responsibility to make sure that research by, for, and about Māori takes place to allow the needs and interests of Māori to be understood and inform actions by Māori and the Crown.

34. There are also arguments to be considered against the Ministry funding and commissioning research on assisted dying.

35. Taking a specific interest in assisted dying would be a departure from how the Ministry supports research in other areas of the health and disability system. This could be perceived by some as the Ministry favouring, promoting, or providing preferential treatment to assisted dying over other health services. It could be argued that research on assisted dying should be subject to the same contestable processes as other research.

We propose to investigate commissioning research in some specific areas

36. On balance, we favour the Ministry taking on an active role related to research, recognising the unique complexities around assisted dying as a new service with significant outcomes specific to Aotearoa, but to limiting this activity to some targeted areas.

37. This sort of targeted approach would allow the Ministry to actively support research, while limiting this to areas that are directly relevant to the Ministry's role and responsibilities related to assisted dying, particularly in ensuring equitable health outcomes for Māori.

38. If you agree that the Ministry should have an active role in funding and commissioning targeted research on assisted dying, we will provide you with some further advice in early 2022.

39. Our current thinking is that further work could potentially involve the Ministry bringing together Māori partners and other stakeholders with an interest in assisted dying, to identify some key research priorities/questions in relation to assisted dying for Aotearoa.

40. The Ministry would then work with our partners to develop requests for research proposals that addresses these priorities/questions, which would then be assessed for funding by the Ministry.

41. Potential options to fund research related to assisted dying could include using unspent contingency funding set aside for assisted dying services, reprioritising funding from other sources, or seeking additional funding through future Budget processes.

As the role of the Ministry changes, its role in supporting research is also likely to change

42. The role of the Ministry in relation to supporting research is expected to change as part of the health and disability system reforms. A Research and Innovation Taskforce Group has been established as part of the health and disability system reform process to consider how the Ministry can best fulfil its stewardship role in relation to research and innovation in the new health system.

43. We expect that data collection, monitoring, and research activities related to assisted dying will remain within the Ministry in the short-term, and may continue to remain in the long-term, though there is a degree of uncertainty given upcoming health and disability system reforms.

44. Over coming months there is likely to be engagement between the Ministry, Health New Zealand, the Māori Health Authority, and the developing Ministry for Disabled People around how data is collected on assisted dying, and processes involving the commissioning and funding of any research. For example, representatives from the Māori Health Authority could be involved in engagements with Māori organisations to determine which areas and questions should be considered a priority for research related to assisted dying.

Next steps

45. If you agree that the Ministry should have an active role in funding and commissioning targeted research on assisted dying, we will provide further advice in early 2022 covering:

- what a process to determine appropriate research areas/questions could look like (eg, which organisations/individuals should be involved, and what the scope should be)
- what decisions would need to be made progress this (eg, the quantum of research that could be supported, how this might be funded, and what the timeline for this could be).

ENDS.

Appendix One: Data collection on assisted dying services

1. In identifying data to be collected on assisted dying, the Ministry has been using the Māori data sovereignty principles and guidance from the Mana Ōrite Agreement between Statistics NZ and the Data Iwi Leaders Group of the National Iwi Chairs Forum.

2. We have also briefed Te Apārangai and Te Ao Marama on data collection and monitoring requirements, have ensured we have a good system in place to record iwi affiliation data and a range of other information that can be used to support analysis of equity outcomes.

Quantitative data

3. A summary of the quantitative information we intend to collect is listed below.

Quantitative data	Rationale for collection
Practitioner name and HPI number/registration number	To deliver the service
Practitioner type (Attending/Independent Medical Practitioner, Psychiatrist)	To deliver the service
Practitioner ethnicity, iwi affiliation and gender	To enable equity analysis
Practitioner specialty/vocational scope	To deliver the service
Practitioner usual service region and available service region(s)	To deliver the service
Practitioner status (active, inactive, unavailable)	Required by the legislation
Practitioner current practising certificate	To deliver the service
Practitioner assisted dying training complete	To deliver the service
Person name and NHI number	To deliver the service
Person ethnicity, iwi affiliation, and gender	To enable equity analysis
Person address	To deliver the service
Person citizenship or residence status	To deliver the service
Whether the person is receiving palliative care services	To enable equity analysis
Person disability status and the use of supported decision making	To enable equity analysis
Patient diagnosis (malignancy/neurodegenerative/other)	To deliver the service
Application date and signed by	To deliver the service
Attending Medical Practitioner assessment date and outcome	To deliver the service
Independent Medical Practitioner assessment date and outcome	To deliver the service
Psychiatrist assessment date and outcome	To deliver the service
Registrar review date and outcome	To deliver the service
Person withdraws from assisted dying process	To deliver the service
Person dies prior to assisted death	To deliver the service
Method of assisted dying and description of medication administration	Required by the legislation
Problems with medication administration (and how they were dealt with)*[1]	Required by the legislation
Place, date, and time the person died*	Required by the legislation
Medical/Nurse Practitioner that was available to the person until they died*	Required by the legislation
Other health practitioners who were present when the patient died*	Required by the legislation
Complaint received from and complaint received date	Required by the legislation
Complaint actioned by, complaint action date, and complaint action taken	Required by the legislation
Complaint outcome and complaint outcome date	Required by the legislation

4. Demographic information will be collected consistent with the Ministry protocols and Statistics NZ classifications.

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[1] ***These items are all part of the assisted dying death report specified in section 21 of the Act. They are a mix of quantitative and qualitative information but have been grouped together here as they form part of a single report.**

5. To address the interests of Māori impacted by assisted dying we intend to collect quantitative data on iwi affiliations and ethnicity from the applicant and health practitioner by following the standard ethnicity data protocols (collecting by disability status, location, gender, palliative care status, institutions – including prisons). We will also collect qualitative information using Māori ethical guidelines.[2]

6. Additional data items will be captured as part of the forms specified in the Act to ensure compliance, but these will not be used for reporting and are not shown. These include check lists where practitioners outline the steps they have followed in conducting their assessments. For example, confirming that the person is expressing their wish free from pressure and that the person is currently competent to make an informed decision.

Qualitative data

7. The following table summarises our current thinking on the qualitative data we intend to collect, and the type of information we might expect to gather.

Qualitative information

Follow-up call with the person's key support person/whānau after an assisted death

This involves a scripted conversation to standardise the communicated information, and collect information on:

- the person's experience with the process, including what went well, whether there were any challenges or difficulties (eg, was there family opposition; how they would have liked their needs to be considered at the time of decision making), and how any issues were responded to (clinical, practical, administrative, personal, emotional, psychological, related to funding etc)
- whānau experiences of, and involvement in, the process, including the extent to which whānau were involved, and how they found the process (eg, how they felt after the assisted dying service was formalised for the person; what sort of guidance they would have liked during the process)
- the pastoral care records provided by the Clinical Advisors in the secretariat (count of calls made) combined with thematic analysis of the data above
- whether the follow-up call was with the same person put forward as the key contact at the beginning of the process.

Clinical peer support conversation with the Attending Medical Practitioner/other practitioners

This collects information on:

- the health practitioner's experience of providing the service, including whether they would provide the service again, and whether they requested support/a buddy for their first event (for the Attending Medical Practitioner role)
- whether there were particular issues/challenges that emerged, and how they were responded to (clinical, practical, administrative, personal, emotional, psychological, cultural, related to funding, etc.)
- the experience of the person seeking assisted dying and their whānau, including whether whānau were involved in clinical consultations, what the health practitioner may have done to address particular cultural needs, and whether the health practitioner informed the family about support they could get.

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[2] https://www.hrc.govt.nz/resources/te-ara-tika-guidelines-maori-research-ethics-0

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Appendix Two: Monitoring and evaluation arrangements for assisted dying

1. There are three levels of monitoring and evaluation that the Ministry intends to carry out, at least initially for the first year of assisted dying services, which are detailed in the table below.

Product and purpose
Regular internal monitoring o To support the case management function delivered by the Registrar and secretariat. o To monitor the service and inform ongoing service improvement. o Records metrics such as details of applications, health practitioners, closed applications, wait time, ineligible applicants, death reports, and complaints. o Operational monitoring and evaluation provided for internal use and decision making. Some insights may also be shared with Health Ministers as needed. o The rationale for this monitoring includes supporting the statutory role of the Registrar in service oversight and compliance, monitoring against Te Tiriti obligations, equity, other aspects of quality assurance (timeliness, accessibility, performance, safety), and informing service improvement. o In terms of frequency, the case management reporting will occur in real-time. Other reporting items are likely to be weekly or monthly.
Annual reporting by the Registrar o The End of Life Choice Act contains a reporting requirement on the following: • total number of assisted deaths; • number of complaints received; and • other matters relevant to the operation of the Act. o Although not a legislative requirement, we are likely to include some additional reporting including details such as equity analysis. o Provided to the Minister of Health and then tabled in the House. The first report will likely cover the period from 7 November 2021 – 30 April 2022. o Provides a degree of accountability and public transparency about the operation of the system. The report is likely to be published on the Ministry website, especially with the strong public interest in the subject.
Post-implementation evaluation o Data analysis and evaluation to examine how assisted dying has been implemented, and whether changes are required to improve the quality of the programme and outcomes. Will evaluate each part of the process (eg, timeframes, adverse events, complaints, any unexpected changes). o Will involve in-depth examination of all data collected and data from other sources (eg, input from Māori and sector organisations; nationally standardised self-harm and suicide data with ethnicity information) to understand implementation and make recommendations for improvement. o To commence 12 months after the service has been in place (from November 2022). o This evaluation is likely to be contracted externally, and funding has been set aside for it. o The evaluation findings will be provided to the responsible manager within the Ministry and to the Minister of Health (with advice on proposed response).

2. The Ministry is developing landing pages, operational dashboards, and service monitoring for the internal electronic reporting platform. This will enable us to carry out case management of applications, regular internal monitoring, and service improvement.