Assisted Dying Service Data and Reporting

Assisted Dying Service yearly report 2021/2022

For the period 7 November 2021 – 6 November 2022

Assisted dying involves a person who is experiencing unbearable suffering from a terminal illness taking or being given medication to end their life. There are strict eligibility criteria to have an assisted death. Not everyone with a terminal illness will be eligible. New Zealanders aged 18 or over who have a terminal illness which is likely to end their life within 6 months may be able to access assisted dying.

The service involves specific steps, medical assessments, and important safeguards. These are to ensure a person is eligible and that they are making the decision for themselves, without pressure from anyone else. The framework for the service and its eligibility criteria and safeguards are set out in the law, called the End of Life Choice Act 2019 (the Act). The Assisted Dying Service is overseen by Manatū Hauora - the Ministry of Health (Manatū Hauora).

This report reflects a summary of individuals' interactions with the Assisted Dying Service during the first year of service (7 November 2021 – 6 November 2022). Note that some applications received during this time were ongoing at the end of the reporting period.

The information routinely collected by Manatū Hauora is determined by the requirements outlined in the Act. This report follows the specific purpose of gathering and reviewing information as mandated within the Act. The content included within this report is presented in the interest of both public and academic review.

Within the document, we use the acronyms AMP (referring to attending medical practitioner) and IMP (referring to independent medical practitioner). These practitioners perform the medical assessments to determine eligibility. For more information relating to practitioner roles, <u>please refer to our website</u> or the <u>End of Life Choice Act 2019</u>.

Certain low numbers relating to applications within the year review are enclosed in full. The decision to disclose this information is made in specific instances with explicit consideration of the protection of privacy of those involved. To protect the privacy of the patients, whanau, and medical practitioners involved with the service, some information has been suppressed.

Assisted Dying applications

Overview of assisted dying applications

Between 7 November 2021 and 6 November 2022, Manatū Hauora received 661 formal applications for assisted dying. Of these 661 applications, 636 have progressed from initial application to AMP assessment. Those 25 who did not progress either:

- withdrew their application
- died before the AMP assessment was formally initiated
- were found to be ineligible prior to formal initiation of the AMP assessment
- the application was still open (had not yet progressed to assessment) during the period set out in this report.

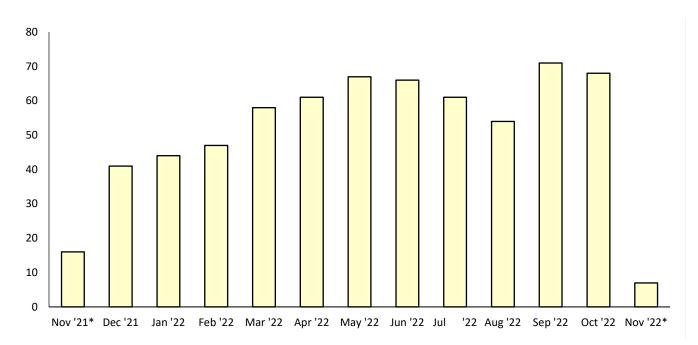
Over this reporting period, AMPs completed 636 assessments and IMPs completed 475 assessments. Of those assessed over the year, 399 applications were confirmed as eligible and 257 assisted deaths occurred. During this period, 305 applications did not proceed to an assisted death following assessment due to:

- the applicant withdrawing their application
- the applicant being found ineligible or not competent to give consent at or following assessment
- the applicant dying as a result of underlying conditions
- the application being found to not comply with the Act at final review.

Figure 1 below outlines the number of applications initiated per month during this period. It shows that the number of applications received increased gradually over the first few months of service, and then remained relatively stable from mid-2022.

Note that both November 2021 and November 2022 in Figure 1 reflect partial months from 7 November 2021 to 6 November 2022.

Figure 1: New applications received by month



Of the 661 new applications received over the year:

- 80.8% were NZ European/Pākehā
- 5.5% were Māori
- 55.2% were Female/Wāhine
- 75.8% were 65 years or older
- 77.0% were receiving palliative care at the time of the application
- 67.9% had a diagnosis of cancer.

Table 1: Demographic summary of new applications

Demographic summary: New Applications (N= 661) 7 November 2021 – 6 November 2022		Number of people ³	% of applications	
Ethnic group ¹	Māori	36	5.45	
	Pacifica	4	0.61	
	NZ European/Pākehā	534	80.79	
	Asian	11	1.51	
	Other	93	14.07	
Sex	Female/Wāhine	365	55.22	
	Male/Tāne	296	44.78	
	Gender diverse	0	0	
Age group	18-44 years	14	2.12	
	45-64 years	146	22.09	
	65-84 years	379	57.34	
	85+ years	122	18.46	
Diagnosis ²	Cancer	449	67.93	
	Neurological condition	67	10.14	
	Chronic Respiratory Disease	32	4.84	
	Cardio-Vascular condition	33	4.99	
	Other organ failure	19	2.87	
	Other diagnosis	42	6.35	
	Not known ⁴	88	13.31	
Receiving palliative care at time of	Yes	509	77.0	
application?	No	149	22.54	
	Not stated	3	0.45	
Reported a disability at time of	Yes	151	22.84	
application?	No	504	76.25	
	Not stated	6	0.91	

Notes:

- 1. Total ethnicity has been used. This means that individuals reporting more than one ethnicity are included within each category to which they identify. In the current report, individual identification as 'European' has been included within the 'Other' category, distinct from NZ European/Pākehā
- 2. Total diagnosis has been used. This means that individuals presenting with multiple diagnoses are included within each applicable diagnostic category.
- 3. Repeat applications are included as unique instances. This means that in cases where an individual submits multiple applications during this period, their information is recorded in the demographic data each time.
- 4. 'Diagnosis not known' includes individuals who have applied but have not yet completed their first assessment with their AMP, as well as those who have withdrawn before assessment, died before this assessment was completed, or were ineligible due to not having a terminal illness.

Applications received by location

Table 2 provides a summary of formal applications by location for the review period (7 November 2021 – 6 November 2022). We have included a summary relating to both the historical DHB (district health board) system, as well as the new observed Te Whatu Ora regions.

Table 2: New applications by location

Region	Locations included	Number of applications	Percentage of total applications
Northern	Auckland	46	29.35
	Counties Manukau	41	
	Northland	38	
	Waitematā	69	
Te Manawa	Bay of Plenty	62	25.72
Taki (Midland)	Lakes	16	
	Tairāwhiti	8	
	Taranaki	15	
	Waikato	69	
Central	Capital and Coast	53	19.52
	Hawkes Bay	30	
	Hutt Valley	11	
	MidCentral	17	
	Wairarapa	11	
	Whanganui	7	
Te Waipounamu	Canterbury	72	25.42
(Southern)	Nelson Marlborough	45	
	South Canterbury	3	
	Southern	39	
	West Coast	9	

Assessments completed during this period

After an application is submitted, an initial assessment is made by an AMP. This practitioner reviews eligibility against the criteria as outlined in the Act. The IMP provides an independent second assessment. For more information relating to practitioner roles, <u>please refer to our website</u> or the <u>End</u> of Life Choice Act 2019.

Applications may be found ineligible at each of these assessments for a variety of reasons. For more information on ineligibility outcomes at assessment for this first year of service please see Table 4.

Following eligible outcomes at both AMP and IMP assessments, AMPs meet with the applicant for further discussion relating to eligibility and the assisted dying process. At this time, some previously eligible applicants may be found not competent to continue. This outcome occurred 6 times between 7 November 2021 to 6 November 2022.

Table 3 outlines the number of assessments undertaken, and the associated outcomes, at each stage of the assisted dying process.

Table 3: Assessment outcomes

	Outcome of assessment	Number of assessments
AMP Assessments	Eligible	545
(N = 636)	Ineligible	91
IMP Assessments	Eligible	443
(N = 475)	Ineligible	32
Eligibility Discussion Following Assessment	Eligible	399
(N = 405)	Ineligible	6

Reasons to be found ineligible at AMP and IMP stage

Not all applications made to the Assisted Dying Service will result in an assisted death; some individuals may be assessed as ineligible. Reasons for ineligibility vary, and may relate to an applicant's age, status as a New Zealand citizen/resident, or considerations relating to their health and physical decline. For more information about eligibility criteria, please refer to our website.

Table 4 outlines a summary of ineligibility decisions at each stage of assessment by AMP and IMPs (referred to in Table 3). Being found eligible at AMP assessment stage and ineligible at IMP assessment stage may occur due to a number of reasons, including but not limited to a change in personal circumstances impacting eligibility and/or a change in prognosis.

Table 4: Ineligibility summaries: Assessed by AMP and IMP

The applicant is	Ineligible at AMP assessment (91)	Ineligible at IMP assessment (32)
Not a New Zealand Citizen/Permanent resident	5	0
Not aged 18 or over	0	0
Not experiencing unbearable suffering in a manner that the person considers tolerable	42	11
Not in an advanced state of irreversible physical decline	40	11
Not suffering from a terminal illness that is likely to end their life within 6 months	67	13

Note:

Total reasons for ineligibility have been applied. This means that individuals may be found to be ineligible across multiple criteria, and each observed reason is included in the report.

Assessed applications not continuing to Assisted Dying

Table 5 summarises applications where an assessment had occurred (at AMP or IMP), but the applicant had not progressed to an assisted death. This table specifically relates to applications not accounted for as ineligible at the AMP or IMP assessments (as per Table 3). Additionally, this table includes applications which are still open at the time of review and are therefore not associated with a known outcome.

There are several reasons why an individual may not continue their application to an assisted death. These include being found ineligible following a prior eligible outcome or becoming unable to make an informed decision/give consent. Individuals may also withdraw their application or die of an underlying condition/terminal illness at any point during the application process or before their scheduled assisted death. Furthermore, individual applications may be found non-compliant with the Act during final review before an assisted death may occur.

Table 5: Application not progressed to an assisted death

	Number of assessments
Died in process	140
Lost competence	22
Lost eligibility	1
Decided to withdraw	11
Application found to be not compliant with the Act at final review	2
Application is still open at the time of review	74

Requested competence assessment

In some situations, a person will also be seen by a psychiatrist. This will happen if the AMP and IMP both think the person is eligible, but one or both have concerns about whether the person is competent to make an informed decision.

During the period described, only six individuals were referred for a competence assessment. All but one were determined to be competent to consent, while the remaining individual died in process before a decision had been completed.

Number of re-applications

Twenty-eight individuals made more than one application for an assisted death during the reporting period. There are several reasons why an individual might make more than one request. This includes, but is not limited to:

- the applicant being assessed as ineligible at the time of the first application, and choosing to reapply
- the applicant withdrawing their original request and then deciding to reapply
- an observed change in the applicant's individual circumstances which affects their eligibility (eg, a change in prognosis).

No individual has made more than one reapplication during this reporting period.

Assisted Deaths

Number of assisted deaths

Between 7 November 2021 and 6 November 2022, 257 people had an assisted death.

The figure below outlines the number of applications initiated, eligible applications following assessment (referred to in Table 3), and assisted deaths by month. Note that both November 2021 and November 2022 in Figure 2 reflect partial months (from 7 November 2021 to 6 November 2022).

80 70 60 50 40 30 20 10 n Nov Dec '21 Jan '22 Feb '22 Mar '22 Apr '22 May '22 Jun '22 Jul '22 Aug '22 Sep '22 Oct '22 Nov '21* '22* ■ Application Initiated ■ Eligible ■ Assisted Deaths

Figure 2: Application and eligibility of assisted deaths

Location of assisted deaths

Assisted deaths can take place at the person's home, in hospital, or in the community. The summary by location for this period of review is:

- 210 (or 81.71%) at the person's home or another private property
- 21 (or 8.17%) in a public hospital
- 18 (or 7.00%) in an aged care facility
- 8 (or 3.11%) in a hospice facility.

SCENZ Group practitioner lists

The Support and Consultation for End of Life in New Zealand group (SCENZ group) is responsible for maintaining the list of medical practitioners and Psychiatrists involved in providing assisted dying services. As of the date of review, there were 147 practitioners registered as members on the SCENZ list.

Medical practitioners can be on the SCENZ list for more than one role, depending on their scope of practice (AMP, IMP, Psychiatrist). The SCENZ group also holds a list of willing Nurse Practitioners. For more information about the SCENZ group and practitioner roles, please refer to our <u>website</u>.

Table 6 outlines the number of each role on the SCENZ list, by region. Due to low numbers, precise numbers by region of Nurse Practitioners (total = 13) and Psychiatrists (total = 13) are suppressed.

More than half of all practitioners (AMP, IMP, Nurse Practitioners, and Psychiatrists) have indicated that they are willing to travel to facilitate access to the service.

Table 6: Health practitioner by location

	Primary Location				
	Northern	Midland	Central	Southern	Willing to Travel
AMP (101)	27	17	24	33	58
IMP (89)	26	19	16	28	56
Both AMP and IMP* (69)	20	12	15	22	44
Nurse Practitioner (13)	S	S	S	S	8
Psychiatrist (13)	S	S	S	S	7

^{*}In the case of AMP and IMP, practitioners may choose to perform either, or both, of the roles. In this reporting, 'Both AMP and IMP' reflects a practitioner who performs both roles. Practitioners performing both roles are also represented within the respective totals included above (ie, AMP 101; IMP 89).

A growing number of health practitioners have chosen to provide services as an AMP for their own patients without registering to be included as a SCENZ member. A portion of these health practitioners have subsequently chosen to join the SCENZ group, and to make themselves available to additional patients.