

Interim report: Voluntary assisted dying in NSW

28 November 2023 to 29 February 2024



Message from the Chair

Professor Jenni Millbank

I am pleased to present the first report of the Voluntary Assisted Dying Board (the Board). This interim report provides an overview of the first three months of voluntary assisted dying activity in NSW. The Board will publish its first annual report after the end of the 2023-24 financial year.

The *Voluntary Assisted Dying Act 2022* (the Act) came into effect in NSW on 28 November 2023, giving eligible people who are at end of life and suffering the option to choose the timing and circumstances of their death.

The Board is established by the Act as an independent oversight body with advisory, monitoring, reporting, referral and decision-making functions.

The Board undertakes a high volume of work associated with its decision-making functions. We currently meet twice weekly in person to review applications and make decisions. We are also often required to make decisions at short notice or in urgent circumstances outside of our regular meeting schedule. This is to ensure that eligible people who are at end of life or at risk of losing decision-making capacity who have applied for voluntary assisted dying are supported to access it.

We know from the experience in other states as well as our first few months of operations that some people who receive a substance authority from the Board may ultimately choose not to take the substance. Knowing the substance is available to them gives these people the power of choice, and may provide a degree of relief and comfort in their final days and weeks.

The Commonwealth *Criminal Code Act 1995* (the Commonwealth Criminal Code) significantly restricts voluntary assisted dying service delivery in NSW, as it does elsewhere in Australia. This is due to offences of the Commonwealth Criminal Code related to using a carriage service, meaning some parts of the voluntary assisted dying process that may otherwise be appropriate and lawful to occur via electronic means must occur face-to-face.

In conjunction with other Voluntary Assisted Dying Boards (or equivalent) around Australia, we will continue to advocate for federal legislative change to remove or amend the carriage service provisions to enable state and territory voluntary assisted dying laws to operate as they were designed to do.

The Board recognises the huge amount of work carried out by the many stakeholders involved in implementing voluntary assisted dying in NSW according to the principles outlined in the Act. These stakeholders include NSW Health staff across local health districts, the NSW Voluntary Assisted Dying Support Services and the NSW Ministry of Health. We also thank our interstate and overseas colleagues who have shared knowledge, experience and reflections to inform the Board's processes and ways of working.

The Board wishes to acknowledge the work of the Secretariat to support the Board and our various functions, particularly its high-quality and professional work to ensure that we can consider applications as soon as practicable.

In addition, the Board extends its thanks to the authorised voluntary assisted dying practitioners who have supported eligible people to access voluntary assisted dying in NSW, as well as all healthcare workers involved in providing care and support to these people throughout the process. This important new end of life option would not be possible without your dedication and commitment to providing high-quality and person-centred care.



Professor Jenni Millbank

Chairperson, Voluntary Assisted Dying Board

About the NSW Voluntary Assisted Dying Board

The NSW Voluntary Assisted Dying Board (the Board) was established under the Voluntary Assisted Dying Act 2022 (the Act), which outlines the legal framework for voluntary assisted dying in NSW. The Board is an independent oversight and decision-making body with a range of functions, including:

- making decisions to approve or refuse applications for voluntary assisted dying substance authorities for individual patients
- making decisions to approve or refuse applications for residency exemptions for individual patients
- providing annual reports on the operation of the Act to the Minister for Health
- collecting statistical information about voluntary assisted dying in NSW
- conducting analysis and research in relation to information given to the Board under the Act
- making referrals for investigations of suspected breaches of the Act.

A full list of Board functions is available in section 136 of the [Act](#).

Under the Act, forms completed by practitioners and patients throughout the process must be submitted to the Board. The Board receives forms via the NSW Voluntary Assisted Dying Portal (the Portal), a secure online platform used for the management of requests and submission of required documentation for voluntary assisted dying in NSW.

The Board meets formally in twice-weekly face-to-face meetings, with additional out-of-session activity as needed to fulfil their responsibilities.

As required by the Act, the Board comprises five members, jointly appointed by the Minister for Health and the Attorney General.

Members of the Board

Professor Jenni Millbank (Chair) is a Distinguished Professor at the Faculty of Law at the University of Technology Sydney where she is currently Associate Dean of Academic Staff and previously was the founding Director of the Law Health Justice Research Centre. Professor Millbank is also a legal practitioner and an experienced tribunal decision-maker.

Mr Patrick Knowles SC (Deputy Chair) is a Barrister at Tenth Floor Chambers. He was admitted as a legal practitioner in 2004, became a Barrister in 2009 and was appointed Senior Counsel in 2022. He specialises in administrative law.

Dr Philip Hungerford has been a staff specialist for over 30 years. He has dedicated most of his career to rural health, practicing in a regional centre and taking on Director positions in the emergency, intensive care, medical retrieval and palliative care sectors.

Dr Tamsin Waterhouse has been a Barrister with Maurice Byers Chambers since June 2021. Also a doctor, her health leadership background includes senior medical management positions at Sydney Local Health District (2013-2018) then Northern Sydney Local Health District from 2018 until she was called to the bar.

Dr Rohan Krishnan is a general dentist who also works in a multi-disciplinary clinic looking after patients with chronic pain. He also has long-standing involvement in the provision of pro-bono care for patients with disability, asylum seekers and refugees.

Introduction

Voluntary assisted dying became a lawful end of life option for eligible people in NSW on 28 November 2023, after an 18-month implementation period.

Ensuring safe and equitable access regardless of a person's setting, geographic location or preferred language underpins the approach to voluntary assisted dying in NSW, the final state in Australia to implement voluntary assisted dying legislation.

The choice to access voluntary assisted dying is deeply personal and does not align with every eligible person's goals of care or personal preferences. Voluntary assisted dying is accessible throughout NSW, with information provided in a range of languages and channels for people seeking information to help inform their end of life choices. Eligible people who choose voluntary assisted dying will still be able to access other care they might want or need.

In line with the Board's role in monitoring the operation of the Act, the purpose of this report is to reflect on the first three months of operations of the Act, from 28 November 2023 to 29 February 2024.

Voluntary assisted dying in NSW

The voluntary assisted dying process (**Figure 1**) is person-centred. Patients can move through the process as slowly as they wish, and they can also pause or stop the process at any time. At each stage of the process, patients must confirm they choose to continue.

Commencement of voluntary assisted dying

Requests for voluntary assisted dying have been consistent with the experience of other jurisdictions with similar legislation and sustained since commencement.

Voluntary assisted dying is a deliberative and structured process. The Act sets minimum timeframes by which a patient can progress through the steps. In select circumstances, the Act also allows for expedited processes if both the coordinating and consulting practitioners are of the opinion that a patient is at risk of dying or losing decision-making capacity in relation to voluntary assisted dying before the end of the specified minimum timeframe.

Some people who are close to end of life when they seek access to voluntary assisted dying can deteriorate very rapidly and will be unable to complete the process. Health services reported this was especially noticeable in the days and weeks immediately following commencement when people who were at the end of life sought access to voluntary assisted dying as soon as the legislation took effect.

Implications of the Commonwealth Criminal Code Act 1995

The implications of the Commonwealth *Criminal Code Act 1995* for voluntary assisted dying appointments mean that practitioners are currently unable to use telehealth in situations where they may otherwise determine it to be clinically appropriate and in the patient's best interest. This can result in a substantial amount of travel for practitioners in particular, which can delay the process for patients and reduce practitioners' time spent in clinical settings due to travel time.

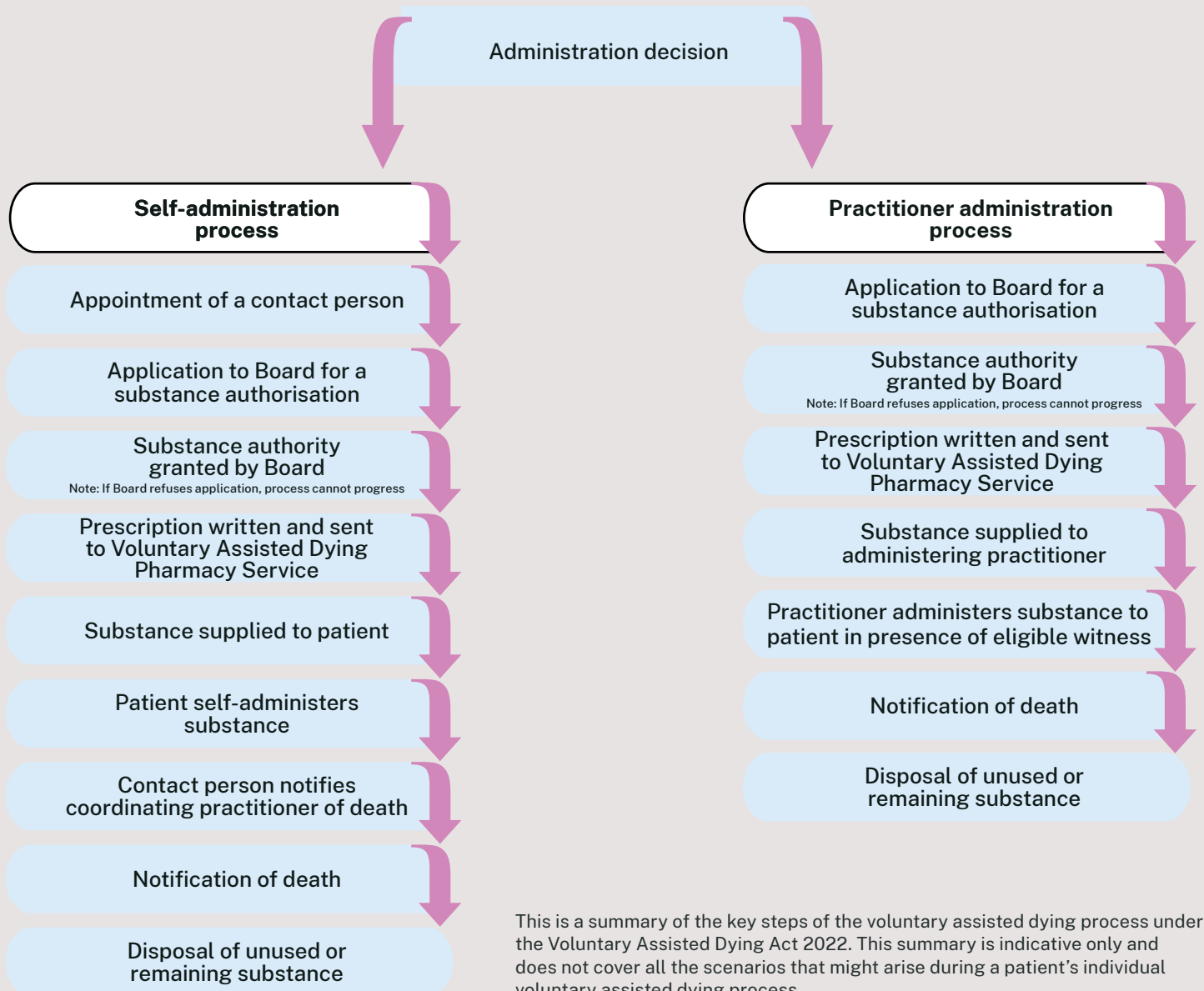
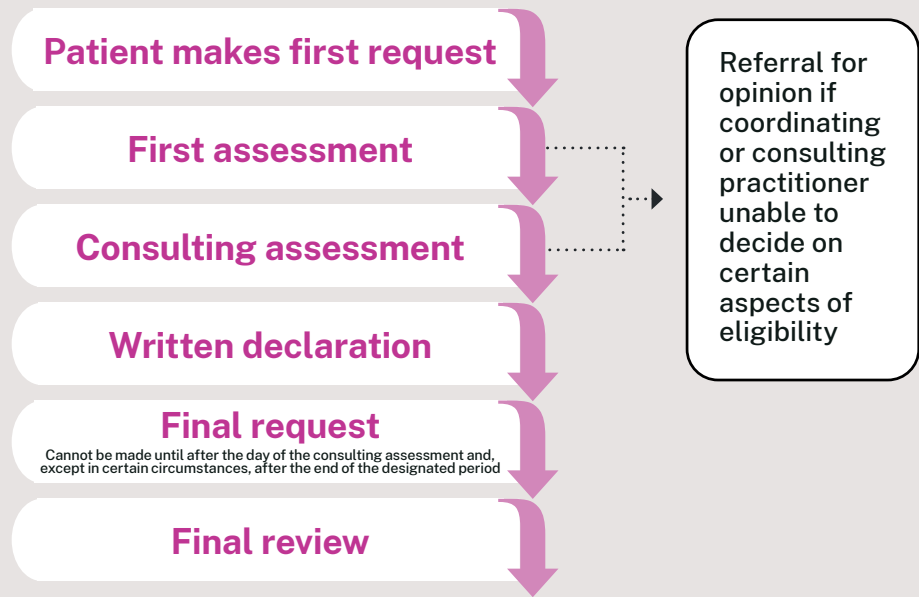
Voluntary assisted dying and palliative care and treatment

One of the principles of voluntary assisted dying in NSW is that a person has the right to be supported in making informed decisions about their medical treatment and should be given, in a way the person understands, information about medical treatment options, including comfort and palliative care and treatment.

A person approaching the end of life should also be provided with high quality care and treatment, including palliative care and treatment, to minimise the person's suffering and maximise the person's quality of life. Every person seeking access to voluntary assisted dying must be informed about all palliative care and treatment options available to them, and the likely outcomes of the care and treatment.

Figure 1. Summary of the key steps of the voluntary assisted dying process

A patient can pause or stop the voluntary assisted dying process at any time



This is a summary of the key steps of the voluntary assisted dying process under the Voluntary Assisted Dying Act 2022. This summary is indicative only and does not cover all the scenarios that might arise during a patient's individual voluntary assisted dying process.

Key safeguards in the voluntary assisted dying process

The process in NSW includes numerous safeguards which are designed to ensure the process is safe and that voluntary assisted dying can only be accessed by those who are eligible and provided by those who are appropriately qualified and trained.

Safeguards include that:

- A person can only request voluntary assisted dying for themselves. No one can request voluntary assisted dying on someone's behalf.
- The patient will need to make three separate requests for voluntary assisted dying (a first request, a written declaration and a final request).
- The patient's decision to request access to voluntary assisted dying must be assessed as voluntary and free from pressure or duress at multiple stages of the process. Their decision-making capacity must also be maintained throughout the process.
- The patient must be assessed by two independent medical practitioners (a coordinating and consulting practitioner) against each of the eligibility criteria.
- A patient's decision to seek information about, or access to, voluntary assisted dying has no impact on their access to high-quality palliative care. Every patient seeking access to voluntary assisted dying must be informed about all palliative care and treatment options available to them, and the likely outcomes of the care and treatment. They must also be provided with information about their diagnosis, prognosis and any available treatment options.
- The patient can be referred to another person with appropriate skills and training to confirm the patient is eligible to access voluntary assisted dying.
- The patient can pause or stop the voluntary assisted dying process at any time.
- It is a criminal offence for anybody to induce another person to request or access voluntary assisted dying.
- Practitioners who provide voluntary assisted dying services must meet professional qualifications and eligibility requirements, including successfully completing mandatory training.
- An authorised voluntary assisted dying practitioner community of practice ensures practitioners are supported with a forum for learning through interactive case-based discussions, mentoring, structured education, and confidential peer support.
- Persons acting in accordance with the Act are protected from liability.
- A healthcare worker is not obliged to participate in the voluntary assisted dying process if they have a conscientious objection. However, they cannot impede or obstruct access to the voluntary assisted dying process.

- The Board has been established to monitor the operation of the Act and make decisions on applications for patients to access voluntary assisted dying.
- In line with the Act, Board membership includes two senior legal practitioners, two medical practitioners and one member with knowledge, skills or experience relevant to the Board's functions.
- The Board must grant a Voluntary Assisted Dying Substance Authority (substance authority) before a prescription for the voluntary assisted dying substance can be issued.
- Authorised voluntary assisted dying practitioners must follow detailed prescription and administration protocols.
- The voluntary assisted dying substance must be stored in a locked box and any unused or remaining substance must be returned and disposed of. The NSW Voluntary Assisted Dying Pharmacy Service manages the safe return and disposal of unused or remaining voluntary assisted dying substance by authorised disposers.

First three months of operations

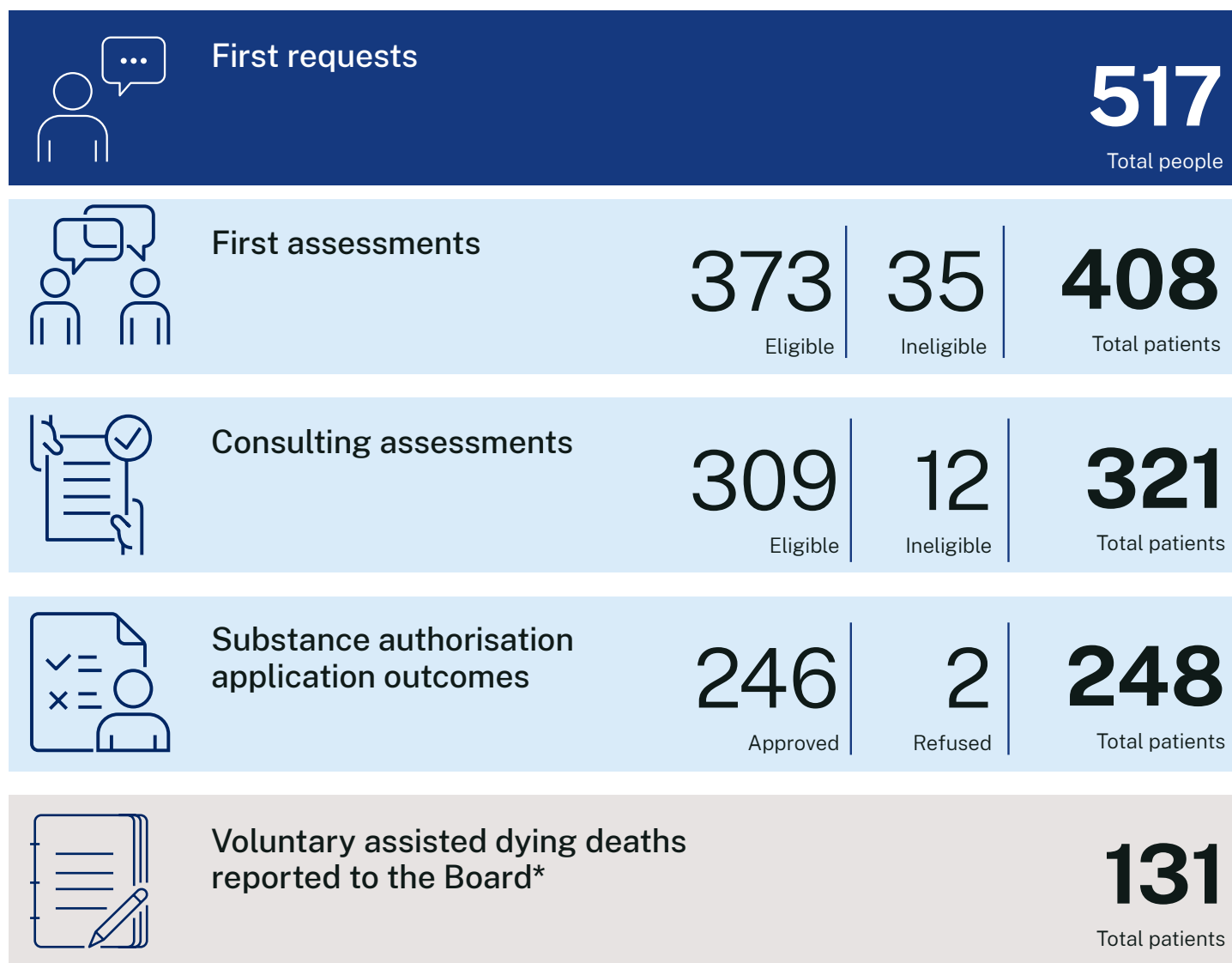
This report contains data extracted from the Portal on activity occurring between 28 November 2023 and 29 February 2024 that was reported to the Board by 16 April 2024.

Data in this report reflects patient-level activity rather than total health service activity. This means that if a patient had more than one voluntary assisted dying application, only information from the most recent application has been included in the report.

Not all people who have made a first request to access voluntary assisted dying between 28 November 2023 and 29 February 2024 will progress to the point of applying to the Board for a substance authorisation or administration of the substance within this same time period. Many scenarios may occur, including that the:

- Patient is found to be ineligible;
- Patient is still progressing through the process;
- Patient chooses to stop the process (or pause the process, and they have not resumed within this three-month reporting period);
- Patient receives the substance but chooses not to administer within this three-month report period;
- Patient dies of a cause other than voluntary assisted dying.

Figure 2. Overview of the first three months of voluntary assisted dying in NSW, 28 November 2023 to 29 February 2024



Notes:
 *Due to separate and independent notification processes, at any point in time there may be differences between the number of deaths reported to the Board and relevant deaths notified to the NSW Registry of Births, Deaths and Marriages.

Figure 2 shows the number of patients who have completed each stage of the process between 28 November 2023 and 29 February 2024 as reported in the Portal at 16 April 2024.

Between 28 November 2023 (commencement of the Act) and 29 February 2024:

- A total of 517 unique people made a first request to access voluntary assisted dying. This includes every person who made a first request, regardless of whether the request was accepted or refused.
- 408 patients (78.9% of the 517 who made a first request) had a first assessment, noting that only patients with an accepted first request can proceed to a first assessment. Of these, 373 (91.4%) were found eligible following their first assessment and 35 (8.6%) were found ineligible.
- 321 patients (62.1% of the 517 who made a first request) had a consulting assessment, noting that only patients found eligible at first assessment can proceed to a consulting assessment. Of these, 309 patients (96.3%) were found eligible following their consulting assessment and 12 patients (3.7%) were found ineligible.
- 248 patients (48% of the 517 who made a first request) had a substance authorisation application considered by the Board. Of these, 246 applications (99.2%) were approved and 2 applications (0.8%) were refused, noting that only patients who have completed the request and assessment process and made an administration decision can apply to the Board for a substance authorisation.
- 131 patients (25.3% of the 517 who made a first request) died from administration of a voluntary assisted dying substance, noting that only patients with a substance authority can access the substance. This does not account for patients who have not yet taken the substance or those who may have died from another cause.

Table 1. First assessments for voluntary assisted dying, NSW, 28 November 2023 - 29 February 2024

	Number	Per cent
Eligibility at first assessment		
Eligible	373	91.4
Ineligible	35	8.6
Gender		
Male	232	56.9
Female	176	43.1
Non-binary	0	0.0
Something different	0	0.0
Prefer not to say	0	0.0
Aboriginality		
Aboriginal*	10	2.5
Non-Aboriginal	376	92.2
Not stated or unknown	22	5.4
Age**		
18-29	0	0
30-39	4	1.0
40-49	13	3.2
50-59	26	6.4
60-69	87	21.3
70-79	146	35.8
80-89	94	23.0
90+	38	9.3
Location (according to residential address)#		
Greater Sydney	142	34.8
Regional	265	65.0
Outside of NSW+	1	0.2
Total first assessments		
Patients	408	

Notes:

*Aboriginal includes people who identified as either Aboriginal or Torres Strait Islander or both Aboriginal and Torres Strait Islander.

**Age is calculated at the time of first request.

#In accordance with the NSW Voluntary Assisted Dying Act 2022, for the purposes of voluntary assisted dying reporting for NSW, Greater Sydney Region has the same meaning as in the [Greater Sydney Commission Act 2015](#) and “regional” means an area of NSW that is outside the Greater Sydney Region.

+Patients with a residency exemption granted by the Board may have a residential address within or outside of NSW.

Table 1 describes the demographic profile of patients who underwent a first assessment between 28 November 2023 and 29 February 2024.

Of the 408 patients who had a first assessment between 28 November 2023 (commencement of the Act) and 29 February 2024:

- 373 (91.4%) were found to be eligible and 35 (8.6%) were found to be ineligible for access to voluntary assisted dying.
- 232 (56.9%) identified as male and 176 (43.1%) identified as female.
- 10 (2.5%) identified as Aboriginal, 376 (92.2%) identified as non-Aboriginal and 22 (5.4%) either did not specify or indicated that this was unknown.
- The most prevalent age group was 70 – 79 years (146, 35.8%), with the next most prevalent age group being 80 – 89 years (94, 23.0%), followed by 60 – 69 years (87, 21.3%), 90 years or older (38, 9.3%), 50 – 59 years (26, 6.4%), 40 - 49 years (13, 3.2%) and 30 – 39 years (4, 1.0%). There were no patients in the 18 - 29 years age group.
- 142 (34.8%) lived in Greater Sydney, 265 (65.0%) lived in regional NSW and 1 (0.2%) lived outside of NSW.

Table 2. Patients with a substance authority, NSW, 28 November 2023 - 29 February 2024

	Number	Per cent
Primary diagnosis at first assessment*		
6 months prognosis: cancer	175	71.1
6 months prognosis: respiratory	17	6.9
6 months prognosis: other	12	4.9
12 months prognosis: neurodegenerative	42	17.1
Administration decision**		
Self-administration decision	73	29.7
Practitioner administration decision	173	70.3
Total patients with a substance authority		
Patients	246	

Notes:

*In the context of eligibility criteria for voluntary assisted dying, a prognosis of 12 months is only applicable for neurodegenerative conditions.

**Where a patient has revoked an administration decision and subsequently made a new administration decision, the most recent decision for that patient will be reflected in this data.

Table 2 describes the primary diagnosis and administration decisions of patients who had a substance authority granted between 28 November 2023 and 29 February 2024.

Of the 246 patients who were granted a substance authority between 28 November 2023 and 29 February 2024, the majority had cancer as a primary diagnosis (175, 71.1%), followed by a neurodegenerative condition such as motor neurone disease (42, 17.1%), respiratory condition such as chronic obstructive pulmonary disease (17, 6.9%) and ‘other’ diagnosis (12, 4.9%).

Many patients applying for voluntary assisted dying have complex presentations that involve multiple comorbid conditions. **Table 2** reports primary diagnosis as recorded at the patient’s first assessment.

173 (70.3%) patients with a substance authority granted during this period made a practitioner administration decision and 73 (29.7%) made a self-administration decision.

Table 3. Deaths reported to the Board, patients with a substance authority, NSW, 28 November 2023 - 29 February 2024

	Number	Per cent
Details of death		
Self-administration of voluntary assisted dying substance	40	25.0
Practitioner administration of voluntary assisted dying substance	91	56.9
Cause other than voluntary assisted dying	29	18.1
Deaths among patients with a substance authority*		
Patients	160	

Notes:
 *Due to separate and independent notification processes, at any point in time there may be differences between the number of deaths reported to the Board and relevant deaths notified to the NSW Registry of Births, Deaths and Marriages.

Of the 246 patients who had a substance authority, the Board was notified of the death of 160 patients between 28 November 2023 and 29 February 2024 (**Table 3**). 91 (56.9%) died from practitioner administration of the voluntary assisted dying substance, 40 (25.0%) died from self-administration of the voluntary assisted dying substance and 29 (18.1%) died from a cause other than voluntary assisted dying.

Authorised voluntary assisted dying practitioner workforce

There are three formal roles for eligible practitioners under the Act, including that of a:

- **Coordinating practitioner:** The authorised voluntary assisted dying practitioner who accepts a patient’s first request for voluntary assisted dying and is responsible for assessing and supporting the patient throughout the voluntary assisted dying process;
- **Consulting practitioner:** The authorised voluntary assisted dying practitioner responsible for undertaking the consulting assessment for the patient, a second, independent eligibility assessment; and
- **Administering practitioner:** The authorised voluntary assisted dying practitioner responsible for administering the voluntary assisted dying substance to a patient who has chosen practitioner administration and has followed all the required steps in the process, including obtaining a substance authority from the Board.

Medical practitioners and nurse practitioners must meet professional qualifications and eligibility requirements to provide formal voluntary assisted dying services under the Act. They must also successfully complete the approved voluntary assisted dying training. These practitioners are collectively referred to as authorised voluntary assisted dying practitioners (authorised practitioners).

Eligible medical practitioners can apply to become an authorised practitioner and can act in the coordinating, consulting or administering practitioner roles. Eligible nurse practitioners can apply to become an authorised practitioner and act in the administering practitioner role.

From 14 August 2023, practitioners have been able to register in the Portal to commence the process to become an authorised voluntary assisted dying practitioner.

At 29 February 2024, a total of 250 practitioners were authorised voluntary assisted dying practitioners in NSW (**Table 4**). Of this 250, 123 authorised practitioners have supported a patient seeking to access voluntary assisted dying.

Table 4. Authorised voluntary assisted dying practitioners, NSW, at 29 February 2024

	Number
Healthcare worker type	
Medical practitioner	228
Nurse practitioner*	22
Role type	
Coordinating, consulting, and administering	217
Administering only	33
Total authorised voluntary assisted dying practitioners	
Practitioners	250

Notes:

*Nurse practitioners are only eligible to act in the administering practitioner role.

Of the 250 authorised voluntary assisted dying practitioners at 29 February 2024:

- 228 (91.2%) were medical practitioners and 22 (8.8%) were nurse practitioners.
- 217 (86.8%) were eligible to act in a coordinating, consulting and administering practitioner role and 33 (13.2%) were eligible to act in an administering practitioner role only.

Supporting regional access to voluntary assisted dying

Equity of access regardless of a person's geographic location is a key principle of voluntary assisted dying in NSW. Supports are in place to assist people in regional NSW to access voluntary assisted dying.

All regional local health districts have local voluntary assisted dying care pathways in place to support patient access.

To support equity and timeliness of access and mitigate potential service gaps due to factors such as the broad geographic spread of the population across NSW, an Access Service was established as part of a broader NSW Voluntary Assisted Dying Support Service (NVSS). The Access Service is a pool of authorised voluntary assisted dying practitioners to whom referrals can be made from anywhere in the state if a local authorised practitioner is not available. The Access Service sits alongside the Care Navigator Service and Pharmacy Service in the NVSS, supporting connected care and timely referrals. The Care Navigator Service and Pharmacy Service also provide services statewide.

Approximately 45% of authorised practitioners reported their primary practice location to be in Greater Sydney, and approximately 55% were in regional NSW. As practitioners may travel to support patients through the voluntary assisted dying process, practitioner location does not necessarily reflect the location where the practitioner provides voluntary assisted dying services.

The NSW Isolated Patients Travel and Accommodation Assistance Scheme (IPTAAS) is also available for regional people to assist with the cost of travel and accommodation to attend appointments required in the voluntary assisted dying process.

The Board will continue to closely monitor access to voluntary assisted dying services for people in regional areas of NSW.

Residency exemptions

Under the Act, one of the eligibility criteria for access to voluntary assisted dying is that the person must have been *ordinarily resident* in NSW for at least 12 months at the time of first request. However, a person who does not meet this criterion may still be eligible to access voluntary assisted dying in NSW if they are granted an exemption from this requirement by the Board.

The Board must grant the exemption if they are satisfied:

- that the person has a substantial connection to NSW, and
- there are compassionate grounds for granting the exemption.

In order to seek a residency exemption, the required documentation must be submitted to the Board, by the patient or a person on the patient's behalf. Documentation includes a Residency Exemption Application Form, evidence of the patient's connection to NSW and evidence of the compassionate grounds on which the exemption is sought.

The Board considers each application as soon as possible. Importantly, every step of the process must occur in NSW for the protections from liability under the Voluntary Assisted Dying Act 2022 and other legislation to apply. This means that both the patient and the authorised practitioner must be physically in NSW for each step. This applies to all patients, including those who obtain a residency exemption to seek access to voluntary assisted dying in NSW.

Between 28 November 2023 and 29 February 2024, the Board received and approved six residency exemptions.

More information

Visit the NSW Health website for information about voluntary assisted dying including in-language resources: health.nsw.gov.au/vad

Contact the free NSW Voluntary Assisted Dying Care Navigator Service for information about voluntary assisted dying. The service is available to everyone including people considering voluntary assisted dying, patients, loved ones, health practitioners and providers.

- Call: 1300 802 133 Monday to Friday, 8:30am to 4:30pm (excluding public holidays)
- Email: NSLHD-VADCareNavigator@health.nsw.gov.au

People considering voluntary assisted dying should also speak to their usual treating team.

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