



Voluntary Assisted
Dying Review Board

Report of operations

July 2021 to June 2022

This is the first annual report from the independent Voluntary Assisted Dying Review Board. The previous five reports were for periods of six months.

It details:

- activity from 1 July 2021 to 30 June 2022 as well as since the commencement of the Voluntary Assisted Dying Act 2017 (the Act) on 19 June 2019
- Board reflections drawn from case reviews and feedback.

This report contains quotes and feedback from people who have chosen to die from taking the voluntary assisted dying substance, those who were with them when they died, and trained medical practitioners involved in voluntary assisted dying cases. These quotes have been de-identified to protect the privacy of individuals. This content may be upsetting to some. Contact details for support organisations can be found on page 32.

By law, the Board is required to report at the end of each financial year. The next report will be submitted by the end of September 2023 and will cover the reporting period 1 July 2022 to 30 June 2023.

More information

www.safercare.vic.gov.au/about/vadrb

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Foreword

This year has been one of change and development for the Voluntary Assisted Dying Review Board as we consolidate the operation of voluntary assisted dying in Victoria. The Board continues to monitor the operation of the voluntary assisted dying system to ensure that a quality service is provided safely for those who wish to choose voluntary assisted dying as an option at the end of their life. It is now able to reflect on the past three years of operation.

The report covers the period from 1 July 2021 to 30 June 2022 and is the first annual report provided by the Board. The annual report provides the opportunity to reflect on the previous year and provide information around how Victorians are accessing voluntary assisted dying and their experience of doing so.

We are fortunate to be able to hear directly from applicants who seek to access voluntary assisted dying, alongside their family and support networks, and from medical practitioners who support the application process. This feedback is invaluable in understanding how voluntary assisted dying is working in Victoria. We thank everyone who has provided their feedback throughout the year.

Focus on quality and safety

The most significant matter to report is that voluntary assisted dying in Victoria continues to operate safely and lawfully. The numerous safeguards in the Act and the integrity of those involved have ensured that those risks that were raised in debates about the Act have been safely avoided.

The Board reviews cases of voluntary assisted dying in Victoria to monitor compliance with the Act. The feedback and information provided to the Board also contribute to improving the quality and safety of the operations of the Act across Victoria. Over this reporting period, four cases were identified as technically non-compliant with the legislation. In reviewing the details of these cases, the Board

considered that the assessments were clinically appropriate and is confident the Act continues to operate in a safe manner.

Compassion and the relief of suffering

The number of people seeking to access voluntary assisted dying continues to increase. This is a further indicator of the success of the system. The total number of applications assessed by two qualified and independent medical practitioners as eligible under the strict criteria rose by 22 per cent on the previous year. The number of deaths from administration of the substance rose by 29 per cent. This represents 0.58 per cent of deaths in Victoria.

These figures alone are not the measure of success of the operation of the Act in providing relief from suffering. Feedback from applicants, families, loved ones and others involved shows the benefits accrue to a far wider group. They include those who obtain comfort from the knowledge that they have an option for end of life treatment; or that they have the substance but may not use it; and for families and loved ones who witness the person's wishes fulfilled and autonomy respected.

Impact of coronavirus (Covid-19)

Covid-19 has continued to impact the lives of Victorians over the past year. We acknowledge the ongoing level of service and care provided by medical practitioners to those seeking to access voluntary assisted dying.

There is insufficient evidence to understand the exact impact that Covid-19 has had on access. The requirement to isolate did impact staff across the health system including those supporting the voluntary assisted dying program. This led to some isolated delays in delivering the voluntary assisted dying substance at the start of 2022. This was temporary and resolved by the Statewide Pharmacy Service quickly with flexible rostering.

The Voluntary Assisted Dying Portal

The Voluntary Assisted Dying Portal provides a secure online system for medical practitioners to lodge the forms required under the Act. This year a significant upgrade took place, which has resulted in a streamlined administrative process for the submission of voluntary assisted dying applications. This project involved significant stakeholder input and the Board would like to thank all those who provided feedback about their experience over the past year.

Research strategy

The Research Working Group has progressed the research and data strategy. We look forward to facilitating research opportunities in the coming year as the volume of data increases providing better privacy protection to those involved, and a greater depth of analysis.

More access for Australians

The past year has seen the implementation of voluntary assisted dying legislation in Western Australia. It was also implemented in New Zealand. Furthermore, Tasmania, Queensland, South Australia, and New South Wales have now passed voluntary assisted dying into law. We have welcomed the opportunity to work with these jurisdictions and share our experience as they embark on their implementation. We look forward to future sharing

and collaboration as these programs are established so that Australians have greater choice in end-of-life care across the nation.

Commonwealth Criminal Code

As access to voluntary assisted dying becomes more widespread in Australia, the Board will continue to advocate for a change in the Commonwealth Criminal Code, which currently impedes the use of telehealth in relation to voluntary assisted dying. The law as it exists creates barriers to access to care and, in some cases, imposes unreasonable travel demands on people suffering from life-ending medical conditions. A change to the law will enhance access for all Victorians, regardless of their location or mobility.

Review of the operation of the Act

The Act requires the Minister for Health to cause a review of the operation of the first four years of the *Voluntary Assisted Dying Act 2017* in Victoria in its fifth year of operation. The Board continuously reviews feedback provided by appointed contact people, medical practitioners and interested stakeholders. Some themes are emerging from this feedback, which have been presented in this report. It is important to acknowledge the themes presented in this report do not reflect the views of the Board per se, however they represent important reflections that merit consideration as part of this review process. Further opportunities to engage in this review will be available once underway.

We are confident the risks identified through the initial public debate on the legislation have not eventuated, and the system overall continues to operate safely.

Appointment as Chairperson

I would like to extend my thanks to Charlie Corke for stewarding the Board as Acting Chair in 2021 before my appointment as Board Chair.

I would also like to extend thanks to Melissa Yang and Danielle Ko (who resigned during the year) for their contribution as Board members over the initial years of the Board's development.

Thank you as always to the health practitioners, statewide services, contact persons and family members for the support and care provided to those who wish to access voluntary assisted dying.

I look forward to the coming year as we continue to grow and support the voluntary assisted dying program for Victorians alongside our other Australian jurisdictions and New Zealand.

A handwritten signature in black ink, appearing to read 'Julian Gardner', with a horizontal line extending to the right.

Julian Gardner AM

Chairperson
Voluntary Assisted Dying Review Board

Snapshot

Table 1: Outcomes of each application stage for voluntary assisted dying*

Stage	2019-20**	2020-21	2021-22	Total to date #	Change from previous year
First assessment completed	355	489	581	1,425	+19%
Eligible	348	467	548	1,363	+17%
Ineligible	7	22	33	62	+50%
Consulting assessment completed	300	408	492	1,200	+21%
Eligible	296	400	486	1,182	+22%
Ineligible	4	8	6	18	-25%
Self-administration permit processed	236	349	384	969	+10%
Permit Issued [^]	206	323	373	902	+15%
Permit Not Issued	30	26	11	67	-58%
Substance dispensed for self-administration	154	259	349	762	+35%
Practitioner administration permit processed	40	50	64	154	+28%
Permit Issued [^]	31	42	60	133	+43%
Permit Not Issued	9	8	4	21	-50%
Substance dispensed for practitioner administration	20	29	38	87	+31%

*This table counts unique applications. A single individual may be linked to more than one application, and some applications may have the same form submitted multiple times.

**This column includes 12 days of 2018-19 financial year as the program commenced on 19 June 2019.

#Total figures are since the commencement of the Act in June 2019.

##There is no requirement in the Act for a medical practitioner to record a case that is considered ineligible. Therefore, this number is not considered an accurate reflection of true ineligible assessments conducted over this reporting period.

[^]There are circumstances where one applicant is issued with two permits; firstly, for self-administration and subsequently if there is a change to practitioner administration.

Table 2: Deaths in applicants issued with permits

Manner of death	2019-20*	2020-21	2021-22	Total to date	Change from previous year
Total deaths	190	310	401	901**	+29%
Voluntary assisted dying substance not administered	59	105	127	291	+21%
Self-administration of the voluntary assisted dying substance	110	176	231	517	+31%
Practitioner administration of the voluntary assisted dying substance	21	28	38	87	+36%

* This column includes 12 days of 2018-19 financial year as the program commenced on 19 June 2019.

** Six applicants who died near the 30 June 2022 did not have their manner of death reported to the Board at the time of analysis.

Medical practitioner involvement

Compassionate and dedicated medical practitioners continue to provide care and support to Victorians seeking access to voluntary assisted dying. Service delivery has been strengthened, and system wide improvements have been informed by the generosity of the medical practitioners who willingly provide feedback to the Board, the Department of Health’s End of Life Care and Palliative Services team and through the Community of Practice.

Medical practitioners are required to complete the online training program prior to conducting eligibility assessments for voluntary assisted dying. Over the three years since voluntary assisted dying became available in Victoria, there has been continued growth in the number of medical practitioners who have completed the training.

The Board recognises the skills and experience of those who choose to be involved in voluntary assisted dying assessments and permit applications.

We thank registered medical practitioners for their care and expertise throughout the sometimes-challenging process.

‘I have found the process to be well managed and efficient and have been kept well informed

throughout. My interactions [with the medical practitioner] have been very professional, thorough and compassionate.’ **Applicant**

‘[The applicant] would’ve liked to click her fingers and have had the substance the same day she decided to take it. We were all very understanding that there was a specific process that had to be followed and both the Care Navigator and the GP talked us through each of the steps and the anticipated timeframes so that was reassuring. We were all so appreciative and thankful that she was able to access voluntary assisted dying, she was ready. And the GP, he just did everything he absolutely could to make the process easy for us..’ **Contact person**

Table 3: Medical practitioner training and involvement since commencement of training availability

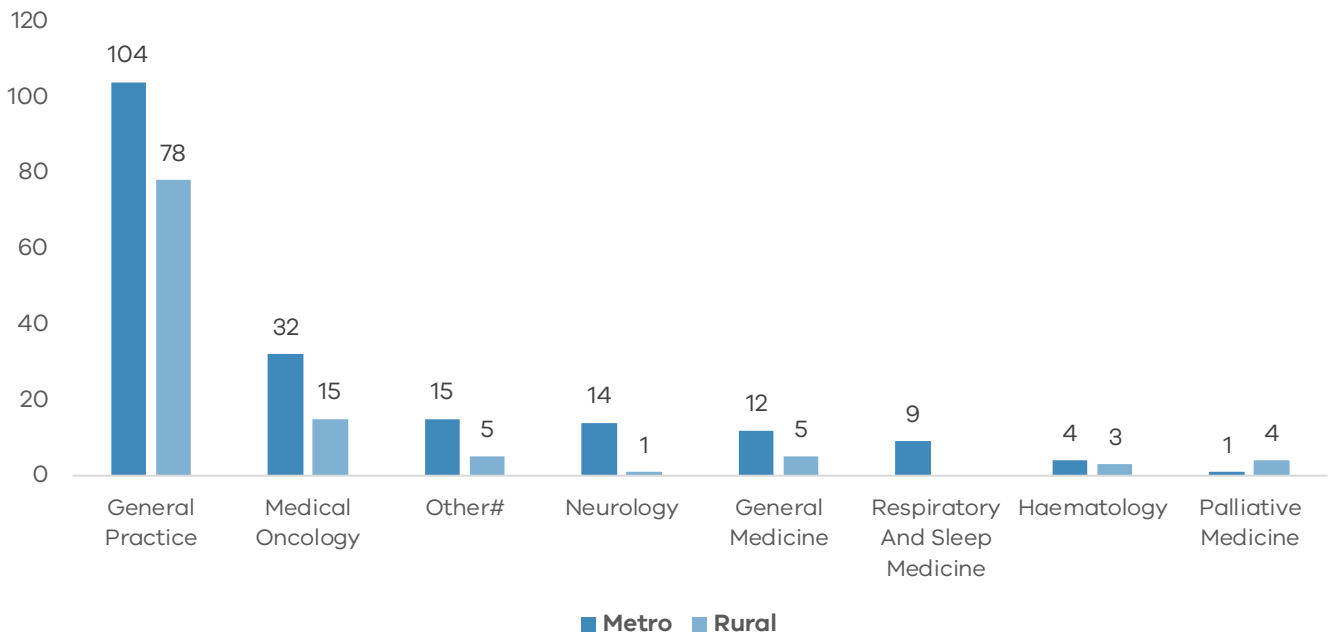
Stage	Description	Total as of 30 June 2021	Total as of 30 June 2022	Change (%)
Online training	Successful completion of the online training program	511	618	+17%
Portal registration	Medical practitioner registration within the Voluntary Assisted Dying portal	234	326	+39%
Case involvement*	Participation by the medical practitioner in one or more cases in the portal as either the coordinating or consulting medical practitioner	154	185	+20%

* Figures presented in previous reports have provided total numbers to date. This report provides trends over time and provides numbers per reporting year.

There were 302 medical practitioners with active profiles in the portal as of 30 June 2022. Practitioner profiles may become inactive after registration if a practitioner retires or ceases to be involved in voluntary assisted dying.

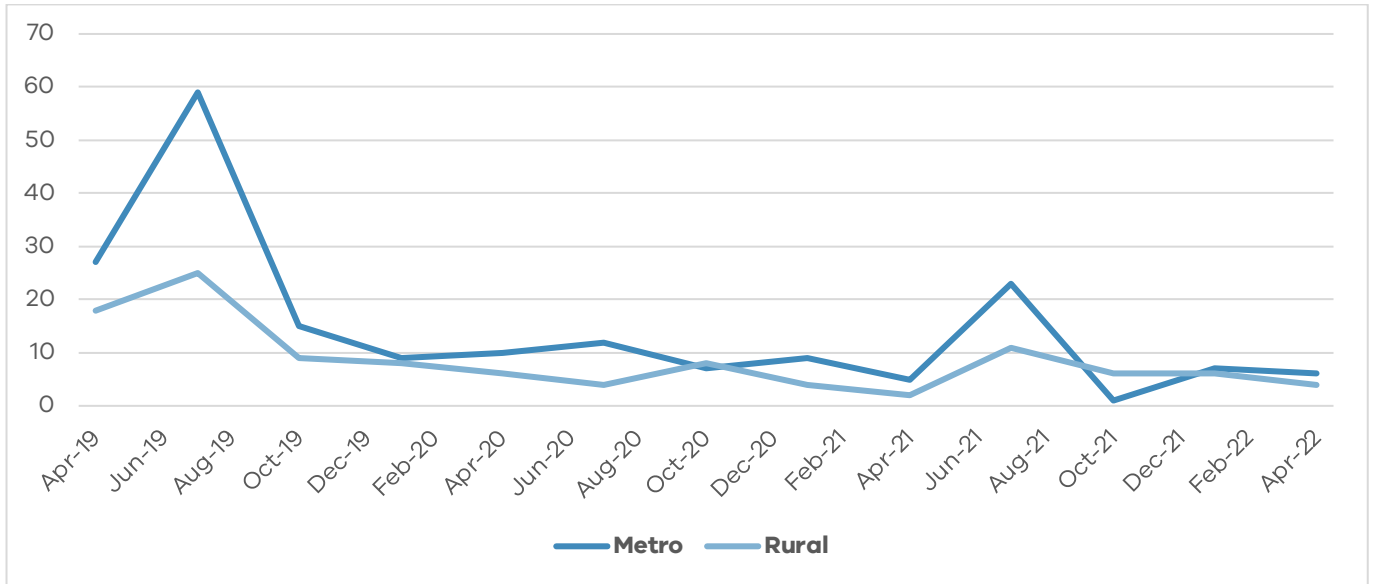
General practitioners make up 60 per cent of all practitioners and 70 per cent of the registered practitioners trained to provide voluntary assisted dying in regional Victoria.

Figure 1: Clinical specialties of medical practitioners by primary location of practice



Other specialty areas include anaesthesia, general surgery, neurosurgery, psychiatry, urology, or do not have a specialty area(s) listed by Australian Health Practitioner Regulation Authority. 'General medicine' includes associated subspecialties including cardiology, gastroenterology and hepatology, geriatric medicine, infectious diseases, intensive care medicine, and nephrology.

Figure 2: Number of practitioners newly registered in the Voluntary Assisted Dying portal



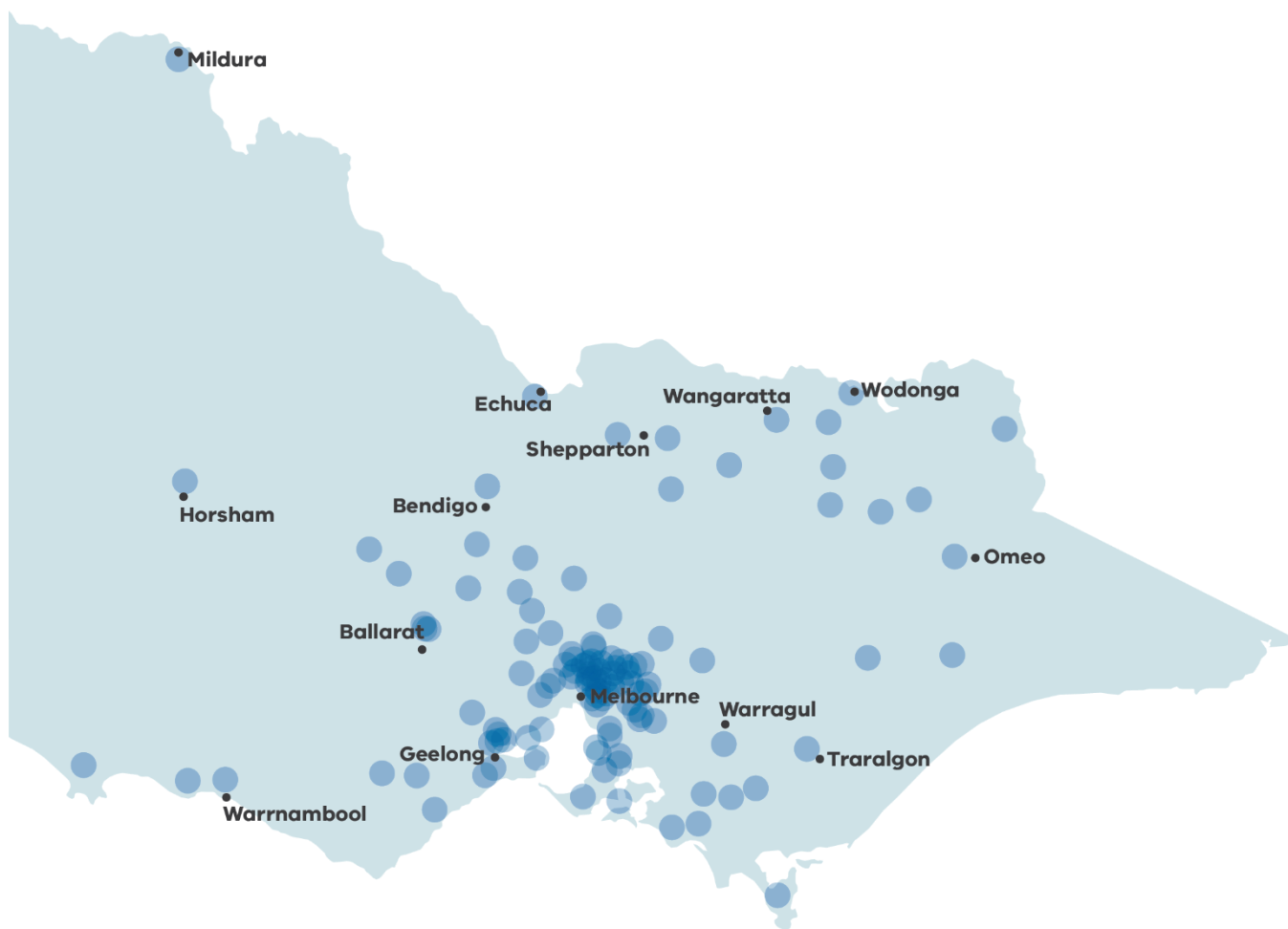
In total, approximately two thirds (65 per cent) of active medical practitioners are in metropolitan Melbourne, and one third (35 per cent) practice in regional Victoria. Practitioners in regional Victoria are concentrated around the larger towns in central Victoria, Geelong and the Bellarine Peninsula, and the Hume region. There are very few practitioners in Western Victoria, with only 10 practitioners serving the entire region west of Ballarat.

The distribution of practitioners is broadly consistent with the distribution of the population in Victoria. Nonetheless, this results in large geographic areas with few, if any, medical practitioners, meaning

regional patients and medical practitioners may have to travel significant distances during the assessment process, given assessments and discussions about voluntary assisted dying need to occur in person.

'We were lucky that we had a doctor in town because it really got to the point that dad couldn't have travelled... if we needed to do that for appointments. The doctor had trained specifically for one of her long-term patients and we got in touch, and she agreed to do it for us too. She came to see us on her day off. She was wonderful.' **Contact person**

Figure 3: Geographic distribution of medical practitioners*



* Locations are approximate, based on the centroid of postcodes. Locations with only one active practitioner in the postcode are not shown.

Community of practice

Medical practitioners who have completed voluntary assisted dying training are able to join the community of practice, which is an online peer support network with 48 members. The community of practice provides support to medical practitioners who are involved in providing services related to voluntary assisted dying.

The community of practice is an invaluable resource for medical practitioners and current membership includes specialists in the fields of oncology, palliative care, geriatrics, anaesthetics, and general practice.

Medical practitioners can join the community of practice after successful completion of the voluntary assisted dying training. Those wishing to join should contact vadcommunity@westvicphn.com.au.

Medical practitioners and other professionals actively involved in the program and those involved in the community of practice have provided a range of insights since the Act came into effect. Their feedback has been incorporated into this report alongside that of contact people.

Applicants and assessments

An applicant is a person seeking to access voluntary assisted dying. They must meet all eligibility criteria, as assessed by their coordinating and consulting medical practitioners. The Statewide Care Navigator Service and the Statewide Pharmacy Service provide support to people, medical practitioners, and health services throughout the application process of voluntary assisted dying. The Services are commissioned by the End of Life and Palliative Services Team in the Department of Health.

As more Victorians become aware of this end of life choice, there is a continued need for statewide services. Additional resourcing for statewide services has been dedicated through the Department of Health to ensure the needs of all Victorians can be met at this crucial time in their lives.

The Board receives positive feedback about the Statewide Pharmacy services. Over the past year, Covid-19 and other resourcing issues have impacted the broader healthcare delivery system – including those directly related to voluntary assisted dying. The Board recognises that additional resourcing to the voluntary assisted dying statewide services have had a positive impact.

Seeking information about voluntary assisted dying

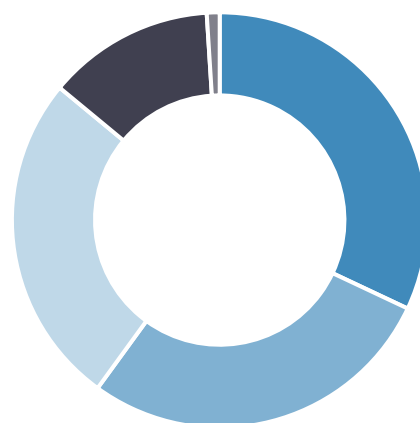
The Statewide Care Navigator Service has provided important advice and support to Victorians, medical practitioners, and health care teams consistently across Victoria over the last three years.

The Care Navigator Service continues to grow to meet the needs of Victorians. As of 30 June 2022, there are nine care navigators located across Victoria, and a manager who oversees the service. These skilled and compassionate nurses, and social workers provide advice and support to Victorians who may be considering voluntary assisted dying as an end of life choice. If necessary, the service also connects people with medical practitioners who have completed the training.

From 1 July 2021 to 30 June 2022, there were 1,062 contacts made to the Care Navigator Service seeking information or support. This is an increase of 8 per cent compared to 985 contacts made in the previous year.

Of these:

- 32 per cent were from applicants
- 28 per cent were from family members or friends
- 26 per cent were from the usual treating team
- 13 per cent were from a voluntary assisted dying clinician (medical practitioner or coordinator)
- 1 per cent was from other sources.



- Applicants
- Family members or friends
- Usual treating team
- Voluntary assisted dying clinician
- Other

30 per cent of contacts to the Care Navigator Service were from regional or rural Victoria.

Of the contacts made from 1 July 2021 – 30 June 2022:

- 48 per cent were for support for applicants who were planning or were in the process of applying for voluntary assisted dying
- 38 per cent were requests for information from those who were considering voluntary assisted dying
- 7 per cent were for assistance in finding a second trained medical practitioner to complete the applicant's eligibility assessment
- 7 per cent were for other reasons.

Contact people and medical practitioners continue to provide positive feedback about the service.

'I wish to express my thankfulness to the way in which you enabled (my dad) to begin the process for his wish to die peacefully at home surrounded by his family. From my first phone call to you, the steps were put in place by you for

his end of life care to be as he wished. You were so caring and professionally skilled in the way you immediately helped us.' **Family member**

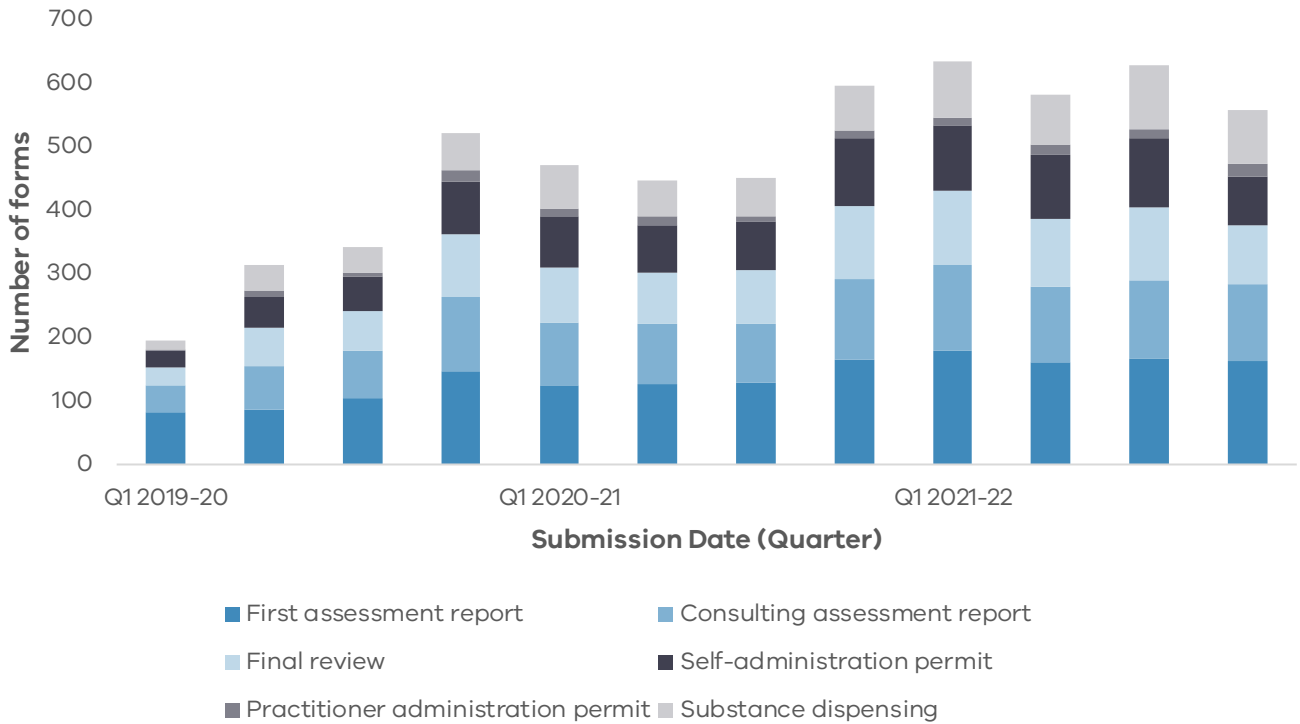
'I so greatly appreciate your help with this case, both before and on the day. You should be proud of the job you do.' **Medical practitioner**

'The Care Navigator... was amazing, she just organised everything to happen. She was always up there seeing [the applicant] and I think he felt very reassured by her presence.' **Contact person**

Voluntary assisted dying applications

The Board continues to see an increase in voluntary assisted dying applications, including those that progress to permit application stage. This is despite the Covid-19 pandemic. There has been some evidence that pandemic orders affected the accessibility of appointments. Feedback received from contact people has indicated that these orders did impact on the experience of grief for some family and support people.

Figure 4: Applications over time (forms submitted by quarter)



The Act requires that a final request is made at least nine days after the first request unless both assessing medical practitioners consider that the

applicant’s death is likely to occur within the nine-day timeframe. The median timeframe from first to last request is 16 days.

Table 4: Timeframes – first to final request

Timeframes – first to final request	Days elapsed
Median	16
Interquartile range	11-33

People who applied for voluntary assisted dying

Since the commencement of the Act, 1,545 people have applied for access to voluntary assisted dying. The median age of applicants was 73 years, and half of all applicants were aged 65-81 years. Just over half of the applicants were male (54 per cent male, 46 per cent female).

Over one third (37 per cent) of applicants lived in regional Victoria, despite only 22 per cent of the Victorian population living in regional areas.

Voluntary assisted dying applicants are considerably more highly educated than the general public of the same age. According to the 2021 census, 39% of

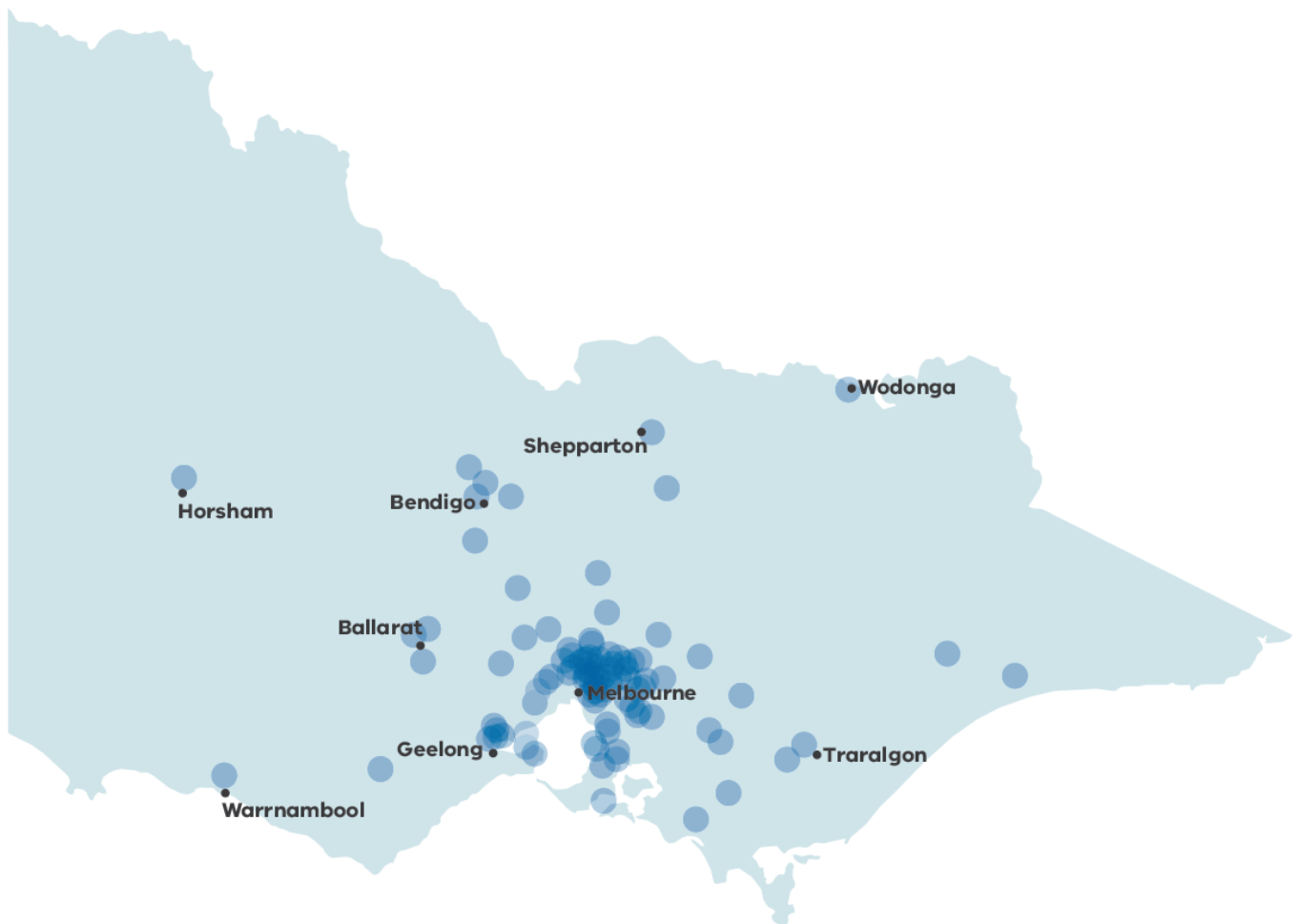
people aged 55 years and older have completed year twelve or equivalent, compared to 59% of voluntary assisted dying applicants.

Table 5: Applicant demographics 19 June 2019 – 30 June 2022 (n=1545)

Characteristics	N	%
Sex		
Male	835	54.0%
Female	709	45.9%
Self-described	1	0.1%
Age		
18-54	127	8.2%
55-64	252	16.3%
65-74	449	29.1%
75-84	454	29.4%
85+	263	17.0%
Median age (IQR)	73	(65-81)
Country of birth		
Australia	1060	68.6%
Other	422	27.3%
Not provided	63	4.1%
Aboriginal or Torres Strait Islander identification		
Yes	6	0.4%
No	1478	95.7%
Unknown	61	4.0%
Language spoken at home		
English	1437	93.0%
Other	58	3.8%
Unknown	50	3.2%

Characteristics	N	%
Interpreter required		
Yes	34	2.2%
No	1487	96.2%
Unknown	24	1.6%
Highest level of education completed*		
No education	1	0.1%
Other education	18	1.2%
Pre-primary education	0	0.0%
Primary education	61	4.0%
Junior secondary education	357	23.1%
Senior secondary education	360	23.3%
Certificate level	84	5.4%
Advanced diploma and diploma level	103	6.7%
Bachelor's degree level	239	15.5%
Graduate diploma and graduate certificate level	33	2.1%
Post graduate level	94	6.1%
Unknown	195	12.6%
Area of residence		
Metropolitan Melbourne	981	63.5%
Regional Victoria	564	36.5%
Living situation		
Private household	1327	81.2%
Long term care or assisted living facility	128	8.3%
Health service	69	4.5%
Unknown	21	1.4%

Figure 5: Geographic distribution of applicants*



* Locations are approximate, based on the centroid of postcodes. Locations with less than five applicants in the postcode are not shown.

Palliative care

Palliative care services are available to all Victorians, with care available dependent on individual need. This may include hospital-based care or care delivered in a person's home or residential facility. It is important to recognise that voluntary assisted dying is not an alternative to palliative care. This is underscored by the fact that 81 per cent of applicants applying for voluntary assisted dying have accessed or are being cared for by a palliative

care service. Palliative care is an essential service, and the integration of palliative care options remains an important aspect of the end of life care delivery model.

'The patient had long held a desire for voluntary assisted dying but as her death approached, she seemed more reluctant to call for the delivery of the [substance]. She died at home with family and good palliative care.' **Medical practitioner**

‘The palliative care doctor was amazing. He spent so much time with us. He checked in with me and all the family that we were ok, really supported us too. He made sure that on the day she wanted to take the substance her favourite nurses were working, and we made the choice to do it at the double shift time to ensure that it was the best for the unit too.’ **Contact person**

Palliative care services provide bereavement services for their registered family and carers. Other bereavement services are available including the Australian Centre for Grief and Bereavement. Further contact details for bereavement support are available on page 32.

Table 6: Use of palliative care by applicants 19 June 2019 – 30 June 2022 (n=1545)

Palliative care services		
Accessed		
Yes, currently	1255	81.2%
Yes, previously	21	1.4%
No	213	13.8%
Not reported	56	3.6%
Duration of engagement with palliative care (n = 1276)		
Less than 12 months	973	76.3%
Greater than 12 months	209	16.4%
Duration of engagement not reported	94	7.4%
Median months (range)	3 months	(0-120 months)

Additional assessments

Additional specialist opinion may be sought by a coordinating or consulting medical practitioner as part of the assessment process to determine whether a person has decision making capacity.

Specialist opinion may also be sought by either medical practitioner to confirm a diagnosis or prognosis as part of the assessment process.

It is a requirement for applicants with neurodegenerative conditions with a prognosis of 6-12 months to seek a further specialist opinion at the coordinating assessment stage.

Table 7: Referrals for additional assessments 19 June 2019 – 30 June 2022

Referrals for additional assessments	N applicants
Decision making capacity	31
Neurodegenerative assessment if prognosis 6-12 months	85

Appointment of a contact person

The Act requires that a contact person is appointed once a final request is made. A contact person has a duty under the Act to return any unused or remaining voluntary assisted dying substance within 15 days after the date of death of the applicant, or if the applicant decides to request a practitioner administration permit.

The Act requires the Board to provide information on the requirement to return the substance and outline support information available to assist the contact person within seven days of being notified of the death of an applicant. As part of this contact, the Board requests feedback on the experience of the process. The Board wishes to thank all those who provided valuable insights on their experience accessing voluntary assisted dying. Feedback has been incorporated through this report and informs

the quality and safety reviews conducted by the Board.

Withdrawal of cases

Since the commencement of the Act, a total of 576 applications have been withdrawn. Reasons for withdrawal include:

- the death of applicant prior to the voluntary assisted dying substance being dispensed
- deterioration or improvement in condition and thus no longer meeting eligibility criteria
- transfer of care to a different medical practitioner or health service
- duplicate applications created in error for a single applicant.

A detailed retrospective review of the reasons for the withdrawal of applications is currently being undertaken.

Table 8: Reason for withdrawal 19 June 2019 – 30 June 2022 (n = 576)

Reason for withdrawal	Number	%
Applicant died	384	66.7%
Coordinating medical practitioner notified of death	205	35.6%
Secretariat notified of death*	179	31.1%
Other	192	33.3%

* The Secretariat may be informed of a death through a health service appointed voluntary assisted dying coordinator, Care Navigator, medical practitioner or through Medical Certificate of Cause of Death or Death Certification.

'We were pleased that once we agreed to voluntary assisted dying that we did not have to proceed. We are indebted to the team who have supported us during this difficult decision time.'

Applicant and contact person

'Patient was thankful; however, she did report she felt it was exhausting and emotionally draining and was pleased once she had received [the substance]. She told me her plan was just to forget about [the substance] for a while and try to enjoy life the best she could but that it was reassuring to have the substance there.' **Medical practitioner**

'We all were happy with the decision that he made and supported him. It gave him great comfort to know that the substance was there if he ever needed it, but he didn't, he just naturally declined.' **Contact person**

'The applicant went through the process but when it got to the end, he had a change of mind and didn't want to take it.' **Contact person**

Permit approvals and substance dispensing

Once the assessment process has been finalised and the applicant is found to be eligible, the coordinating medical practitioner must apply for a permit to dispense the substance. The Secretary, Department of Health, or their delegate, reviews and considers all voluntary assisted dying permit applications. It is the applicant's choice to decide if and when they want to access the voluntary assisted dying substance. The Statewide Pharmacy Service visit applicants anywhere in Victoria to dispense the substance.

Between 1 July 2021 and 30 June 2022, the Secretary, Department of Health issued 433 self-administration or practitioner administration permits.

This reporting cycle has seen a significant reduction in the number of permits not issued due to administrative reasons. This is a result of the growing experience of medical practitioners in completing these forms as well as the Voluntary Assisted Dying Portal Enhancements Project. The ability to review and correct administrative errors related to substances, dosages or formulations was a key piece of stakeholder feedback during the development of this project.

Timeliness

The *Voluntary Assisted Dying Regulations 2018* state that the Secretary, Department of Health has three business days to determine the outcome of a permit application. Outcomes for 99 per cent of permit applications were determined within this timeframe, with 96 per cent approved within two business days.

Delays to a permit application may occur when incomplete paperwork is provided as part of the assessment process, or the Secretary seeks further information to assess the application.

The Secretariat for the Board conducts an administrative check on all assessment forms as they are lodged. If necessary, it provides feedback to medical practitioners to promote compliance with the Act. It is entirely a matter for the medical

practitioners to act on this feedback. However, the Secretary in making the final determination to grant or not grant the permit considers the application as soon as it is complete. This is when all relevant information has been provided and checks are completed on whether all forms are compliant with the Act.

Once all required application steps have been completed, the Secretary of the Department of Health grants a voluntary assisted dying permit. Then the applicant decides if, and when, they want to access the voluntary assisted dying substance.

Statewide Pharmacy Service

The Pharmacy Service, based at Alfred Health, continues to develop and respond to the needs of Victorians, and during 2021-22 expanded capabilities to increase trained pharmacists and administration support. This expansion ensured the Pharmacy Service continued to provide a sustainable, timely, patient-directed service.

The pharmacy service dispenses the voluntary assisted dying substance to each applicant at a time and location of their choosing. To do this, pharmacists travel throughout the state to provide education and support to applicants, their families, and medical practitioners. They also dispose of any unused substance returned by the contact person or medical practitioner.

During 2021–22:

- 76 per cent of applicants had the substance provided on their preferred delivery day
- 92 per cent of applicants had the substance provided within two business days of their preferred delivery day
- 58 per cent of visits were to metropolitan applicants
- 42 per cent of visits were to regional applicants*.

* These figures represent all pharmacy visits to applicants and medical practitioners with a permit who have requested to receive the substance. It may not result in the dispensing of the substance due to patient choice or deterioration. The total number of dispensed substances in 2021-22 indicates that 37% are dispensed to applicants in a regional area.

Feedback provided by contact people and applicants about the Pharmacy Service enables continuous performance monitoring and evaluation. Feedback from those who provided a response showed:

- 92 per cent reported excellent service from the pharmacist(s)
- 98 per cent said the pharmacist visited at a time that suited them.

'The two pharmacists who came to the facility were amazing, the one who took the lead had the most impeccable bedside manner. I really couldn't have wished for anything better.'

Contact person

'The pharmacy came out to us, the palliative care team came along too as they had not dealt with a voluntary assisted dying case before. My sister, myself and dad had a round table discussion with everyone. It was explained very clearly, and it was very easy to understand.'

Contact person

'The information [provided by the Pharmacists] was very informative and thorough. They were very patient as we went through practising the process. The instructions were very clear, and they were sensitive when handing over the substance to us.' **Contact person**

Deaths

Since the commencement of the Act, 1,292 applicants have died following their first assessment. Of these, 901 were issued with a permit and 604 permit holder deaths were as a result of using the substance.

Cause of death data from Medical Certificates of Cause of Death was available for 1,243 of deceased applicants. Applicants who have died recently do not yet have an underlying cause of death reported.

Table 9: Underlying cause of death in applicants 19 June 2019 – 30 June 2022 (n = 1243)

Underlying cause of death	N	%
Malignancy (primary site)	1,014	81.58%
Lung malignancy	208	16.73%
Colorectal malignancy	124	9.98%
Other gastrointestinal malignancy	123	9.90%
Pancreas malignancy	89	7.16%
Breast malignancy	84	6.76%
Prostate malignancy	71	5.71%
Gynaecological malignancy	60	4.83%
CNS malignancy	51	4.10%
Haematological malignancy	40	3.22%
Melanoma	24	1.9%
Other malignancy*	140	11.3%
Neurodegenerative disease	120	9.65%
Motor neurone disease	95	7.64%
Other neurodegenerative diseases**	25	2.01%
Other conditions	109	8.77%
Cardiovascular disease	23	1.85%
Respiratory failure	52	4.18%
Other#	34	2.74%

* Other malignancies include sarcomas, renal cancer, and metastatic cancers of unknown primary site

** Other neurodegenerative diseases include Parkinson's disease and rare neurodegenerative disorders

Other conditions include conditions such as renal failure, and cases where only an immediate cause of death was recorded, e.g. respiratory arrest or pneumonia.

Manner of death

In total, 901 applicants who were issued with a permit for self-administration or practitioner administration of a voluntary assisted dying substance subsequently died.

Practitioner administration permits may be applied for when an applicant is physically incapable of self-administration or digestion of the substance.

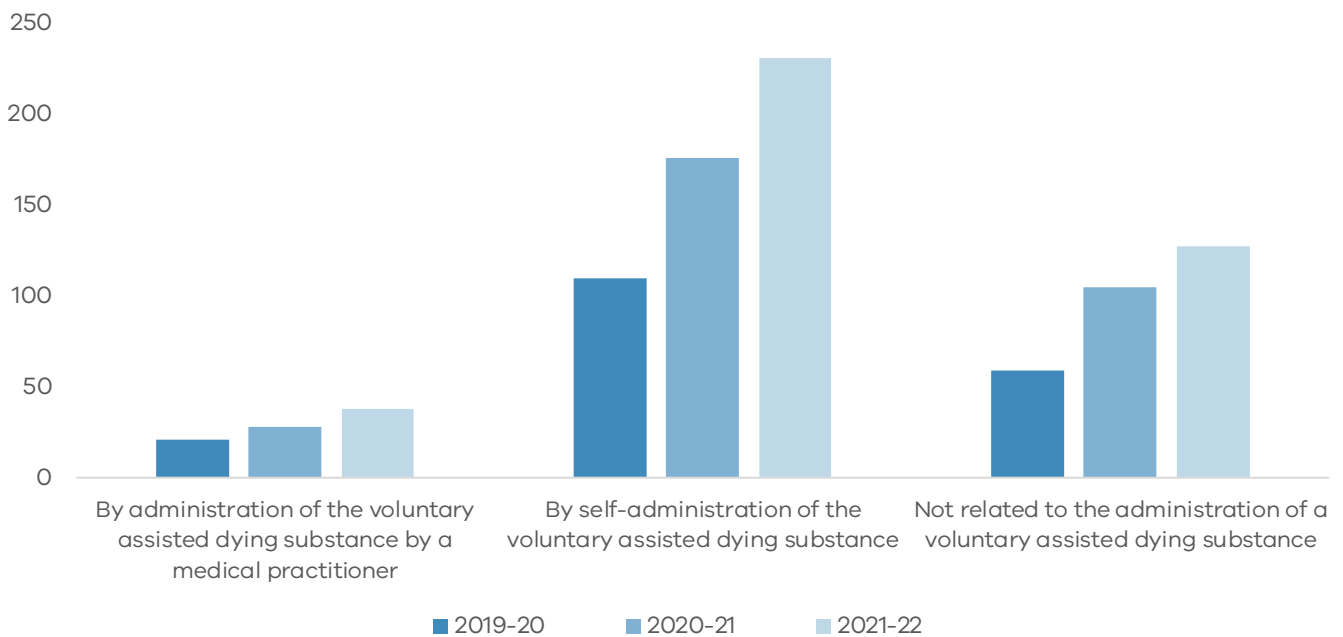
Among the permit holders who died:

- 57 per cent died through self-administration of a voluntary assisted dying substance

- 10 per cent died by administration of a voluntary assisted dying substance by a medical practitioner
- 32 per cent died without the administration of a voluntary assisted dying substance
- 1 per cent died recently and their manner of death has not yet been reported to the Board.

These proportions have been stable over time, although the number of people granted permits has increased each year since the Act commenced.

Figure 6: Manner of death for all permit holders who died (n = 901) *



* Note that data from 2018-19 has not been presented in this figure as only one death occurred in the nine days of operation of the Act in this financial year. Six permit holders who died recently have not yet had their manner of death reported to the Board.

'We have a picture of the family right before he took the substance and there wasn't a happier man. He had lived a good life and was comfortable with his decision. Our mum died earlier in the year and her death was a 3-day drawn out affair. It was awful and dad didn't want that. He said if he has the choice he'll opt for a different path, and he did.' **Contact person**

'It was a beautiful experience. [The applicant] died being held by her husband and both of her children holding her hands. The whole family are very grateful that voluntary assisted dying was available, and that the applicant was able to go in the way she wanted.' **Contact person**

Compliance reviews

The *Voluntary Assisted Dying Act 2017* was designed to deliver the most conservative and safe legislation in the world, with 68 safeguards and a scrupulous oversight scheme in place. The Act is interpreted in a very strict way, and the Board continues to have a very low threshold for errors that impact on compliance with the legislation or inconsistencies in applications to maintain public safety.

Case compliance

Between 1 July 2021 and 30 June 2022, the Board found four cases to be non-compliant with the Act.

Return of substance

Three cases were determined as non-compliant because there was a delay with the return of the substance to the Statewide Pharmacy. The contact person is required by Section 39(2)(a) of the Act to return any outstanding substance within 15 days of the death of an applicant.

Feedback provided by contact people shows there are a variety of reasons why this requirement was not met. For those involved in the assessment process, it is advised to ensure the contact person is aware of this requirement when they are appointed.

No further action will be taken regarding the non-compliant cases related to late return of substance; however, it is clear in the legislation that the penalty associated with this oversight can be severe. Therefore, a focus on the provision of appropriate information and support for contact people is paramount.

Signing of behalf of an applicant

One further case was found to be non-compliant with section 40(3)(b)(ii), which prohibits someone signing on behalf of an applicant from also being a witness to the document. The Board investigated the incident with the full cooperation of those involved in the assessment process. The Board considered an

oversight had occurred and no further action was taken. The case was considered clinically appropriate.

Referral to other agencies

During this reporting period, no deaths were considered to require further investigation by the State Coroner. There were no referrals made to the Chief Commissioner of Police or the Australian Health Practitioner Regulation Agency.

Access to voluntary assisted dying

As part of the compliance review process, the Board reflects on individual cases. Issues that impede access to voluntary assisted dying are identified and discussed. These reviews allow the Board to perform one of its key functions in supporting continuous improvement to the program.

Commonwealth Criminal Code

The Commonwealth Law as it exists creates barriers to accessing care and, in some cases, creates unreasonable travel demands for people suffering from life-ending medical conditions. This law impedes the use of telehealth for the conduct of voluntary assisted dying assessments. The Board will continue to advocate for a change in the criminal code to promote access for all Victorians, regardless of location or mobility.

Access to specialists

Although the number of medical practitioners completing the training and registering on the Portal continues to grow, there remains some gaps in specialist care across the state. The Board continues to work with the End of Life Care and Palliative Services team and Statewide Care Navigator service to promote training across specialist areas. The Statewide Care Navigators conduct regular webinars and training sessions throughout Victoria with a focus on areas with less representation.

Timing of access

Access to voluntary assisted dying in Victoria is an established process, which requires eligibility to be assessed throughout the legislated timeframe. The Board continues to advocate that voluntary assisted dying is not an emergency procedure. Requests and assessments should be addressed with enough time to ensure the process does not add an unnecessary burden of stress on an applicant and those supporting the process at the end of life.

The Board is also aware of some of the reasons there are delays in access, including applicants being obstructed and cases where the applicant has not known what to ask for and has had numerous attempts at the request.

'[The applicant was] a single man living alone with a period of decline prior to his final admission to hospital. Neither he nor friends could find evidence of Australian citizenship. He had to apply for a new extract of birth certificate which delayed his application approximately two weeks.' **Medical practitioner**

'We didn't have any barriers. [The applicant] was very clear when he got his diagnosis, which was very advanced cancer, that he didn't want any treatment and he wanted to die when he was ready. He was very proactive and got the

process underway early on to make sure he had it when he needed it. I don't think people understand how long the process takes, just the time interval between each step. We were lucky as the people involved were proactive too.'

Contact person

Obstruction of access

The Board receives feedback that some individuals and health services continue to actively discourage or even impede access to voluntary assisted dying. The law provides and the Board supports the right of health practitioners who have a conscientious objection to voluntary assisted dying to decline to take part in any part of the process, but not to be obstructive.

While the Act provides for an offence to coerce a person from accessing or using voluntary assisted dying, it does not create an offence for coercing patients from applying for or impeding the use of the voluntary assisted dying substance. The Board strongly supports the consideration that those who do not support voluntary assisted dying be required to make information available that enables potential applicants to contact the Statewide Care Navigator Service for the required information and support.

'[The applicant]'s palliative care physician tried to talk her out of it. They described the process as bureaucratic and said, "why bother with it".'

Contact person

'Some difficulties [were experienced] within the hospital with obstruction from some of the senior medical staff to the process. This bordered on discriminatory behaviour.' **Medical practitioner**

'When we got to the oncologist...the secretary said to us "we actually treat people here". [The applicant] had a big go at her being disrespectful. I was so angry and couldn't believe how rude she was. I understand that people have different opinions, but I think professional people should be respectful.' **Contact person**

'Only barrier experienced was with [the hospital] objecting to [the applicant] administering the voluntary assisted dying substance. As [the applicant] did not wish to administer the substance at home, [the co-ordinating medical practitioner] arranged for him to be hospitalised [at another hospital], so he would be able to self-administer.' **Contact person**

Voluntary Assisted Dying Portal

The Voluntary Assisted Dying Portal is the platform where trained medical practitioners can complete, submit, view, and download forms required under the *Voluntary Assisted Dying Act 2017* and the *Voluntary Assisted Dying Regulations 2018*. Safer Care Victoria, as the Secretariat to the Voluntary Assisted Dying Review Board, is responsible for the maintenance, review, and future development of the Portal.

Launched in April 2019, the Portal was developed in advance of the commencement of the Act as a minimum viable product to support the submission of the voluntary assisted dying assessment forms. In 2020, additional funding was granted to meet the rapid growth for access to voluntary assisted dying. As part of this funding, Safer Care Victoria upgraded Portal functionality and increased operational support to ensure timely access to voluntary assisted dying.

Extensive stakeholder consultation identified a significant number of enhancements for the project. A prioritisation exercise identified key deliverables with the objectives of enhanced usability and user experience, reduction of manual processes, and increased data functionality.

In July 2021, a project team was appointed to develop significant enhancements, which were released over the lifecycle of the Portal enhancements project.

Overall, the project has delivered significant improvements for all users of the Portal. Positive feedback has been received regarding the usability and clarity of the submission process for medical practitioners, which has a subsequent positive flow on effect to the applicants.

Alongside this delivery, an updated user guide and new user support videos were released to support

registered users to navigate the new Portal features and better understand the assessment process.

Reduction of common errors

The Board has previously reported on common errors that occurred on the forms, which impacted on the turnaround time of a permit application. These included:

- inadequate evidence of eligibility
- incorrect dates for completion of form
- inconsistencies in spelling of name and address details
- incorrect substance name, dosage, or route
- missing referrals to specialists for neurodegenerative diagnosis and prognosis.

The Portal enhancements have resulted in over a 50 per cent reduction in the incidence of permits not issued. Where they occur, the ability to review and amend within the Portal environment has contributed to a more responsive system. This in turn reduces the impact of potential delays to the process for the applicant. It is expected this number will reduce further in the next reporting period as the enhancements were released halfway through this reporting year.

Research

As outlined in the Act, one of the functions of the Board is to conduct analysis and carry out research in relation to information or forms given to the Board. The Research Working Group comprises Board members with an active role or interest in research. It reports to the Board and has focused on the development of the Board's research strategy.

Development of a research strategy

A review of the data collection and privacy impacts is underway to build a strong foundation for future research using data on voluntary assisted dying in Victoria. This approach will ensure a robust framework for data sharing, as well as clarifying the main research priorities.

The Board aims to develop a collaborative research program with existing research entities. It will adopt a research partnership model with provisions to commission research and will make de-identified data available to researchers interested in conducting their own research. Further information about the strategy and accessing data will be made available over the next year.

Review of the dataset

A review of the data captured through the voluntary assisted dying assessment and compliance processes is underway. The review will consolidate the data collected over the first three years of the program's operation and streamline recording and reporting processes. This will support the implementation of a new research strategy, including through the creation of a de-identified dataset for research.

Review of the operation of the legislation

The *Voluntary Assisted Dying Act 2017* requires that the Minister for Health must cause a review of the operation of the Act in its fifth year. The review will encompass the first four years of operation of the Act. The Board appreciate the feedback and experience of all people involved in accessing voluntary assisted dying. This will form the basis of some of the Board recommendations on the operation of the Act with a focus on improvements in access and safety.

The following feedback has been received by the Board. It should be noted the Board does not provide this information as a representation of Board opinion, rather as a demonstration of the feedback that has been received to date about the operation of the Act.

Communicating about voluntary assisted dying

The Act currently prohibits medical practitioners from initiating a discussion about voluntary assisted dying. Feedback from medical practitioners, applicants and contact people have constantly highlighted this as a barrier to accessing voluntary assisted dying in Victoria. One consequence of this is that some applicants may only begin the process when their illness is at a very advanced stage, by which time going through the application process is challenging.

Other jurisdictions who have brought in similar legislation do not restrict medical practitioners from initiating conversations around voluntary assisted dying provided they give information about all options, including palliative care. To improve the operation of the legislation, authorising medical practitioners and clinical staff to initiate discussions may facilitate access for those who wish to access voluntary assisted dying in Victoria.

Specialist opinion for a neurodegenerative prognosis of 6-12 months

The Act requires that a third specialist opinion is sought for a disease, illness or medical condition that is neurodegenerative where the prognosis is 6-12 months. For applicants with mobility issues and those situated in regional and remote areas, this often requires extensive travel and delays to assessment. Deterioration of an applicant over this time may have further impact on their ability to complete an assessment process.

The Act already requires that at least one of the medical practitioners completing an assessment must have relevant expertise and experience in the disease, illness or medical condition expected to cause the death of the person being assessed. Consequently, one medical practitioner assessing an applicant with a neurodegenerative condition will be an expert in the neurological condition on which the application is based. It may be considered that this is sufficient without a third opinion, regardless of the prognosis of the applicant seeking voluntary assisted dying. This would allow an equal access process for all applicants for voluntary assisted dying.

Access from other jurisdictions who provide voluntary assisted dying

People in other Australian states and in New Zealand will, in time, have access to voluntary assisted dying. New Zealand and Western Australia have commenced their voluntary assisted dying program. Tasmania, Queensland, New South Wales, and South Australia are implementing new legislation. Given the legislations in those jurisdictions are similar in nature, this opens the potential to understand how a reciprocal approach to accessing voluntary assisted dying may operate across these jurisdictions. This would benefit those who are citizens of both countries as well as those who have moved states to be nearer to family or carer after a life-limiting diagnosis. It will also impact those citizens of New Zealand who have lived in Victoria under reciprocal agreements, however, have not sought Australian citizenship or permanent residency.

Self-administration and practitioner administration choice

The Act requires that the medical practitioner must apply for a self-administration permit unless the applicant is unable to self-administer or digest the substance. Should an applicant deteriorate after receiving a self-administration permit, a further application for a practitioner administration permit is required. At times, this delays access to a voluntary assisted dying substance while an applicant is actively dying.

Contact people have also provided feedback around the perceived pressure of supporting an applicant during dispensing or preparation of the substance, and how greater access to an IV self-administration process or practitioner administration would remove barriers.

Key contacts

Safer Care Victoria Secretariat

VADboard@safercare.vic.gov.au

03 9668 7016

Statewide Care Navigator Service

vadcarenavigator@petermac.org

03 8559 5823

0436 848 344

Statewide Pharmacy Service

statewidepharmacy@alfred.org.au

03 9076 5270

End of Life and Palliative Services Team, Department of Health

EndofLifecare@health.vic.gov.au

Join a community of practice

For healthcare professionals who support people to access voluntary assisted dying.

vadcarenavigator@petermac.org

For medical practitioners who have completed the voluntary assisted dying training.

vadcommunity@westvicphn.com.au

Grief and bereavement services

Lifeline (call 13 11 14) provides telephone or online support and counselling 24 hours a day, 7 days a week.

Australian Centre for Grief and Bereavement (Tel. 1800 642 066) provides a statewide specialist bereavement service (including counselling and support groups) for individuals, children, and families.

Beyond Blue (Tel. 1300 224 636) provides support 24 hours a day, 7 days a week, with options including telephone, online, email and forums.

Palliative Care Victoria (www.pallcarevic.asn.au) provides information and resources about grief and loss, including details for grief and bereavement services.

Board members

The Board currently has 11 members representing a wide range of expertise and skills to help perform the functions and duties of the Board.

Chairperson

Julian Gardner AM
Lawyer

Deputy Chairperson

Charlie Corke
Intensive care specialist

Members

Margaret Bird
Consultant physician in geriatric medicine

Molly Carlile AM
Senior healthcare leader and palliative care expert

Mitchell Chipman
Medical oncologist and palliative care physician

John Clements
Consumer and IT consultant

Sally Cockburn
Specialist general practitioner (VR) and health educator

Jim Howe
Neurologist

Margaret O'Connor AM
Emeritus Professor of Nursing

Nirasha Parsotam
Medication safety specialist

Paula Shelton
Lawyer

