



23 September 2022

s 9(2)(a)

By email: s 9(2)(a)

Ref: H2022011175

Tēnā koe s 9(2)(a)

Response to your request for official information

Thank you for your request under the Official Information Act 1982 (the OIA) to Manatū Hauora (Ministry of Health) on 26 August 2022 for information regarding the Assisted Dying Service. You can find a full copy of your request attached as Appendix 1. While context and graphs were provided as part of your request, I have only outlined the parts of your request which ask substantive questions. Please find a response to each part of your request below.

Why was the statistical integrity of the separate ethnic breakdown reporting of the Pacific group discarded in the second quarterly report to be bundled with what would seem to be a very different and probably more international ethnic group?

What are the numbers of Pacific applicants to 30 June 2022?

Does the MOH intend to update it's website to correct this statistical reporting consistency problem by separating the Pacific ethnic group and adding this back into the June reporting for public view?

These parts of your request are withheld under section 9(2)(a) of the OIA, to protect the privacy of natural persons, including deceased natural persons. When choosing to release data, Manatū Hauora must consider the privacy of individuals, including deceased natural persons and will release data when we are satisfied it will not identify the individuals involved including Pacific groups.

How can applications be made by people where there has been no information provided on the diagnosis of the patient?

'Diagnosis not known' includes the following:

- People that applied but had not yet had their first assessment with their attending medical practitioner (AMP)
- Withdrew their application
- Died before this assessment was completed
- Were ineligible due to not having a terminal illness.

People can apply for an assisted death which will be recorded in our data, but until they have met with the first assessing practitioner their diagnosis will not be available to the secretariat. At any time in our data, there will be several applicants whose diagnoses are not known because although their initial application will have been received, they have not progressed sufficiently through the process where data is made available.

Should a diagnosis be a precursor and requirement of the application?

*Are all applications with 'Diagnosis not known' assessed as not eligible?
If not, how many people with 'Diagnosis not known' were assessed as eligible.*

The eligibility criteria are contained in Section 5 of the End of Life Choice Act 2019 (EOLC Act). Once an application is made, the attending medical practitioner determines whether the applicant meets the eligibility criteria. All applications for assisted dying services go through an assessment process to determine if a person is eligible to receive the service. You can read more about the application process on our website at: www.health.govt.nz/our-work/life-stages/assisted-dying-service/assisted-dying-information-public/assisted-dying-eligibility-and-access.

How many were offered palliative care?

If some were offered, how many went on to get palliative care?

How many were unable to access palliative care due to inequity of access or other barriers?

What other supports were offered to applicants who were not receiving palliative care?

These parts of your request are refused under section 18(g) of the Act, as this information is not held by Manatū Hauora or any other agency subject to the Act.

Information regarding whether a patient is receiving palliative care is only sought at the time of their first assessment after the application. However, the AMP may discuss the care a patient is receiving at the time of their application and may discuss the management of their illness with the care team supporting the person. It is important to remember that assisted dying gives people who meet the criteria another option. It does not replace the care a person is already getting, including palliative.

Of the applicants who had not stated if they were receiving palliative care at the time of application, why was this critical information not gathered in order to be able to process these applications?

We are not required to collect this information under the EOLC Act. Therefore, this part of your request is refused under section 18(g) of the OIA.

Why was the statistical integrity of the report seemingly been compromised by removing the 'Psychiatrist' category which showed in the March report from the June report, and adding in an additional different category called 'Registrar'?

We chose to omit this figure as the number was 0. We will look to include this in the following year's report for clarity and consistency.

What are the numbers of declined applicants for 'which practitioner' under the 'Psychiatrist' category to June 30 2022?

What are the numbers of declined applicants for 'which practitioner' under the 'Registrar' category to March 31 2022?

There were none.

Does the MOH intend to update its website reports to correct this statistical reporting consistency problem by adding 'Psychiatrist' back as a fourth category, and updating numbers to reflect this?

As mentioned above, this was not an inconsistency as we chose to omit these figures. Manatū Hauora will keep what it is in the current report but will consider including these figures in the next report.

Why are proportionally and numerically less people being deemed ineligible than in December 2021, shortly after the Act came into force?

*Have IMPs or AMPs used a more relaxed view when determining eligibility as these numbers would suggest may be the case?
If not, please explain or provide evidence.*

The OIA does not support requests where an opinion, comment, argument, or hypothetical statement is put to the Ministry for response, couched as a request for information. Therefore, this part of your request is refused under section 18(g) of the OIA, as this information is not held by Manatū Hauora or any other agency subject to the Act. The assisted dying service is a relatively new service, and it is too early to draw any conclusions. Health practitioners and the Secretariat follow the process set out in the EOLC Act. This includes several important safeguards.

How many people have applied and been deemed ineligible, to then reapply additional times to be found eligible?

*Are people that have applied more than once counted as:
one person and two+ applications,
two persons+ and one application,
or one person and one application – with the earlier ineligible application being not counted in reporting?*

We are not required to record this information under the EOLC Act. Therefore, this part of your request is refused under section 18(g) of the OIA. There are several reasons why a person may make more than one application to the service, such as a change in their eligibility status, change of mind or deteriorating medical condition. We may consider doing so in future as uptake of the service grows and if disclosing this will not breach privacy of individuals. People who have applied more than once are counted as one person and two (or more) applications.

Why have the Assisted Dying Service quarterly reports not included information on the methods of administration?

Does the MOH intend to include the methods of administration in its quarterly reports in future?

Information regarding the method of administration is not required to be reported in our annual reports as per the EOLC Act. We may consider doing so in future as uptake of the service grows.

However, services are patient centred and we are cautious in publishing data that may influence a person into choosing a specific method of administration. A person should choose the method they think is the best for themselves in discussion with their attending medical practitioner.

Why have the Assisted Dying Services reporting not included information on any of the following, and does the MOH intend to report on any of these factors?

*Number of assisted suicide prescriptions written vs number of doses actually used,
Ineligible patient application characteristics, including:
city/town and suburb of residence,
duration of the relationship with the declining medical practitioner
whether family members were informed of the application,
previous family incidences of assisted suicide or euthanasia, and duration since,
reason(s) for requesting euthanasia or assisted suicide*

Total number of people still living, who were approved more than 6 months ago, 12 months ago, 2 years ago, 3 years ago, 4 years ago, 5 years ago or more (provide exact duration for each),

*Approved applicant patient characteristics, including:
duration of the relationship with the approving medical practitioner
duration between initial request and death by euthanasia or assisted suicide
underlying illness and prognosis,
complications arising from administering or ingesting of the lethal dose,
whether the method used was assisted suicide, euthanasia, or the patient died naturally,
whether family members were informed,
previous family incidences of assisted suicide or euthanasia, and duration since,
type of pharmaceuticals prescribed and/or administered
duration of time from administration/ingestion to death,
reason(s) for requesting euthanasia or assisted suicide,
if the approving or prescribing practitioner was present at the time of death
whether any practitioner was present at the time of death
were independent witnesses present at time of death, and how many
Of the SCENZ Group practitioner lists, how many requests each practitioner has processed, approved and declined.*

No other health service collects this level of detailed information. We are only required to report on information outlined in the EOLC Act. Furthermore, we appreciate that this is a sensitive subject matter and do not want to collect very personal and intrusive information without cause or mandate. We will continue to fulfil our reporting requirements under the EOLC Act, while taking into consideration patient privacy.

We may consider releasing more data when we are satisfied it will not identify the individuals involved nor impose unreasonably on those engaging with the service.

You may wish to refer to section 36 of the EOLC Act at:

www.legislation.govt.nz/act/public/2019/0067/latest/whole.html#LMS225667.

To address some of your specific queries in this part of your request:

Total number of people still living, who were approved more than 6 months ago, 12 months ago, 2 years ago, 3 years ago, 4 years ago, 5 years ago or more (provide exact duration for each),

The EOLC Act 2019 only came into force from November 2021, therefore, people could not apply for this service prior to this date. Section 17(2)(e)(i) allows a patient to receive the medication later than initially chosen (so long as it is not longer than six months from the original date).

whether the method used was assisted suicide, euthanasia, or the patient died naturally,

The EOLC Act refers to Assisted Dying, therefore we will refer to this rather than the terms you have used. Please refer to section 4 of the EOLC Act for more information about interpretation.

whether family members were informed,

Assisted Dying is a person-centred service and individual applicants will choose who to inform and who they will want to involve in the process. Please refer to section 11(2)(f) of the EOLC Act.

type of pharmaceuticals prescribed and/or administered

For safety reasons the detail of the medicine regimes will only be provided directly to the practitioners providing the service. Details and names of the medicines will not be made publicly available due to restrictions on promotion and legislative criteria.

if the approving or prescribing practitioner was present at the time of death

The terms you have used are unclear. The AMP prescribes the medication and will administer it to the eligible person unless they are working with an Attending Nurse Practitioner (ANP) who may administer the medications for an assisted death.

whether any practitioner was present at the time of death were independent witnesses present at time of death, and how many

Please refer to section 20 of the EOLC Act. The AMP or ANP must be available until the person dies or arrange for another medical practitioner or nurse practitioner to be available to the person until the eligible person dies. The patient may choose to have their family with them; however an independent witness is not required.

What communications, if any, did any MOH or SCENZ representatives have with any media company, contractor or staff member, spokesperson, funding agency, or government department about the following New Zealand TV broadcasted and streamed programs before, during or after they went on air:

The Pact, TVNZ's euthanasia drama

TVNZ Sunday Program, 'Esther's Story' broadcast May 15 2022.

No communication was found within the scope of this part of your request. Therefore, this part of your request has been refused under section 18(g) of the OIA as the information requested is not held by the Ministry.

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

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

Nāku noa, nā



Ruihua Gu
**Acting Group Manager, Quality Assurance and Safety
Regulatory Services**

I hope this email finds you well.

It's come to our attention, that the reporting standards between the first report on Assisted Dying Service to March 31 2022, and the second to June 30 2022, have changed in some areas, and we'd like to ask some questions around this. We've also got a couple more information requests below that we'll put in the same email for convenience.

Reporting Differences for Pacific Ethnic Group

The March report on Assisted Dying Service had five ethnic group breakdowns.

1. Maori
2. Pacific
3. Asian
4. NZ European/Pakeha
5. Other ethnic groups

<http://web.archive.org/web/20220422031722/https://www.health.govt.nz/our-work/life-stages/assisted-dying-service/assisted-dying-service-data-and-reporting>

Demographic breakdown		Number of people	% of applicants
Ethnic group	Māori	12	5.8
	Pacific	0	0.0
	Asian	5	2.4
	NZ European/Pākehā	162	78.6
	Other ethnic groups	27	13.1

The June report however only reported on four ethnic groups and strangely bundled two.

1. Maori
2. Asian
3. NZ European/Pakeha
4. Pacific and Other ethnic groups

<https://www.health.govt.nz/our-work/life-stages/assisted-dying-service/assisted-dying-service-data-and-reporting>

Demographic breakdown		Number of people	% of applicants
Ethnic group	Māori	19	4.8
	Asian	9	2.3
	NZ European/Pākehā	318	79.5
	Pacific and Other ethnic groups	57	14.3

1. Why was the statistical integrity of the separate ethnic breakdown reporting of the Pacific group discarded in the second quarterly report to be bundled with what would seem to be a very different and probably more international ethnic group?
2. What are the numbers of Pacific applicants to 30 June 2022?
3. Does the MOH intend to update it's website to correct this statistical reporting consistency problem by separating the Pacific ethnic group and adding this back into the June reporting for public view?

Diagnosis Not Known

There is a diagnosis category called "Diagnosis not known".

1. How can applications be made by people where there has been no information provided on the diagnosis of the patient?
2. Should a diagnosis be a precursor and requirement of the application?
3. Are all applications with 'Diagnosis not known' assessed as not eligible?
 - a. If not, how many people with 'Diagnosis not known' were assessed as eligible.

Palliative Care Status

Of the applicants who were not receiving palliative care at the time of application:

1. How many were offered palliative care?
 - a. If some were offered, how many went on to get palliative care?
2. How many were unable to access palliative care due to inequity of access or other barriers?
3. What other supports were offered to applicants who were not receiving palliative care?

Of the applicants who had not stated if they were receiving palliative care at the time of application:

1. Why was this critical information not gathered in order to be able to process these applications?

Reporting Differences for Applications assessed as ineligible by reason and assessing practitioner

The March report on Assisted Dying Service had three breakdowns for 'Which practitioner'.

1. Attending medical practitioner
2. Independent medical practitioner
3. Psychiatrist

<http://web.archive.org/web/20220422031722/https://www.health.govt.nz/our-work/life-stages/assisted-dying-service/assisted-dying-service-data-and-reporting>

Which practitioner	Attending medical practitioner (AMP)	32	80.0
	Independent medical practitioner (IMP)	8	20.0
	Psychiatrist	0	0.0

The June report however on Assisted Dying Service had three different breakdowns for 'Which practitioner'.

1. Attending medical practitioner
2. Independent medical practitioner
3. Registrar

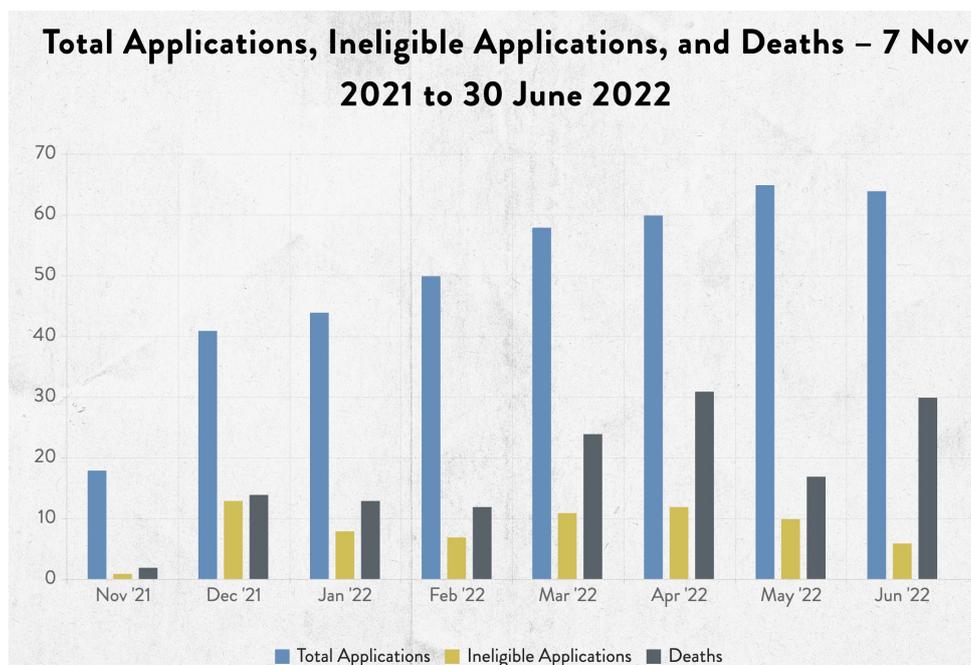
<https://www.health.govt.nz/our-work/life-stages/assisted-dying-service/assisted-dying-service-data-and-reporting>

Which practitioner	Attending medical practitioner (AMP)	53	77.9
	Independent medical practitioner (IMP)	13	19.1
	Registrar	2	2.9

1. Why was the statistical integrity of the report seemingly been compromised by removing the 'Psychiatrist' category which showed in the March report from the June report, and adding in an additional different category called 'Registrar'?
4. What are the numbers of declined applicants for 'which practitioner' under the 'Psychiatrist' category to June 30 2022?
5. What are the numbers of declined applicants for 'which practitioner' under the 'Registrar' category to March 31 2022?
2. Does the MOH intend to update its website reports to correct this statistical reporting consistency problem by adding 'Psychiatrist' back as a fourth category, and updating numbers to reflect this?

On Ineligibility Reporting

When comparing the March to June reports, we can see that applications and deaths have risen steadily since the Act came into force, while the amount of ineligible applications has been generally decline monthly, especially when overlayed over the amount of applications and deaths as a percentage thereof. See below The Defender's overlayed graphs from provided MOH data:



1. Why are proportionally and numerically less people being deemed ineligible than in December 2021, shortly after the Act came into force?
2. Have IMPs or AMPs used a more relaxed view when determining eligibility as these numbers would suggest may be the case?
 - a. If not, please explain or provide evidence.
3. How many people have applied and been deemed ineligible, to then reapply additional times to be found eligible?
 - a. Are people that have applied more than once counted as:
 - i. one person and two+ applications,
 - ii. two persons+ and one application,
 - iii. or one person and one application – with the earlier ineligible application being not counted in reporting?

Differences between Registrars Report and Assisted Dying Service Report

The Registrars report includes a breakdown of “the number of deaths occurring through each of the methods of administration of medication”.

1. Why have the Assisted Dying Service quarterly reports not included information on the methods of administration?
2. Does the MOH intend to include the methods of administration in its quarterly reports in future?

Omissions from the Reporting

1. Why have the Assisted Dying Services reporting not included information on any of the following, and does the MOH intend to report on any of these factors?
 - a. Number of assisted suicide prescriptions written vs number of doses actually used,
 - b. Ineligible patient application characteristics, including:
 - i. city/town and suburb of residence,
 - ii. duration of the relationship with the declining medical practitioner
 - iii. whether family members were informed of the application,
 - iv. previous family incidences of assisted suicide or euthanasia, and duration since,
 - v. reason(s) for requesting euthanasia or assisted suicide
 - c. Total number of people still living, who were approved more than 6 months ago, 12 months ago, 2 years ago, 3 years ago, 4 years ago, 5 years ago or more (provide exact duration for each),

- d. Approved applicant patient characteristics, including:
 - i. duration of the relationship with the approving medical practitioner
 - ii. duration between initial request and death by euthanasia or assisted suicide
 - iii. underlying illness and prognosis,
 - iv. complications arising from administering or ingesting of the lethal dose,
 - v. whether the method used was assisted suicide, euthanasia, or the patient died naturally,
 - vi. whether family members were informed,
 - vii. previous family incidences of assisted suicide or euthanasia, and duration since,
 - viii. type of pharmaceuticals prescribed and/or administered
 - ix. duration of time from administration/ingestion to death,
 - x. reason(s) for requesting euthanasia or assisted suicide,
 - xi. if the approving or prescribing practitioner was present at the time of death
 - xii. whether any practitioner was present at the time of death
 - xiii. were independent witnesses present at time of death, and how many
- e. Of the SCENZ Group practitioner lists, how many requests each practitioner has processed, approved and declined

Other Media Related Questions

1. What communications, if any, did any MOH or SCENZ representatives have with any media company, contractor or staff member, spokesperson, funding agency, or government department about the following New Zealand TV broadcasted and streamed programs before, during or after they went on air:
 - a. The Pact, TVNZ's euthanasia drama
 - b. TVNZ Sunday Program, 'Esther's Story' broadcast May 15 2022.

Many thanks and kind regards.

Apologies there's a fair bit in here this time Meredith!

Cheers,

s 9(2)(a)

