Review of the Operation of Victoria's *Voluntary Assisted Dying Act 2017*

October 2024

VICTORIA
State
Government

Department
of Health

This report contains content about end of life and voluntary assisted dying, which you may find distressing.

If you are in distress and require immediate support Lifeline is available anytime by phone on 13 11 14 or by text/online chat via their website <https://www.lifeline.org.au/>. There are a number of other telephone or online services <https://www.health.vic.gov.au/mental-health-services/telephone-and-online-services>.

You may also like to speak with the Voluntary Assisted Dying Care Navigator Service. The care navigators are available to anyone in Victoria seeking information or support regarding voluntary assisted dying, including discussing the eligibility requirements or finding a medical practitioner who can assess a person for eligibility to access voluntary assisted dying. The care navigators can be contacted during business hours from anywhere in Victoria by the following methods:

- Phone: (03) 8559 5823
- Email: vadcarenavigator@petermac.org

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In this document, 'Aboriginal' refers to both Aboriginal and Torres Strait Islander people. 'Indigenous' or 'Koori/Koorie' is retained when part of the title of a report, program or quotation.

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Available at Voluntary Assisted Dying <https://www.health.vic.gov.au/patient-care/voluntary-assisted-dying>.

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Glossary

Terms	Definition
Applicant	A person that is seeking to access voluntary assisted dying and is in the process of applying for a voluntary assisted dying permit.
Care navigator	Care navigators provide information and support to a person seeking voluntary assisted dying and health practitioners. Care navigators can refer to individuals employed under the Statewide Care Navigator Service or local care navigators employed by health services to assist individuals and health practitioners through the process.
Consulting medical practitioner	A registered medical practitioner who accepts a referral to conduct a consulting assessment of a patient who has requested voluntary assisted dying.
Coordinating medical practitioner	A registered medical practitioner who accepts a patient's first request for access to voluntary assisted dying.
Contact person	A person chosen by the person seeking voluntary assisted dying to take on legislated responsibilities under the *Voluntary Assisted Dying Act 2017*. These include returning any unused voluntary assisted dying substance following death and providing feedback to the Voluntary Assisted Dying Review Board about the person's experience.
Health practitioner	A collective term used to define health practitioners in the health system, including nurses, allied health professionals and medical practitioners.
Medical practitioner training (may also be referred to as approved training)	Voluntary assisted dying training which provides a detailed overview of Victoria's voluntary assisted dying legal framework. Before assisting people seeking voluntary assisted dying, a medical practitioner must complete the approved training. On successful completion of the training medical practitioners can apply for access to the portal.
Permit	A permit means either a self-administration or practitioner administration permit issued under the *Voluntary Assisted Dying Act 2017*. A permit authorises the use of the voluntary assisted dying substance to bring about death. Access to voluntary assisted dying is controlled through a permit process and a series of forms documenting the person's eligibility under the law. VAD medical practitioners coordinate this process on the individual's behalf. The application for a permit must be approved by the Secretary of the Department of Health before the coordinating medical practitioner can write a prescription for the substance.

Terms	Definition
Person seeking voluntary assisted dying	An individual that is seeking to access voluntary assisted dying. This term can refer to an individual who has commenced the process of accessing voluntary assisted dying, or individuals who have not yet commenced the process but are intending to make this choice.
Portal	The electronic platform used by the Department of Health to receive voluntary assisted dying forms from medical practitioners. Voluntary assisted dying medical practitioners are given access to the portal and relevant forms following completion of the approved training.
Statewide Care Navigator Service	Commissioned by the Department of Health, the Statewide Care Navigator Service provides information and support to people seeking voluntary assisted dying, their families and support people, health practitioners and health care settings.
Statewide Pharmacy Service	Commissioned by the Department of Health and based at Alfred Health, the Statewide Pharmacy Service is responsible for importing, storing, preparing and dispensing the voluntary assisted dying substance. Once a prescription is written by the coordinating medical practitioner, the person seeking voluntary assisted dying contacts the Statewide Pharmacy Service to organise an appointment for them to dispense the substance. The Statewide Pharmacy Service will deliver the substance to the person anywhere in Victoria.
Voluntary assisted dying (VAD)	Voluntary assisted dying refers to the administration of a substance for the purpose of causing death in accordance with the process set out under the *Voluntary Assisted Dying Act 2017*.
Voluntary assisted dying medical practitioner	A medical doctor, general practitioner or other specialist with appropriate experience and who has completed voluntary assisted dying training to assist a person through the process.
Voluntary assisted dying substance	A medication specified in a voluntary assisted dying permit that is used to cause death in accordance with the *Voluntary Assisted Dying Act 2017*.
Voluntary Assisted Dying Review Board	Established under section 92 of the *Voluntary Assisted Dying Act 2017*, the Voluntary Assisted Dying Review Board oversees the safe operation of the Act. The Voluntary Assisted Dying Review Board review and monitor voluntary assisted dying activities in Victoria.

Executive summary

The *Voluntary Assisted Dying Act 2017* (the Act) provides a legal framework for eligible people to choose the manner and timing of their death. The Act came into effect on 19 June 2019, making Victoria the first state in Australia to pass voluntary assisted dying (VAD) legislation.

VAD means administering a substance for the purpose of causing death in accordance with the process set out in law. VAD must be voluntary and initiated by the person themselves and is usually self-administered. The law means that a person may be assisted by medical practitioners to access a substance to end their life at a time of their choosing. The process is designed to ensure the person's decision is voluntary and enduring and provides clear guidance for how medical practitioners can lawfully support individuals in this choice.

In Victoria, VAD is available for those who face imminent death because of an incurable disease, illness or medical condition. The law provides a range of protections to ensure that VAD is safely implemented and monitored in Victoria.

This is a review of the operation of the first four years of the Act, from June 2019 to June 2023, as required under section 116 of the Act. The Department of Health's Centre for Evaluation and Research Evidence (CERE), an independent specialist evaluation unit within the department, undertook the review between June 2023 and July 2024. This included interviews and focus groups with 119 stakeholders and analysing 303 survey responses and 257 written submissions.

The scope of the review included the systems, processes and practices that facilitate operation of the Act. The review included equity of access, the effectiveness of safeguards and protections, and reviewing the roles of the Department of Health, the VAD Review Board and other services and support programs. Suggested or required amendments to the Act were out of scope for this review.

Overall, VAD is operating as intended, providing a safe and compassionate end of life choice to eligible Victorians. Access to VAD is safe, efficiency and timeliness of processes are improving, performance monitoring and oversight mechanisms are working adequately, and most supports are effective. However, the review identified that some processes and safeguards impede access, undermining patient-centred care, and would benefit from improvement.

This report makes a series of recommendations to improve operation of the Act, including addressing gaps in community awareness, raising literacy about VAD for people and their families, supporting the workforce, and continuing to build strong leadership and accountability.

What is working well in the operation of VAD?

Access to VAD is safe. The program is working as envisioned, with no reports of ineligible individuals gaining access to the substance. Compliance with the Act has been very high, and the median time in which people can access VAD is progressively shortening.

VAD has given individuals greater autonomy and choice at the end of their lives, with many people seeking VAD while also accessing palliative care. Community acceptance and support for VAD is increasing and there is growing expectation for broader eligibility and access. Most people seeking VAD, and their families, expressed appreciation for the availability of VAD, highlighting that it provides relief and autonomy in end-of-life decisions.

Most supports for both people seeking access to VAD and health practitioners are effective. Medical practitioners who provide VAD services are highly dedicated. The Statewide Pharmacy and Care Navigator services are consistently meeting key performance indicators, and both community members and health practitioners report high levels of satisfaction with these services. Among participating medical practitioners there is a high level of satisfaction with the VAD medical practitioner Community of Practice, which is appreciated as a valuable confidential peer support network. Additionally, some health services, community groups, and non-government organisations have developed or initiated supports to assist people seeking VAD and their families.

This review found feedback, performance monitoring, oversight and accountability mechanisms are working well overall. The VAD Review Board monitors the operation of the Act. It is achieving its responsibilities to promote and ensure compliance with the Act, report to parliament, refer any issues or breaches to appropriate authorities, collect data about VAD, and provide information to the community.

The Department of Health sets policy, commissions services, and manages provider performance, while also supporting the VAD Review Board, the operation of the permit process and the VAD portal. Enhancements to the portal have addressed some administrative issues, though further portal improvements in data collection, extraction, usability, and communication would be beneficial.

What operational areas of VAD could be improved?

Access to VAD through implementation of the Act is working well. However, there is evidence that access is variable across the state. Further communication and accessible information, including in relation to grief and bereavement support, would improve the experience of those wanting to understand VAD as an option and improve equity in access. In particular, there is currently limited tailored information and support available for Aboriginal and Torres Strait Islander people, and people from multicultural communities. This impedes the ability of people in these communities to make informed choices about VAD, highlighting the need for improved engagement with Aboriginal and Torres Strait Islander communities and multicultural communities to better meet these information needs.

The VAD medical practitioner workforce is small, with a few practitioners delivering the majority of care. This workforce would benefit from more support to enable timely care and meet demand. Currently, VAD training, education activities and information would benefit from significant enhancement and expansion to better meet VAD medical practitioner needs and reach a broader segment of the health workforce.

Currently, pockets of resistance and unclear guidance for health and care organisations and individual health practitioners can delay or create a barrier to access VAD. Clearer guidance would enable services to continue to develop policies in line with their organisation's values while also reducing the risk of unintended access barriers.

Outside of Victoria's jurisdiction, the review identified areas to advocate for improvement with the Commonwealth Government. Adequate remuneration would reduce barriers for practitioners and patients. In addition, an outcome of restrictions imposed by the Commonwealth *Criminal Code Act 1995* (Criminal Code) results in preventing the use of telehealth to support VAD access.

The recommendations provided in this report reflect an approach to continuous improvement across the VAD process.

Interest in legislative change

While assessing the VAD legislation itself was outside of the review's scope, many contributors provided feedback about the legislation, including where certain provisions create barriers to access and timeliness. This feedback has been included in *Addendum to Review of the Operation of Victoria's Voluntary Assisted Dying Act 2017 – Stakeholder feedback regarding legislation*.

Recommendations

Recommendation 1:
Increase the provision of sector guidance and build on approaches to continuous improvement

a) Provide further guidance for health practitioners and health and care services to ensure patient requests and access rights to information are equitably addressed.

b) Initiate further enhancements to the VAD portal to improve functionality and processing time.

Recommendation 2:
Enhance community awareness of VAD and grief and bereavement supports

a) Improve awareness of VAD as a legal end of life option through enhancement of information and resources.

b) Engage with Aboriginal and Torres Strait Islander people, as well as multicultural communities, to codesign culturally appropriate end of life information, care pathways and services to support equitable access to VAD.

c) Develop targeted resources aimed at carers supporting a person seeking VAD and investigate the need for further VAD specific grief and bereavement supports.

Recommendation 3:
Support the workforce to ensure VAD is accessible, viable and sustainable

a) Monitor trends in workforce capacity to ensure the sustainability and capacity of statewide service models to meet future demand and long-term effectiveness.

b) Consider options for ensuring statewide availability of the VAD medical practitioner workforce, including hospital based and visiting medical practitioners, and specialists and GPs located in regional areas.

c) Support the psychological safety and wellbeing of the VAD workforce, including options for more consistent support, communication and improved networking across VAD practitioners.

d) Continue with the current redesign of the VAD medical practitioner training.

Recommendation 4:
Consider enhancements to the statewide service models to meet anticipated future demand

a) Improve access to and promotion of support packages to aid patients, carers and families with out-of-pocket expenses.

b) Continued enhancements that improve the efficiency of the Statewide Pharmacy Service's model should be considered.

Recommendation 5:
Advocate to the Commonwealth Government for greater federal support for VAD

a) Engage with the Commonwealth Government on matters related to the Criminal Code related to the use of carriage services for VAD services.

b) Engage with the Commonwealth Government on the specific VAD funding options.

Introduction

About the VAD review

Purpose and scope of the review

This report summarises findings from a review of the operation of the first four years of the *Voluntary Assisted Dying Act 2017* (the Act) from 19 June 2019 to 30 June 2023.[1] The review included looking at how the legislation has been implemented and is operating to enable access for Victorians seeking this end-of-life choice, as well as evaluating the systems, processes and programs that support VAD (see Appendix 1 for an overview of the operation of VAD in Victoria).

The review meets the requirements of section 116 of the Act, which stipulates that:

- The Minister must cause a review of the operation of this Act to be conducted.
- The review must be conducted in the fifth year of the operation of the Act and be a review of the first four years of operation of the Act.
- On completion, the Minister must cause a report to be tabled before each House of Parliament.

The program logic and methods for the review are in Appendix 2.

About VAD in Victoria

Overview

The Act provides a legal framework for eligible people to choose the manner and timing of their death. The Act came into effect on 19 June 2019, making Victoria the first Australian state to pass VAD legislation.[2]

Victorians who are at the end of life and who meet the eligibility criteria can request access to VAD, which involves the administration of a substance for the purpose of causing death in keeping with process set out in law. VAD must be voluntary and be initiated by the person themselves. The legislation provides a range of protections to ensure VAD is safely implemented and monitored.

The Act outlines 10 principles to guide those who are exercising a power or performing a function or duty under the Act. These principles acknowledge that every human life has equal value; a person's autonomy and culture, beliefs and values should be respected; and every person approaching end of life should receive quality care to minimise suffering and maximise quality of life.

The principles focus on the significance of supportive and open therapeutic relationships around treatment and care preferences to enable informed decision making which promote a person's preferences and values, and the need to protect those who may be subject to abuse.

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[1] The 30 June 2023 date makes the review scope slightly longer than the four years required in the Act. This date was used instead of 19 June 2023 to align with secondary data reporting that was available on a financial-year basis. Primary data collection was conducted from November 2023 to February 2024.

[2] Between 2019 and 2024, all other Australian states and territories (except the Northern Territory) enacted VAD legislation.

To be eligible for VAD a person must be aged 18 years or older and

a) be an Australian citizen or permanent resident
b) be ordinarily resident in Victoria, and at the time of making a first request, have been ordinarily resident in Victoria for at least 12 months
c) have decision-making capacity in relation to VAD
d) be diagnosed with a disease, illness or medical condition that is incurable, advanced, progressive, expected to cause death within 6 months (12 months for those with neurodegenerative conditions) and is causing suffering that cannot be relieved in a manner the person considers tolerable.

People who have lost decision-making capacity and those who have a mental illness only (without a condition that meets criterion (d) above) are not eligible for VAD.

How VAD works in Victoria

Voluntary assisted dying is an option for some people in the late stages of advanced disease. A VAD medical practitioner can prescribe a substance that will bring about their death. A person's decision to ask for voluntary assisted dying must be:

- voluntary (the person's own decision)
- consistent (the person makes three separate requests)
- fully informed (the person is well-informed about their disease, treatment and palliative care options).

There are conditions and an application process. People who meet the conditions and follow the process can access the substance.

There are several steps a person needs to take to access voluntary assisted dying (Figure 1). The process makes sure people are eligible and that they are making a consistent choice. The process takes at least ten days, however, it may take several weeks to organise appointments and collect documents.[3]

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[3] More detailed information on the process is available on the Better Health Channel and the department's website.
<https://www.betterhealth.vic.gov.au/health/servicesandsupport/voluntary-assisted-dying>
<https://www.health.vic.gov.au/voluntary-assisted-dying/community-and-consumer-information>

Figure 1: The voluntary assisted dying assessment and prescription process[4]

1. **Step 1: First request**
   Ask the doctor for help to access the voluntary assisted dying medication. If the doctor agrees with your request, they will become your 'coordinating doctor'

2. **Step 2: First assessment**
   Your coordinating doctor assesses if you are eligible for voluntary assisted dying

3. **Step 3: Consulting assessment**
   Another doctor (called the 'consulting doctor') assess if you are eligible for voluntary assisted dying

4. **Step 4: Consider who you may want to choose as a contact person**
   Consider who may be suitable and willing to return unused voluntary assisted dying medication to the Voluntary Assisted Dying Statewide Pharmacy Service, if you die before taking the medication or decide not to take it

5. **Step 5: Written Declaration**
   Sign a form requesting voluntary assisted dying

6. **Step 6: Final request**
   At least 9 days (including weekends) after the day of your first request, ask your coordinating doctor again for help to access voluntary assisted dying medication

7. **Step 7: Complete the Contact Person Appointment Form**
   You and your contact person complete the Contact Person Appointment Form

Steps 5 to 7 can be done in the same doctor's appointment if the appointment is **at least 9 days after the day of your first request, and on a different day to your consulting assessment**

8. **Step 8: Doctor applies for permit to prescribe voluntary assisted dying medication**
   Your coordinating doctor will apply for a permit to prescribe the medication.
   The permit will allow either self-administration (you taken the medication yourself) or practitioner-administration (the doctor administers you the medication)

9. **Step 9: Receive access to the medication**
   Your coordinating doctor will write a prescription for the medication

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Step 9(a): If you are self-administering, decide if you want to fill the prescription. If so, pick up the medication or have it delivered from the Voluntary Assisted Dying Statewide Pharmacy Service and store the medication safely at home.

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Step 9(b): If your coordinating doctor is administering the medication to you (practitioner-administered), they will pick up the medication and store it for you.

Source: Department of Health Information for people considering voluntary assisted dying
<https://www.health.vic.gov.au/voluntary-assisted-dying/guide-for-people-considering-voluntary-assisted-dying>

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[4] 'Doctor' means 'medical practitioner'.

A range of functions enable operation of the Act. These are:

a) **the VAD Review Board (VADRB)**, which monitors the operation of the Act. Its responsibilities include promoting and ensuring compliance with the Act, reporting to parliament, referring any potential issues or breaches to appropriate authorities, collecting data about VAD, and providing information to the community. The VADRB does not provide VAD assessments or grant permits.

b) **the Department of Health (the department)**, which delivers:
   - **operational support**, including determining applications for a permit, data collection, and supporting the operation of the portal.[5] This includes supporting medical practitioners to access, complete and submit all legislated forms, conducting compliance checks of submitted documentation and managing the approval process to permit.
   - **policy development**, which involves providing advice to government, developing resources, monitoring emerging issues, and undertaking research and data analysis.
   - **community information**, which involves developing resources for people seeking VAD, their families and carers, resources for health practitioners and care settings, maintaining the department's website information, and responding to enquiries and correspondence.
   - **commissioning and performance monitoring** of the Statewide Care Navigator Service, the Statewide Pharmacy Service, and the VAD medical practitioner Community of Practice.[6]
   - **VAD medical practitioner training** which provides a detailed overview of Victoria's VAD legal framework. Under the Act, medical practitioners must complete the training to be eligible to provide VAD services in Victoria. Core training was initially developed and administered by the Queensland University of Technology until June 2022, after which the department assumed this role.[7]

c) **the Statewide Care Navigator Service**, which provides a point of contact for the community, health practitioners, and health and care services across Victoria seeking information about or support with accessing VAD. The service is based at the Peter MacCallum Cancer Centre and integrated into five regional health services.

d) **the Statewide Pharmacy Service**, located at Alfred Health, is responsible for importing, storing, preparing and dispensing VAD substances. The service provides support and advice to coordinating medical practitioners about prescribing VAD substances. They also provide support and information to people accessing VAD, their families and carers, and health care services.

e) **the VAD Medical Practitioner Community of Practice**, a platform for VAD medical practitioners to connect, discuss questions or matters of concern, establish peer connections, enable de-identified case profile discussion, and facilitate access to key resources. The Western Victoria Primary Health Network is currently funded to deliver this service.

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[5] VAD operations and the secretariat support of the VADRB were located within Safer Care Victoria during the period of the review. In early 2024, these functions moved into the department.

[6] The recently revised Victorian Health Services Performance Monitoring Framework outlines how the department oversees the performance of health services.

[7] This training was available from April 2019 and updated July 2021. It was evaluated by the CERE in 2023.

The medical practitioners who assess a person seeking to access voluntary assisted dying must have completed the mandatory VAD online training.[8] The training is about the voluntary assisted dying application process. Each medical practitioner must:

- make sure that the person seeking to access VAD is fully informed about their illness or disease, and their treatment and palliative care options
- make sure that voluntary assisted dying is the person's own choice
- let the person know that they can change their mind about accessing voluntary assisted dying at any time.

Health and care services can decide whether or how they will support access to voluntary assisted dying, depending on whether:

- they have staff with appropriate skills and expertise
- they have the capacity to support the process
- supporting access to voluntary assisted dying aligns with the values of the service.

Specific VAD coordinator roles have been created by some health services in metropolitan and regional areas to provide information and support to their patients.

Health services should have patient-centred policies and processes for managing requests for voluntary assisted dying. All staff should be aware of and be able to access information about the health service's position on voluntary assisted dying. A patient who asks for information about, or access to, voluntary assisted dying should be provided with information and support. A health service or practitioner should tell the patient as soon as possible if they will not support access to VAD and refer them to another health service, medical practitioner or the Statewide Care Navigator Service for assistance. They should not obstruct or unnecessarily delay a patient's access to voluntary assisted dying.

VAD in other jurisdictions

Victoria was the first state in Australia to legalise VAD in November 2017. However, similar legislation is now in operation, or soon will be, in all jurisdictions across Australia except for the Northern Territory.

In Australia, the broad model of VAD includes eligibility requirements that require a person to be aged 18 or over and to be terminally ill and approaching end of life. There are consistent themes across each jurisdiction regarding the need to be assessed as eligible by two medical practitioners (or one medical practitioner and one nurse practitioner in the ACT), to make at least three separate requests for VAD, including a written request, and to have decision-making capacity throughout the process.

All Australian jurisdictions with VAD legislation have mandatory training for VAD medical practitioners, and specialist pharmacy, care navigation and support services. Each jurisdiction also has an oversight body, which is intended to ensure that every case adheres to the law.

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[8] The VAD mandatory online training is hosted by the department <https://vicvadlearninghub.com/>

Key findings

In general, VAD is operating as intended, providing a safe and compassionate end of life choice to eligible Victorians. Evidence has emerged about things that are working well, and where there are opportunities for improvement, which has led to five recommendations.

VAD is generally accessible as an end-of-life choice

VAD has been effectively delivered to people in Victoria. Between 2019 and 2023, 1,527 permits were issued for people who were eligible to access VAD (Figure 2).[9] Of these, 912 individuals (60%) chose to use the VAD substance, while another 400 individuals had the substance dispensed but did not use it.[10] The number of permits issued each year has increased over time, effectively doubling between 2019–20 (237 permits) and 2022–23 (485 permits). Demand for VAD is anticipated to increase as community awareness of VAD increases, with modelling projecting that there will be about 700 applicants per year by 2028.

The rate of Victorian deaths that involved taking the VAD substance have gradually risen each year, from 4.4 VAD deaths per 1,000 deaths in 2020 to 6.1 VAD deaths per 1,000 deaths in 2022 (Table 1). The increase occurred across various demographics examined. The rate of VAD deaths was consistently higher in regional and rural Victoria compared with metropolitan areas. Portal data from VAD applicants in the first four years showed that 88% of rural and regional applicants and 83% of metropolitan applicants were accessing palliative care when they first requested VAD, suggesting that the higher rate of VAD uptake in regional and rural Victoria does not reflect difficulties accessing palliative care, and that VAD is appropriately being accessed alongside palliative care, rather than as an alternative to palliative care. Further discussion of how access to VAD can be made more equitable is provided later in this report.

Table 1: Rate of VAD deaths per 1,000 Victorian deaths by selected demographic characteristics, 2020–2022

VAD deaths per 1,000 deaths	2020	2021	2022
All deaths	4.4	5.5	6.1
Male deaths	4.1	5.5	6.4
Female deaths	4.8	5.6	5.9
Aboriginal and Torres Strait Islander deaths	Not available	Not available	3.0
Metropolitan deaths	4.4	5.2	5.6
Regional and Rural deaths	4.5	6.3	7.3
Cancer deaths	10.8	14.7	17.9

Source: VAD portal; Australian Bureau of Statistics[11,12]

Interpretation: rates show the number of VAD deaths for a specific characteristic per 1,000 deaths for that characteristic.

Note: The ABS data uses a marginally larger regional/rural area than the VAD portal data meaning that the regional/rural rates may be an underestimate and the metro rates an overestimate. The trend for higher rates of regional/rural deaths associated with VAD remain, regardless of this limitation. Deaths among Victorian Aboriginal communities (not VAD deaths) was only available for 2022.

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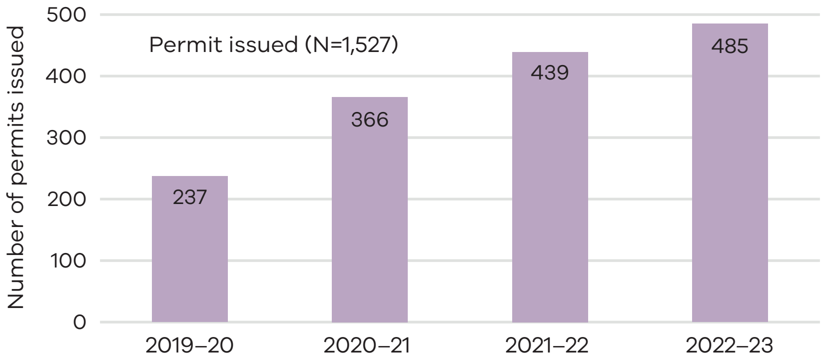
[9] The number of permits issued is not the same as the number of people issued a permit. There are circumstances where one applicant may be issued with two permits, including if they changed from self-administration to practitioner administration. Withdrawn cases can include: the applicant dying before the substance was dispensed; the applicant withdrawing their application at any point during the request, application or permit approval phase, or where duplicate applications were created in error for a single applicant.

[10] Unused substance in the community is monitored. The nominated contact person is legally obliged to return any unused substance to the Statewide Pharmacy Service within 14 days of the permit holder's death.

[11] Australian Bureau of Statistics. Deaths, Australia: Statistics about deaths and mortality rates for Australia, states and territories, and sub-state regions. 2023.

[12] Australian Bureau of Statistics. Causes of Death, Australia: Statistics on the number of deaths, by sex, selected age groups, and cause of death classified to the International Classification of Diseases (ICD). 2023.

Figure 2: Number of VAD permits issued in Victoria, 2019–20 to 2022–23



Source: VADRB 2022–23 annual report.

However, access has not been equitable and barriers remain. In particular, there was low awareness of VAD among people with lower education, those with poor health literacy, and among people who speak languages other than English. Further information about the characteristics of VAD applicants appears later in this report and in Appendix 3.

Most people seeking VAD and their families expressed appreciation for the Act, highlighting that it provides relief, autonomy, and empowerment in end-of-life decisions. VAD is a safe and compassionate end of life choice available to eligible Victorians. By integrating VAD as a choice within the broader health care system, individuals can benefit from a holistic approach to end-of-life care that aligns with their values and preferences.

In addition, the VAD workforce appreciate VAD being available as an option in the context of end-of-life care. One palliative care physician highlighted that, even with the best palliative care clinicians and excellent medication options, there can still be suffering at the end of life.

> *My mum got to choose when she was ready to opt out …The day that she got delivered the medication, I said, "how do you feel?" and she said, "relieved". She felt empowered just knowing that she didn't have to use it, but if things got too unbearable, she could.*
>
> (Family member of person who used VAD)

Timeliness of the VAD application process is improving

The median time taken to access VAD has decreased since the introduction of VAD in Victoria. The median time to obtain a permit has decreased from 28 days to 21 days (Figure 3), noting that for a small number of people it can take a long time to go through the VAD assessment process. The VAD application process is a comprehensive process with many steps. Evidence from stakeholder consultation suggests that some people seeking VAD could not gain access or experienced it as a slow and difficult process. Some people seeking VAD, their families and medical practitioners reported that delays in access for someone wanting to end their suffering were burdensome and distressing.

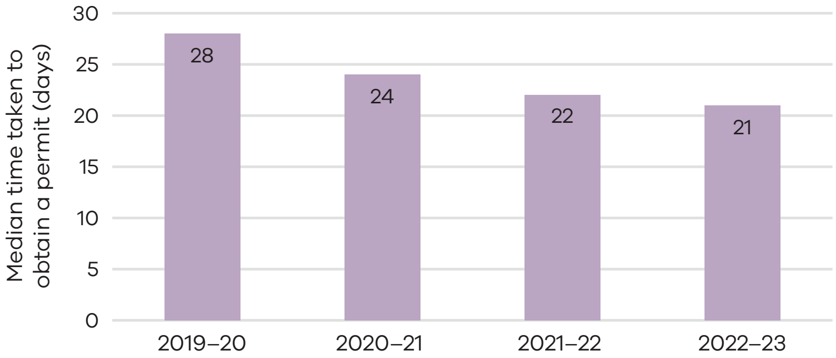
The Voluntary Assisted Dying Regulations (2018) require that the Secretary, Department of Health, determine the outcome of a permit application within three business days. Of all applications, 99% were determined within this timeframe, with 95% approved within two business days.

Since commencement of the Act, 765 applications (35% of all applications) were withdrawn before the substance was dispensed.[14] This includes 579 (26% of all applications) who died and 56 (3% of all applications) who were either too unwell or lost decision-making capacity before they could access VAD. The percentage of withdrawn applications has remained relatively stable over time. Currently, there is no way to assess the number of people who try to access VAD but are unable to commence their application.

Applications being received very close to death were evident, with 16% of all applications from people who died less than two weeks after the request that led to their first assessment. The State Coroner provided four case studies to the review where, in the investigating coroner's opinion, the deceased appeared to meet eligibility for VAD and began engagement with the VAD process but ultimately suicided.[15]

During the period being reviewed, the VAD Secretariat implemented enhancements to improve efficiencies and functionality, such as the introduction of a compliance officer, and improvements to the VAD portal. VAD medical practitioner feedback suggests that more enhancements to the VAD portal could deliver improved efficiency and further reduce delays in the application process.

Figure 3: Median time (days) taken to obtain a permit from first request, 2019–20 to 2022–23



Source: VAD portal data

Note: This data also includes 12 days of the 2018–19 financial year because voluntary assisted dying became available on 19 June 2019.[13]

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[13] Voluntary Assisted Dying Regulations 2018, s 3.

[14] VADRB annual report 2022–23. See also Appendix 3, Table 3.1.

[15] Data provided pertains to cases identified by the Coroner's Court of Victoria as being relevant to the scope of this review; it does not include open cases and should not be interpreted as describing the entire relevant population of Victorian deaths.

Families valued the compassionate care provided

Feedback from families consistently highlighted that VAD medical practitioners, care navigators, and pharmacists deliver caring, respectful, and person-centred services, balancing empathy with practicality, and often involved medical practitioners working outside normal business hours to ensure timely access to VAD. This positive feedback was provided in consultations, submissions, and survey responses (see Appendix 3).

Seventy-seven percent of people seeking VAD and 93% of families/contacts reported that the process was compassionate. Qualitative data from family interviews and survey responses suggested that VAD practitioners were the primary drivers behind compassionate experiences of the VAD process, as they often devoted countless hours providing support to patients and their families.

Care navigators were also particularly valued for their role in supporting both people seeking VAD and medical practitioners. They assist in finding VAD-trained medical practitioners, facilitating difficult conversations, and supporting families with death planning and bereavement. Many family members reported that care navigators provided valuable support and information before and after a VAD death.

Currently the VAD portal does not record whether a patient has had contact with the care navigator service. As such, it is difficult to estimate how many people who undertake VAD assessment access care navigator support or are aware of the service availability. Data linkage between care navigator and portal data may assist in better understanding how the care navigator service operates.

Survey responses from VAD applicants and their families indicated high satisfaction with key VAD services, including medical practitioners (91%; Figure 4), care navigators (which could include the Statewide Care Navigator Service and/or hospital-based VAD navigators) (76%), and pharmacy services (85%).

> *The application was as good as it possibly could be. It was exceptionally streamlined and handled compassionately and efficiently, facilitated by the dedicated doctor and administrator at the hospital where my partner was a patient.*
>
> (Family member /contact person)

Fictionalised vignette

Even before my dad was sick, he always said that he wanted to live his life and death on his terms. Choice was important to him, particularly after he saw a loved one suffer through illness. So, when he was diagnosed with cancer, just knowing that he had the option to access VAD was huge for him, even if he never ended up needing to use it. The navigators and our doctors were all incredibly helpful for us, we couldn't have asked for more. They were so professional and compassionate, despite doing this job which must be so hard. When the time came for dad to use VAD, he was able to take control in peace, with the support of his family. It was a relief for him and for us, and I am so grateful for that.

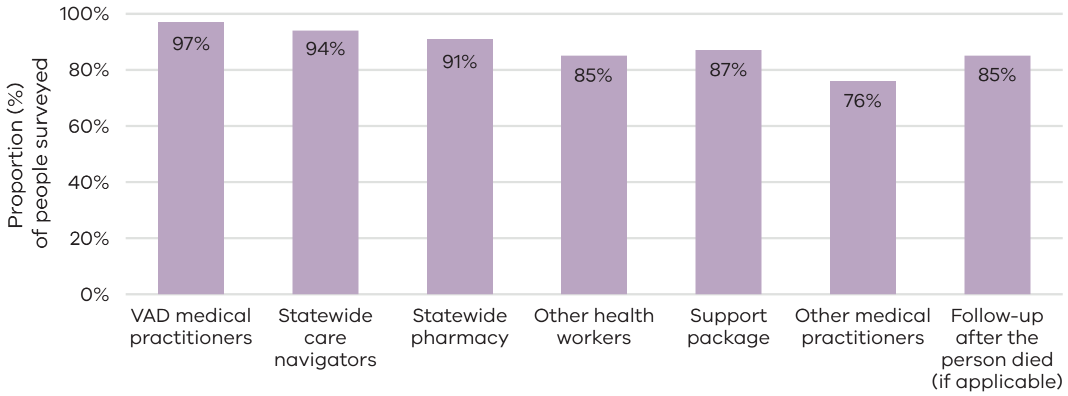
* Fictional account based on information provided to the review

The Statewide Pharmacy Service was also described as caring and compassionate:

> *Excellent. Excellent … the most beautiful, compassionate women and really quite efficient … anyone that is able to actually explain the process, tell you what you need to do, do all of that, leave the room, and you can remember it all and do it, must be doing a really good job.*
>
> (Daughter of a woman who took a VAD substance)

The commitment of VAD medical practitioners and the support from hospital coordinators help facilitate VAD access within health care services. Moreover, volunteers contribute by providing essential witnessing services.

Figure 4: Proportion (%) of people seeking VAD and families/contacts who were somewhat to very much satisfied with support (n=99)



Source: Engage Victoria survey

Note: Valid percentages are shown (excluding missing data)

Health and care service providers could benefit from additional policy guidance

The department is responsible for providing policy guidance to health practitioners and to health and care services regarding VAD. The review identified that clearer guidance could support improved access.

Clarification is needed on providing information and responding to requests for VAD access

There was evidence from different stakeholder groups that organisations that did not support VAD could still meet the requirements of the Act, providing transparency in their approach while still respecting their patient's choices and not preventing access to VAD. However, this was not consistently the experience of people accessing VAD. Many stakeholders reported that some applicants were purposefully obstructed from accessing VAD.

Departmental guidelines for health services, aged care services and health practitioners are not sufficiently clear about minimum expectations or obligations for practitioners and organisations.

A third of interviews with family members and a tenth of written submissions from people seeking VAD and their families described their experience of access barriers due to obstruction from organisations and individual practitioners. This was often, but not always, related to religious beliefs and organisational policies.

Family members reported declines in the level of support from some palliative care services once VAD was mentioned. Where palliative care services did not support VAD, families reported that open discussions about palliative care treatment and options became limited and holistic and continuous care restricted. Some families reported patients had felt forced to choose between VAD and palliative care, a contravention of the principles of the Act.

One family reported the experience of being required to put in writing that their parent would not take the substance in their residential aged care facility. Another individual who was admitted to hospital a few days prior to scheduled delivery of the VAD substance, and due to the hospital's religious affiliation, was subsequently prevented by the hospital from being able to receive the substance. While these two examples are single events, they may provide insight into a broader issue.

Fictionalised vignette

The checks and balances are obviously critically important, but there could be better supports and structures to make the whole process faster and simpler – to make sure our patients are protected without delays. I have heard colleagues talk about the fear of getting a fine or having their registration revoked. There is an assumption that we aren't allowed to talk about it unless a patient says the words "voluntary assisted dying", which isn't true, but that fear makes some of us overly cautious. With better guidance and systems, it would be so much easier to confidently have these conversations and focus our energy on supporting our patients through this really important time in their lives.

* Fictional account based on information provided to the review

More information is needed for medical practitioners who conscientiously object to VAD

Medical practitioners who conscientiously object or do not want to support VAD have a right not to provide it. However, clearer communication about their obligation to respond to a request (under section 13(1) of the Act) and accountability in relation to the provision of timely responses to requests for information or VAD access is necessary. The review heard a barrier to VAD access for many people was finding a medical practitioner who would accept or at least respond to a first request.

Obstruction or inaction from medical or health practitioners is inconsistent with person-centred care and the Act's principle that individuals should be encouraged to openly discuss death and dying and an individual's preferences and values should be encouraged and promoted.[16] It is also inconsistent with the codes of conduct for medical practitioners and nurses[17] and with the Department of Health's expectations of government funded services.

To address these access challenges, information, guidance and sector engagement should more clearly outline minimum expectations for health practitioners and services when responding to requests for VAD.

Fictionalised vignette

The impact of not responding to requests is illustrated by the experience of an individual who requested VAD from multiple medical practitioners across 3 health and palliative care services. Their requests were never responded to, nor were they or their family provided with information about how to access the VAD care navigators. The individual died before locating a VAD medical practitioner, leaving family feeling disappointed and frustrated that services had failed to meet the individuals wishes at the end of their life.

* Fictional account based on information provided to the review

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[16] *Voluntary Assisted Dying Act 2017,* ss 5(1)(f).

[17] Ahpra Medical Board, 2020; Ahpra Nursing and Midwifery Board of Australia, 2022

The VAD measures support the safe operation of the Act

The Act has 68 safeguards to ensure robust oversight and thorough monitoring mechanisms are in place throughout all steps of the VAD process. As a result of these legal and system controls, while groundbreaking at the time of its commencement, the Victorian model of VAD is now widely regarded as a conservative model in Australia with a strong focus on safety. Findings from this review further support this view, indicating that VAD in Victoria has been safe for patients, families and the community at large.

The VAD system has received positive feedback from within the medical community. Most health workforce survey respondents agreed that VAD is safe, with 94% of VAD registered medical practitioners and 84% of other health practitioners sharing this view.[18] Ninety-two per cent of people seeking VAD and 95% of families/contacts reported that they felt the VAD process to be safe.

Records show compliance with the Act

The VADRB reports that there has been high compliance with the Act, with 99.3% compliance for all completed applications. Only 14 cases did not comply with the Act (0.7%), and one case (0.05%) was referred to another agency – the Australian Health Practitioners Regulation Agency (Ahpra). The case referred to Ahpra involved non-compliance with the VAD permit application process for which the medical practitioner was fined.

Half of the cases of non-compliance involved the contact person not returning the substance within 15 days of the person's death as required in the Act. These cases were attributed to procedural delays and delays due to the fact that contacts are usually a close relative grieving the person and not able to manage the return of the substance within the specified time. There have been no reported instances of mishandling or misuse of the VAD substance.

During the conduct of the review there were no reported cases of a VAD substance failing to result in death. Surveys of contact people, collected since 2021, however, show a very small number of reports of issues with substance administration such as difficulty swallowing, having a negative reaction to the substance (pain, burning feeling, convulsions and vomiting) and the substance leading the person to fall asleep quickly but taking a longer than anticipated time to die. Further guidance and resources may help mitigate potential safety risks and ensure a smoother end-of-life experience for all involved, such as reviewing the patient information booklet, in consultation with families and practitioners involved in the delivery of VAD.

The Voluntary Assisted Dying Review Board has functioned effectively

The VADRB reviews all assessments and forms retrospectively. They do not grant or refuse applications for VAD.

Overall, the monitoring and oversight mechanisms of the VADRB are functioning effectively, and meeting obligations (see Appendix 4). The VADRB reports of operation were tabled in parliament and published on the Safer Care Victoria website for the first four years of operation of the Act. Future reports will be published on the Department of Health website. These reports illustrate that the VADRB has performed its functions.

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[18] Survey data, Engage Victoria 2024. See Appendix 3, Table 3.10.

Feedback from VADRB members indicates that their role during the first few years of the operation of the Act focused on implementation and monitoring. Now that the Act is embedded, VADRB members feel that their focus could shift towards promoting continuous improvement. Adequate visibility of information about complaints and other information about service quality and experience would assist the VADRB to further contribute to continuous improvement efforts.

Recommendation 1:
Increase the provision of sector guidance and build on approaches to continuous improvement

a) Provide further guidance for health practitioners and health and care services to ensure patient requests and access rights to information are equitably addressed.
b) Initiate further enhancements to the VAD portal to improve functionality and processing time.

Further public facing information may improve awareness about VAD

Effective communication and accessible information are essential for improving awareness of VAD to ensure people can make a fully informed end of life choice. Feedback from all stakeholder groups through evaluation surveys and interviews reported a low level of community awareness about VAD.

While community awareness is crucial, raising awareness among health practitioners is also important because they deal directly with patients and can respond to requests for information or facilitate access. Low levels of awareness and lack of clear guidance can result in delays for patients initiating the VAD application process and may delay the granting of a permit to access the VAD substance.

Culturally appropriate information and engagement may enhance access for First Nations

Findings from the First Nations consultation report completed as part of the review (see Appendix 5) identified a lack of culturally appropriate resources and information as a key barrier to effective implementation and access to VAD in Aboriginal communities.

There is limited tailored information and support available for Aboriginal and Torres Strait Islander people which reduces their ability to make informed choices about VAD. This suggests a potential gap in communication and understanding, leading to confusion or exclusion. To address this, First Nations stakeholders emphasised the need for improved communication, education, resources and advocacy to empower individuals in making informed decisions about their end-of-life care.

Key considerations relate to cultural needs and norms regarding death and dying, stigma associated with choices such as VAD, and use of appropriate and familiar language. Some Aboriginal stakeholders indicated that they are only familiar with the term 'euthanasia', not 'Voluntary Assisted Dying'. There was also recognition of the impacts of historical and ongoing trauma and disempowerment on First Nations people about access to healthcare more broadly.

Raising community awareness among Aboriginal communities needs to be linked with creating an environment where VAD-related discussions can occur openly, with access to appropriate information, guidance and support that respects cultural values, autonomy and self-determination. The First Nations consultation also highlighted that family and community play a vital role in VAD related decisions, emphasising the need to extend information beyond patients to include their families and close community members. This underscores the need for VAD-related information to be culturally appropriate and sensitive, to promote equity in information dissemination and informed decision making among Aboriginal communities.

Culturally appropriate information and engagement may enhance access for people from multicultural communities

Feedback to this review also demonstrated low awareness of VAD among multicultural communities. This is consistent with independent research conducted in Victoria[19] that found that most people from multicultural communities are unaware of the existence of VAD as a legal option. Less than 4% of permit holders spoke a language other than English at home, compared to almost 28% of the Victorian population who reported speaking a language other than English at home according to the 2021 Census.

Case study

Specific efforts to engage multicultural communities led to increased VAD-related referrals. For instance, internal stakeholders heard a metropolitan hospital noted a rise in referrals after discussing VAD through a presentation at the Chinese Women's Society, which is understood to have resulted in greater awareness and referrals among Chinese patients.

Information about VAD is published on the Department of Health website in 17 community languages. While this is a step at improving awareness of VAD among multicultural communities, overall access to the translated information is low. From 17 June 2019 to 17 June 2024, these pages had been accessed by 260 Victorian users. Data for each language page was available from 3 October 2022 to 17 June 2024 and shows low usage with only Chinese (62 views), Arabic (20 views) and Amharic (19 views) language pages having more than 10 views.[20] Other forms of engagement with multicultural communities could increase awareness of VAD and improve the usability of the translated resources.

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[19] White BP, Jeanneret R, Willmott L. Barriers to connecting with the voluntary assisted dying system in Victoria, Australia: A qualitative mixed method study. Health Expectations. 2023.

[20] Data supplied by the Digital Content team, Department of Health.

There is a need for increased VAD-specific grief and bereavement resources and supports

The review identified the need for increased grief and bereavement support for VAD applicants, their families and carers. It is important for the person seeking VAD prior to their death, and for their families and carers before and following the person's death.

Many families members and carers did not feel prepared and supported before, during and after the VAD process. This was even more evident for those families and carers where the person who had sought VAD could not access it or died before they could access it. Families and carers often noted they struggled to find time or energy to read information, and suggested that preparatory videos (for example, featuring family members who have a lived experience of a VAD death), would help them understand what to expect and plan for the supports or resources they think will help them.

Recommendation 2:
Enhance community awareness of VAD and grief and bereavement supports

a) Improve awareness of VAD as a legal end of life option through enhancement of information and resources.

b) Engage with Aboriginal and Torres Strait Islander people, as well as multicultural communities, to codesign culturally appropriate end of life information, care pathways and services to support equitable access to VAD.

c) Develop targeted resources aimed at carers supporting a person seeking VAD and investigate the need for further VAD specific grief and bereavement supports.

Medical practitioner supply and distribution is challenged

The VAD medical workforce is small and unevenly distributed across the state. Some stakeholders suggested this is potentially resulting in medical practitioner burnout, and further constraining the small workforce. Analysis of VAD portal data from 2019 to 2023 showed that after an initial period of growth in medical practitioner registrations on the VAD portal, the number of medical practitioners registering annually has plateaued at an average of 59 over the past three financial years.

The VAD portal data also showed that a small number of medical practitioners are responsible for the bulk of VAD activities. One-fifth of medical practitioners registered in the VAD portal had carried out over 80% of all completed assessments. A third had completed a single or no assessments.

In addition to being dependent on a small number of people, the VAD medical workforce is also unevenly distributed geographically and by speciality. General Practitioners (GPs) who are registered on the VAD portal are more widely available than other medical practitioners, while other specialists who are registered on the VAD portal are highly concentrated in metropolitan Melbourne. This supports the feedback received from families and workforce about the difficulties people living in regional areas face in finding VAD-registered practitioners, particularly non-GP specialists. Yet despite this, proportionately more rural and regional Victorians have accessed VAD.

Accessing a neurologist for VAD assessments was frequently cited as a barrier to access throughout stakeholder consultations. Of 199 patients with neurodegenerative conditions who sought VAD in the first four years, 64 lived in rural areas. However, only seven assessments were completed by neurologists registered outside of Melbourne, indicating that most rural patients travelled to Melbourne for their assessment, or that a neurologist travelled to them.

Medical practitioner support and retention could be improved

Even though this could not be quantified using data available for this review, retention of VAD medical practitioners was identified as an important operational issue by various stakeholders. Regional areas were reported to be especially vulnerable to workforce attrition, impacting VAD accessibility.

VAD medical practitioners and sector stakeholders raised concerns about the sufficiency of financial remuneration for VAD services. Other factors inherent to the operation of the Act are disincentives for medical practitioners to become or continue to be involved with VAD. Stakeholders reported fear of legal repercussions, insufficient time to manage VAD care alongside a normal clinical load (often resulting in VAD assessment being delivered out of hours), the complexity of the VAD application process, and the role of the coordinating VAD medical practitioner being administratively cumbersome.

Increased support is required to maintain wellbeing, such as enhanced peer support and opportunities for collaboration, and to offset the demands of the workload and the challenging nature of the work. Support as an enabler of medical practitioner retention will also help to ensure timely VAD access for people.

The VAD medical practitioner Community of Practice is valued

The VAD medical practitioner Community of Practice is a highly valued, confidential and important peer support service for medical practitioners. The number of VAD trained medical practitioner participants in the VAD medical practitioner Community of Practice has increased from 17 members in April 2020 to 63 in May 2023. As of May 2023, 64% of participants were GPs and 36% were other specialists.

Surveys conducted by the VAD medical practitioner Community of Practice reported high levels of satisfaction among participants. Consultations confirmed that the Community of Practice provided an important advisory and support role, particularly for new and more isolated VAD medical practitioners. However, some medical practitioners suggest that involvement in their dedicated Community of Practice should be an automatic process at the time of VAD registration, with the option for opting out. The current opt-in requirement means some medical practitioners may not realise it is available.

Building on the existing training model may improve medical practitioner uptake and readiness

Of medical practitioners who contributed to the review by survey, 78% indicated they were satisfied or very satisfied with the mandatory medical practitioner training.[21]

Ensuring workforce sustainability and buy-in will continue to be important for the successful operation of VAD. Part of this is to ensure VAD training, education, and information is expanded to reach a broader segment of the workforce. Additionally, VAD medical practitioner training and information resources should be expanded to cover a range of additional topics. Key areas to consider for medical practitioner training and information resources include:

1. improving the balance between legal and clinical aspects of VAD implementation, and understanding the ethical issues involved.
2. training on documentation of diagnosis and prognosis.
3. providing appropriate documentation on use of the VAD portal.
4. understanding the role of medical practitioners in providing grief and bereavement support to families.

These changes may support increased uptake, suitability, and readiness among medical practitioners.

Recommendation 3:
Support the workforce to ensure VAD is accessible, viable and sustainable

a) Monitor trends in workforce capacity to ensure the sustainability and capacity of statewide service models to meet future demand and long-term effectiveness.

b) Consider options for ensuring statewide availability of the VAD medical practitioner workforce, including hospital based and visiting medical practitioners, and specialists and GPs located in regional areas.

c) Support the psychological safety and wellbeing of the VAD workforce, including options for more consistent support, communication and improved networking across VAD practitioners.

d) Continue with the current redesign of the VAD medical practitioner training.

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[21] Survey data, Engage Victoria 2024. See Appendix 3, Table 3.11.

The Statewide Care Navigator Service provides extensive support

The Statewide Care Navigator Service provides education and support to medical practitioners and the broader health and aged care sectors about VAD. It also facilitates connections between people seeking to access VAD and medical practitioners who have completed VAD training. The Statewide Care Navigator Service also administers support packages in accordance with departmental guidelines. Support packages are typically used to cover out-of-pocket medical practitioner consultation fees and/or travel costs associated with appointments required as part of the VAD application process. The service was expanded regionally in 2019–20 as a hub and spoke model.

Care navigator annual reporting showed that in 2022–23 almost 65% of medical practitioners who completed VAD training did so via care navigator training days. Families and the VAD workforce described the navigator service as a critical part of the operation of, and experience of, the VAD process. The service may also boost the efficiency of other parts of the system – for example, reducing the administrative burden on medical practitioners by helping families find the paperwork they need to apply for a permit.

In 2023, the Statewide Care Navigator Service enhanced its data collection mechanisms to improve program and demand monitoring. Through the review, the navigator service reported service demand pressures.

Between 2020–21 and 2022–23, the Statewide Care Navigator Service had contact with almost 3,000 individuals (60% patients or families; 40% health practitioners) and ran 565 workshops, information sessions and webinars for health and aged care services and practitioners.

> *All regional navigators work far in excess of their allocated 0.4 EFT. The role requires a very high level of diverse skills and VAD-specific expertise and all struggle to deliver and service development (for example, capacity building, doctor support and growth) beyond direct patient care within their allocated EFT.*
>
> (Organisational written submission)

The Statewide Pharmacy Service is responsive and could continue to evolve

The Statewide Pharmacy Service is licensed to import, store and dispense the VAD substance and provides information and support to medical practitioners.

The majority of family participants who interacted with the Statewide Pharmacy Service provided positive reports about the support and information provided by the service. Key functions included a timely response, clear instructions, demonstrations about how to mix and administer the VAD substance and a patient information booklet with clear instructions and information.[22]

Since inception, the Statewide Pharmacy Service has undergone several operational changes that have improved the service's efficiency and responsiveness including:

- rostering to enable patient visits on public holidays.
- streamlined delivery of practitioner-administration kits to experienced practitioners.
- an extended shelf-life for practitioner-administration kits.
- funding of an after-hours telephone service for VAD medical practitioners.

In interviews and written submissions to the review, it was suggested that there may be further opportunities for reducing duplication and/or enhancing the service model delivery of the pharmacy service. Stakeholders recommend reviewing dispensing practices, including whether it remains necessary to have two pharmacists visiting patients for dispensing, and two pharmacists delivering practitioner-administration kits, especially in the case of experienced medical practitioners.

It was also suggested that a hub-and-spoke model for the Statewide Pharmacy Service be considered, similar to the Statewide Navigator Service.

Recommendation 4:
Consider enhancements to the statewide service models to meet anticipated future demand

a) Improve access to and promotion of support packages to aid patients, carers and families with out-of-pocket expenses.

b) Continued enhancements that improve the efficiency of the Statewide Pharmacy Service's model should be considered.

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[22] Each year, substance delivery has occurred within two business days for at least 96% of requests. See Appendix 4, Table 4.3.

The restriction on the use of telehealth is a barrier to VAD access

Currently, under s 474.29A of the Criminal Code, it is an offence to use a carriage service (such as telephone, videoconference, email or other forms of electronic communication) to provide or share information regarding suicide. In the recent Federal Court ruling in Carr v Attorney-General [2023], the Federal Court found VAD falls under the definition of suicide for the purposes of the Criminal Code. As such, department guidance advises avoiding the use of carriage services for VAD. This means all discussions about VAD should not take place using a carriage service, resulting in reliance on face-to-face conversations. This has disproportionate impacts on people seeking to access VAD who live in regional or rural areas, or who have mobility challenges.

Inadequate remuneration for medical practitioners presents a barrier to the provision of VAD services

VAD medical practitioners and sector stakeholders raised concerns about the sufficiency of financial remuneration for VAD services. Some stakeholders raised as a possible solution that Medicare reforms which enable wider use of the Medicare Benefits Schedule to support people to access VAD services may address this barrier.

Recommendation 5:
Advocate to the Commonwealth Government for greater federal support for VAD

a) Engage with the Commonwealth Government on matter related to the Criminal Code related to the use of carriage services for VAD services.

b) Engage with the Commonwealth Government on the specific VAD funding options.

Appendices

Appendix 1: Overview of Voluntary Assisted Dying (VAD) in Victoria

Establishment of the Voluntary Assisted Dying Act and VAD operation

In June 2016 the *Inquiry into End-of-Life Choices* recommended legalising voluntary assisted dying (VAD) in Victoria.[23] Following consultation led by the Ministerial Advisory Panel on Voluntary Assisted Dying, the Voluntary Assisted Dying Bill was subsequently passed by Parliament in November 2017, establishing the *Voluntary Assisted Dying Act 2017*. Over an 18-month implementation period (February 2018 to August 2019) key projects were conducted to establish core bodies and elements of VAD operation (outlined in Table 1.1) and to ensure sector readiness for the start of the Act, which came into force on 19 June 2019.

Table 1.1: Core bodies and elements enabling VAD operation

Body/element	Responsibilities	Administered by
VAD Review Board	The VAD Review Board (VADRB) oversees the safe operation of the Act. As outlined in s 93 of the Act, its functions and powers include: • monitoring VAD activity • promoting and ensuring compliance the Act • reporting to parliament • referring any issues or breaches to the appropriate authorities • promoting continuous improvement • collecting data about VAD and providing information to the community while maintaining people's privacy. The VADRB reviews all assessments and forms retrospectively; they do not grant or refuse applications for VAD. Terms of reference govern the VADRB and were updated in April 2023.	Safer Care Victoria (to Jan 2024) Department of Health (from Feb 2024)
VAD secretariat	The VAD secretariat supports the operation of the VADRB including: • providing secretariat support for VADRB proceedings and working with the VADRB to establish and maintain operational systems to support the functions of the board • managing the VAD portal • conducting administrative reviews of assessment forms submitted to the VAD portal • coordinating period reporting.	Safer Care Victoria (to Jan 2024) Department of Health (from Feb 2024)
Secretary, Department of Health	As outlined in s 49, the Secretary of the Department of Health (or their delegate) must determine an application for a VAD permit. The Secretary may also amend a permit.	Department of Health

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[23] Parliament of Victoria Legislative Council Legal and Social Issues Committee. Inquiry into end of life choices: Final Report. 2016. <https://www.parliament.vic.gov.au/get-involved/inquiries/inquiry-into-end-of-life-choices/reports>

Table 1.1: Core bodies and elements enabling VAD operation (continued)

Body/element	Responsibilities	Administered by
Department of Health on behalf of the Minister for Health	The Department of Health is responsible for monitoring performance of the VAD system, using Performance Monitoring Framework, including: • monitoring risks to the Victorian government • monitoring sustainability of the program • managing the performance of statewide services • reporting on performance to VADRB • collecting data and intelligence across the sector to inform policy improvement.	Department of Health: • Permits and Licensing team • Projects, Engagement, and Policy team.
Statewide Care Navigator Service	The Statewide Care Navigator Service provides general and individualised VAD information, education and support to the Victorian community, health practitioners and health services. The service also helps to connect patients to VAD medical practitioners, provides information and access to support packages and advice on end-of-life care services.	Peter MacCallum Cancer Centre (from Mar 2019)
Statewide Pharmacy Service	The Statewide Pharmacy Services is responsible for developing and annually updating the VAD medication protocol, supporting importation, safe storage, and dispensing of the VAD substance to those who have a VAD permit, and receiving and destroying unused medication in line with protocol.	Alfred Health
VAD medical practitioner Community of Practice	The Community of Practice (CoP) facilitate peer support among VAD medical practitioners. Funding for the CoP supports licensing the secure IT Basecamp platform to support communication, employing of administrative staff to develop and moderate the CoP and clinical input to help establish and moderate the Community of Practice.	Victorian and Tasmanian Primary Health Network Alliance (now known as Western Victorian Primary Health Network) (initially funded for five years)
VAD medical practitioner training	All medical practitioners must complete the approved online training program (developed by Queensland University of Technology) before providing VAD services.	Queensland University of Technology (to Jun 2022) Department of Health (from Jul 2022)

Accessing VAD for an individual

The VAD process begins when a person makes a request for VAD to a medical practitioner. As outlined in the Act, the practitioner must advise the person within seven days whether they will accept this request and agree to become their 'coordinating medical practitioner'. The coordinating medical practitioner, after completing the first assessment, refers to a 'consulting practitioner' for a second assessment. After the coordinating and consulting medical practitioners have each conducted an independent assessment and confirmed eligibility for VAD, the person seeking VAD must complete a written declaration witnessed by two independent people (one of whom must not be a family member) in the presence of the coordinating medical practitioner. This is then followed by a final verbal request to the coordinating practitioner and appointment of a contact person who is responsible for returning any unused substance.

VAD medical practitioners apply for a VAD permit via an online portal. Applications are reviewed by the VAD secretariat and the department's Permits and Licensing team in Regulatory Services. The departmental Secretary then determines whether to issue a self-administration permit, issue a practitioner-administration permit, or refuse to issue a permit. If the person can swallow the VAD substance, a self-administration permit will be sought. If a person cannot self-administer or digest the substance, a practitioner-administration permit will be sought. Once a permit has been issued, the coordinating medical practitioner is informed and provides a prescription for the VAD substance to the Statewide Pharmacy Service. They advise their patient, who can then contact the Statewide Pharmacy Service to deliver the substance in a locked box. Two pharmacists provide a patient information booklet that provides instructions on how to take the substance and talk through the instructions with the patient, answering any questions the patient, family, and/or contact person may have. For practitioner-administration, the pharmacists arrange delivery of the kit via courier or visit the medical practitioner in person to deliver the substance if it is the practitioner's first time completing practitioner-administration. If a person is in the process of applying for a self administered permit or has received one but subsequently loses the ability to self-administer, they must begin a new application for a practitioner-administered permit. Their coordinating practitioner must agree to undertake this role, or they will need to appoint a new coordinating practitioner. If the person has already received the VAD substance, they must return the substance before a new permit application can be submitted.

People seeking VAD can choose at any stage to withdraw from the process or not take the substance.

People seeking to access VAD must have decision-making capacity at all stages of the process.

Appendix 2: Review approach and methods

Program logic

The review approach is informed by the program logic (Figure 2.1), which articulates how VAD was intended to operate.

Figure 2.1: Program logic

Situation
Over three-quarters of Australians are supportive of VAD as a way of optimising choice, autonomy, dignity, and relief from suffering at the end of life.[1] Victoria's Voluntary Assisted Dying Act 2017 came into effect in June 2019. It provides a legal framework to allow people who are suffering and dying to choose the manner and timing of their death.

Inputs
Voluntary Assisted Dying Act 2017 State government funding, policy, Department of Health staff, Safer Care Victoria staff, and VAD Review Board Governance and funding arrangements for commissioned services Medical practitioners willing to assist Victorians who request access to VAD

Activities	Outputs
Administration of the VAD portal including quality control, online assessment forms and annual reporting	Medical practitioner registration and VAD permit applications are centrally managed
Provision of training for medical practitioners Provision of information and support for health professionals, health care settings and the community on VAD processes	Medical practitioners with the knowledge, skills, and authorisation to provide VAD services are available to assist eligible Victorians in line with the Act
VAD Review Board monitors the safe operation of the Act and retrospectively reviews VAD assessments VAD Review Board annual reporting	All VAD cases/applications retrospectively reviewed to ensure compliance Regular reports on VAD operation provided to Parliament and DH Secretary
Delivery of Care Navigator Service through hub-and-spoke model	Victorians are supported to successfully navigate VAD process
Delivery of communities of practice for medical practitioners and health professionals	Medical practitioners and health professionals with an interest in VAD are provided with ongoing peer support and information
State-wide Pharmacy Service oversees dispense and management of VAD substance and destruction of unused substance	VAD substance is made available to approved patients in a timely manner

Outcomes		
Service system	**Eligible Victorians**	**Broader community**
The operation of the Act is monitored for safety and compliance Government is assured of the quality and safety of VAD law operation Health practitioners across Victoria feel supported and confident when engaging with VAD processes	Eligible Victorians are able to access VAD Services according to the process set out in the VAD Act – no matter where they live or their personal circumstances Eligible Victorians have choice and autonomy at the end of life and may choose the manner and timing of their death. Eligible Victorians seeking VAD experience a safe and compassionate system Eligible Victorians may access VAD in a way that is timely and minimises unnecessary suffering	Community assured of the quality and safety of VAD law operation

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[1] Kresin, T. et al. 2021, *Attitudes and Arguments in the Voluntary Assisted Dying Debate in Australia: What Are They and How Have they Evolved Over Time?,* Int J Environ Res Public Health, 18(23): 12327.

Assumptions associated with the effectiveness of the program

- Victorians are aware that VAD is a legal and available end-of-life choice.
- Victorians can easily access the services required to process their request for VAD.
- Safeguards and processes outlined in the law provide an appropriate balance between safety and accessibility to VAD for eligible Victorians.
- A person's location of residence, medical condition(s) or personal circumstances are not barriers to their engagement with VAD.
- Systems and processes underpinning the operation of the Act are appropriately resourced.
- There are enough medical and health practitioners in Victoria's health system who are willing to support eligible Victorians to engage with VAD, should they express a desire to.
- Training and supports will provide medical practitioners and health practitioners with the necessary skills, knowledge and confidence to assist Victorians in accessing VAD.

External factors influencing the effectiveness of the program

- Across Victoria, there is broad community acceptance and support for VAD to be made available to eligible people, should they want it.
- The policy position of some medical and health peak bodies, religious and aged care health settings may prevent/dissuade support for VAD.
- The cultural and/or faith-based beliefs of some people may prevent them from considering VAD as an end of-life choice, or from being willing to support/assist people seeking information about, or a patient expressing a wish to access, VAD.
- The COVID-19 pandemic, and associated public health measures, may have impacted people's ability to access VAD services, especially in 2020–21.
- Medical practitioners and health practitioners cannot be penalised under the Criminal Code Act (Cth) for assisting eligible Victorians to access VAD, if acting within the boundaries outlined in the Victorian Act.
- The Criminal Code Act (Cth) does not permit the use of telehealth for VAD-related consultations. This may affect access for people living in regional and rural areas.
- Economic constraints could have an impact on program resourcing.
- Chronic health workforce shortages, especially in regional or rural areas, may influence the operation of the Act in those areas.
- Lack of specific financial support (for example, VAD-specific items) in the Medicare Benefits Schedule is an issue for medical practitioners assisting patients in access VAD.
- Amendments to the content of the Act, including eligibility criteria, are outside of the scope of this review.

Key stakeholders

In undertaking the review, CERE engaged with a broad range of stakeholders including people considering VAD and their families, carers and nominated contact people; providers of VAD services; providers of other health, palliative and aged care services; and policymakers.

Design and methods

The review design drew on process and outcome evaluation approaches to assess the implementation of the Act and the ongoing operation of the various processes and systems set up under the Act. The review examined the key questions across the evaluation domains of appropriateness, effectiveness, efficiency and impact (Table 2.1). A mixed methods approach was used, incorporating quantitative and qualitative data from multiple sources.

Data sources

Data was collected on the implementation and operationalisation of VAD, and stakeholders' experiences, views and perspectives regarding VAD. Key data sources were:

- **Interviews and focus group discussions**, conducted with 119 people. To ensure the review considered the views and experiences of Aboriginal communities in a culturally safe and sensitive way, Karabena Consulting was contracted to undertake interviews and focus groups with Aboriginal communities (13 participants) and to make recommendations relating to their key findings.
- **Surveys and written submissions**, collected via the Victorian Government's Engage Victoria platform (publicly available) over 12 weeks from 1 December 2023 to 23 February 2024. The survey was completed by 303 individuals and 257 written submissions were received.

Table 2.1: Review questions

Domain	Questions
Appropriateness	1.1 Did the systems, processes and practices established to facilitate access meet the needs of eligible people seeking VAD? 1.2 Did VAD systems, processes and practices meet the needs of eligible people seeking VAD and their families and carers? 1.3 Did VAD systems, processes and practices meet specific needs of various population groups?
Effectiveness	2.1 Were VAD systems, processes and practices operating to support the Act? 2.2. What were the barriers and enablers to stakeholder compliance, understanding and operation of the Act?
Efficiency	3.1 Have VAD systems, processes and practices had sufficient resources? 3.2 Is resourcing sufficient to implement ongoing delivery? 3.3 Could resources be allocated differently in the future? If so, how?
Impact	4.1 Was the VAD legislative goal achieved across Victoria? 4.2 Were VAD systems, processes and practices timely, safe and compassionate? 4.3 Have VAD systems, processes and practices generated unintended consequences? If so, what are they, and how can they be addressed?

- **Data recorded in the VAD portal**, obtained from the VAD secretariat,[24,25] relating to:
  - **VAD medical practitioners** – data obtained included the local government area of their practice, age category at VAD training, the date that they completed their training and registration, their speciality type and the number of coordinating and consulting assessments they had completed.
  - **VAD applicants** – data obtained included all key dates in the process (applicant's first request, first assessment, consulting assessment, final request, permit approval date, date of death), type of permit, permit type changed, main diagnosis and demographic characteristics. Individual-level data was provided for all applications entered on the VAD portal by VAD registered medical practitioners between 19 June 2019 and 30 June 2023.
  - **Contact peoples' experiences** – 412 surveys administered by the VAD secretariat and completed by a contact person soon after an applicant's death.
  - **Medical practitioners' experiences** – feedback on 319 individual cases reported by medical practitioners.
- **Reports provided to the department** by the Statewide Care Navigator Service, the Statewide Pharmacy Service and the VAD medical practitioner Community of Practice moderators.
- **Coronial data** relating to cases involving VAD.
- **Case reviews of VAD assessments** from Victorian Civil and Administrative Tribunal (VCAT) and the Australian Health Practitioner Regulation Agency (Ahpra).
- **CERE evaluation of VAD training** conducted in 2023.
- **VAD long-term activity projection model**, developed by the department's eHealth division in August 2024.

Surveys and interview schedules were checked for clarity by departmental staff, VAD statewide care navigators, a VAD medical practitioner and the spouse of someone who had accessed VAD.

Participant engagement and representation

A range of strategies was used to raise awareness of the review and promote broad participation, including:

- Human services and aged care service managers in selected LGAs promoted surveys to local community groups such as ethnic communities, and older populations.
- Peak bodies representing diverse communities including ethnic communities, seniors' groups, palliative care and the Cross Border Commissioner were invited to promote the review to their members and communities.
- The Engage Victoria consultation page included links to information about VAD and the VAD review in 17 community languages[26] and invited people to contact the review team through the Translating and Interpreting Service.

The sampling strategy developed for data collection activities undertaken by the review team aimed to recruit broad representation of participants from different demographic (e.g. geographic region, ethnicity) and service use characteristics (e.g. year of VAD access, permit type).

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[24] Identifiable information such as names, addresses and date of birth were removed before individual-level data was securely provided to the review team for analysis

[25] It took considerable time to access the data (including ethics, VADRB approvals, data extraction and data cleaning), meaning that data was not provided to the review team until February 2024

[26] Refer to <https://www.health.vic.gov.au/voluntary-assisted-dying/about#in-your-language-and-easy-english>

Recruitment and data collection – families, carers and contact people

Hearing the voice of those who had sought VAD, and their families and contacts was critical to the meaningfulness and usefulness of the review. Contacts of people who had sought VAD between February 2022[27] and December 2023 were invited to participate in the review by the VAD secretariat, on behalf of CERE. They were sent a link to the survey on the Engage Victoria platform and were invited to contact the CERE team if they were interested in taking part in an interview. Interviews were arranged in the format preferred by the contact – in-person, telephone or via Microsoft Teams. Analysis of demographic characteristics of survey and interview participants shows that the minimum target of five participants was reached for all categories except for people from Aboriginal backgrounds. A separate Aboriginal-led consultation process supplemented this to ensure appropriate representation of Aboriginal perspectives.

A distress protocol was established to minimise and manage any distress created through the conduct of the review. Interview participants were offered up to six sessions of professional grief counselling if they appeared distressed during the interview. Participants were also provided information about available support services. Family members were offered a gift voucher for their time in taking part in an interview.

Recruitment and data collection – health practitioners, policymakers and organisations

VAD medical practitioners registered as of December 2023 and medical practitioners who had registered for but not completed VAD training, were emailed by the VAD secretariat, with a link to the Engage Victoria survey and an invitation to take part in an interview. Members of the VAD medical practitioner Community of Practice were invited by moderators to take part in focus groups or interviews. CERE emailed invitations to department stakeholders, VADRB members, the VAD secretariat, statewide pharmacy and care navigators and hospital coordinators to participate in an interview or focus group. Five hundred and forty-five organisations representing Victorian health practitioners, unions, medical indemnity insurers, health, aged care and palliative care services, health service and residential aged care facility board chairs, government agencies, and advocacy, research or special interest groups were invited to provide written submissions and/or distribute to employees and/or members as relevant. Most of the interviews and focus groups were conducted using Microsoft Teams, with a small number held in person.

Data analysis

Interviews and focus groups were audio-recorded (with participant consent) and transcribed verbatim and deidentified.[28] Written submissions received through Engage Victoria were reviewed and six submissions (2%) that were out of scope and did not address the current operation of the Act were excluded from analysis.

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[27] Prior to portal enhancements, email addresses for contacts were not recorded in the portal.

[28] Two participants did not consent to being recorded but agreed to extensive notes being taken instead.

All qualitative data (interview and focus group transcripts and notes, written submissions and open survey responses) were thematically analysed. A matrix was created in Microsoft Excel with a row of coding for each record and columns representing the various themes in the framework. Each column was then reviewed and synthesised into key themes.

Participant characteristics, levels of service from statewide VAD services and responses to survey questions (e.g. Likert scales of satisfaction) were analysed using descriptive statistics (e.g. frequencies, percentages, cross-tabulations), with non-parametric measures (i.e. medians) reported for skewed data.

To examine availability of VAD medical practitioners, LGA data for VAD-registered medical practitioners was mapped against the total population aged older than 60 years derived from Australian Bureau of Statistics and against the total proportion of registered medical practitioners and medical practitioner age categories as recorded in the National Health Workforce Dataset for 2022.

Findings from the analysis of data from the VAD portal were reviewed by the VAD secretariat to ensure accuracy in analysis and interpretation.

Ethics and privacy

The Department of Health and Department of Families, Fairness and Housing Human Research and Ethics Committee reviewed and approved all data collection (Project ID 100702). A privacy impact assessment (PIA) was undertaken for parts of the review that involved collecting and using personal data in line with the department's requirements and legal obligations under the *Privacy and Data Protection Act 2014* and the *Health Records Act 2001.* The PIA was completed in conjunction with an Information Security Classification process.

Limitations of the Review

- Efforts were made to recruit people currently seeking VAD but given end of life is a difficult time for people and taking part in the review may not have been a priority, participation was limited (24 survey respondents, no interviews). To help address this, feedback was sought from family members who could provide varied and rich accounts of the experiences of accessing VAD in Victoria.
- The review team's ability to identify and recruit people who had been unable to access VAD was limited.
- Data collection was conducted in English only, creating challenges engaging with multicultural communities; only three family members of a person who sought VAD who spoke a language other than English were included in the interview sample.
- Contacts who were invited to participate in an interview were also invited to complete the Engage Victoria survey. As survey completion was anonymous, it is not possible to calculate the number of family members who provided input into the review through both the survey and through interview.
- Approval and access processes for VAD portal data were complex and approval was not obtained until February 2024, resulting in limited time to undertake data analysis.
- VAD portal enhancements undertaken in 2021 and 2022 impacted the availability of data and the ability to extract contact information.

Table 2.2: Number of participants by stakeholder group and method of participation[1]

Stakeholder group	Individuals or organisations contacted	Interviews	Focus Groups	Surveys	Written submissions
People seeking VAD	N/A	0	--	24	--
People formally appointed as a contact person for a VAD applicant	1,150	40	--	123	171
VAD Registered Medical practitioners (active and inactive)	388	9	3	33	--
Statewide and Regional Care Navigator Service	N/A	0	1	0	--
Health service-based VAD care coordinator	N/A	1	1	0	--
Statewide Pharmacy Service	N/A	--	1	--	1
VAD Review Board Members and VAD Secretariat	N/A	9	1	--	1
Internal Department of Health teams	N/A	5	3	--	2
Public/private health service and residential aged care facility board chairs	81	--	--	6	--
Medical practitioners not registered to provide VAD	N/A	1	--	22	--
Other health practitioners (e.g. nurse, allied health, aged care worker)	N/A	--	--	95	26
Public and private health and residential aged care services	352	--	--	--	10
Community palliative care services	12	--	--	--	1
Registered community health services	23	--	--	--	0
Victorian branches of medical practitioner, nursing, pharmaceutical and/or allied health practitioner organisations/unions	28	--	--	--	5
Government agencies (excluding the Department of Health)	10	1	--	--	0
Peak bodies (representing groups including palliative care, disability, LGAs, carers, Aboriginal communities, ethnic communities) and special interest groups	30	--	1	--	15
Research institutes with interest in VAD and/or end of life in Victoria	6	--	--	--	3
Medical indemnity insurers	5	--	--	--	0
General community	N/A	--	--	--	22
Total	**2,085**	**66**	**11**	**303**	**257**

[1] Interviews and focus groups were the key methods of data collection for those with a direct interest in the review (e.g. family members of people who had sought VAD, VAD medical practitioners, VAD-related policy and service delivery). Other stakeholder groups primarily contributed via online surveys (health workforce) and written submissions. -- Denotes methods of data collection not targeted to this stakeholder group; N/A: Not applicable – number of individuals or organisations contacted to participate cannot be specified.

Note: 43 family members were interviewed during 40 interviews. Some family members may have provided input through multiple processes.

Appendix 3: Additional tables and figures

VAD processes and applications

Table 3.1: Number of events at each stage of the VAD process, 2019–20 to 2022–23

Event type	2019–20	2020–21	2021–22	2022–23	Total
First assessments completed[1] (N)	353	487	585	610	**2,035**
First assessments completed that were eligible[2] (N, %)	346 (98%)	465 (96%)	552 (94%)	600 (98%)	**1,963 (97%)**
Withdrawn applications[3] (N)	--	--	--	--	**782**
Permits issued (N)	237	366	439	485	**1,527**
Self-administration permit	207	323	379	403	**1,312**
Practitioner administration permit	30	43	60	82	**215**
VAD substances dispensed (N)	175	291	394	452	**1,312**
Deaths from administration of VAD substance (N)	129	202	275	306	**912**
By self-administration	108	174	236	257	**775**
By practitioner administration	21	28	39	49	**137**

Source: VADRB 2022–23 annual report

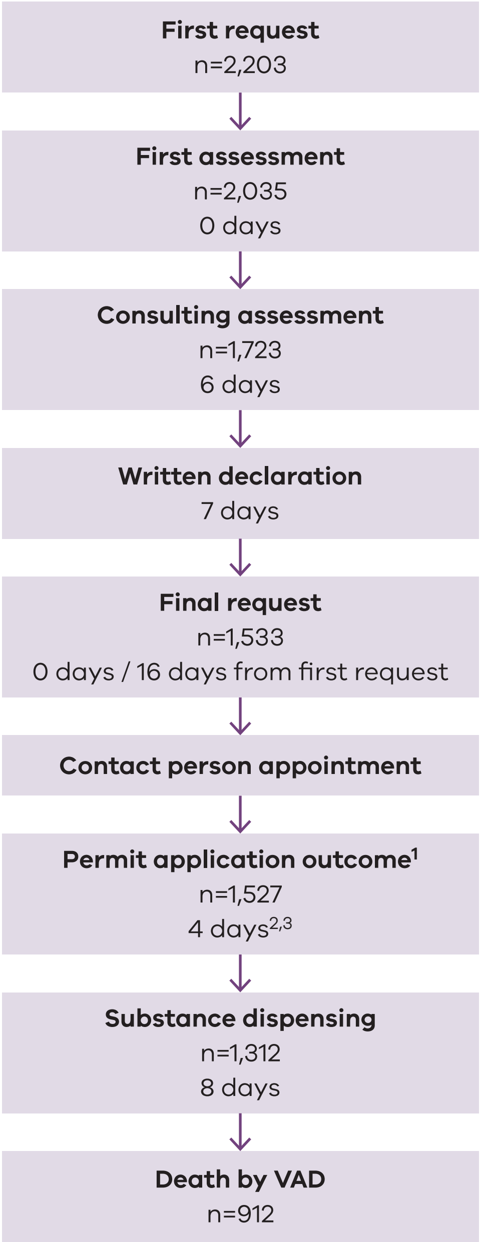
[1] This differs from the number of applicants referred to elsewhere in this report as not all applicant profiles created by medical practitioners receive an assessment (for example, an applicant may die before the assessment or choose not to proceed after the medical practitioner has created the profile). Some of these profiles may also have been created close to the end of the reporting period, with medical practitioners uploading their assessments after the reporting period.

[2] This reflects data recorded in the VAD Portal. There may be many more assessments considered ineligible that are not recorded in the Portal by the medical practitioner at the time of assessment.

[3] Withdrawn applications result from the applying dying, becoming too unwell and/or losing capacity, or choosing not to proceed. The reason for withdrawal was not recorded in all cases.

-- Annual data breakdown unavailable

Figure 3.1: Median time between key steps in VAD process and number of applicants at each stage, June 2019 to June 2023



Source: VADRB 2022–23 annual report

1 There are circumstances where one applicant is issued two permits – first for self-administration and subsequently if there is a change to practitioner-administration.

2 Median time to permit approval if the applicant changed permits was 81 days; however, this includes 73 days when the person had a self-administration permit before a practitioner-administration permit was sought. The median time it took them to obtain their self-administration permit was three days and the median time to obtain the second practitioner-administration permit was 2 days

3 Median time from first request to permit approval was 22 days for self-administration permit holders and 25 days for practitioner-administration permit holders

Table 3.2: Reported barriers encountered at each stage of the VAD process, that were believed to have contributed to delays

Stage	Reported barriers
First request	• Lack of information and knowledge of VAD in the community • Prohibition of medical practitioners raising VAD with patients • Delays in medical practitioner responding to first request • Access to interpreters
First assessment	• Access to VAD medical practitioners including limited availability, lack of timely response, difficulty travelling to appointment • 6m prognosis (12m for neurological conditions) considered inappropriate by stakeholders • Neurological conditions with 6–12month prognosis requiring a specialist opinion at first assessment • Finding a specialist medical practitioner that meets the requirements specified in the Act
Written declaration	• Difficulty finding independent witnesses • Organisations not allowing VAD medical practitioners on site
Final request	• Minimum of 9 days between first and final request as mandated by the Act
Permit approval outcome / switching permits	• Substantial paperwork involved • Incorrect or insufficient data on assessments and permit applications • VAD process impacted by weekends, public holidays, and leave • Patient unaware a new permit is needed • Patient is too unwell to travel for new appointments • Requirement to return self-administration substance • New application for practitioner-administration substance required
Substance dispensing	• Patient may be unaware they need to contact the pharmacy service • Occasional delays in delivery of the substance

Source: Stakeholder interviews

Table 3.3: Number of referrals to specialists and reasons for referral, by timing of referral

	Number of specialist referrals made	
Reason for specialist referral	**Following first assessment**	**Following consulting assessment**
To confirm decision-making capacity	20	9
To confirm eligibility of medical condition	93	33
To assess whether neurological condition is expected to cause death in 6–12 months	120	N/A

Source: VAD portal, June 2019 – June 2023

VAD applicants[29]

Table 3.4: Demographic characteristics of all VAD applicants, those who obtained a VAD permit, and those who obtained a VAD permit within 21 days or less, June 2019 – June 2023

Characteristic	All VAD applicants N=2,099 n (%)	Subset of applicants who obtained a permit N=1,476 n (%)	Subset of applicants who obtained a permit within 21 days N=716 n (%)
Sex			
Female	969 (46%)	711 (48%)	342 (48%)
Male	1,130 (54%)	765 (52%)	374 (52%)
Age group			
18–69 years	731 (35%)	545 (37%)	256 (36%)
70+ years	1,369 (54%)	931 (63%)	460 (64%)
Country of birth			
Australia	1,433 (72%)	1,003 (72%)	472 (70%)
Other	564 (28%)	396 (28%)	198 (30%)
Language spoken at home			
English	1,941 (96%)	1,372 (96%)	654 (96%)
Language other than English	79 (4%)	51 (4%)	30 (4%)
Aboriginal and/or Torres Strait Islander			
No	1,989 (99%)	1,395 (99%)	675 (100%)
Yes	11 (<1%)	8 (<1%)	<5 (<1%)
Educational completion			
End of high school or lower	1,001 (56%)	670 (53%)	315 (53%)
Beyond high school	793 (44%)	585 (47%)	276 (47%)
Location			
Metropolitan Melbourne	1,335 (64%)	952 (65%)	507 (71%)
Regional Victoria	756 (36%)	524 (36%)	209 (29%)
Main diagnosis			
Cancer	1,588 (81%)	1,144 (80%)	616 (89%)
Other	371 (19%)	278 (20%)	75 (11%)
Accessed palliative care			
Yes	1,711 (85%)	1,195 (85%)	608 (90%)
No	299 (15%)	216 (15%)	71 (10%)

Source: VAD portal, June 2019 – June 2023.

Note: Valid percentages are shown (excluding missing data)

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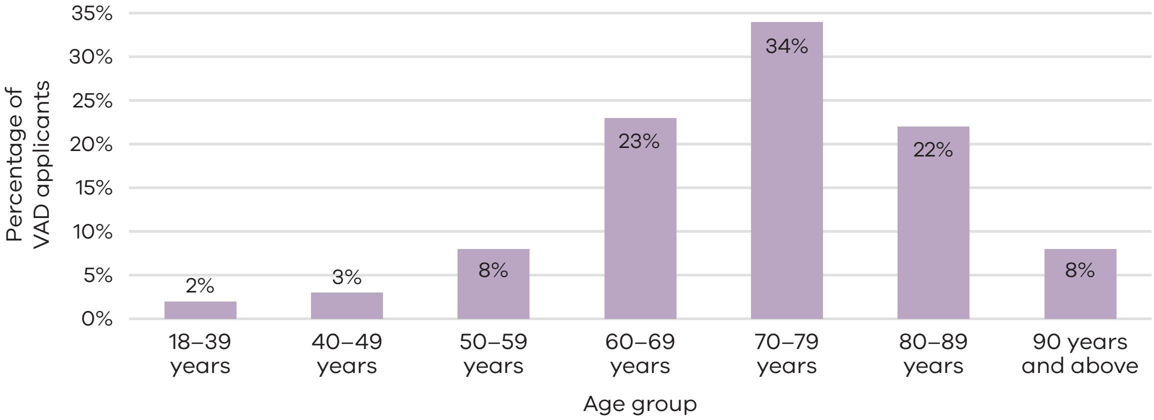
[29] The term applicant refers to a person that is seeking to access voluntary assisted dying and is in the process of applying for a voluntary assisted dying permit.

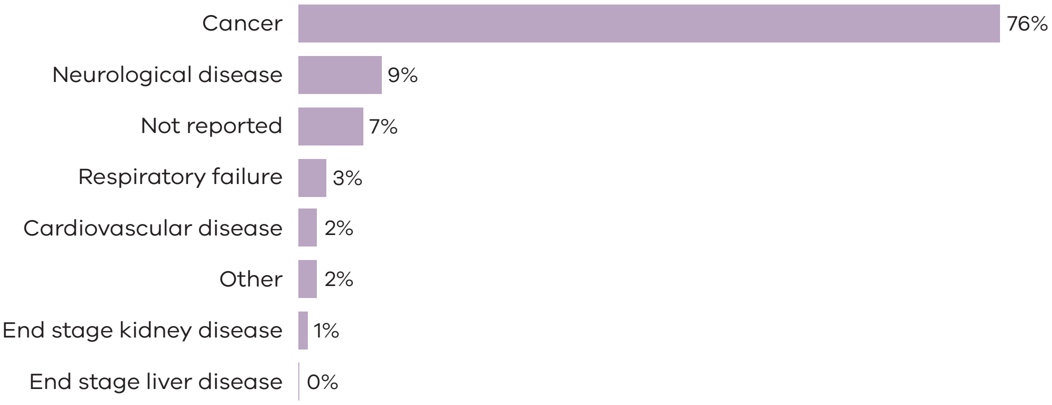
Figure 3.2: Age distribution of VAD applicants, June 2019 – June 2023 (n=2,096)



Source: VADRB 2022–23 annual report

Note: Valid percentages are shown (excluding missing data)

Figure 3.3: Life-limiting conditions of VAD applicants, June 2019 – June 2023 (n=2,100[1])



Source: VAD portal data, June 2019 – June 2023

[1] Missing data occurs where the medical practitioner has not selected a condition in the online patient profile. This profile is used for monitoring purposes; eligibility for a permit is determined through assessment).

People seeking VAD and their families/contacts

Table 3.5: Experiences of VAD processes for eligible people seeking access to VAD among people seeking VAD and their families/contacts

Variable	Applicants N=24 n (%)	Families/contacts N=123 n (%)	Total N=147 n (%)
Compassionate			
Very much	6 (46%)	83 (73%)	89 (70%)
Somewhat	4 (31%)	18 (16%)	22 (17%)
A little	2 (15%)	5 (4%)	7 (6%)
Not at all	1 (8%)	8 (7%)	9 (7%)
Safe			
Very much	8 (67%)	96 (89%)	104 (87%)
Somewhat	3 (25%)	6 (6%)	9 (8%)
A little	0 (0%)	0 (0%)	0 (0%)
Not at all	1 (8%)	6 (6%)	7 (6%)
Timely			
Very much	5 (42%)	57 (50%)	62 (50%)
Somewhat	1 (8%)	24 (21%)	25 (20%)
A little	1 (8%)	10 (9%)	11 (9%)
Not at all	5 (42%)	22 (19%)	27 (22%)
Applicant/family/carer wishes and needs supported			
Very much	3 (27%)	88 (69%)	88 (69%)
Somewhat	3 (27%)	18 (14%)	18 (14%)
A little	3 (27%)	8 (6%)	8 (6%)
Not at all	2 (18%)	14 (11%)	14 (11%)
Applicant/family/carer cultural, linguistic and/or spiritual needs supported			
Very much	3 (50%)	57 (77%)	60 (75%)
Somewhat	1 (17%)	8 (11%)	9 (11%)
A little	0 (0%)	3 (4%)	3 (4%)
Not at all	2 (33%)	6 (8%)	8 (10%)

Source: Survey data, Engage Victoria 2024

Note: Valid percentages are shown (excluding missing data)

Table 3.6: Satisfaction with VAD systems, programs and processes among people seeking VAD and their families/contacts

System, program or process	Applicants N=6 n (%)	Families/contacts N=93 n (%)	Total N=99 n (%)
VAD doctors			
Very much	2 (75%)	82 (91%)	84 (90%)
Somewhat	0 (0%)	6 (7%)	6 (7%)
A little	1 (25%)	1 (1%)	2 (2%)
Not at all	0 (0%)	1 (1%)	1 (1%)
Other doctors			
Very much	3 (75%)	49 (56%)	52 (57%)
Somewhat	0 (0%)	17 (20%)	17 (19%)
A little	1 (25%)	11 (13%)	12 (13%)
Not at all	0 (0%)	10 (11%)	10 (11%)
Other healthcare workers			
Very much	2 (50%)	60 (65%)	62 (65%)
Somewhat	2 (50%)	17 (19%)	19 (20%)
A little	0 (0%)	10 (11%)	10 (10%)
Not at all	0 (0%)	5 (5%)	5 (5%)
Statewide Care Navigator Service			
Very much	2 (100%)	66 (84%)	68 (84%)
Somewhat	0 (0%)	8 (10%)	8 (10%)
A little	0 (0%)	3 (4%)	3 (4%)
Not at all	0 (0%)	2 (2%)	2 (2%)
Statewide Pharmacy Service			
Very much	2 (75%)	67 (85%)	69 (84%)
Somewhat	0 (0%)	6 (8%)	6 (7%)
A little	0 (0%)	3 (4%)	3 (4%)
Not at all	1 (25%)	3 (4%)	4 (5%)

Table 3.6: Satisfaction with VAD systems, programs and processes among people seeking VAD and their families/contacts (continued)

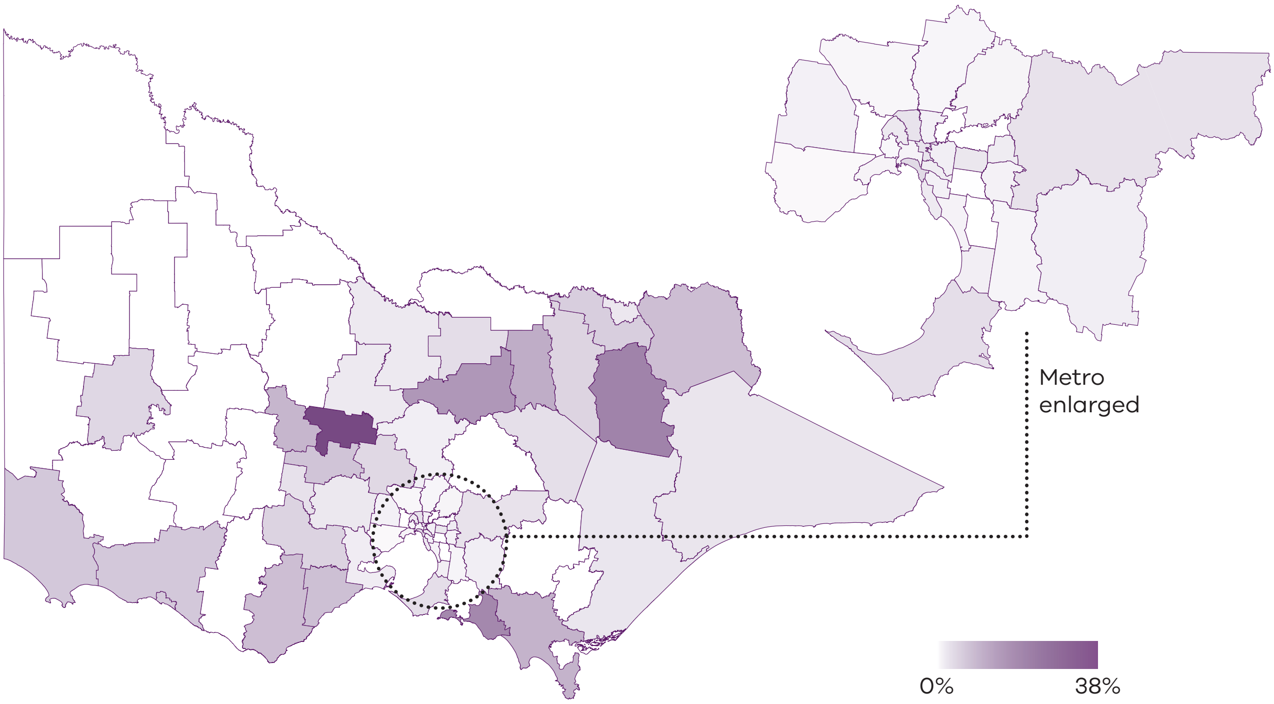
System, program or process	Applicants N=6 n (%)	Families/contacts N=93 n (%)	Total N=99 n (%)
Provision of a support package			
Very much	1 (50%)	44 (64%)	45 (63%)
Somewhat	0 (0%)	17 (25%)	17 (24%)
A little	0 (0%)	1 (1%)	1 (1%)
Not at all	1 (50%)	7 (10%)	8 (11%)
Follow-up after the person died			
Very much	N/A	42 (56%)	42 (56%)
Somewhat	N/A	22 (29%)	22 (29%)
A little	N/A	3 (4%)	3 (4%)
Not at all	N/A	8 (11%)	8 (11%)

Source: Survey data, Engage Victoria 2024

Note: Valid percentages are shown (excluding missing data). Percentages may not add up to 100% due to rounding.

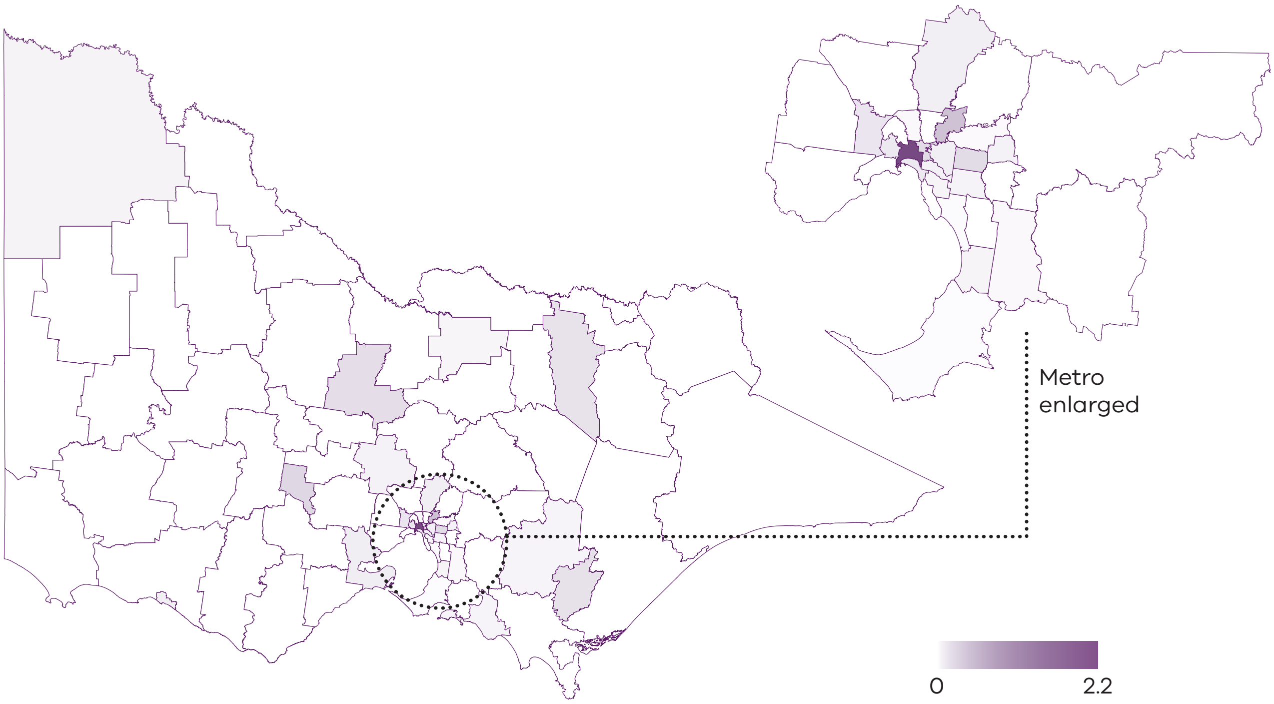
VAD-registered medical practitioners

Figure 3.4: Percentage of GPs who are VAD-registered, by local government area



Source: VAD Portal data and National Health Workforce Dataset 2022

Figure 3.5: Rate of VAD-registered non-GP specialists per 1,000 population aged 60+ years



Source: VAD portal, 30 June 2023

Table 3.7: VAD medical practitioner's perception of their and their patients' experiences of the VAD process

Variable	Responses N=319[1] n (%)
Applicant did not experience barriers accessing VAD	
Strongly agree	101 (32%)
Agree	115 (36%)
Neither agree nor disagree	23 (7%)
Disagree	65 (20%)
Strongly disagree	15 (5%)
VAD process worked well for the applicant	
Strongly agree	119 (37%)
Agree	133 (42%)
Neither agree nor disagree	30 (9%)
Disagree	32 (10%)
Strongly disagree	5 (2%)
Coordinating medical practitioner did not experience barriers in the VAD process	
Strongly agree	121 (38%)
Agree	136 (43%)
Neither agree nor disagree	22 (7%)
Disagree	33 (10%)
Strongly disagree	7 (<1%)
Coordinating medical practitioner received adequate support throughout the VAD process	
Strongly agree	160 (50%)
Agree	136 (43%)
Neither agree nor disagree	19 (6%)
Disagree	2 (<1%)
Strongly disagree	2 (<1%)

Source: VAD portal survey feedback after 319 VAD-related deaths, June 2019 – June 2023

[1] Responses by medical practitioners reflecting upon 319 records of VAD-related deaths; not unique providers

Note: Valid percentages are shown (excluding missing data)

Healthcare workforce

Table 3.8: Characteristics of health practitioner survey respondents

Characteristic	Medical practitioners VAD-registered N=33 n (%)	Medical practitioners Not VAD-registered N=22 n (%)	Other health care workers N=95 n (%)
Practice location			
Metropolitan Melbourne	22 (71%)	13 (65%)	55 (59%)
Regional/rural Victoria	9 (29%)	7 (35%)	39 (41%)
Job role			
Nurse	N/A	N/A	60 (65%)
Health service manager	N/A	N/A	9 (10%)
Other	N/A	N/A	24 (26%)
Primary setting of practice			
General Practice	12 (36%)	5 (23%)	6 (6%)
Hospital	15 (45%)	14 (64%)	48 (51%)
Non-GP specialist in private practice	4 (12%)	2 (9%)	0 (0%)
Community-based palliative care	N/A	N/A	20 (21%)
Residential aged care	N/A	N/A	5 (5%)
Other	2 (6%)	1 (5%)	12 (13%)

Source: Workforce survey

Note: Valid percentages are shown (excluding missing data); Data relates to people who responded to the health workforce survey and is not necessarily representative of the workforce more broadly.

Table 3.9: Involvement with VAD among medical practitioners who responded to the health practitioner survey, by training completion status (N=55)

	VAD training status		
Type of involvement with VAD	**Trained and registered N=33 n (%)**	**Trained but not registered N=3 n (%)**	**Not trained N=19 n (%)**
Not yet involved in a VAD assessment	2 (6%)	N/A	N/A
Self-administrating coordinator	26 (79)	N/A	N/A
Practitioner-administrating coordinator	15 (45%)	N/A	N/A
Consulting/assessment	26 (79%)	N/A	N/A
Interested in providing VAD but have yet to do the mandatory training	N/A	N/A	4 (21%)
Would consider providing VAD if one of my existing patients expressed a wish for it	N/A	0 (0%)	1 (5%)
Not opposed to VAD, but do not wish to be involved	N/A	2 (100%)	11 (58%)
Conscientiously object to VAD	N/A	0	3 (16%)

Source: Survey data, Engage Victoria 2024

Note: Valid percentages are shown (excluding missing data); Data relates to people who responded to the health workforce survey and is not necessarily representative of the workforce more broadly.

Table 3.10: Health practitioners' perceptions about Victoria's current processes for eligible people to access VAD

	Medical practitioners		
Variable	**VAD medical practitioner N=33 n (%)**	**Not VAD-registered N=22 n (%)**	**Other health care workers N=95 n (%)**
Compassionate			
Strongly agree	8 (24%)	1 (5%)	15 (16%)
Agree	14 (42%)	8 (36%)	48 (50%)
Neither agree nor disagree	2 (6%)	8 (36%)	9 (10%)
Disagree	3 (9%)	3 (14%)	12 (13%)
Strongly disagree	2 (6%)	2 (9%)	6 (6%)
Safe			
Strongly agree	21 (64%)	6 (27%)	41 (43%)
Agree	10 (30%)	7 (32%)	39 (41%)
Neither agree nor disagree	0 (0%)	3 (14%)	6 (6%)
Disagree	0 (0%)	4 (18%)	5 (5%)
Strongly disagree	2 (6%)	2 (9%)	4 (4%)
Timely			
Strongly agree	3 (9%)	1 (5%)	7 (7%)
Agree	11 (33%)	4 (18%)	24 (25%)
Neither agree nor disagree	7 (21%)	7 (32%)	17 (18%)
Disagree	11 (33%)	6 (27%)	29 (30%)
Strongly disagree	1 (3%)	4 (18%)	16 (17%)
Enable a person's wishes and needs to be supported			
Strongly agree	7 (21%)	2 (9%)	14 (15%)
Agree	16 (48%)	7 (32%)	45 (47%)
Neither agree nor disagree	5 (15%)	8 (36%)	12 (13%)
Disagree	4 (12%)	4 (18%)	20 (21%)
Strongly disagree	1 (3%)	1 (5%)	4 (4%)
Enables a persons' cultural, linguistic and/or spiritual needs to be supported			
Strongly agree	6 (18%)	1 (5%)	15 (16%)
Agree	15 (45%)	4 (18%)	38 (40%)
Neither agree nor disagree	7 (21%)	11 (50%)	30 (32%)
Disagree	3 (9%)	3 (14%)	9 (10%)
Strongly disagree	1 (3%)	3 (14%)	2 (2%)

Source: Survey data, Engage Victoria 2024

Note: Valid percentages are shown (excluding missing data)

Table 3.11: Satisfaction with VAD resources or services among VAD-registered medical practitioners and other health practitioners

VAD resource/service	VAD-registered medical practitioner N=33 n (%)	Other health practitioners N=95 n (%)
Victoria's mandatory VAD training		
Very satisfied	16 (50%)	N/A
Satisfied	9 (28%)	N/A
Neither satisfied nor dissatisfied	3 (9%)	N/A
Dissatisfied	3 (9%)	N/A
Strongly dissatisfied	1 (3%)	N/A
VAD portal		
Very satisfied	5 (16%)	N/A
Satisfied	16 (52%)	N/A
Neither satisfied nor dissatisfied	5 (16%)	N/A
Dissatisfied	4 (13%)	N/A
Strongly dissatisfied	1 (3%)	N/A
Information provided by the Department of Health		
Very satisfied	N/A	20 (24%)
Satisfied	N/A	37 (45%)
Neither satisfied nor dissatisfied	N/A	16 (20%)
Dissatisfied	N/A	8 (10%)
Strongly dissatisfied	N/A	1 (1%)
Statewide Care Navigator Service		
Very satisfied	26 (84%)	43 (54%)
Satisfied	4 (13%)	16 (20%)
Neither satisfied nor dissatisfied	1 (3%)	15 (19%)
Dissatisfied	0 (0%)	4 (5%)
Strongly dissatisfied	0 (0%)	1 (1%)
Statewide Pharmacy Service		
Very satisfied	26 (84%)	37 (52%)
Satisfied	4 (13%)	16 (23%)
Neither satisfied nor dissatisfied	1 (3%)	15 (21%)
Dissatisfied	0 (0%)	2 (3%)
Strongly dissatisfied	0 (0%)	1 (1%)

Table 3.11: Satisfaction with VAD resources or services among VAD-registered medical practitioners and other health practitioners (continued)

VAD resource/service	VAD-registered medical practitioner N=33 n (%)	Other health practitioners N=95 n (%)
Hospital-based VAD coordinator		
Very satisfied	16 (73%)	38 (55%)
Satisfied	3 (14%)	13 (19%)
Neither satisfied nor dissatisfied	3 (14%)	10 (14%)
Dissatisfied	0 (0%)	4 (6%)
Strongly dissatisfied	0 (0%)	4 (6%)
Community of Practice		
Very satisfied	8 (40%)	16 (24%)
Satisfied	7 (35%)	16 (24%)
Neither satisfied nor dissatisfied	5 (25%)	21 (32%)
Dissatisfied	0 (0%)	11 (16%)
Strongly dissatisfied	0 (0%)	3 (4%)
VAD permit application process		
Very easy	3 (9%)	N/A
Easy	8 (25%)	N/A
Neither easy nor difficult	11 (34%)	N/A
Difficult	9 (28%)	N/A
Very difficult	1 (3%)	N/A

Source: Survey data, Engage Victoria 2024

Note: Valid percentages are shown (excluding missing data)

Appendix 4: Summary of activity – VAD core bodies

Table 4.1: VAD Review Board activity

Activity	2019–20	2020–21	2021–22	2022–23	Total
Annual reports to Parliament required under the Act	6-monthly reports: 2 Establishment report (2018–19): 1	6-monthly reports: 2	Annual reports: 1	Annual reports: 1	**7**
Number of noncompliant cases[1]	Medical practitioner failure to comply with procedural requirements: 1	Delayed substance return: 2 Medical practitioner error: 5	Delayed substance return: 3 Witness error: 1	Delayed substance return: 2	**14 (0.7%)[2]**
Number of cases referred to other agencies	Medical practitioner referred to Ahpra: 1	0	0	0	**1 (0.05%)[2]**

Source: VADRB annual reports

1 The VADRB has reviewed all VAD applications after case closure.

2 Percentage of total completed VAD applications (782 withdrawn cases plus 1,344 applicants who have died).

Table 4.2: Statewide Care Navigator Service activity

Activity	2019–20	2020–21	2021–22	2022–23	Total
Annual reports	1	1	1	1	**4**
Number of people assisted with navigating VAD process	Community members: 613 Health practitioners: not reported	Total: 946 (71% patients or family; 27% health practitioners)	Total: 1,062 (60% patients or family; 40% health practitioners)	Total: 957 (49% patients or family; 51% health practitioners)	**2,965[1]** **(60% patients or family; 40% health practitioners**
Number of workshops, information sessions, and webinars for health and aged care services / practitioners	130	113	144	178	**565**

Source: VADRB annual reports

1 Excludes 2019–20 as breakdown of patients/family and health practitioners unavailable

Table 4.3: Statewide Pharmacy Service activity

Activity	2019–20[1]	2020–21	2021–22	2022–23	Total
Reports to the department	Monthly	Monthly & annual	Monthly & annual	Monthly & annual	**N/A**
Number of prescriptions received[2]	-	305	414	455	**N/A**
Number of substance deliveries	170	289	361	398	**1,218**
Percentage of deliveries within two business days of being requested	100%	100%	96%	99%	**N/A**

Source: VADRB annual reports

[1] Data for 2019–20 is only available from April 2020 when request dates began to be collected.

[2] Prescriptions were received either via email or during doctor visits.

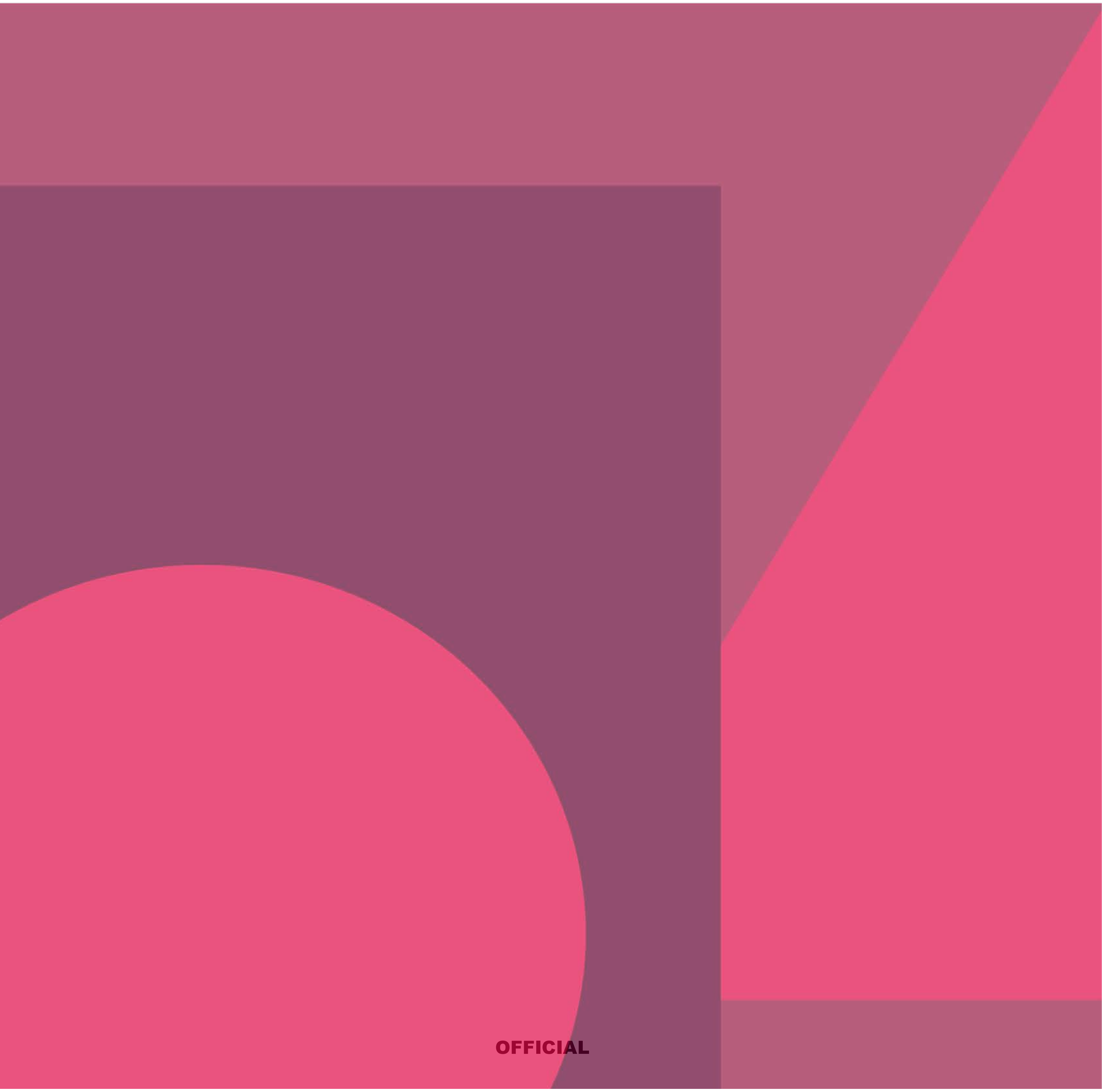
Table 4.4: VAD medical practitioner community of practice activity

Activity	2019–20	2020–21	2021–22	2022–23	Total
Reports to the department	–	1	2	2	**5**
Number of participants	17 (Apr 20)	37 (May 21)	48 (Apr 22)	63 (May 23)	**63**
Number of active contributors to posts	13 (Apr 20)	20 (May 21)	29 (Apr 22)	18 (May 23)	**18**
Estimated percentage of members actively participating	77%	54%	62%	29%	**N/A**

Source: VADRB annual reports

Appendix 5: First Nations consultation report

Victoria First Peoples' Consultation:
Five-year review of the operation of the *Voluntary Assisted Dying Act 2017*



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Acknowledgements: We acknowledge the Traditional Owners of the Lands on which we live, work and play. It is an honour to grow our families on your Country, the place of your ancestors. As is our culture, we pay respects to Elders past and present. We extend thanks to Aboriginal and Torres Strait Islander people everywhere for your strength, courage and resilience. We also acknowledge our friends, families and allies for giving true value and meaning to the words 'our fellow Australians'. We are all the richer for our relationships.

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On the matter of voluntary assisted dying:

> *‘...the two questions we need to ask is, firstly, if we're [the dying patient] not able to talk for ourselves, then who's going to talk for us? The second question is, ‘and would they [the person talking on our behalf] know what we would want?’ If we can't answer those two questions, then we're leaving our death in the hands of staff, in clinical hospitals, our families and friends, rather than ourselves. So we have to be able to answer those two questions. Who would we ask? And would they know what to say?’*

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Executive Summary

To evaluate the first four years of the Victorian *Voluntary Assisted Dying Act 2017*, Karabena Consulting was engaged by the Centre for Evaluation and Research Evidence (CERE) to conduct culturally sensitive data collection with Aboriginal and Torres Strait Islander people. Focusing on experiences with death, dying, and voluntary assisted dying (VAD) accessibility, key questions addressed how VAD systems meet First Nations peoples' needs, barriers to compliance, and the safety and compassion of VAD processes. We interviewed 13 stakeholders, and data were analysed using Indigenous research methodologies including Dadirri and yarning. The findings significantly enhance understanding of the legislation's impact on Victoria's First Peoples.

The evaluation reveals that the current transactional and impersonal nature of end-of-life care does not align with the cultural values and needs of First Nations communities. It highlights the necessity for more culturally respectful and inclusive approaches, advocating for Aboriginal-led VAD processes to ensure appropriate practices and build trust. The importance of self-determination and autonomy in end-of-life decisions was raised, with a call to respect individual rights and wishes, which often conflict with medical interventions and are often denied because the family are '***not prepared to let someone go***'. Additionally, significant resource allocation gaps, particularly the absence of Aboriginal death and dying navigators and support personnel (death doulas), need addressing to improve accessibility and effectiveness of VAD services. Incorporating healing processes into end-of-life care is important for patients, their families, and communities to address past traumas and promote collective healing.

Focusing on quality of life and death, with comprehensive and respectful care options, is necessary for ensuring dignified and peaceful endings. Revitalising and integrating Aboriginal stories and traditions around death can help communities better understand and embrace end-of-life concepts. The narratives and language used by end-of-life practitioners, including palliative care professionals and those involved in the VAD process, are indispensable in shaping the experiences of individuals facing terminal illnesses. However, these narratives often focus on clinical efficiency and risk reduction, meeting legislative requirements rather than providing culturally sensitive care. The opportunity to engage in cultural practices is limited because VAD and end-of-life practitioners are not asking if people identify as Aboriginal and Torres Strait Islander consistently and have no cultural capacity to respond to ceremonial requirements over clinical processes at this point in time. A strong clinical focus can inadvertently create a cold and impersonal atmosphere, particularly for Aboriginal and Torres Strait Islander people who value relational and community-based approaches to care.

For many Aboriginal and Torres Strait Islander individuals, the process of seeking a VAD permit can be distressing and triggering, especially for those who have faced lifelong discrimination and are members of the Stolen Generations. The requirement to obtain permission from a non-Indigenous authority to end one's life evokes deep-seated trauma and feelings of disempowerment. As one participant noted, '***Imagine having to ask permission to die from the very system that once denied your right to live as an Aboriginal person***'. This statement encapsulates the pain and indignity felt by those who must navigate a system that has historically oppressed them.

The current end-of-life narratives and practices fail to acknowledge and accommodate the cultural needs and histories of Aboriginal and Torres Strait Islander peoples. The language of 'permits', of being clinically 'assessed', and strict adherence to legislation often neglects the importance of culturally caring practices that honour the individual's cultural identity and life experiences. These insights form the foundation for tailored recommendations that respect cultural values, enhance self-determination, ensure adequate resources, and promote holistic and dignified end-of-life care for Aboriginal and Torres Strait Islander peoples.

Recommendations

To provide truly compassionate and respectful end-of-life care, these narratives must change. Practitioners could adopt a more culturally sensitive approach that prioritises relational care, community involvement, and the emotional and spiritual needs of the person. The following recommendations are categorised into short-term, medium-term, and long-term actions to ensure immediate, sustained, and future improvements in culturally sensitive end-of-life care.

Short-term Actions (0-1 year)

Inform people about their rights to VAD so people know to ask for this as an option.

1. **Enhance Education and Awareness about VAD:** Develop and disseminate culturally tailored educational materials that explain VAD and the availability of this option. Use stories, case studies and testimonials from within the community to make the information more relatable and less intimidating.
2. **Train and Employ Aboriginal Health Workers in VAD Processes:** Invest in training for Aboriginal Health Workers to specialise in VAD processes, ensuring that they can advocate effectively for patients and guide them through the VAD process with understanding and respect for cultural values.
3. **Promote Open Conversations About Death and Dying:** Organise community forums and discussion groups to talk openly about death, dying and VAD. These should aim to reduce stigma and fear associated with talking about death and promote a more supportive environment for discussing end-of-life choices, as well as alerting people to the necessity of advance care planning.
4. **Inclusive Language Guidelines:** Develop and distribute guidelines for using inclusive and culturally sensitive language in end-of-life care communications and documentation.
5. **Community Consultations:** Conduct regular consultations with Aboriginal and Torres Strait Islander communities to gather input and feedback on VAD processes and ensure their voices are heard and respected.
6. **Cultural Safety Audits:** Perform audits of current VAD practices and environments to identify and address areas lacking cultural safety.

Medium-term Actions (1-3 years)

Develop a culturally competent workforce, who can facilitate ceremonial and clinical end-of-life practices.

1. **Develop Cultural Safety Training for Health Care Providers:** Provide cultural safety training for all health care providers involved in end-of-life care, focusing on understanding and respecting Aboriginal cultural practices and values. This training should help providers recognise the importance of a holistic approach that includes physical, spiritual and community health.

2. **Establish Aboriginal-led Support Teams:** Create support teams consisting of Aboriginal Health Workers, spiritual advisors, and community Elders to assist patients and families through the VAD process. This team would ensure that all aspects of the patient's cultural, spiritual and emotional needs are met.
3. **Holistic Care Models:** Develop and implement holistic care models that integrate physical, emotional, spiritual and cultural aspects of end-of-life care.
4. **Advance Care Planning Workshops:** Organise workshops on advance care planning and VAD options, led by Aboriginal Elders and health professionals, to educate and empower communities.

Long-term Actions (3-5 years)

Work with services to ensure Aboriginal-centric end-of-life VAD can be delivered in line with Treaty aspirations for self-determination across a person's entire life, including their death.

1. **Advocate for Policy Changes to Support Culturally Safe VAD:** Work with policymakers to adapt VAD legislation and health care practices to be more inclusive and reflective of Aboriginal cultural practices and values. This could involve amendments that allow greater family involvement and community consultation in the decision-making process.
2. **Incorporate Traditional Practices and Rituals:** Encourage and facilitate the inclusion of traditional Aboriginal practices and rituals in the end-of-life care plan. This could include ceremonies, storytelling, or other culturally significant activities that honour the patient's life and heritage.
3. **Improve Access to Pain Management Resources:** Ensure that all patients have access to effective pain management options, including VAD if chosen. This involves training more health care providers in pain management techniques and ensuring that these resources are readily available in Aboriginal communities.
4. **Sustainable Funding:** Secure sustainable funding for Aboriginal-led VAD programs and initiatives to ensure their long-term viability and success.
5. **Regular Review and Feedback Mechanisms:** Implement a system for regular review and feedback involving community members to continuously improve the cultural appropriateness and effectiveness of VAD services offered to Aboriginal people.
6. **Research and Evaluation:** Conduct ongoing research and evaluation to monitor the effectiveness of implemented changes and continuously improve VAD services for Aboriginal and Torres Strait Islander communities.

Conclusion

These recommendations aim to enhance the support for Aboriginal and Torres Strait Islander peoples in accessing VAD. By addressing educational needs, enhancing cultural safety, establishing supportive structures, advocating for policy changes, incorporating traditional practices, improving pain management resources, and ensuring regular community feedback, we can create a more inclusive and respectful end-of-life care system. This approach will help mitigate the distress and trauma experienced by those who have faced discrimination, such as members of the Stolen Generations, ensuring their end-of-life journey is dignified and culturally appropriate.

Karabena Consulting

Introduction and Methodology

To comprehensively evaluate the first four years of the Victorian *Voluntary Assisted Dying Act 2017* (the Act), the Centre for Evaluation and Research Evidence (CERE) engaged Karabena Consulting, a Torres Strait Islander woman-owned and led organisation. Karabena Consulting was tasked with leading culturally sensitive data collection with Aboriginal and Torres Strait Islander people and service providers. With a deep understanding of cultural nuances, and because of the recent work supporting Aboriginal and Torres Strait Islander people through their cancer journey, Karabena Consulting completed consultations focused on Aboriginal and Torres Strait Islander people's experiences of death and dying, and the accessibility of voluntary assisted dying (VAD). Our consultations focused on the following questions:

1. To what extent do VAD systems, processes, and practices meet the needs of First Nations communities?
2. What were the barriers and enablers to First Nations compliance, understanding, and operation of the Act?
3. To what extent were VAD systems, processes and practices timely, safe and compassionate for First Nations communities?

The outcomes will significantly contribute to the evidence on the appropriateness, effectiveness, and impact of the Act's operations for Victoria's First Peoples. We interviewed 13 stakeholders using semi-structured, open-ended questions, maintaining confidentiality and respecting cultural sensitivities. We developed flyers and reached out to individuals we had engaged through projects related to culturally safe cancer care, as well as members of the community who had experienced the loss of loved ones. We spoke with men and women both online and face-to-face, including those whose family members, partners and children had passed away in hospitals, palliative care facilities, and at home. Most people's experiences were framed by a hospital context. We also spoke with family members caring for parents who wanted a 'self-determined death' and wished to die at home. Additionally, we engaged staff working in palliative care, funeral homes, pharmacists, and Statewide VAD Care Navigators.

As a result of the VAD workshop with Elders at a community organisation, these professionals have been invited to conduct a workshop on advance care planning and VAD options. These are important, though rarely discussed, educational programs needed in the community. Thus, the project achieved both evaluation outcomes and community education outcomes.

In large part, these outcomes can be attributed to the use of Indigenous research methodologies, including Dadirri (deep listening) and yarning (informal two-way conversation). These methods ensure the integrity, respect and safety of Aboriginal and Torres Strait Islander people throughout the consultation process. Data from interviews were audio-recorded, transcribed, and analysed using inductive thematic analysis techniques.

Experiences of Death and Dying

The experiences of death and dying among First Nations peoples are deeply influenced by cultural, spiritual and historical contexts. This section explores the various dimensions of end-of-life care for Aboriginal and Torres Strait Islander communities, highlighting the importance of culturally sensitive practices, the role of family and community, and the need for healing and dignity in end-of-life processes. By integrating quotes from stakeholders, we aim to provide a nuanced understanding of how VAD can be approached in a way that honours the values and traditions of First Nations peoples. This exploration highlights the necessity for an enabling environment that respects individual autonomy, promotes informed decision making, and addresses the complex emotional and cultural layers involved in end-of-life care.

End-of-life care disparities

Disparities exist in access to both end-of-life care and resources, influenced by geographical location and socioeconomic status. Achieving equitable support for all individuals necessitates addressing systemic barriers to ensure universal access to comprehensive care options.

Trauma and colonisation

There are lingering effects of trauma and colonisation on Aboriginal and Torres Strait Islander communities' experiences of death and dying. There needs to be acknowledgment and redress of historical injustices while advocating for culturally sensitive end-of-life care practices that respect Aboriginal and Torres Strait Islander perspectives and traditions.

Role of family and community

Our evaluation found that for Aboriginal and Torres Strait Islander people, within the context of VAD, families and communities have not been allowed to be part of the process of having open communication, understanding, and respect for individual choices within familial and cultural contexts. Stakeholders noted that a major reason why there is a low uptake of VAD among Aboriginal and Torres Strait Islander people is because these conversations are not happening early enough.

One participant expressed, ***'I think we all need to be on the right page and have the best interests of the patient at heart. And then I don't think we can go wrong, to be honest, if we're on the same page, but thinking about the best possible care for that patient'***.

Another shared, ***'Sometimes us the living ones hold on to the person that's passing so they know that that person is hanging on and until they're okay, they're not going to go. So I think with voluntary assisted dying, I think that it's not just about the person that is about to pass, it's about everyone around them and they need to be able to understand it and give their permission for that person to pass as well. And then I think it's a much easier passage for them to do what they need. So I'm all for it, to be honest. I'd never ever want to see, I've seen a few people… when [they] passed in so much pain, so I think that when, you know, if you're still of the right mind, well then you need to be able to make that decision'***.

Cultural beliefs, spirituality and religious influences

Cultural and religious backgrounds among Aboriginal and Torres Strait Islander communities significantly influence their attitudes towards VAD. Stakeholders noted spirituality is important in how individuals and communities perceive and handle end-of-life decisions rather than systemic processes or practices. The community argued it needs to reclaim spirituality to cope with the fear surrounding death, particularly when considering VAD.

One participant emphasised, ***'I think people need to understand that when you are passing, your loved ones that are in spirit will be there to help you cross over as well. And I think a lot of people are scared of that, those ideas and those sorts of things, but it is really, really something that's real'***.

Another reflected on cultural traditions: ***'For a really long time, like going back to when I was a kid, there was this notion that Dad had, that when your time is up, you accept it. And, and I think that acceptance helped us when he was dying because we knew he knew his time was up and could accept it. I was reading a story about Dad's great-great-grandmother recently, and she'd said that when an old person in the area that she came from knew they were close to death, they would go and lie down next to where they were going to be buried. It was just that acceptance and that's something that Dad had.'***

Additionally, another participant discussed the importance of spiritual guides: ***'Maybe there's a journeyman somewhere in the culture who comes in and says, listen I'm going to help you mob go through this journey. And they take them out of the bush and sit out there knowing time's getting near.'***

The integration of cultural beliefs and practices into end-of-life care is important. One participant mentioned, ***'I think there's a medical way of doing things and then I also think we've got our spiritual way of doing things that can be blended in a really beautiful, safe way and a really… one for everyone to have the healing. Because when spirit leaves, there's a part of us that dies and grieves and goes with them and vice versa. So I think it can help and by talking or whether there's smoking or there's music or conversation, something that will change that for everyone to help, but I really think it's, you got to talk about it early'.***

Stakeholder insights on choice and control

Our evaluation highlighted the importance of choice and control in end-of-life care from an Aboriginal and Torres Strait Islander perspective. Participants suggested the need for expanded options and choices, including natural and alternative methods.

One participant pointed out, ***'People are not knowing [the] choice. They're not even knowing [the] choice about how to bury someone differently… and some people have got all these different ways of thinking about it. I just noticed being a part of the funeral service… people don't know that they have [a] choice'.***

Another reflected on personal autonomy, ***'I thought about it. I don't know if I want to donate my organs now… and you know that's pushed into people a lot about donating organs and you're doing a better thing, but how do you keep intact about your own spirituality? We shouldn't be made to sort of feel guilty about we're going to take our organs with us, we should be able to make it, it's just a whole part of the package. How do we want to go? If we're making decisions about giving up our organs, we need to talk a bit more about that as well… That could be the time to go, what about voluntary death? That should be brought up in there… It's about the person, not what we can get from you when you're gone, it's actually how do I go in a peaceful manner? And I need to be in control about that'.***

Our evaluation revealed the need to prioritise cultural safety and respect for diverse traditions and beliefs in end-of-life care, particularly from an Aboriginal and Torres Strait Islander viewpoint. Equitable support and the integration of cultural practices are critical for ensuring comprehensive and respectful care experiences for all.

Improving VAD service experience for First Nations people

Some stakeholders believe that creating an enabling environment that facilitates informed decision making is key for First Nations people seeking advice, support or information about this particular way of dying. They suggested it would be beneficial for individuals at the end of their lives to have a dedicated professional to guide these discussions while respecting the autonomy and cultural values of the person involved. These meetings would allow family members to come together, understand the wishes of their loved ones, and determine how they can support them. This approach helps address any potential misconceptions or concerns, ensuring that the individual's decisions are respected and supported. Additionally, it addresses the cultural and emotional complexities involved in discussing end-of-life decisions, especially in communities where stoicism and resilience are highly valued traits.

One stakeholder stated, ***'Someone should have a conversation with them, even though it's going to be their decision'.***

Another shared, ***'VAD needs to be an option. You know, it's like it can be really hard, but when we [Aboriginal Hospital Liaison] go into an appointment with a patient and it's not looking great for them … and the doctors want to cure or they want to do their thing. A couple of times when I've been in appointments and the doctor said, 'you can do this or you can do this, these are the side effects of this treatment, these are the side effects of this one', and I've actually turned around and said to the patient, 'the other option is always that you could do nothing'. Because doctors, they just don't say that and a lot of mob will just go along with it because that's what the doctor said. And it's a shame job if you question them. And I think that there needs to be, you know, more widely known that you don't have to do what the doctor says'.***

Healing trauma

It is key to incorporate healing into end-of-life processes, not only for the patient but also for those surrounding them. Witnessing loved ones' suffering and navigating the health care system is traumatic.

The opportunity to have open dialogue and support to address past traumas and promote healing in end-of-life care is required.

One participant mentioned, ***‘It’s also healing. If we had such traumatic lives, it still can be a part of the healing process if we can control how we go. If we can make our families feel good and make them feel fine, you know, it's OK, I know what's happening and this is what I want, and all I want is to be assisted in how to go and that shouldn't be a real medical trauma’.***

Another noted, ***‘If we talk about it as in healing, it’s not just that person that is about to pass. It’s everyone that’s involved with that person’.***

A further reflection was, ***‘I think it is truly about that healing side of things because, you know, you hear a lot, especially men will say ‘I’m not scared about dying’… but when it comes to the nitty gritty, [people] are scared of being scared of passing which is really understandable. You know, no one really wants to die to be honest. But if that healing process has started, where they are able to start their healing process about passing away, I think that plays a big part in it too. So I think that, you know, there needs to be that work done with people that may be able to use this VAD. And I think that's really important to be able to have that, I suppose, that pre-passing but then after the passing as well, there needs to be a lot of work done as well’.***

Quality of life and death

We need to focus on the quality of life and death, so that people can have peaceful and dignified endings. It is necessary to have comprehensive end-of-life care options that prioritise individual preferences and values, ensuring that individuals can die with comfort and respect.

One stakeholder observed, ***‘We do have our elderly people who are older and frail but then actually diagnostically have [nothing] wrong with them, and then they still can't access [care]. I've been almost like everybody else, but I've been pretty fit and strong my life. And it's not ever something that I would have contemplated until, until I got what I've got’.***

Another shared, ***‘…Watching people not have quality of life… we need to be in control of how we die’.***

A particularly heartfelt account was, ***‘[The nurse] had been giving her… some drug to assist with there not being pain when you are in the last week or so of dying. But she was still breathing but she wasn't there. And she was like skeletal. It was terrible. It was like she was frozen in time. And all you could hear was this gurgling noise, which was her dying, which was fucking awful. I think, if it's possible for assistance when you're like that, just do it’.***

Our evaluation shows the need to promote cultural safety and respect for diverse traditions and beliefs in end-of-life care, particularly from an Aboriginal and Torres Strait Islander viewpoint. Equitable support and the integration of cultural practices are required for ensuring comprehensive and respectful care experiences for all.

Implications for VAD and First Peoples in Victoria

In considering the Act and other legislation in Victoria, it is vital to prioritise cultural perspectives in end-of-life care for Aboriginal and Torres Strait Islander peoples. Cultural safety must be ensured, respecting diverse traditions and beliefs surrounding death. Stakeholders argued for expanded options and choices in end-of-life care, including natural and alternative methods.

Creating an enabling environment that facilitates informed decision making is needed. Dedicated professionals should guide these discussions, respecting the autonomy and cultural values of the individuals involved. This approach allows family members to come together, understand their loved ones' wishes and support them, addressing potential misconceptions or concerns and ensuring that the individual's decisions are respected and supported.

Healing should be incorporated into end-of-life processes, not only for the patient but also for those surrounding them. Witnessing loved ones' suffering and navigating the health care system can be traumatic, so open dialogue and support to address past traumas and promote healing in end-of-life care are important. Focusing on quality of life and death is needed to ensure individuals can have peaceful and dignified endings. Comprehensive end-of-life care options should prioritise individual preferences and values, allowing individuals to die with comfort and respect.

Challenges in navigating end-of-life care include access to appropriate services, managing pain and symptoms, and addressing individual preferences and needs. Improved support systems are needed to address these challenges. Additionally, revitalising and teaching Aboriginal stories and traditions around death, which are rich with lessons about life's responsibilities and the cycle of life, would help communities understand and integrate the concept of death more widely.

By addressing these considerations and incorporating them into the operationalisation of the Act and other legislation, we can ensure that end-of-life care for Aboriginal and Torres Strait Islander peoples in Victoria is respectful, dignified and culturally appropriate.

Project Findings – Emerging Themes

VAD systems, processes and practices

To what extent do VAD systems, processes and practices appropriately meet the needs of First Nations communities?

Transactional end-of-life care

Aboriginal stakeholders were of the view that the current VAD systems, processes and practices do not fit well with the cultural values of First Nations communities. They pointed out that the current approach to end-of-life care is too transactional/business-like and impersonal. It does not respect the cultural and personal connections that are important in Aboriginal traditions. For them, the VAD practices do not create a safe and welcoming space for Aboriginal people, often ignoring the important role of community during this critical time. A stakeholder recalled:

'...it's still very transactional, which is the Western consciousness. It's incredibly, you know, transactional and linear… everything was medical. There was no sense of relationships or so, for me, that is not culturally safe. Because you have to have those around you that journey through that with you. Despite the compassion and the understanding. I don't consider that very cultural now.'

Our evaluation shows a clear need to change how end-of-life care that may potentially lead to engaging in VAD is handled to make sure it respects and includes the cultural needs of Aboriginal communities.

Aboriginal-led VAD processes

A prominent theme from the discussions was that the VAD systems, processes and practices are insufficient because they lack Aboriginal leadership. Our evaluation revealed that Aboriginal communities strongly believe that VAD processes should be led by Aboriginal people, especially for First Nations Victorians seeking access to VAD. They argued that this leadership is required to ensure the practices are culturally respectful and appropriately tailored to meet their specific needs.

'If [we] are going to improve the services for First Nations Victorians who are trying to seek access to voluntary assisted dying, I would like to be guided by someone with skills within Aboriginal Health [workers] to be able to feel comfortable to have conversations.'

This approach would help in building trust and making the services more accessible and relevant to Aboriginal communities.

Self-determination, autonomy and dignity

Another key theme that emerged is the lack of self-determination and autonomy within these systems. Stakeholders raised the importance of respecting individual rights and the self-determination of Aboriginal people in making end-of-life decisions. They expressed a strong desire to have their end-of-life wishes respected as most times there are tensions between medical intervention and the personal desires of the patients and their families, particularly concerning powers of attorney.

'...People that are watching you make these decisions gasped at the reality that you're making a choice and what happens if the issue of a power of attorney is present and other people have to make choices, but the individual had already made their choice known'

In another instance, a stakeholder expressed: ***'It's about honouring the individual in our lives, respecting their wishes, and celebrating their life as they requested.'***

Others highlighted the importance of genuinely listening to what the community wants: ***'I think it's about that real authentic voice of listening to what mob really want.'*** Additionally, the sentiment was shared that when individuals are mentally capable, they should have the right to decide their own end-of-life timing and manner: ***'If you're in the right mind and you've said your goodbyes, it's really that person's right to say, this is my time now.'***

'It's absolutely dreadful, because [this] is all about trying to get control at the end of life. But when you go through the assessment process, you actually relinquish all control, [because] you need to be assessed by two doctors, and they need to apply for [a permit] to find that you're eligible when they get the [permit]. So you're at the mercy of others.'

Our evaluation also found that it is important to consider the difference between self-determined death, where community members maintain control over their end-of-life experience without formal assistance, and VAD, which involves legal and medical processes.

> ***'[People discuss] how your burial is going to be, or your after-death experience is going to be, what about how you want to die? That is not on the table. How many of our families actually do suicide themselves? Which is, in that sense, it's a terrible word for that. To me, I think that suicide is a violent thing. This is not violent, is it?'***

For Aboriginal communities, having control over their own end-of-life process, including the timing and manner of death is important.

Resource allocation

Stakeholders shared their experiences regarding the availability and support of VAD doctors, navigators, hospital coordinators and pharmacists. They noted that the limited information on VAD among Aboriginal people, combined with the resource constraints of these professionals, hampers the effectiveness of VAD systems in meeting the needs of First Nations communities. Our evaluation found that there is a notable absence of support within the current system, suggesting that there are no dedicated personnel available to guide or support Aboriginal people and their families through the process of VAD. A stakeholder expressed a concern that, within the context of resource allocation, the establishment of such roles has not been prioritised particularly in regional areas.

> ***'…We don't have those [Aboriginal] navigators. We don't have people that can walk beside us or anything like that, because that's just another resource and there's other more, more important resources to have in your hospital. No one came near us. No one really came to us and asked, what support do we need?'***

One stakeholder suggested: ***'I think [we] should have as many or intermediaries [including] Indigenous health workers who might want to train in this area.'***

Discussion

The evaluation has highlighted several critical issues and implications for recommendations concerning VAD systems, processes and practices for Aboriginal and Torres Strait Islander peoples in Victoria. Firstly, the current transactional and impersonal nature of end-of-life care does not align with the cultural values and needs of First Nations communities, indicating a need for more culturally respectful and inclusive approaches. There is a strong call for Aboriginal-led VAD processes to ensure culturally appropriate practices and to build trust within the community. The importance of self-determination and autonomy in end-of-life decisions was raised, with stakeholders highlighting the need to respect individual rights and wishes, often in tension with medical interventions.

Additionally, significant resource allocation gaps, especially the absence of Aboriginal navigators and support personnel, must be addressed to improve accessibility and effectiveness of VAD services. Incorporating healing processes into end-of-life care is key, not only for patients but also for their families and communities, to address past traumas and promote collective healing. Promoting quality of life and death, with comprehensive and respectful care options, is required for ensuring dignified and peaceful endings. Lastly, revitalising and integrating Aboriginal stories and traditions around death can help communities better understand and embrace end-of-life concepts. These findings highlight the need for tailored recommendations that respect cultural values, enhance self-determination, ensure adequate resources, and promote holistic and dignified end-of-life care for Aboriginal and Torres Strait Islander peoples.

Barriers and enablers

As part of the evaluation, Aboriginal stakeholders were asked to identify the barriers and enablers to First Nations compliance, understanding, and operation of the Voluntary Assisted Dying (VAD) Act. Their insights provide a comprehensive view of the factors that either hinder or facilitate the effective implementation and uptake of the Act within Aboriginal and Torres Strait Islander communities.

Lack of resources and information

Our evaluation found that there are key concerns around the scarcity of accessible information and support, particularly surrounding VAD. Stakeholders noted that there is a need for improved communication, education, resources and advocacy to empower individuals in making informed decisions about their end-of-life care. Some stakeholders also mentioned that the only term they are familiar with is 'euthanasia' rather than VAD.

> ***'So the question then becomes one of what is the wish of that person in terms of do I want to continue my life journey and put up with the suffering until the end and have a natural death for whatever reason, or would I prefer to actually set a date. I'm out of here, get everything organised. Say goodbye to everyone, and then off we go. And that's where the voluntary assisted dying stuff comes into it. I think the challenge with that though, is people understanding what the [I'll use this term loosely] administrative process is.'***

One critical insight from the consultations is the importance of broadening the scope of information beyond the patients to include their families and friends. This approach helps to ensure that the entire support network understands the available end-of-life options and the rights of the person considering VAD. As one stakeholder noted, ***'I think [what is needed is] a better understanding for everyone, not just the person that's passing. If we could have more information for people that when they go in and not just for them, but for their family and friends as well, I think that goes a long way to helping people and putting people at peace because ultimately that's what we're trying to do… if we can overcome that fear with peace and love, then I think it goes a long way. It's about having more information readily available for people'.***

Stakeholders pointed out the gaps in the community's knowledge and resources concerning VAD, which is often cast as a sensitive and taboo topic. This deficiency in accessible information obstructs the initiation of meaningful discussions about end-of-life options, preventing individuals and their families from engaging fully and openly in these crucial conversations.

> ***'…it's really like a taboo topic in our community, we don't talk about this.'***

Other stakeholders raised the notion that the scarcity of resources extended to online searches and health care settings, where information was either outdated or non-existent, and the need for approval from multiple health care providers posed additional barriers.

Regulatory restrictions on health professionals

Feedback from Aboriginal stakeholders highlighted the regulatory limitations faced by health professionals, including Aboriginal Health Workers, regarding discussions on VAD. Current regulations strictly prohibit these professionals from initiating conversations about VAD with patients. This includes the prohibition of distributing written materials on the subject; the patient must be the one to initiate any discussion related to VAD.

> ***'Health professionals etc. are not permitted to initiate VAD discussions with a patient, including giving a patient written information. The person needs to initiate that. Even then it can be very challenging.'***

> ***'…In Victoria, no one can raise VAD with a person. And so it's a real disadvantage [to] people because the clinicians will have an end of life conversation about options, but it's actually not equity, because they're giving them options except for VAD.'***

This situation creates a disparity in the health care system, as health professionals can discuss various end-of-life options with their patients, except VAD. This restriction is seen as a significant barrier, denying patients a comprehensive understanding of all available options, which is essential for making informed decisions about their end-of-life care.

Limited health conditions eligible for VAD access

During consultations with Aboriginal stakeholders on the implementation of the Act, a key issue that emerged was the restrictive eligibility criteria for accessing VAD. Stakeholders expressed concerns that these criteria are too narrow, effectively excluding individuals with certain health conditions, such as dementia or mental health issues. Specifically, the current requirement that a person must have a life expectancy of six months or less means that those suffering primarily from mental health conditions, without a terminal diagnosis, are unable to utilise VAD. This limitation has raised significant concerns about the accessibility and fairness of the Act.

> ***'Dementia is a huge issue. Some people have what appears to be a good quality of life living with dementia, they remain pleasantly confused enjoying their life until the dementia progresses, until they decline and have a peaceful ending. However, there are some that are agitated, tormented and their quality of life is severely adversely impacted with no relief. Palliative sedation can ease physical and psychological distress at the end of life, however some people want VAD before the end of life.'***

Furthermore, stakeholders highlighted that in cases where an individual experiences mental anguish or suicidal ideation alongside a physical illness, the current procedure involves the coordinating medical practitioner seeking a specialist opinion, such as from a psychiatrist. While this step is relevant for a thorough evaluation of an individual's mental health status, the approach also inhibits the need for broader considerations in the eligibility criteria, to ensure that all aspects of a person's health, both mental and physical, are appropriately addressed in the decision-making process.

Reluctance from family

Family and community play a pivotal role in navigating end-of-life care. Decisions about end-of-life care frequently involve family conflict. A point highlighted by Aboriginal stakeholders is the reluctance from family members to First Nations compliance, understanding, and operation of the Act. We found that this hesitation can stem from a variety of factors such as denial and unwillingness to engage with the process, leading to potential conflicts. A stakeholder noted, ***'there will be some people within the family who will absolutely not accept it, will put them on life support, and say, "don't turn them off because we don't want them to die"'.***

In the same vein, one stakeholder recalled:

> ***'She [my sister] was on machines. But the husband and the kids were still holding on but the poor woman was in pain. So it would have been helpful for her to be able to have this choice.'***

> ***'You've got people that are in palliative care, and their family members refuse to let them go.'***

Our evaluation found that families often insist on treatment and refuse to discuss alternative options, creating a pervasive sense of denial that is deeply saddening.

Cultural acceptance and stigma

Our evaluation found that within Aboriginal communities, there are ongoing challenges and taboos associated with death, including the reluctance to openly discuss end-of-life preferences and the stigma associated with choices like VAD.

> ***'I think mob's so scared to talk about death. I think that unknown, as spiritual as we are, there's still that fear. I think we've got to get okay with going, okay I want to be cremated, I want to be buried, I want my ashes spread out here or whatever. But I think there's got to be that one person in family that you do have that conversation with…'***

VAD health care professionals database

In discussions with Aboriginal stakeholders about the implementation of the Act, a key enabler identified was the creation of a registry of Aboriginal health care professionals who support VAD. This registry would serve an important role by allowing individuals to make informed decisions when selecting medical practitioners (particularly those who identify as Aboriginal and/or Torres Strait Islander). The goal is to ensure that people receive support from compassionate health care professionals who respect and facilitate their end-of-life choices, thereby upholding the dignity of their final wishes.

> ***'...We have a register, for donating our organs and all that kind, which is really interesting, because they're our wishes and we put them on our licence. Nothing's really said about that. But once you start talking about being assisted to die, it goes against the grain.'***

Such a measure would not only promote autonomy but also protect against undue influence during these sensitive decisions.

Modifying VAD services for better access

A supportive measure identified was the need to modify or adapt the VAD services to improve accessibility for those in need. This change would not only provide relief but also a sense of security to those considering VAD, knowing that it remains an available option, thus protecting their right to choose their own end-of-life journey.

> ***'I truly hope that the VAD service is modified to improve access to those wanting it, even if it's just easier to access the information. Some people may never go through with it, but just knowing they can is a safeguard.'***

This adaptation ensures that the dignity of choice is both respected and facilitated, offering peace of mind to those considering their future. As a stakeholder stated, ***'there was someone who wanted to know about VAD, and they had the script, but they never ever used it. Just knowing it was there as an option was enough'.***

Effective pain management

Aboriginal stakeholders discussed the importance of effective pain management for terminally ill patients. This aspect is considered a key enabler for improving compliance and understanding of the Act, as well as enhancing the quality of life during the final stages of illness.

> ***'I don't think [he] thought he had an option of going, "can I get out of this quicker because I'm in so much pain?" And by the time he got to that point, there was nothing that could help him with pain. Because he was in so much pain… and I think people need to know that [VAD] is a choice, that you can ask.'***

One stakeholder shared the painful experience of a relative, including the severity of his suffering. They recounted, ***'...In those last few days, if he [could have] been able to pass away, he would have because he was in that much pain and he was suffering that much. We heard him on the phone and he was just crying in pain and that's not [him]'.***

This testimony shows the impact that effective pain management has on end-of-life experiences and how integral it is to the dignity and quality of life of terminally ill individuals. The ability to alleviate severe pain not only transforms the final days for the patient but also deeply affects their loved ones. When patients are made aware of VAD as an available option, it offers a meaningful choice to those enduring unbearable pain, providing a pathway to alleviate suffering and uphold the dignity of those nearing the end of life.

Advance care plan

One key enabler to First Nations compliance, understanding, and operation of the Act is advance care planning. Despite the availability of services like palliative care, many people often avoid engaging in advance care planning. This highlights the need for proactive discussions about end-of-life preferences.

Stakeholders noted that many Aboriginal people find themselves in difficult end-of-life situations. In these moments, making informed decisions can be challenging and often someone else must step in, particularly regarding pain management, where death might be a possible outcome.

One stakeholder shared a story about her sister who was in end-of-life care for cancer. She expressed that when her sister had been able to speak and engage in discussions earlier, an advance care plan, including the opportunity to access VAD, would have significantly helped. This experience shows the importance of having these conversations early, while individuals are still capable of making their own decisions.

For many Aboriginal individuals and families, discussing death is uncomfortable, yet necessary. One person noted, ***'A lot of people don't like to talk about passing, which is understandable, but the conversation needs to happen much earlier'.***

> ***'Mum and Dad had been very upfront about their wishes over quite a number of years. They'd already prepaid their funerals, so they already had that in hand, and what they wanted to do in terms of resuscitation, they'd been very open about that, and what they wanted to do with their bodies once they'd passed. That had been a conversation we'd had for a long time. That conversation helped us through the experience of Dad dying.'***

A request for VAD in an advance care plan helps to have a structure to have those important conversations with those that we love and those around us. These conversations become part of the last wishes – the pain management experience an individual wants to have, designating who will communicate on one's behalf to other family members etc. This clarity helps to spell everything out, leaving nothing unsaid. One stakeholder considered this ***'an act of love towards the family and community and that by planning ahead, you remove the burden of making difficult decisions from your loved ones, alleviating them from the guilt and stress of those choices'.***

Early conversations about advance care planning can ensure that people are prepared and can work through their preferences for end-of-life care and facilitate better compliance, access and understanding of the Act for First Nations people.

The language and practices of end-of-life care

The narratives and language used by end-of-life practitioners, including palliative care professionals and those involved in the VAD process, play a role in shaping the experiences of individuals facing terminal illnesses. However, these narratives often lean towards clinical efficiency and risk reduction, focusing on meeting legislative requirements rather than providing culturally sensitive care. This clinical focus can inadvertently create a cold and impersonal atmosphere, particularly for Aboriginal and Torres Strait Islander people who value relational and community-based approaches to care.

The impact on Aboriginal and Torres Strait Islander peoples

For many Aboriginal and Torres Strait Islander individuals, the process of seeking a VAD permit can be distressing and triggering, especially for those who have faced lifelong discrimination and are members of the Stolen Generations. The requirement to obtain permission from a non-Indigenous authority to end one's life evokes deep-seated trauma and feelings of disempowerment. As one participant emotionally noted, ***'Imagine having to ask permission to die from the very system that once denied your right to live as an Aboriginal person'***. This statement encapsulates the pain and indignity felt by those who must navigate a system that has historically oppressed them.

By shifting the narrative from one of clinical compliance to one of cultural care and compassion, end-of-life practitioners can help alleviate the trauma and distress experienced by Aboriginal and Torres Strait Islander peoples. This change is needed to ensure that the end-of-life journey is as dignified and respectful as possible, honouring the individual's life and cultural heritage.

Impact of VAD systems, processes and practices

To what extent were VAD systems, processes and practises timely, safe and compassionate for First Nations communities?

Support from health workers

It is evident from our evaluation that there is a low uptake of VAD by Aboriginal people. One reason stakeholders believed VAD systems, processes and practices might not have been timely, safe and compassionate for Aboriginal people is the inadequate training and support from health care workers.

A stakeholder recounted how an elderly family member, in the final stages of life, was moved from palliative care to a rehabilitation ward—an environment ill-suited for end-of-life care, characterised by minimal intervention and support. Family members were dismayed and in shock from watching their loved one through this phase. Another stakeholder recalled:

> ***'…my own father was in an Aboriginal ACF. The week he passed I got a call from the ACF saying he had a choking episode and was very unwell. I did tell the staff he most likely aspirated and got Pneumonia and to keep him comfortable and he was not for hospital. The staff ignored me and sent him to hospital. My Dad had [always] expressed he never wanted to be kept alive if his quality of life would be impacted adversely. He passed away 1 week later, and we were by his side to ensure he got the care he needed.'***

The stakeholder pondered whether a more proactive approach to discussing VAD might have alleviated some of the trauma experienced by both the patient and his family.

In contrast, a stakeholder described how the health care system and the VAD processes provided safe, timely and compassionate support. They recounted the case of a young man in his thirties who was in the palliative care ward and chose to pursue VAD. He insisted on receiving the procedure at a hospital closer to his home. The staff facilitated this request, arranging for his transfer to a nearby palliative care ward. Throughout the process, he obtained all necessary consents from various doctors within the hospital. Similarly, one of our stakeholders recalled:

> ***'During COVID we had a palliative patient from Western Australia who had been over here for about 10 years. She was having treatment that whole time and then it came near the end. It was really hard to get anyone back to WA but we made it happen. It was tough, but we did it.'***

These examples highlight the mixed impact of the VAD systems and processes in terms of being safe, timely and compassionate for First Nations people.

Self-harm due to lack of opportunities

Aboriginal stakeholders are of the view that because of the lengthy and time-consuming process, the current VAD systems and processes are putting Aboriginal people at risk of self-harm. We found that there is a distressing tendency within the Aboriginal communities to resort to self-harm or suicide due to perceived prolonged suffering, especially when they feel that all other avenues (including VAD) for relief are closed to them. Stakeholders noted that the VAD process, which involves a lengthy and complex permit-assessment procedure, stringent eligibility criteria, and the need for approval from two doctors, often feels burdensome and inaccessible.

> ***'VAD has got to be easier than suicide. You know, at least you can bring people along with you on a journey rather than just do it quietly by yourself at a great deal of risk.'***

> ***'It's knowing that it is an option or a choice that I can make, rather than it not being there. The other option to VAD is suicide. In VAD you're letting your loved ones know this is your choice, and I would like to use this whereas suicide ... people do it alone, for the most part.'***

A stakeholder reported observing several distressing cases where Aboriginal individuals diagnosed with dementia or suffering from long-term, treatment-resistant mental health conditions like depression and schizophrenia expressed a wish to die. These individuals often resorted to severe self-harm before being admitted for care. Tragically, in one instance, the stakeholder stated an individual took their own life shortly after being discharged.

VAD medication and administration

Our evaluation found the current VAD process, systems and practices in terms of VAD medication and administration appear to be safe, timely and compassionate. Currently, support personnel like pharmacists visit patients in their homes, ensuring comfort and familiarity for the patients. The entire process is patient driven. Pharmacists can stay during medication administration and typically provide information, respecting patients' autonomy and decision making. One stakeholder noted:

> ***'There are always two pharmacists that go out and visit these patients. The whole process is driven by patients. So at no point in time we make contact or make initial contact with the patients or the family members. We can only go out and visit these patients when they call us.'***

Moreover, we found that the operational framework of the VAD service includes detailed procedures for pharmacist visits, prescription handling and patient support. Protocols ensure patient safety, with options for medication storage and administration discussed with patients.

> ***'In terms of storage, the legal requirement is that the substance needs to be kept in the lockbox that we supply [a steel box with a key]. If we have any concerns, say family members, or friends accessing the medication when it's kept at home. We will most likely not leave it there.'***

In terms of training, support personnel undergo comprehensive training and adapt their approach based on cultural considerations. Team debriefs, individual reflections, and access to mental health professionals help manage vicarious trauma and maintain wellbeing. They also undertake training on difficult conversations, cultural awareness, psychological first aid, as well as grief and bereavement support. Although patients have the option of having a support person (family or friends), support personnel prioritise maintaining confidentiality and discretion during the visits.

Recommendations

To enhance the understanding and accessibility of VAD for Aboriginal and Torres Strait Islander peoples, we have developed a comprehensive program of actionable recommendations. These recommendations are categorised into short-term (0-12 months), medium-term (1-2 years), and long-term (3-5 years) actions to ensure immediate, sustained and future improvements in culturally sensitive end-of-life care. The proposed measures aim to address educational needs, enhance cultural safety, establish supportive structures, advocate for policy changes, incorporate traditional practices, improve pain management resources, and ensure regular community feedback. By implementing these recommendations, we can create a more inclusive, respectful and supportive system for Aboriginal and Torres Strait Islander peoples considering VAD, ensuring their end-of-life journey is dignified and culturally appropriate.

Short-term Actions (0-1 year)

Enhance Community Education and Awareness about VAD

Develop and disseminate culturally tailored community educational materials that explain VAD, focusing on pain management and the availability of this option. Use stories, case studies, and testimonials from within the community to make the information more relatable and less intimidating.

Train and Employ Aboriginal Health Workers in VAD Processes

Invest in training for Aboriginal Health Workers to specialise in VAD processes, ensuring that they can advocate effectively for patients and guide them through the VAD process with understanding and respect for cultural values.

Promote Open Conversations About Death and Dying

Organise community forums and discussion groups to talk openly about death, dying and VAD. These should aim to reduce stigma and fear associated with talking about death and foster a more supportive environment for discussing end-of-life choices.

Medium-term Actions (1-3 years)

Establish Aboriginal-led Support Teams

Create support teams consisting of Aboriginal Health Workers, spiritual advisors, and community Elders to assist patients and families through the VAD process. This team would ensure that all aspects of the patient's cultural, spiritual and emotional needs are met.

Advance Care Planning Workshops

Organise workshops on advance care planning and VAD options, led by Aboriginal Elders and health professionals, to educate and empower communities.

Long-term Actions (3-5 years)

Advocate for Policy Changes to Support Culturally Safe VAD

Work with policymakers to adapt VAD legislation and health care practices to be more inclusive and reflective of Aboriginal cultural practices and values. This could involve amendments that allow greater family involvement and community consultation in the decision-making process.

Regular Review and Feedback Mechanisms

Implement a system for regular review and feedback involving community members to continuously improve the cultural appropriateness and effectiveness of VAD services offered to Aboriginal people.

Research and Evaluation

Conduct ongoing research and evaluation to monitor the effectiveness of implemented changes and continuously improve VAD services for Aboriginal and Torres Strait Islander communities.

Broader recommendations relating to palliative care

Inclusive Language Guidelines

Develop and distribute guidelines for using inclusive and culturally sensitive language in end-of-life care communications and documentation.

Community Consultations

Conduct regular consultations with Aboriginal and Torres Strait Islander communities to gather input and feedback on VAD processes and ensure their voices are heard and respected.

Cultural Safety Audits

Perform audits of current VAD practices and environments to identify and address areas lacking cultural safety.

Develop Cultural Safety Training for Health Care Providers

Provide cultural safety training for all health care providers involved in end-of-life care, focusing on understanding and respecting Aboriginal cultural practices and values. This training should help providers recognise the importance of a holistic approach that includes physical, spiritual and community health.

Holistic Care Models

Develop and implement holistic care models that integrate physical, emotional, spiritual and cultural aspects of end-of-life care.

Incorporate Traditional Practices and Rituals

Encourage and facilitate the inclusion of traditional Aboriginal practices and rituals in the end-of-life care plan. This could include ceremonies, storytelling, or other culturally significant activities that honour the patient's life and heritage.

Improve Access to Pain Management Resources

Ensure that all patients have access to effective pain management options. This involves training more health care providers in pain management techniques and ensuring that these resources are readily available in Aboriginal communities.

Sustainable Funding

Secure sustainable funding for Aboriginal-led VAD programs and initiatives to ensure their long-term viability and success.

Conclusion

These recommendations aim to enhance the support for Aboriginal and Torres Strait Islander peoples in accessing VAD. By addressing educational needs, enhancing cultural safety, establishing supportive structures, advocating for policy changes, incorporating traditional practices, improving pain management resources, and ensuring regular community feedback, we can create a more inclusive and respectful end-of-life care system. This approach will help mitigate the profound distress and trauma experienced by those who have faced discrimination and are part of the Stolen Generations, ensuring their end-of-life journey is dignified and culturally appropriate.

Appendices

Appendix 1: Quotes and Themes

Role of Family and Community	*'I think we all need to be on the right page and have the best interests of the patient at heart. And then I don't think we can go wrong, to be honest, if we're on the same page, but thinking about the best possible care for that patient.'* *'Sometimes us as the living ones hold on to the person that's passing so they know that that person is hanging on and until they're okay, they're not going to go. So I think with voluntary assisted dying, I think that it's not just about the person that is about to pass, it's about everyone around them and they need to be able to understand it and give their permission for that person to pass as well. And then I think it's a much easier passage for them to do what they need. So I'm all for it, to be honest. I'd never ever want to see, I've seen a few people… when [they] passed in so much pain, so I think that when, you know, if you're still of the right mind, well then you need to be able to make that decision.'* *'Until we get that balance right where, you know, the people that we're leaving are okay with it, then I think that the VAD, I think patients will be more looking for that, if you like.'* *'For a really long time, like going back to when I was a kid, there was this notion that Dad had, that when your time is up, you accept it. And, and I think that acceptance helped us when he was dying because we knew he knew his time was up and could accept it. I was reading a story about Dad's great-great-grandmother recently, and she'd said that when an old person in the area that she came from knew they were close to death, they would go and lie down next to where they were going to be buried. It was just that acceptance and that's something that Dad had.'*
Cultural Beliefs, Spirituality and Religious Influences	*'Maybe there's a journeyman somewhere in the culture who comes in and says, listen I'm going to help you mob go through this journey. And they take them out the bush and sit out there knowing time's getting near.'* *'I think people need to understand that when you are passing, your loved ones that are in spirit will be there to help you cross over as well. And I think a lot of people are scared of that, those ideas and those sort of things, but it is really, really something that's real.'* *'How can we get back to our own spirituality here? How do we be in a situation where we can make our own decision?... Isn't that part of that whole process of colonisation that we were made Christians? Isn't this*

	part of decolonisation as well?... and so we have that decision making about our life. You should be able to have our decisions about life and about death.' *'We dream a lot … we see our old fellas in our dreams and we know they're coming. We've gotta get some of these guys to see that they're coming and they're coming to take you with them and they're coming to take you home. You need to have that in the language.'* *'I really think from what I've learned working in the funeral service… there was always a conflict when [death occurred] in a hospital. If someone was at home, there'd be a different story of the experience of them passing… and I really feel that those that pass at home pass a lot easier than what they would in the hospital.'* *'I thought about it. I don't know if I want to donate my organs now… and you know that's pushed in to people a lot about donating organs and you're doing a better thing, but how do you keep intact about your own spirituality? We shouldn't be made to sort of feel guilty about we're going to take our organs with us, we should be able to make, it's just a whole part of the package. How do we want to go? If we're making decisions about giving up our organs, we need to talk a bit more about that as well… That could be the time to go, what about voluntary death? That should be brought up in there… It's about the person, not what we can get from you when you're gone, it's actually how do I go in a peaceful manner? And I need to be in control about that.'*
Cultural Perspectives in Death and Dying	*'I just don't think there was enough support from the hospital. I don't think they have enough understanding of our culture.'* *'I think there's a medical way of doing things and then I also think we've got our spiritual way of doing things that can be blended in a really beautiful, safe way and a really… one for everyone to have the healing. Because when spirit leaves, there's a part of us that dies and grieves and goes with them and vice versa. So I think it can help and by talking or whether there's smoking or there's music or conversation, something that will change that for everyone to help, but I really think it's, you got to talk about it early.'* *'People are not knowing choice. They're not even knowing choice about how to bury someone differently… and some people have got all these different ways of thinking about it. I just noticed being a part of the funeral service… people don't know that they have choice.'* *'More and more people are being cremated but families are not happy about that either.'*

	part of decolonisation as well?... and so we have that decision making about our life. You should be able to have our decisions about life and about death.' *'We dream a lot … we see our old fellas in our dreams and we know they're coming. We've gotta get some of these guys to see that they're coming and they're coming to take you with them and they're coming to take you home. You need to have that in the language.'* *'I really think from what I've learned working in the funeral service… there was always a conflict when [death occurred] in a hospital. If someone was at home, there'd be a different story of the experience of them passing… and I really feel that those that pass at home pass a lot easier than what they would in the hospital.'* *'I thought about it. I don't know if I want to donate my organs now… and you know that's pushed in to people a lot about donating organs and you're doing a better thing, but how do you keep intact about your own spirituality? We shouldn't be made to sort of feel guilty about we're going to take our organs with us, we should be able to make, it's just a whole part of the package. How do we want to go? If we're making decisions about giving up our organs, we need to talk a bit more about that as well… That could be the time to go, what about voluntary death? That should be brought up in there… It's about the person, not what we can get from you when you're gone, it's actually how do I go in a peaceful manner? And I need to be in control about that.'*
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	'I had to go and get Nanny Lorna. She's an experienced Elder in births and deaths, the celebration and the passing and I said, 'oh you gotta help me here, Aunty, you gotta help me get my sister home' because I thought, culturally something might be able to help her. And she was lovely. She kind of brought a bit of calmness … she said, 'just let her go now, just let her go'. Like that resonated for us, 'you've got to let her go now, accept that you've got to let her go'. And I think that once that occurred for us, we were all in a better space.'
Improving VAD Service Experience for First Nations	*'… Someone should have a conversation with them, even though it's going to be their decision.'* *'VAD needs to be an option. You know, it's like it can be really hard, but when we [Aboriginal Hospital Liaison] go into an appointment with a patient and it's not looking great for them … and the doctors want to cure or they want to do their thing. A couple of times when I've been in appointments and the doctor said, 'you can do this or you can do this, these are the side effect of this treatment, these are the side effects of this one, and I've actually turned around and said to the patient, 'the other option is always that you could do nothing'. Because doctors they just don't say that and a lot of mob will just go along with it because that's what the doctor said. And it's a shame job if you question them. And I think that there needs to be, you know, more widely known that you don't have to do what the doctor says.'*
Healing Trauma	*'It's also healing. If we had such traumatic lives, it still can be a part of the healing process if we can control how we go. If we can make our families feel good and make them feel fine, you know, it's OK, I know what's happening and this is what I want and all I want is to be assisted in how to go and that shouldn't be a real medical trauma.'* *'If we talk about it as in healing, it's not just that person that is about to pass. It's everyone that's involved with that person.'* *'I think it is truly about that healing side of things because, you know, you hear a lot, especially men will say "I'm not scared about dying"… but when it comes to the nitty gritty, [people] are scared of being scared of passing which is really understandable. You know, no one really wants to die to be honest. But if that healing process has started, where they are able to start their healing process about passing away, I think that plays a big part in it too. So I think that, you know, there needs to be that work done with people that may be able to use this VAD. And I think that's really important to be able to have that, I suppose, that pre-passing but then after the passing as well, there needs to be a lot of work done as well.'*

Quality of Life and Death	*'We do have our elderly people who are older and frail but then actually diagnostically have [nothing] wrong with them, and then they still can't access…'* *'I've been almost like everybody else, but I've been pretty fit and strong my life. And it's not ever something that I would have contemplated until, until I got what I've got.'* *'…Watching people not have quality of life… we need to be in control of how we die.'* *'[The nurse] had been giving her… some drug to assist with there not being pain when you are in the last week or so of dying. But she was still breathing but she wasn't there. And she was like skeletal. It was terrible. It was like she was frozen in time. And all you could hear was this gurgling noise, which was her dying, which was fucking awful. I think, if it's possible for assistance when you're like that, just do it.'*
Navigating End-of-life Care	*'The other thing too, as we know, before this voluntary assisted dying stuff came in, there were people that were saying, I really want to get out of here. And then you had this unfortunate situation of them asking their loved one or a partner or whatever, or their doctor say, look, I really, really, really, really want to go, I don't want to be here anymore. Because I just, I need to move on and sort of end my life journey here. It's about the dignity of death. Is that person wanting to, or able to have a dignified death?'* *'When my sister died, after three days of being in the most awful pain, I know the doctor knew what we were saying and you know what … they probably do it anyway. They're doing this, they're just not calling it VAD.'* *'If Mum fell over and she was never about to walk again or done some real damage, what capacity does she have to actually have assisted dying? She doesn't want to lay in bed and have people come visit her. It would be terrible for everybody. So at what point can you do that? So, you know, my Mum could be a real candidate. She should have that choice. But how do you go about getting that choice?'*
Life-Death-Life	*[We] never spoke about death [this way]. Never did we speak about death [this way]. We just spoke about living.'* *'I don't think anybody has thoughts about assisted dying.'* *'No one really mentions it [VAD], but then it's that whole thing. People don't mention cancer if they can help it, which I think is part of the reason why so many people come to us when they're already palliative.'* *'I think that we just need to be able to talk about it [VAD]. And we need*

	to make sure that we've got the right resources and we need some training.' *'It's like the legislation's there but the practice isn't.'* *'Some people will not acknowledge that death is a part of life's journey. And then might not be prepared for those left behind and what will happen to them in terms of, okay you know, this person's dead now. Some people want to hang on to life for as long as possible, even though you know, their health is challenging for them. And then, in terms of dying, I mean, it comes back to in part whether that person is focusing on quality of life or longevity.'*

Appendix 6: Addendum to Review of the Operation of Victoria's *Voluntary Assisted Dying Act 2017* – Stakeholder feedback regarding legislation

Background

The *Voluntary Assisted Dying Act 2017* (the Act) provides a legal framework for eligible people in prescribed circumstances to choose the manner and timing of their death. The Act came into effect on 19 June 2019.

The Victorian Department of Health (the department) funds a range of functions to enable operation of the Act including the Voluntary Assisted Dying (VAD) Review Board, statewide services such as pharmacy and care navigator services, and VAD support programs. In July 2023, the Centre for Evaluation and Research Evidence (CERE) was commissioned to review the operation of the first four years of the Act from 19 June 2019 to 18 June 2023. The final evaluation report was completed in August 2023.

Although the scope of the review did not include the Act itself, various stakeholders consulted during the review expressed views that some elements of the legislation were resulting in unintended consequences, creating barriers to access and uptake of VAD. This addendum to the review is provided to summarise this feedback and present information for future policy consideration.

Feedback regarding legislation that may impact access to VAD

Restrictions to health practitioners initiating discussion regarding VAD

Section 8 of the Act specifies that a registered health practitioner may not initiate discussion regarding VAD and restricts health practitioners to providing information about VAD only when a patient explicitly requests assistance to end their life. Stakeholders expressed views that this restriction prevents practitioners from offering all available end-of-life options to patients, which in turn limits informed decision-making. Additionally, VAD-registered practitioners report that non-VAD medical practitioners may interpret this requirement too restrictively, particularly regarding first request. Removing this restriction would address this barrier to access. Alternatively, improved guidance could provide greater clarity on what doctors can and cannot say to patients.

Organisations and practitioners unsupportive of VAD

Section 7 of the Act allows registered health practitioners to conscientiously object to providing VAD. Although feedback to the review indicated broad support, some concerns were raised regarding s 7(a) which states that health practitioners with a conscientious objection can refuse to provide information about VAD. Family members and health practitioners indicated that some requests for VAD were blocked or ignored, resulting in the needs and wishes of patients being unmet. Further, although safeguards in the Act prevent coercion, they do not provide clear parameters to prevent health practitioners from trying to dissuade people from accessing VAD. Guidelines for health practitioners provided by the department, however, state that medical practitioners who refuse to provide information should not impede or obstruct access to VAD. The review heard cases of patients being pressured to not proceed with VAD by health practitioners who conscientiously object.[30] This is inconsistent with the Act's principle that *'individuals should be encouraged to openly discuss death and dying and an individual's preferences and values should be encouraged and promoted'* (s 5(1)(f)) and with principles of person-centred practice outlined in Ahpra codes of conduct for doctors and nurses in Australia.[31] A minimum requirement for medical

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[30] Reported outcomes for patients who experienced obstruction to VAD included: delays throughout the VAD application process leading to patients not pursuing their application or dying before securing a permit, distressing experiences trying to obtain verification of death or certification, and having to move institutions in the last days or hours of life to take the VAD substance within a service that was supportive of VAD. Where palliative care services did not support VAD, some family members reported that open discussions about palliative care treatment and options became limited, and holistic and continuous care restricted.

[31] Australian Health Practitioner Regulation Agency, <https://www.ahpra.gov.au/Resources/Code-of-conduct.aspx>

practitioners to provide contact details for the statewide care navigator service, with penalties for non-compliance, could go some way to addressing this.

In addition to health practitioner conscientious objection, people have also experienced obstruction from organisations. This has meant that some people have had to move location in the hours or days before they take the VAD substance. This sometimes means that access to palliative care is impeded.

Requirements for coordinating and consulting medical practitioners

Section 10 of the Act specifies minimum requirements for coordinating and consulting medical practitioners, which includes that:

- Both practitioners must hold a fellowship with a specialist medical college or be vocationally registered as a general practitioner.
- One assessing practitioner must have practised as a registered medical practitioner for at least 5 years after completing a fellowship with a specialist medical college or vocational registration (as the case requires).
- One assessing practitioner must have relevant expertise and experience in the condition expected to cause the death of the person being assessed.

Feedback to the review from medical practitioners and special interest groups is that the expertise and experience requirement is overly restrictive and open to interpretation. It can also have unintended consequences, including creating delays in the application process if decisions about whether the requirement has been satisfied need to be escalated.

Feedback also noted that the requirement for 'relevant expertise and experience' has typically been interpreted as needing to hold a particular fellowship or specialisation, constraining the pool of medical practitioners able to assist with VAD. For example, this could lead to situations where a medical practitioner who may otherwise hold relevant expertise and be known to the person applying for VAD – such as palliative care specialists and geriatricians – can't assess the person if the other medical practitioner involved doesn't satisfy the relevant expertise and experience requirement. The requirement for VAD medical practitioners to have relevant expertise and experience in the applicant's condition was also identified as a barrier for people with rarer conditions. In these cases, some people may need to be assessed by a medical practitioner with relevant expertise and experience who is unknown to them or hasn't provided care to the person for some time.

Removing the expertise and experience requirement would be consistent with other jurisdictions, while improving guidance for how to interpret the Act would provide more clarity for medical practitioners.

Federal prohibition of telehealth consultations

The review heard that precluding the use of telehealth has created barriers to equitable and timely access to VAD. The prohibition arises because VAD meets the definition of suicide under the *Criminal Code Act 1995* (Cth), and it is a criminal offence to use a carriage service – including any form of electronic communication like videoconference, telephone or email – to provide or share information that counsels, incites or encourages suicide. The need for all appointments to be conducted in person was noted to have financial, logistical and time repercussions. This particularly disadvantaged applicants living in regional or rural Victoria (especially if they require an assessment by a specialist medical practitioner not available near their local area), people with significant mobility constraints, and people who require interpreter services. Seeking to distinguish VAD from suicide within the Criminal Code would resolve this issue.

Feedback regarding specific eligibility criteria within the Act

Section 9 of the Act specifies the eligibility criteria for access to VAD. Stakeholders provided feedback regarding eligibility criteria which they believed created barriers to VAD access and/or operational challenges.

Residency status requirements

The review heard that eligibility criteria limiting VAD access to Australian citizens and permanent residents (s 9(1)(b)(i)) prevented some applicants who would otherwise be eligible from accessing VAD. Examples provided included situations where applicants had lived in Australia for extended periods but did not have the required documents to prove citizenship or permanent residency, including New Zealand citizens and people who moved to Australia through assisted migration schemes following World War II. The time it would take to apply for new documents was too long for some applicants who only had weeks to live.

Section 9 (s 9(1)(b)(ii) and (iii)) also specifies that the applicant must ordinarily be a resident in Victoria and, at the time of making a first request, have been ordinarily a resident in Victoria for at least 12 months. Stakeholders reported that this requirement created undue stress for some applicants by delaying the application process. Removing this requirement could address this issue and may be appropriate now that nearly all Australian jurisdictions have implemented or are currently implementing VAD.

The requirement that the applicant must ordinarily reside in Victoria creates inequity for individuals based in border communities and for those who move to access health care, aged care and family support. The increased care needs of someone with a terminal condition means that some people relocate interstate to be nearer to family who can provide support. This can make the individual ineligible in both the jurisdiction where they lived previously and in Victoria until twelve months after relocation.

The requirement for a six-month death prognosis

The review heard that the eligibility requirement in the Act for the disease, illness or medical condition to be *'expected to cause death within weeks or months, not exceeding 6 months'* (s 9 (1)(d)(iii)) created difficulties and variability in how the Act is operationalised. Medical practitioners noted that prognosis is often imprecise, and that this requirement unintentionally creates delays in the VAD application process. The requirement to receive prognosis verification from two medical practitioners may result in discrepancies, leaving applicants uncertain as to their eligibility. The review heard that some patients delayed initiating the VAD process until clear deterioration, subsequently requiring an urgent request.

Some medical practitioners raised concerns regarding fears of getting a prognosis wrong and being held liable. Several stakeholders suggested that in the absence of legislative change, this concern could partly be addressed by providing operational guidance to medical practitioners to clarify that the Act states that death is 'expected' within this timeframe and there are no legal ramifications if they underestimate their prognosis.

The requirement for those with neurodegenerative conditions to obtain another opinion for a six-to-12-month prognosis

The Act requires that when a VAD coordinating medical practitioner assesses a VAD applicant as having a neurological condition that is expected to cause death between six and 12 months, they must refer the patient to another specialist with appropriate skills in that disease, illness or medical condition to confirm the prognosis (s 18(4) and (5)). Although this medical practitioner does not need to be VAD-registered, it does create further delays having to make an additional face-to-face appointment with another neurologist. Some feedback queried why a written prognosis of less than

12 months completed by a neurologist before the first VAD assessment was not considered enough evidence to remove the need for the coordinating practitioner to refer the patient to another neurologist.

Although the Act does not specifically exclude people with dementia, the requirement for a 12 month prognosis is likely to occur after the person has lost decision-making capacity in relation to VAD, meaning they would be ineligible. There were submissions to the review, mainly from people living with dementia and their families, requesting eligibility requirements be expanded for people with dementia. Advance care directives were proposed as a mechanism for supporting people living with dementia to access VAD.

Other feedback related to legislation

The default permit for self-administration of the VAD substance

Sections 47 and 53 of the Act specify that self-administration of the VAD substance is the default method and practitioner-administration is permitted only if the patient is physically unable to self administer or ingest the VAD substance. The review heard feedback that although the self administration default emphasises the voluntary nature of VAD, it unintentionally results in a lack of flexibility that can compromise timely and compassionate access to VAD. Feedback indicated that delays can occur in instances where a practitioner-administration permit needs to be applied for when a previously able patient loses capacity to self-administer the substance. This is exacerbated if neither the coordinating nor consulting practitioner are willing to administer the VAD substance, in which case a new application is needed with a new practitioner who is willing to provide practitioner-administration. Delays were also reported to occur when a self-administration substance had been dispensed as this is required to be returned before a permit change is allowed. There is a need to offer patients the choice between self-administration and practitioner administration, rather than defaulting to self-administration. It is understood that many patients would opt for practitioner-administration if this option were available. Additionally, providing enhanced support for families is crucial to ensure both patient and family safety, as well as emotional wellbeing, in these situations.

Table 6.1: Relevant sections of legislation

Concern raised	Relevant legislation
Restrictions to health practitioners initiating discussion regarding VAD limits informed decision making	**8. Voluntary assisted dying must not be initiated by registered health practitioner** (1) A registered health practitioner who provides health services or professional care services to a person must not, in the course of providing those services to the person— (a) initiate discussion with that person that is in substance about voluntary assisted dying; or (b) in substance, suggest voluntary assisted dying to that person. (2) Nothing in subsection (1) prevents a registered health practitioner providing information about voluntary assisted dying to a person at that person's request. (3) A contravention of subsection (1) is to be regarded as unprofessional conduct within the meaning and for the purposes of the Health Practitioner Regulation National Law.
People being cared for by organisations and practitioners unsupportive of VAD may not have their needs and wishes met	**7. Conscientious objection of registered health practitioners** A registered health practitioner who has a conscientious objection to voluntary assisted dying has the right to refuse to do any of the following— (a) to provide information about voluntary assisted dying; (b) to participate in the request and assessment process; (c) to apply for a voluntary assisted dying permit; (d) to supply, prescribe or administer a voluntary assisted dying substance; (e) to be present at the time of administration of a voluntary assisted dying substance; (f) to dispense a prescription for a voluntary assisted dying substance. **5. Principles** (1) A person exercising a power or performing a function or duty under this Act must have regard to the following principles— (a) every human life has equal value; (b) a person's autonomy should be respected; (c) a person has the right to be supported in making informed decisions about the person's medical treatment, and should be given, in a manner the person understands, information about medical treatment options including comfort and palliative care; (d) every person approaching the end of life should be provided with quality care to minimise the person's suffering and maximise the person's quality of life; (e) a therapeutic relationship between a person and the person's health practitioner should, wherever possible, be supported and maintained; (f) individuals should be encouraged to openly discuss death and dying and an individual's preferences and values should be encouraged and promoted; (g) individuals should be supported in conversations with the individual's health practitioners, family and carers and community about treatment and care preferences; (h) individuals are entitled to genuine choices regarding their treatment and care; (i) there is a need to protect individuals who may be subject to abuse; (j) all persons, including health practitioners, have the right to be shown respect for their culture, beliefs, values and personal characteristics.

Table 6.1: Relevant sections of legislation (continued)

Concern raised	Relevant legislation
Requirements for coordinating and consulting medical practitioners are overly restrictive	**10. Minimum requirements for co-ordinating medical practitioners and consulting medical practitioners** (1) Each co-ordinating medical practitioner and consulting medical practitioner must— (a) hold a fellowship with a specialist medical college; or (b) be a vocationally registered general practitioner. (2) Either the co-ordinating medical practitioner or each consulting medical practitioner must have practised as a registered medical practitioner for at least 5 years after completing a fellowship with a specialist medical college or vocational registration (as the case requires). (3) Either the co-ordinating medical practitioner or each consulting medical practitioner must have relevant expertise and experience in the disease, illness or medical condition expected to cause the death of the person being assessed.
Residency status requirements prevented some applicants who would otherwise be eligible from accessing VAD **The six-month death prognosis is challenging to operationalise and creates delays in the VAD application process.**	**9. Eligibility criteria for access to voluntary assisted dying** (1) For a person to be eligible for access to voluntary assisted dying— (a) the person must be aged 18 years or more; and (b) the person must— (i) be an Australian citizen or permanent resident; and (ii) be ordinarily resident in Victoria; and (iii) at the time of making a first request, have been ordinarily resident in Victoria for at least 12 months; and (c) the person must have decision-making capacity in relation to voluntary assisted dying; and (d) the person must be diagnosed with a disease, illness or medical condition that— (i) is incurable; and (ii) is advanced, progressive and will cause death; and (iii) is expected to cause death within weeks or months, not exceeding 6 months; and (iv) is causing suffering to the person that cannot be relieved in a manner that the person considers tolerable. (2) A person is not eligible for access to voluntary assisted dying only because the person is diagnosed with a mental illness, within the meaning of the Mental Health and Wellbeing Act 2022. (3) A person is not eligible for access to voluntary assisted dying only because the person has a disability, within the meaning of section 3(1) of the Disability Act 2006. (4) Despite subsection (1)(d)(iii), if the person is diagnosed with a disease, illness or medical condition that is neurodegenerative, that disease, illness or medical condition must be expected to cause death within weeks or months, not exceeding 12 months.

Table 6.1: Relevant sections of legislation (continued)

Concern raised	Relevant legislation
The default permit for self-administration of the VAD substance compromises timely and compassionate access	**47. Application for self-administration permit** (1) Subject to subsection (3), the co-ordinating medical practitioner for a person may apply to the Secretary for a self-administration permit in respect of the person if the person is physically able to self-administer and digest the poison or controlled substance or the drug of dependence proposed to be specified in the permit for the purpose of causing the person's death. (2) An application for a self-administration permit must— (a) be in the prescribed form; and (b) identify the person in respect of whom the permit is sought; and (c) specify the poison or controlled substance or the drug of dependence the applicant seeks to prescribe or supply in a sufficient dose to the person, for the purpose of self-administration to cause the person's death; and (d) specify the contact person in respect of the person; and (e) be accompanied by a copy of the completed final review form and all forms referred to in section 41(1)(a); and (f) be accompanied by a statement that the applicant is satisfied of the matters specified in subsection (3). (3) The co-ordinating medical practitioner must not apply for a self-administration permit unless the co-ordinating medical practitioner is satisfied that— (a) the person has decision-making capacity in relation to voluntary assisted dying; and (b) the person's request for access to voluntary assisted dying is enduring. **53. Person may request co-ordinating medical practitioner apply for a practitioner administration permit** (1) A person may request the co-ordinating medical practitioner for the person to apply for a practitioner administration permit if— (a) the person is the subject of a self-administration permit; and (b) the person has lost the physical capacity to self-administer or digest the voluntary assisted dying substance specified in the permit. (2) The person must make the request personally. (3) The person may make the request verbally or by gestures or other means of communication available to the person.

Table 6.2: Jurisdictional comparisons

The following considerations for change to the Victorian VAD Act are compared with States/Territories that have a similar approach to the proposed changes.

		States/Territories with an approach similar to the proposed changes					
Considerations for change	**VIC**	**NSW**	**QLD**	**SA**	**TAS**	**WA**	**ACT**
Allow conscientious objection and organisational non-participation but require provision of information and/or referral.		●	●	●			●
Allow VAD to be raised as part of end-of-life planning.		●	●		●	●	●
Make residency requirements more inclusive.		●	●		●		●
Extend admissible period of death prognostication to 12 months for all conditions.			●				●
Reduce requirements for specialist assessments.		●	●				●
Allow nurse practitioners to be involved in VAD as an administering practitioner.		●	●		●	●	●
Enable issuance of a single permit, allowing clinical indication and patient choice to inform route of substance administration.		●	●		●	●	●
Broaden the types of interpreters able to assist			●				●
Remove forms to enable future adjustments without legislative change.		●	●	●	●	●	●

Note 1: This table provides a simplified overview of differences in legislation between jurisdictions in Australia with VAD legislation. There are complex differences between states and territory legislation that have not been reflected in this table.

Note 2: The ACT VAD Act does not specify a prognosis timeframe.

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