



Government of **Western Australia**
Department of **Health**

Ministerial Expert Panel on Voluntary Assisted Dying

Final Report

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Ministerial Expert Panel on Voluntary Assisted Dying

Final Report

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Honourable Roger Cook MLA
Minister for Health
Level 13, Dumas House
2 Havelock Street
West Perth WA 6005

Dear Minister Cook,

On behalf of the Members of the Ministerial Expert Panel, I present to you the Panel's Report, with its recommendations on a number of specific elements which the Panel considers should be included in the proposed legislation for voluntary assisted dying.

In making these recommendations, the Panel has been conscious of the crucial importance of ensuring that there are strong safeguards in the legislation. At the same time the Panel has been mindful, for compassionate and humane reasons, of not placing so many obstacles in the chosen path of people to access voluntary assisted dying, that it becomes unnecessarily too difficult, and their suffering is prolonged.

The starting point for the work of the Panel was the list of recommendations made in the Joint Select Committee's (JSC) Report on End of Life choices, *'My Life, My Choice'*, delivered on 23 August 2018, which was the result of extensive consultations undertaken by the JSC, over some 12 months. That Report was directed not only to the question of voluntary assisted dying, but also to the very important end of life matters of palliative care and advance health directives.

It contained, at para 7.89, a Legislation Framework for voluntary assisted dying. This has been an important guide for the Panel. The Legislation Framework is reproduced in this Report.

In accordance with its brief, and the terms of reference also reproduced in this Report, the Panel has consulted widely to seek the views of our diverse community, special interest groups and experts in their particular areas of expertise.

At the outset, to assist in these consultations, a Discussion Paper was produced and made available on the Panel's website. In addition, copies were made available to those attending public forums, to special interest groups and to experts whose views and comments were sought.

The Discussion Paper proved to be invaluable, both in explaining the nature of the issues, and in raising questions related to those issues for consideration and discussion. It received much favourable comment.

From 19 March 2019 to 24 May 2019, the Panel heard from 867 participants through public forums, roundtables and other meetings and received 541 written submissions (online, email and mail). Most of those submissions were quite detailed, and demonstrated that considerable analysis and thought had gone into them.

The public forums were held in Kalgoorlie, Geraldton, Joondalup, Maylands, Murdoch, Broome, Bunbury, Mandurah, Northam, Karratha and Carnarvon. Webinars were also conducted which enabled the Panel to hear from over 60 people in 15 smaller towns across the State. Over 100 people in Albany took part in a number of information sessions.

The views and suggestions received by the Panel in this way have been very helpful, and have informed the Panel's recommendations on the elements of the proposed legislation, to ensure both safe and compassionate processes for voluntary assisted dying.

The Panel is most grateful to all those who participated in this consultation process, always in a thoughtful and measured manner.

Many of the participants in public forums expressed their appreciation at being consulted by the Government on the content of this important and significant legislation.

Apart from the consultations that I have detailed, the Panel has reviewed a broad range of relevant research, both in Australia and overseas, has held discussions with an expert and experienced practitioner from Oregon (which has had such a law operating for over 20 years) as well as experts from Canada (one being the President-Elect of the Canadian Medical Association). All Canadian provinces have similar laws, as a result of a decision by the Supreme Court of Canada, that to deny access to voluntary assisted dying was a breach of human rights and contrary to the Canadian Charter of Human Rights.

Victoria was the first state in Australia to enact a *Voluntary Assisted Dying Act*, which it did in 2017. Following its enactment, before it came into force this month, there has been an implementation period of some 18 months during which actions have been taken to facilitate the operation of the law. It is clear that an implementation period, before the law became effective, was most important in (among other things) setting up procedures, education and an oversight body.

The Victorian Act, and Victoria's experience in the implementation period, have been very helpful to the Panel, serving as a useful guide or template. However, the Panel has been mindful of differences between Western Australia and Victoria, in particular, the much larger geographical area of Western Australia, its smaller population, and the great diversity, cultural and linguistic, that is a singular feature of this State. As appears from this Report, the Panel has taken those considerations into account in making recommendations appropriate for Western Australia.

Various approaches have been taken in other jurisdictions where voluntary assisted dying legislation in some form has been enacted, namely, Belgium; Netherlands; Luxembourg; Switzerland; Colombia; Victoria; Canada (all 10 provinces and 3 territories); 7 States of the USA (Oregon, Vermont, Colorado, Washington State, District of Columbia, California, Hawaii) in addition to New Jersey and Maine (yet to come into force) and Montana (where a Court ruling has permitted physicians to assist in voluntary dying).

Some of those differences can be discerned from the table contained in this Report. One common principle is clear. The primary purpose of all such laws is a compassionate one, of giving people who are at the end of their lives the right to choose the timing and circumstances of their death, whilst ensuring strong safeguards against any possible undue influence or coercion.

Central to the whole question of voluntary assisted dying is, of course, the role of medical practitioners.

The Panel has recommended that any healthcare practitioner who objects to participating in voluntary assisted dying shall be under no obligation whatever to do so. That has been the overwhelming view emerging from our consultations. That right to object should extend, the Panel has concluded, to the right not to refer a patient to a specific health practitioner who is willing to participate, as that may be seen by some as participating in the process and against conscience. However, the Panel recognises that a person should not be left in limbo, and has recommended that there be a formal means whereby the person has ready access to necessary information.

The Victorian Act is the only legislation that prohibits a practitioner from starting a discussion about voluntary assisted dying with a patient. The Panel strongly recommends against this, supported by views equally strongly expressed in the consultation period. Such a prohibition risks creating more barriers to timely end-of-life and advance care planning discussions, exposes medical practitioners to the fear of litigation, and impedes the open dialogue inherent in a trusting doctor-patient relationship. Rather the Panel considers that voluntary assisted dying is a matter for the individual doctor and patient to discuss if they wish, in the manner most appropriate to each individual case.

As part of the assessment of eligibility, the Victorian Act requires that assessment of a person's capacity and eligible condition be made by two medical practitioners, independently of each other. That is viewed as an important safeguard to ensure that the person is eligible, has capacity to make such an important choice, and that it is an informed and voluntary decision. The Panel has adopted that safeguard. However, having regard to the scarcity of medical practitioners in many country districts and towns of Western Australia, the Panel has recommended that the second (consulting) practitioner may be a qualified nurse practitioner.

The Committee has also recommended that no practitioner may undertake an assessment for voluntary assisted dying without first completing a course of relevant training, which should be made available during the recommended implementation period following enactment of the legislation. Knowledge and skills going beyond standard medical training may be required for capacity assessment, prognostication, palliative care, cultural competency, medication management, legislative requirements, self-awareness, self-care and communication. The lessons learnt during the Victorian implementation period will be invaluable for Western Australia.

There are, of course, some in the community (a minority according to a series of polls) opposed to the very concept of voluntary assisted dying, for such reasons as conscientious objection, or concern that the safeguards against coercion may never be sufficient. As to the latter, the recommended process of assessment by two independent health practitioners, the requirement for an oral request, a reflection period, a witnessed written request and an additional oral request should serve to allay those concerns. Certainly, that has been the overwhelming feedback received from the consultation process. A considerable number suggested, however, that such safeguards may place an undue burden on a person who is suffering and at the end of his or her life.

What was described as a thorny question in one submission is whether, as (for example) in Victoria and those states in the USA with such a law, administration of the lethal medication (whatever the medication or method) must be by the person, not by the medical practitioner; or whether, as in Canada, it be optional, at the election of the person. The Canadian approach (in Ontario 98% of administration is in fact by a medical practitioner) has much to commend it. As the President-Elect of the Canadian Medical Association put to us, it reduces the risk of complications, and means that the medication remains in the possession of the medical practitioner. However, the Panel has concluded, following consultation and submissions, that the preferred method should be self-administration as proposed by the JSC; but that it may be by a practitioner if, for any of several specified reasons, a clinical determination is made that it is the wish of the patient, and appropriate in all the circumstances, for the administration to be by a medical practitioner or nurse practitioner.

As the JSC Report pointed out, the reality is that medical practitioners already are trusted to use their discretion, and their compassion, in the case of a person at the end of life, to prescribe medication in sufficient quantities to diminish or eliminate suffering, even though that may have the unintended result of shortening the person's life. The Courts have held that to be lawful, provided that the purpose is to prevent continuation of suffering, not to cause death. Similarly, medical decisions to cease life-prolonging treatment, although legal, have none of the legislative safeguards proposed for voluntary assisted dying decisions.

The problem is, however, that both of these practices fall within something of a 'grey area', and are attended by a degree of uncertainty on the part of some practitioners.

The Panel's recommendations are intended to dispel that uncertainty by providing clear directions as to the course that may lawfully be taken if a person who is at end of life, and suffering, wishes to permanently end the suffering by accessing voluntary assisted dying. In formulating its recommendations, the Panel considered every fundamental element of end of life medical decision-making to set a new standard of prudent legislative oversight of these decisions.

Although it is not within the Panel's brief, nor does it appear in the JSC's Legislation Framework, the Panel considers that it should acknowledge the strong body of opinion that has been expressed, during the consultation period and in submissions, that there should be legislation to enable a person to express, in an advance health directive, a wish to access voluntary assisted dying at a point where all enjoyment of life has disappeared and he or she no longer has capacity as, for example, in the case of dementia; and that such directive must be acted on. Those views, by members of the Western Australian public, have also been expressed in Canada and other jurisdictions. However, when this has been raised in submissions, or by those attending the public forums, Panel members have been at pains to explain that this will not form part of the Panel's recommendations, as it is not within our terms of reference.

As can be seen from the Curricula Vitae of the Panel members, they have a wide range of relevant experience and qualifications, and I sincerely thank each and every one of them for the invaluable contribution they have made in completing the brief with which we were entrusted earlier this year. It has been a pleasure, and an education, to work with them. Each member was assiduous in conscientiously applying to the task his or her knowledge, experience, time and effort, unstintingly, and always willingly. It is pertinent to observe that, despite the demands made on them, each clearly regarded fulfilling their duty as very worthwhile and rewarding.

Finally, on behalf of the Panel, I sincerely thank the Secretariat team in the Department of Health for the skill and dedication which they displayed before and throughout the consultation process, and in the completion of this Report. It has been no easy task to organise the submissions, arrange public forums, compile the results, and provide progress reports to the Panel. We are all most grateful.

Marion Huntly, your Senior Policy Advisor, who was a member of the Secretariat to the JSC on End of Life Choices (and who therefore has a close understanding of the issues) gave the Panel constant and invaluable assistance and research.

It has truly been a team effort.

Yours faithfully,



Malcolm McCusker AC, QC,
Chairman of Ministerial Expert Panel on
Voluntary Assisted Dying

The Ministerial Expert Panel



Mr Malcolm McCusker AC QC – Chairman

Mr Malcolm McCusker AC QC is Queen's Counsel and former Governor of Western Australia. He is the current Chair of the WA Health Translation Network.



Dr Penny Flett AO – Deputy Chair

Dr Penny Flett AO is a retired medical practitioner and has worked on state and national developments in aged care over many years. She is the former Chief Executive Officer of Brightwater Care Group and former Chair of the WA Aged Care Advisory Council.



Associate Professor Kirsten Auret – Member

Associate Professor Kirsten Auret is Deputy Director of the Rural Clinical School of WA and an Associate Professor of rural and remote medicine. She is a palliative care specialist and Adjunct Professor at Curtin University and Notre Dame University.



Dr Scott Blackwell – Member

Dr Scott Blackwell is a General Practitioner with expertise in palliative care and aged care. He is the former President of the Australian Medical Association (AMA – WA Branch) and a life member of the Royal Australian College of General Practitioners.



Dr Elissa Campbell – Member

Dr Elissa Campbell is a consultant geriatrician, palliative care specialist and current President of Palliative Care WA.



Professor Phillip Della AM – Member

Professor Phillip Della is the head of Nursing, Midwifery and Paramedicine at Curtin University and the former Chief Nurse of Western Australia.

Ms Noreen Fynn – Member

Ms Noreen Fynn is a consumer representative with 30 years of experience in Western Australia in the carer, disability, aged care and mental health sectors. She has worked extensively with community and government organisations at both the state and federal level.



Ms Kate George – Member

Ms Kate George is a senior lawyer specialising in human rights, international law and indigenous matters with experience in private, public and non-government sectors.



Dr Roger Hunt – Member

Dr Roger Hunt is a senior consultant in palliative medicine and a Founding Fellow of the Australasian Chapter of Palliative Medicine. Dr Hunt was a member of the Victorian Ministerial Advisory Panel on Voluntary Assisted Dying.



Ms Samantha Jenkinson – Member

Ms Samantha Jenkinson is the current Executive Director of People With disabilities WA and former acting Chief Executive Officer of the Australian Federation of Disability Organisations. She is a senior advocate and advisor to the government in relation to disability.



Ms Maria Osman – Member

Ms Maria Osman is a senior consultant and advisor specialising in human rights, diversity and gender matters. She is the former Executive Director of the WA Office of Multicultural Interests and the WA Office for Women's Policy.



Ms Fiona Seaward – Member

Ms Fiona Seaward is a Commissioner of the Law Reform Commission of Western Australia and Senior Assistant State Counsel for the State Solicitor's Office.



Dr Simon Towler – Member

Dr Simon Towler is the Clinical Lead of the South Metropolitan Health Service Futures program and a Staff Specialist Intensive Care at Fiona Stanley Hospital. He is the former Chief Medical Officer of Western Australia.



Ministerial Expert Panel Recommendations

In this list of recommendations, the Panel has specifically included points of agreement with the Joint Select Committee that are significant to ensure that the recommendations of the Panel are not considered in isolation.

Guiding Principles

Ministerial Expert Panel recommendation 1:

The following Guiding Principles should be included in the legislation to help guide interpretation:

- Every human life has intrinsic value.
- A person's autonomy should be respected.
- People have the right to be supported in making informed decisions about their medical treatment, and should be given, in a manner they understand and is culturally appropriate, information about medical treatment options, including comfort and palliative care.
- People approaching the end of life should be provided with high quality care, including access to specialist palliative care, to minimise their suffering and maximise their quality of life.
- A therapeutic relationship between a person and their health practitioner should, wherever possible, be supported and maintained.
- People should be encouraged to openly discuss death and dying, and their preferences and values should be encouraged and promoted.
- People should be supported in conversations with their health practitioners, family, carers and community about treatment and care preferences.
- People are entitled to genuine choices regarding their treatment and care; this should be regardless of their geographic location and take into account their ability as well as individual cultural and linguistic needs.
- People should be supported in their right to privacy and confidentiality regarding their choices about treatment and care preferences.
- People who may be vulnerable to coercion and abuse in relation to end of life choices and decisions should be protected.
- All people, including health practitioners, have the right to be shown respect for their culture, religion, beliefs, values and personal characteristics.

Policy intent: *The principles reflect the values underpinning the Panel's considerations and should be used to interpret the recommendations and the legislation.*

Part A: Eligibility

Ministerial Expert Panel recommendation 2:

To access voluntary assisted dying a person must meet all of the following eligibility criteria:

1. be an adult, aged 18 years or over; and,
2. be an Australian citizen or permanent resident and have been ordinarily resident in Western Australia for 12 months at the time of making the request; and,
3. have decision-making capacity in relation to a decision about voluntary assisted dying; and,
4. be diagnosed with an eligible condition, where an eligible condition is an illness, disease or medical condition that:
 - a. is advanced, progressive and will cause death; and,
 - b. is causing suffering to the person that cannot be relieved in a manner the person considers tolerable; and,
5. death is reasonably foreseeable for the person within a period of 12 months.

Policy intent: *To ensure that it is clear for whom voluntary assisted dying is intended. To ensure that access to voluntary assisted dying is limited to those for whom it is intended.*

Ministerial Expert Panel recommendation 3:

For access to voluntary assisted dying, the person must have been ordinarily resident in Western Australia for 12 months at the time of making the first request.

There should be provision for application to the State Administrative Tribunal for relief from the strict requirements of residency for 12 months in exceptional circumstances, on compassionate grounds.

Policy intent: *To provide clarity as to the meaning of 'ordinarily resident' for the purposes of access to voluntary assisted dying and to provide the opportunity for relief from the requirement for 12 months residency for exceptional circumstances.*

Ministerial Expert Panel recommendation 4:

Where the assessing practitioner is unable to determine that the person's decision is voluntary and valid, they should refer to a health practitioner with relevant expertise for further assessment.

That if, after further assessment, there is still uncertainty about whether the person's decision is voluntary and valid, such cases should be referred to the State Administrative Tribunal.

Policy intent: *To ensure that people are making a voluntary and valid decision to access voluntary assisted dying and that this decision is not subject to coercion. To ensure that access to voluntary assisted dying is not unreasonably restricted through limiting referrals by specialist type.*

Ministerial Expert Panel recommendation 5:

Provision of information to the person by the co-ordinating and consulting practitioners must include: the nature of their disease or illness, the prognosis, any available curative treatments, any available palliative treatments, information specific to voluntary assisted dying medications and must also inform the person that they may withdraw their consent at any time.

This information must be provided in a language and format that the person understands.

Policy Intent: *To ensure that people are provided with information sufficient to make fully informed decisions at end of life.*

Ministerial Expert Panel recommendation 6:

Health practitioners are able to appropriately raise the topic of voluntary assisted dying with a patient.

Policy intent: *To ensure that people are able to make fully informed decisions at end of life. To ensure that access to voluntary assisted dying is not impeded by a health practitioner not discussing what would be a legal option at end of life for some people.*

Ministerial Expert Panel recommendation 7:

The eligibility criteria for voluntary assisted dying includes reference to an illness, disease or medical condition that is advanced, progressive and will cause death.

Policy intent: *To clearly emphasise the terminal nature of the illness or disease as part of consideration as an eligible condition.*

Ministerial Expert Panel recommendation 8:

The eligibility criteria for voluntary assisted dying includes that the eligible condition 'is causing suffering to the person that cannot be relieved in a manner the person considers tolerable'.

Policy intent: *To ensure a compassionate person-centred approach to suffering in the eligibility criteria for voluntary assisted dying. To ensure that it is not necessary for a person to prove the degree of their suffering which is, by definition, subjectively determined.*

Ministerial Expert Panel recommendation 9:

The eligibility criteria for voluntary assisted dying specify that death is a reasonably foreseeable outcome for the person within 12 months.

Policy intent: *To provide clarity for both the person and assessing practitioners regarding the eligibility for voluntary assisted dying.*

Ministerial Expert Panel recommendation 10:

A person with a mental illness or disability who meets the eligibility criteria shall not be denied access to voluntary assisted dying.

Having a mental illness or disability, in itself, would not be considered to meet the eligibility requirements for voluntary assisted dying.

***Policy intent:** To ensure that a person with a mental illness or disability is not discriminated against in seeking access to voluntary assisted dying but to also ensure clarity that a mental illness or disability on its own would not meet the eligibility criteria for voluntary assisted dying.*

Part B: Process

Access

Ministerial Expert Panel recommendation 11:

The Government should play a central role in providing information to the general public and health professionals about how to access voluntary assisted dying.

This information must be translated, culturally appropriate and accessible via multiple formats.

***Policy intent:** To ensure that people who may seek to request voluntary assisted dying are provided with timely and appropriate information in a manner they understand that enables them to raise this question with their health professional.*

Ministerial Expert Panel recommendation 12:

The Government should develop a system of care navigators as part of any implementation of voluntary assisted dying in Western Australia.

***Policy intent:** To ensure that people requesting voluntary assisted dying and their families, carers and health practitioners are provided with information, support and advice throughout the process.*

First request

The Ministerial Expert Panel agrees with the recommendation of the Joint Select Committee:

Joint Select Committee recommendation:

7.89 Voluntary Assisted Dying Legislation Framework

Procedure

A person must make an initial verbal request to a doctor to access assisted dying. A doctor must include a record that a verbal request has been made in the medical record.

The Ministerial Expert Panel agrees with the recommendation of the Joint Select Committee:

Joint Select Committee recommendation:

Recommendation 20

The Minister for Health should ensure that health professionals are not compelled to participate if any voluntary assisted dying framework is developed for Western Australia.

Ministerial Expert Panel recommendation 13:

A health practitioner or health service that is unwilling to be involved in the voluntary assisted dying process must provide information sufficient to enable the person to access information regarding voluntary assisted dying.

Policy intent: *To ensure that a person requesting voluntary assisted dying is able to be connected with information that meets their needs in a way that does not compromise the right of a health practitioner to conscientiously object to being involved in voluntary assisted dying.*

Ministerial Expert Panel recommendation 14:

If a medical or nurse practitioner is unwilling to participate in voluntary assisted dying the practitioner must inform the person immediately.

If the practitioner requires time to consider the request for some other reason the practitioner must inform the person of their decision within two working days.

Policy intent: *To ensure that a person requesting voluntary assisted dying is provided with a timely response about whether the medical or nurse practitioner can accept their request. To provide the practitioner with time to check their availability, consider if they can undertake training or otherwise be able to fulfil the requirements of being a co-ordinating or consulting practitioner.*

The Ministerial Expert Panel agrees with the recommendation of the Joint Select Committee:

Joint Select Committee recommendation:

7.89 Voluntary Assisted Dying Legislation Framework

Procedure

Following this request, providing that the doctor does not personally object to voluntary assisted dying, they must provide the person with information regarding:

- a. the nature of the disease or illness;
- b. the prognosis;
- c. any possible curative treatments;
- d. any available palliative treatments;
- e. the nature, effects and risks of the lethal medication that may be prescribed; and
- f. that the person's consent to assisted dying may be withdrawn at any time.

Assessment

The Ministerial Expert Panel agrees with the recommendation of the Joint Select Committee subject to recommendation 16:

Joint Select Committee recommendation:

7.89 Voluntary Assisted Dying Legislation Framework

Assessment

Two doctors must assess the person. Each doctor must be independently satisfied that [the person meets the eligibility criteria].

Either or both doctors can be a general practitioner and neither doctor is required to be a specialist regarding the person's disease or illness.

Ministerial Expert Panel recommendation 15:

Medical practitioners who may seek to become co-ordinating or consulting practitioners for the purposes of voluntary assisted dying must:

1. Currently hold Specialist Registration with AHPRA and have practised as a registered specialist for at least one year; or,
2. Currently hold General Registration with AHPRA and have practised as a generally registered medical practitioner for 10 or more years; or,
where it has been demonstrated that no local provider meets the above requirements be:
3. An internationally trained medical specialist currently holding Limited or Provisional Registration for:
 - a. work in a gazetted Area of Need or as a sponsored provider within a health service in Western Australia; and,
 - b. who has undergone a formal assessment by the relevant Australian College; and,
 - c. for whom the relevant College has approved their specialist pathway and supervision program; and,
 - d. who has five years' experience as a specialist consultant; and,
 - e. has completed 12 months working in a supervised position within Western Australia.

Policy intent: *To ensure that the medical practitioners seeking to become co-ordinating or consulting practitioners for the purpose of voluntary assisted dying are only those that are appropriately qualified, skilled and experienced.*

To ensure that there is appropriate access to voluntary assisted dying across the geographically diverse state of Western Australia.

To ensure that trainees or junior medical practitioners do not able to be either a co-ordinating or consulting practitioner for voluntary assisted dying.

Ministerial Expert Panel recommendation 16:

The co-ordinating practitioner must be a medical practitioner that meets the following qualification requirements:

- a. Registered in Australia according to the medical practitioner qualification requirements for voluntary assisted dying previously specified; and,
- b. Must have successfully completed mandatory approved voluntary assisted dying training.

The consulting practitioner:

- a. May be a medical practitioner (with same requirements as for co-ordinating practitioner); or,
- b. May be a nurse practitioner registered in Australia on an ongoing basis; and,
- c. Must have successfully completed mandatory approved voluntary assisted dying training.

Policy intent: To ensure that only appropriately qualified, skilled and experienced practitioners are able to undertake voluntary assisted dying assessments. To ensure that there is appropriate access to voluntary assisted dying across the geographically diverse state of Western Australia.

Ministerial Expert Panel recommendation 17:

The co-ordinating practitioner must successfully complete approved voluntary assisted dying training before commencing the first assessment.

The consulting practitioner must successfully complete approved voluntary assisted dying training before commencing the second assessment.

Policy intent: To ensure that all practitioners who undertake the process for voluntary assisted dying have successfully completed appropriate training for this purpose.

Second request and written declaration

The Ministerial Expert Panel agrees with the recommendation of the Joint Select Committee:

Joint Select Committee recommendation:

7.89 Voluntary Assisted Dying Legislation Framework

Procedure

The person must provide the initial assessing doctor with a signed written request using a standard template. The written request must be filed with the oversight body.

Ministerial Expert Panel recommendation 18:

The written request is a declaration of the person's considered and enduring request for voluntary assisted dying.

The written declaration must be completed after the first assessment and before the third request.

Where the person is unable to sign the written declaration of request, the person may direct another person to sign on their behalf (where that person is not also a witness).

The written declaration of request will be witnessed by two witnesses to establish that the person requesting voluntary assisted dying signed the declaration voluntarily. The witnesses will be people who are aged 18 or over and have no reasonable grounds for belief that they will financially benefit from the person's death. Neither the co-ordinating nor consulting practitioner may be a witness for the person.

Policy intent: *To ensure that the request is formalised after the person has received information about all of their options and been assessed as eligible by at least one practitioner. To ensure that the witnessing of the written declaration of request does not unduly delay the process. To ensure that the purpose of witnessing the written declaration of request is clear. To ensure that the written declaration of request is witnessed in a safe and responsible way. To ensure that a person who is unable to sign the written declaration of request is able to have the written declaration of request completed in a manner that fulfils the requirement under the legislation.*

Third request

The Ministerial Expert Panel agrees with the recommendation of the Joint Select Committee:

Joint Select Committee recommendation:

7.89 Voluntary Assisted Dying Legislation Framework

Reflection period

In order to provide a period of reflection a prescription for medication must not be filled sooner than prescribed under the legislation as determined by the expert panel.

Ministerial Expert Panel recommendation 19:

The time period for reflection be defined as: the person's third request to be made at least nine days after the day on which the person made the first request.

The voluntary assisted dying medication must not be prescribed before the third request.

Policy intent: *To ensure that the process affords the person an adequate time for reflection and demonstrates the enduring nature of their decision but does not unduly delay their access to voluntary assisted dying.*

Ministerial Expert Panel recommendation 20:

Where the co-ordinating practitioner is of the opinion that the person's death is likely to occur before the expiry of the reflection period or that the person is likely to lose decision-making capacity before the expiry of the reflection period, and that this opinion is consistent with the assessment by the consulting practitioner, then the reflection period may be reduced to not less than one day after the consulting assessment.

Policy intent: *To provide clear direction to the co-ordinating practitioner regarding when the time period may be reduced.*

Approval

Ministerial Expert Panel recommendation 21:

There be no legislated requirement for an additional permit approval system in Western Australia.

Policy intent: *To ensure that the voluntary assisted dying process is not burdened by bureaucratic oversight that may not materially add to the safety of the process.*

Ministerial Expert Panel recommendation 22:

Authorisation for prescription of voluntary assisted dying medication be managed through existing mechanisms under the *Medicines and Poisons Act 2014*.

Policy intent: *To provide clarity that appropriate authorisation of the prescription of voluntary assisted dying medication can be controlled under existing Western Australian legislation.*

Medication

The Ministerial Expert Panel agrees with the recommendation of the Joint Select Committee:

Joint Select Committee recommendation:

7.89 Voluntary Assisted Dying Legislation Framework

Medication

The choice of lethal medication for voluntary assisted dying should remain a clinical decision based on the prescribed list of medications for this purpose. The WA Government should review current federal laws in relation to scheduling of medication in Australia, and negotiate with the Federal Government and the Therapeutic Goods Administration for the use of the best medication(s) for assisted dying.

Pharmacists dispensing the lethal medication(s) must report the dispensing of the medication to the oversight body.

Ministerial Expert Panel recommendation 23:

1. Administration of the voluntary assisted dying medication should usually be by self-administration.
2. Administration of the voluntary assisted dying medication may be by practitioner administration as a result of a clinical determination where consideration has been given to:
 - a. the person's ability to self-administer, including concerns regarding self-administration;
 - b. the administration method(s) that are suitable for the person;
 - c. the voluntary assisted dying medication that is suitable for the person; or
 - d. other matters that the clinician or person may see as necessary to the decision-making.

Policy intent: *To ensure it is clear in the first instance that voluntary assisted dying medication should be self-administered. To ensure that people who are otherwise not able to self-administer can have voluntary assisted dying medication administered by a practitioner.*

Ministerial Expert Panel recommendation 24:

The Government should establish regulatory processes for the secure prescription, dispensing, handling, administration and disposal of voluntary assisted dying medication.

Policy intent: *To ensure the safe and secure management of voluntary assisted dying medication. To ensure that there are clear roles and responsibilities for the person, their family, the contact person and health professionals for medication used in voluntary assisted dying.*

Death Certification

Ministerial Expert Panel recommendation 25:

Voluntary assisted dying not be recorded by the medical practitioner as the cause of death at Part 1(a) of the Medical Certificate Cause of Death or reported on the Death Certificate issued by the Registrar of Births Deaths and Marriages.

A separate reporting system should be established requiring the medical practitioner to inform the voluntary assisted dying oversight body when voluntary assisted dying is the cause of death of a person and requiring the voluntary assisted dying oversight body to inform the Registrar of Births Deaths and Marriages.

Policy intent: *To ensure the need for data collection and accurate record keeping surrounding voluntary assisted dying and the underlying illness or medical condition is met, and to ensure the community's expectations for privacy and confidentiality are fulfilled.*

Ministerial Expert Panel recommendation 26:

A death that occurs through voluntary assisted dying should not be a reportable death for the purposes of the *Coroners Act 1996* unless the death is referred to the Coroner by the voluntary assisted dying oversight body.

Policy intent: *To ensure that an appropriate mechanism is in place to report any concerns regarding deaths occurring through voluntary assisted dying to the Coroner for investigation, without otherwise lawful deaths occurring through voluntary assisted dying being the subject of an unnecessary investigation.*

Part C: Oversight

The Ministerial Expert Panel agrees with the recommendation of the Joint Select Committee:

Joint Select Committee recommendation:

7.89 *Voluntary Assisted Dying Legislation Framework*

Oversight

An oversight body must be established [...]

Ministerial Expert Panel recommendation 27:

The membership of the voluntary assisted dying oversight body should comprise a suitable mix of appropriate and relevant medical, legal and pharmacy expertise related to voluntary assisted dying as well as community representation and be reflective of the citizens of Western Australia.

Policy intent: *To ensure that the oversight body is able to appropriately and effectively undertake its functions and responsibilities. To ensure that the oversight body is contemporary and representative of the citizens of Western Australia.*

Ministerial Expert Panel recommendation 28:

Data collection in relation to voluntary assisted dying should include all aspects of the process of voluntary assisted dying and comprehensive information relating to the person accessing voluntary assisted dying.

Policy intent: *To enhance current and future knowledge and understanding of voluntary assisted dying in the broader context of end of life.*

Education and training

Ministerial Expert Panel recommendation 29:

Mandatory training and education provided to those seeking to become co-ordinating and consulting practitioners for voluntary assisted dying should be informed by the Panel's consultation.

Voluntary assisted dying mandatory training for co-ordinating and consulting practitioners must include a focus on ensuring the voluntary and valid decision of the person.

All training in relation to voluntary assisted dying must promote culturally competent practice in relation to voluntary assisted dying.

Policy intent: *To ensure that the mandatory training and education is effective in promoting the competencies required by practitioners to complete the voluntary assisted dying process in a way that is safe, effective and culturally appropriate.*

Part D: Implementation

Ministerial Expert Panel recommendation 30:

There should be at least an 18 month period between passage and commencement of voluntary assisted dying legislation.

Policy intent: *To enable sufficient time to plan, consult on and develop guidelines and protocols to ensure that the legislation is translated safely, effectively and appropriately for Western Australia.*

Ministerial Expert Panel recommendation 31:

The legislation should initially be reviewed three years after the date of operation of the legislation, and every five years thereafter.

Policy intent: *To ensure that the legislation remains in line with contemporary views and practices.*

Executive Summary

Purpose

The purpose of this Executive Summary is to provide an overall picture of the background and scope of work of the Ministerial Expert Panel on Voluntary Assisted Dying Legislation.

Background

In August 2017 a cross-party Joint Select Committee comprising four members of the Legislative Council of Western Australia and four members of the Legislative Assembly was appointed to conduct an inquiry into End of Life Choices. Following its year-long inquiry the Joint Select Committee tabled its report *My Life, My Choice* in both Houses of Parliament.^{1,2}

Based on the Joint Select Committee's finding that some people experience unnecessary suffering at end of life and that there is broad community agreement on the importance of individual autonomy and choice, the *My Life, My Choice* report recommended that the Western Australian Government draft and introduce a Bill for voluntary assisted dying. The Joint Select Committee proposed a framework to support the development of the legislation ([refer Appendix 1](#)).

In November 2018 the Government announced it would introduce legislation into Parliament to permit voluntary assisted dying in Western Australia. In accordance with the Joint Select Committee's recommendations, the Minister for Health established a Ministerial Expert Panel (the Panel) to undertake consultation to inform the Panel's recommendations for development of legislation for voluntary assisted dying in Western Australia.

The Panel, chaired by Malcolm McCusker AC QC, includes expertise from clinical, legal, consumer, disability, and culturally and linguistically diverse groups. The members of the Panel and their backgrounds are outlined on [page viii](#).

Scope

In establishing the Panel and proposing its Terms of Reference ([refer Appendix 2](#)) the Government was mindful that extensive work and consultation was done by the Joint Select Committee and that legislation for voluntary assisted dying was passed in Victoria in November 2017.

The Victorian legislation presented Western Australia with an opportunity to examine the approach taken and use this as a basis for the design of legislation suitable for the needs of Western Australians.³

In considering the Victorian legislation the Government was also aware that Western Australia is different from Victoria in many respects. Western Australia has a lower population than Victoria and is the most culturally and linguistically diverse state in Australia with Aboriginal people, migrants and refugees accounting for nearly 30% of its population.⁴ There is also significant geographical diversity in Western Australia which presents both challenges and opportunities to providing services in rural and remote areas.

1 *'My Life, My Choice'* report of the Joint Select Committee on End of Life Choices, Parliament of Western Australia (August 2018).

2 Ministerial Expert Panel on Voluntary Assisted Dying Discussion Paper, Department of Health, Western Australia (2019).

3 Ibid.

4 WA Health System Language Services Policy Guidelines, Department of Health, Western Australia (2017).

For these reasons, the Government determined that the scope of the Panel's work would focus on the Joint Select Committee's recommendations and on elements of the Victorian legislation that might not be fit for purpose for Western Australia.

As stated in the Panel's Terms of Reference, the role of the Panel was to provide advice to Government to assist in the development, consultation and implementation of new legislation for voluntary assisted dying. The Panel's role did not extend to drafting the legislation itself or focussing on the detail of implementation.

Panel process and consultation

The Panel commenced its work in December 2018 with an extensive review of literature, the experience in other jurisdictions, and meetings with selected experts. This informed the development of a Discussion Paper which was released for public consultation in March 2019.⁵

The Discussion Paper was distributed to over 500 stakeholders across the community including health services, aged care providers, advocacy groups and peak bodies.

The Panel undertook extensive consultation from 19 March until 24 May 2019 as detailed in the Consultation section. This consultation included an online consultation survey, 11 public forums and two webinars across metropolitan and rural areas, stakeholder roundtables and meetings with topic experts. There were a total of 867 participants involved in the consultation process and a further 541 submissions received by the Panel – a total of 1,408 consultation interactions. Submissions that were received by the Panel are to be published on the project website (unless the submitter has requested confidentiality).

The Panel's consultations were structured as an opportunity to respond to the questions for consideration in the Discussion Paper. These questions focussed on how Western Australia could legislate for voluntary assisted dying and how it could be implemented safely and compassionately. The consultation was not on the 'for and against' positions in relation to voluntary assisted dying.

The Panel was very clear that it wished to hear directly from members of the public as well as health professionals and other subject matter experts. Additional public forums were scheduled in some rural areas to respond to demand and were well attended. Sixty five percent of all participants in public forums or webinars were from rural areas.

Throughout the consultation the Panel listened carefully and respectfully to different views, comments and suggestions.

In reaching its conclusions the Panel considered the findings of the consultation, the recommendations of the Joint Select Committee, the Victorian *Voluntary Assisted Dying Act 2017* and the experience to date in Victoria of preparing for implementation of this legislation. The Panel sought information about implementation in other jurisdictions, and spoke to health practitioners from Canada and Oregon (USA) about their experience of implementing voluntary assisted dying. The Panel referred to the extensive research undertaken in Victoria and by the Joint Select Committee and sought updated evidence to complement this existing body of research.

Through its deliberations the Panel carefully considered the range of views and significant volume of information available to it. Where there were different perspectives to resolve, the Panel referred to its Guiding Principles and particularly to the importance of a person-centred approach.

5 Ministerial Expert Panel on Voluntary Assisted Dying Discussion Paper, Department of Health, Western Australia (2019).

Next steps

The recommendations of the Panel will be considered by Government and approved elements will be included in the legislation to be developed for voluntary assisted dying in Western Australia. This legislation is due to be tabled in Parliament in the second half of 2019.

Some elements of the Panel's recommendations relate more to implementation and will be referred to as required if legislation is passed by the Parliament of Western Australia.

Introduction

Purpose of the Report

This Final Report of the Ministerial Expert Panel on Voluntary Assisted Dying (the Report) presents the Panel's expert advice and policy recommendations to the Minister for Health to inform the development of safe and compassionate voluntary assisted dying legislation in Western Australia.

Established through Recommendation 21 of the Joint Select Committee's report *My Life, My Choice*,⁶ the Panel consulted extensively, drawing on the experience, knowledge and insights of the Western Australian community and of relevant experts and representatives of specific clinical and population groups, in addition to its own expertise.

In producing this Report, the Panel has integrated the Joint Select Committee's recommendations with the views expressed in the consultation submissions to develop recommendations regarding a complete picture of how safe, compassionate and workable legislation should be produced for Western Australia.

The consultation was guided by the Ministerial Expert Panel on Voluntary Assisted Dying Discussion Paper.⁷ The Discussion Paper incorporated the elements from the Joint Select Committee Report that were recommended as needing further consideration by the people of Western Australia, the situation in other jurisdictions, and associated evidence.

These recommendations, developed after careful consideration of the input received, will support the Western Australian Government's commitment to introduce the voluntary assisted dying legislation to Parliament in the second half of 2019.

Background

The Joint Select Committee on End of Life Choices

The Joint Select Committee consisting of cross-party members of the Legislative Council of Western Australia and the Legislative Assembly was appointed in August 2017 to conduct an inquiry into End of Life Choices.

During its year-long inquiry the Joint Select Committee considered more than 700 submissions and supplementary submissions, held 81 hearings and took evidence from more than 130 witnesses. It visited metropolitan and country regions (Great Southern and Kimberley) to consult with hospital and community palliative care providers, residential care facilities, Aboriginal health services and local communities.

The Joint Select Committee also reviewed international jurisdictions that have already legislated for some form of voluntary assisted dying and conducted international conferences by video and phone with persons having acknowledged experience in this subject. While the Joint Select Committee inquiry was underway, the Victorian Parliament passed the *Voluntary Assisted Dying Act 2017*.

6 *'My Life, My Choice'* report of the Joint Select Committee on End of Life Choices, Parliament of Western Australia (August 2018).

7 Ministerial Expert Panel on Voluntary Assisted Dying Discussion Paper, Department of Health, Western Australia (2019).

The Victorian *Voluntary Assisted Dying Act 2017* provides Western Australia with the opportunity to examine the approach taken in Victoria and to use it as a basis for the design of legislation suitable for the specific needs of Western Australians.

On 23 August 2018 the Joint Select Committee Report was tabled in both Houses of Parliament. It is available at www.parliament.wa.gov.au. It outlined 52 findings and made 24 recommendations relating to advance care planning, end-of-life and palliative care and voluntary assisted dying.

Based on its finding that ‘some people experience unnecessary suffering at the end of life’, and that there was broad community agreement regarding the importance of individual autonomy and choice, the Joint Select Committee recommended that the Western Australian Government draft and introduce a Bill for voluntary assisted dying.⁸

Recommendation 21 in the Joint Select Committee Report recommends that ‘the Minister for Health establishes an expert panel including health and legal practitioners and health consumers, to undertake consultation and develop legislation for voluntary assisted dying in Western Australia, and that this report, together with the Framework ([refer Appendix 1](#)) be considered by that Panel’.⁹

The Panel, appointed by the Minister for Health in December 2018, includes health practitioner, legal practitioner, health consumer, multicultural and disability advocate representation ([refer page viii](#)).

Western Australian context

Western Australia covers 2.5 million square kilometres of the Australian mainland, being the largest state in the Commonwealth. Although most of the Western Australian population resides in Perth and surrounds, there is a significant part of the population that is vastly dispersed across the state. According to the Australian Bureau of Statistics, almost 40% of Western Australia’s Aboriginal population lived in remote or very remote locations compared to just under 5% for non-Indigenous populations.¹⁰ Apart from the challenges presented by its geographical size and location, Western Australia is also the most culturally and linguistically diverse state in Australia with Aboriginal people, migrants and refugees accounting for nearly 30% of its population.¹¹

Western Australia’s Sustainable Health Review (2019) guides the ‘direction of the WA health system to deliver patient first, innovative and financially sustainable care’.¹² Strategy Three sets out a commitment to ‘Great beginnings and a dignified end of life’ and includes promoting integrated social approaches to dying, death and bereavement in everyday lives.¹³

8 ‘*My Life, My Choice*’ report of the Joint Select Committee on End of Life Choices, Parliament of Western Australia (August 2018).

9 Ibid.

10 Australian Bureau of Statistics. 2016 Census Counts Aboriginal and Torres Strait Islander Peoples (by Remoteness area). <https://www.abs.gov.au/AUSSTATS/abs@.nsf/Lookup/2075.0Main+Features202016?OpenDocument>.

11 WA Health System Language Services Policy Guidelines, Department of Health, Western Australia (2017).

12 Sustainable Health Review: Final Report to the Western Australian Government, Department of Health, Western Australia (2019).

13 Ibid.

End of life and palliative care context

It is acknowledged internationally that Australia has some of the best palliative care in the world.¹⁴ Ensuring every Western Australian with a life-limiting illness has a right to high-quality integrated end-of-life and palliative care is a key priority of the Western Australian Government.¹⁵

End-of-life and palliative care in Western Australia is delivered by all health services caring for people with a life-limiting illness. Care is provided in a range of settings from acute care (including but not limited to specialist palliative care units) to aged care, correctional and mental health services, to primary and community-based care, often in people's homes.¹⁶

Providing co-ordinated care to Western Australians who are at end of life relies on collaboration across geographic and jurisdictional boundaries to ensure the patient's wishes are placed firmly at the centre of their care.

Western Australia's size and geographic diversity mean that particular approaches are needed to meet the needs of people who live outside the metropolitan area or major regional centres. In regional and remote areas, nurse-led teams provide specialist palliative care capacity building and/or direct care, linking with existing health, community and aged care services in the region. Telehealth plays an increasingly key role in delivering specialist advice and support to these areas. Aboriginal health services link with local health and community services to facilitate the cultural and spiritual support that is needed at end of life for people, their families and communities.¹⁷

The WA End of Life and Palliative Care Strategy 2018 – 2028 (the Strategy) outlines the vision, values and priorities to guide strategic, statewide policy for end-of-life and palliative care to improve the lives of all Western Australians.¹⁸

The Strategy provides the context that 'end-of-life care is care that affects us all and is not a response to a particular illness or condition ... Death is unavoidable; however, we can change the way we talk about and manage end of life, death and bereavement and the way we plan, care and support those who are dying, including those who are close to them, such as their families and carers'.¹⁹

14 The 2015 quality of death index: the state of palliative care across the world, The Economist Intelligence Unit, Lien Foundation, London (2015).

15 WA End-of-Life and Palliative Care Strategy 2018-2028. WA Cancer and Palliative Care Network, Department of Health (2018).

16 Ibid.

17 Rural Palliative Care Model of Care, WA Palliative Care and Cancer Network, Department of Health, Western Australia, (2008).

18 WA End-of-Life and Palliative Care Strategy 2018-2028. WA Cancer and Palliative Care Network, Department of Health (2018).

19 Ibid.

The Strategy outlines six priority areas to guide and inspire the provision of best practice end-of-life care and palliative care:

1

Care is accessible to everyone, everywhere.

I have access to good quality end-of-life and palliative care, regardless of who and where I am, or how I live my life.

2

Care is person-centred.

I am seen as an individual, and I have the opportunity to be involved in honest discussions with those important to me about my care. My values, culture and spirituality are respected and taken into account when care is given.

3

Care is coordinated.

I receive the right care at the right time, in the right place, from the right people. My care occurs within a coordinated/collaborative approach, enabling care to be delivered seamlessly.

4

Families and carers are supported.

Those close to me and/or caring for me are supported and involved in my care. The contributions made by my family/carer are recognised and valued by those providing my care, including their need to be supported during and after my death.

5

All staff are prepared to care.

Wherever and whenever I am cared for, all staff involved in my care have expertise, empathy and compassion. All staff provide confident, sensitive and skilful care, before, during and after my death.

6

The community is aware and able to care.

I feel supported and empowered to make decisions. My individual preferences are expressed through Advance Care Planning (ACP) and reflected in my end-of-life and palliative care. My community is aware and able to support me and those close to me.

Many submissions stressed the importance of ongoing access to excellent end-of-life care and palliative care, since it is key to ensuring that patients are informed and supported to make genuine choices. The Australian Medical Association (WA) makes a strong case that the ‘correction of deficiencies in palliative care and end of life decision-making must be a prerequisite to the introduction of voluntary assisted dying legislation for community and parliamentary debate’.²⁰

20 Submission: Australian Medical Association (WA) to the Ministerial Expert Panel on Voluntary Assisted Dying (2019).

Palliative Care Nurses Australia advocates for a parallel increase in investment in end-of-life and palliative care, 'particularly important for the Western Australians who currently have more limited access to palliative care',²¹ including those who live in regional and remote areas, those from culturally and linguistically diverse backgrounds, Aboriginal people and socio-economically disadvantaged Western Australians.

On a similar point the Australian College of Nurses' submission states 'a person making the choice to undergo voluntary assisted dying must have the same continual access to palliative care services'.²²

Language

There are many important conversations that Western Australians have had in relation to voluntary assisted dying during the deliberations of the Joint Select Committee and Panel's consultation period. These will be ongoing.

It is critical that these conversations continue to take place respectfully and with clarity about what is being said. Having a common, easy-to-understand approach to the meanings of key words and phrases can help to ensure clarity and to avoid the misunderstandings that can sometimes derail helpful discussion.

Various different terms and definitions have been used in Australia and around the world in relation to voluntary assisted dying. The approach taken by the Panel is to use words and definitions that are consistent with the key principles of choice and keeping the person who is at the end of their life at the centre of all considerations. Please refer to Appendix 3 for explanations of the terminology used for the voluntary assisted dying consultation and referred to in this Report.

Key Terms

Voluntary assisted dying

The term 'voluntary assisted dying' is used by the Joint Select Committee and the Panel. It emphasises the voluntary nature of the choice of the person to make this decision.²³ Throughout the process of voluntary assisted dying, the person must have the capacity to make a voluntary choice. To be eligible the person must already be suffering and dying as a result of an illness, disease or medical condition. It reflects a person-centred approach focused on those who are eligible to access assisted dying. Voluntary assisted dying involves a process to access medication and to enable a person to legally have choice about the manner and timing of their death.

Person

Throughout this report the Panel uses the word 'person' to refer to the person who is approaching the end of their life. 'Person' is preferred over the terms 'patient' or 'client'.

This emphasises the key principles of autonomy and choice in voluntary assisted dying'.²⁴

21 Submission: Palliative Care Nurses Australia to the Ministerial Expert Panel on Voluntary Assisted Dying (2019).

22 Submission: Australian College of Nursing to the Ministerial Expert Panel on Voluntary Assisted Dying (2019).

23 Ministerial Advisory Panel on Voluntary Assisted Dying Final Report, Department of Health and Human Services, State of Victoria (July 2017).

24 Ministerial Expert Panel on Voluntary Assisted Dying Discussion Paper, Department of Health, Western Australia (2019).

Person-centred

Like the Joint Select Committee, the Panel recognised that end-of-life care needs to be person-centred. Person-centred care is a philosophical approach to clinical care and service delivery that sees services provided in a way that is respectful of, and responsive to, the preferences, needs and values of people and those who care for them.²⁵

Co-ordinating practitioner

A registered medical practitioner who accepts the person's first request or a consulting practitioner who accepts a transfer of the role of co-ordinating practitioner voluntary assisted dying.²⁶

Consulting practitioner

A medical or nurse practitioner who accepts a referral to conduct a consulting assessment of the person for voluntary assisted dying.²⁷

Terms not used

The following terms were not used by the Panel because they are not an accurate description of the process, who is in control of the process, or because of the value judgements implicit in these terms. These have been well described in the Victorian Ministerial Advisory Panel on Voluntary Assisted Dying Final Report and are reproduced with amendment.²⁸

Euthanasia

'Euthanasia refers to the situation when death is induced to relieve suffering. The term derives from the Greek for 'good death'. The term, however, can carry connotations of something bad as well as something good, because of its historic abuse in involuntary euthanasia, which raises the prospect of medical practitioners or society killing people whose lives are thought to have little value. Many people are familiar with the idea of euthanasia from the practice of relieving the suffering of family pets. [...] When applied to humans, euthanasia is often similarly understood to be a procedure that is provided to a passive patient'.²⁹ By contrast, voluntary assisted dying is a process that is requested and led entirely by the person.

25 Valuing people, What is person-centred care?, Alzheimer's Australia, <http://valuingpeople.org.au/the-resource/what-is-person-centred-care>; cited in Ministerial Advisory Panel on Voluntary Assisted Dying Final Report, Department of Health and Human Services, State of Victoria (July 2017).

26 *Voluntary Assisted Dying Act 2017* (Victoria).

27 Adapted from *Voluntary Assisted Dying Act 2017* (Victoria).

28 Ministerial Advisory Panel on Voluntary Assisted Dying Final Report, Department of Health and Human Services, State of Victoria (July 2017).

29 Ibid.

Assisted suicide

Suicide involves the tragic loss of life of a person who is typically not dying, whereas voluntary assisted dying involves a person's choice about their mode of death when they are already dying. Suicide is usually undertaken alone, whereas voluntary assisted dying is a pathway involving medical and family support. Suicides are potentially avoidable; 'every effort should be made to prevent these deaths'³⁰ and there is a 'range of critical work being undertaken to prevent suicide'.³¹ By contrast, the people 'who are the focus of voluntary assisted dying face an inevitable death as a result of an incurable disease, illness or medical condition. It would not be appropriate to use the same terminology to describe'³² their choice about the circumstances of their impending death. For these reasons, the Panel agreed the word 'suicide' should not be used in relation to voluntary assisted dying. It is wrong to confuse these two very different kinds of deaths.

Other terms

Voluntary assisted dying is one element of a broader range of end of life choices. It sits within the context of a person exercising a number of choices as they approach the end of their life from a terminal disease or terminal illness. Voluntary assisted dying would only ever be one small part of the person's overall care. Some of the other terms associated with end of life are outlined below. These definitions have been chosen by the Panel for their use of simple, person-centred language.

End-of-life care

End-of-life care is care needed for people who are likely to die in the next 12 months due to progressive, advanced or incurable illness. During this period, people may experience rapid changes and fluctuations in their condition and require support from a range of people, including health services, as well as family and carers.³³

Palliative care

Palliative care helps people with any life-limiting or terminal condition to live their lives as fully and as comfortably as possible. It is not just for people with cancer. Palliative care identifies and treats symptoms which may be physical, emotional, spiritual or social. It also provides practical and emotional support to family and carers.³⁴

Guiding Principles

The Panel adopted the approach of the Victorian *Voluntary Assisted Dying Act 2017* and the Joint Select Committee considerations to ensure human rights principles were present as core values in the legislation.³⁵ These were considered for addition or amendment during the consultation.

The key human rights highlighted were that everyone has the right to meaningfully participate in decisions that affect their lives and the importance of privacy and confidentiality.³⁶ Maintaining a balance between personal autonomy and appropriate safeguards was a central theme throughout the discussions.

30 Ibid.

31 Ibid.

32 Ibid.

33 WA End-of-Life and Palliative Care Strategy 2018-2028, Department of Health, Western Australia (2018).

34 <https://www.palliativecarewa.asn.au/palliative-care>.

35 Australian Human Rights Commission <https://www.humanrights.gov.au/human-rights-based-approaches>; *Equal Opportunity Act 1984* (Western Australia).

36 Ibid.

The consultation demonstrated to the Panel the importance of including the Guiding Principles in the voluntary assisted dying legislation.

'Alzheimer's WA strongly supports the adoption of the set of Guiding Principles for inclusion in the proposed Voluntary Assisted Dying Bill'

(Submission by Alzheimer's WA)

A variety of submissions were provided to the question *'Are there other guiding principles that should be considered for the Bill?'* Most responses endorsed the proposed principles while some suggested additional areas of focus.

'A guiding principle could include reference to equality of access – which may be impacted by disability, age, geographical location, language etc.'

(Submission by the Brightwater Care Group)

'AHCWA [...] support the principle which states; 'people have the right to be supported in making informed decisions about their medical treatment, and should be given, in a manner they can understand, information about medical treatment options, including comfort and palliative care.' However, AHCWA recommends that greater emphasis is required to ensure that culturally appropriate information about VAD is made available to Aboriginal people, families and communities.'

(Submission by the Aboriginal Health Council of Western Australia)

During the consultation the Panel was informed of current examples of best practice that demonstrate an holistic approach to early advance care planning that involves the person and their family. This ensures that the person's wishes remain primary and are met within a cultural framework. The Panel also heard examples of treating practitioners, health services and local Aboriginal medical services collaborating to respect a person's choices and ensure that their family and community are supported, for example in the case of a person who has made a decision to cease medication or renal dialysis.³⁷

In light of these suggestions the Panel reviewed and made amendments to the Guiding Principles.

The Guiding Principles³⁸ adopted for consideration for inclusion in the legislation reflect the issues underpinning the Panel's considerations.

- Every human life has intrinsic value.
- A person's autonomy should be respected.
- People have the right to be supported in making informed decisions about their medical treatment, and should be given, in a manner they understand, and is culturally appropriate, information about medical treatment options, including comfort and palliative care.
- People approaching the end of life should be provided with high quality care, including access to specialist palliative care, to minimise their suffering and maximise their quality of life.
- A therapeutic relationship between a person and their health practitioner should, wherever possible, be supported and maintained.
- People should be encouraged to openly discuss death and dying, and their preferences and values should be encouraged and promoted.
- People should be supported in conversations with their health practitioners, family, carers and community about treatment and care preferences.

37 Ministerial Expert Panel on Voluntary Assisted Dying Consultation Meeting: Aboriginal Health Council of WA (2019).

38 Reproduced with amendments: *Voluntary Assisted Dying Act 2017* (Victoria).

- People are entitled to genuine choices regarding their treatment and care; this should be regardless of their geographic location and take into account their ability as well as individual cultural and linguistic needs.
- People should be supported in their right to privacy and confidentiality regarding their choices about treatment and care preferences.
- People who may be vulnerable to coercion and abuse in relation to end of life choices and decisions should be protected.
- All people, including health practitioners, have the right to be shown respect for their culture, religion, beliefs, values and personal characteristics.

Ministerial Expert Panel recommendation 1:

The guiding principles listed above should be included in the legislation to help guide interpretation.

Policy intent:

The principles reflect the values underpinning the Panel's considerations and should be used to interpret the recommendations and the legislation.

Consulting Western Australians

Process and methodology

The Ministerial Expert Panel undertook extensive consultation with a diverse range of stakeholders, a broad cross-section of the public, specific population groups and key experts to inform their recommendations regarding the development of safe, compassionate and workable legislation.

The consultation ran for approximately ten weeks from 19 March to 24 May 2019. People's views were received at public forums, targeted stakeholder roundtables and meetings, via mail, email and online through Citizen Space. A Discussion Paper was developed to provide support and focus to the consultations. This was complemented by a plain language fact sheet that was made available in 16 different languages.

The 38 questions posed in the Discussion Paper were replicated in the Citizen Space online consultation ([see Appendix 4](#) for full list of questions). The public forums focused on the decision, eligible conditions and aspects of the process. Specific sets of questions from the Discussion Paper were asked at the relevant stakeholder roundtables (for example questions from the medication section were posed at the medications and approval roundtable). All questions came directly from the Discussion Paper. Email and mail submissions were freeform although many referred to the Discussion Paper questions. It should be noted that a one-week extension was granted to 10 organisations for the provision of submissions.

Public forums were held throughout the state with the Panel hearing from people directly in Kalgoorlie, Geraldton, Joondalup, Maylands, Murdoch, Broome, Bunbury, Mandurah, Northam, Karratha and Carnarvon. Additional webinars enabled access to over 60 people in 15 small towns including Boyup Brook, Hopetoun, Walpole and Quairading ([refer Appendix 4](#)). In Albany over 100 people took part in information sessions led by Panel member Associate Professor Kirsten Auret.

Stakeholder meetings and roundtables were held with topic experts, groups who might be impacted by the legislation (including health professionals), and peak bodies representing specific populations such as Aboriginal people, culturally and linguistically diverse groups and people living with disability ([Appendix 4](#)).

Participants and submissions

There were a total of 867 participants involved in the consultation process and a further 541 submissions received by the Panel – giving a total of 1,408 consultation 'interactions'. Participants were involved by providing their views at public forums (557), at stakeholder roundtables or meetings (194) or attendance at 'grassroots' sessions (116). The 541 submissions were received either online (417), by email (110) or mail (14) ([see Appendix 4](#) for further details).

The community involvement resulted in a vast amount of consultation material to be transcribed, collated, thematically coded and analysed. Contributions from attendees at public forums resulted in approximately 1,200 pages of content that consisted of many thousands of comments.

Analysis and outcomes

The consultation material was transcribed, collated, thematically coded and analysed. An iterative approach was taken to identifying the key themes from responses to the Discussion Paper questions. Submissions ranged in length and complexity with some comments applicable across multiple identified themes.

Analysis was undertaken on the commentary received across the 38 Discussion Paper questions. The results of the analysis were supplemented with quotes from stakeholder roundtables and meetings, public forums and organisational responses. These added to the depth and richness of the Panel's deliberations and are reflected in the consultation and discussion sections of this Report. Each Panel member received a complete set of all submissions received (via email, mail, Citizen Space), public forum summaries and notes from all stakeholder roundtables and meetings.

Demographic characteristics were captured for the 417 responses received via Citizen Space. They were not recorded at public forums, stakeholder roundtables and meetings, or from emails and letters so the following breakdown *relates only to the online Citizen Space submissions*.

Of the 417 online responses received:

- majority were from individuals (412 of 417)
- majority of respondents were female (295 of 417)
- most common age of respondents was 65-74 years (94 of 417)
- majority of respondents provided their views as a private citizen (326 of 417)
- majority of respondents normally resided in Western Australia (377 of 417)
- minority had a culturally and linguistically diverse background (39 of 417)
- minority had an Aboriginal or Torres Strait Islander background (5 of 417).

The age distribution of attendees at the public forums was not systematically captured but the Panel noted that participants were typically aged 65 years and over.

Part A: Eligibility

Eligibility overview

The Joint Select Committee on End of Life Choices outlined the following in relation to eligibility for voluntary assisted dying.

Joint Select Committee recommendation:

7.89 Voluntary Assisted Dying Legislation Framework

Eligible Conditions

The legislation is intended to provide assisted dying for those for whom death is a reasonably foreseeable outcome as a result of an eligible condition.

An eligible condition is an advanced and progressive:

- a. terminal illness or disease;
- b. chronic illness or disease; or
- c. neurodegenerative illness or disease,

where death is a reasonably foreseeable outcome of the condition.

The person's suffering

The person's suffering must not be temporary nor able to be treated or remedied in a manner acceptable to the person. The suffering:

- a. must be related to an eligible condition;
- b. must be grievous and irremediable;
- c. cannot be alleviated in a manner acceptable to the person; and
- d. must be subjectively assessed – that is, from the person's point of view.

Age

The person must be aged 18 years or over.

Capacity

In order to request assisted dying the person must have decision-making capacity in relation to a decision about voluntary assisted dying.

Residency

Eligibility requires ordinary residence in Western Australia and either Australian citizenship or permanent residency.

The Joint Select Committee also made the following recommendations:

Recommendation 22

The Minister for Health should ensure that legislation require that death be reasonably foreseeable as a consequence of the condition.

Recommendation 23

That the Minister for Health ensure the eligibility requirement in the legislation include that the person is experiencing grievous and irremediable suffering related to an advanced and progressive terminal, chronic or neurodegenerative condition that cannot be alleviated in a manner acceptable to the person.

The Joint Select Committee also made the following findings:

Finding 45

With regard to timeframes, whatever model of assisted dying is enacted in Western Australia should reflect the best possible clinical practice.

Finding 52

Individuals wishing to access voluntary assisted dying in Western Australia must be a citizen or permanent resident of Australia ordinarily resident in Western Australia, as defined by the expert panel.

Discussion

The Panel has carefully considered the Joint Select Committee Legislation Framework and the *My Life, My Choice* report, alongside the Panel's consultation findings and evidence associated with eligibility in other jurisdictions.

The Panel acknowledges and agrees that all the eligibility criteria must be met for a person to be considered eligible for access to voluntary assisted dying. The flow chart on [page 18](#) seeks to clearly demonstrate this requirement.

Overall, the Panel has sought to ensure clarity of the intention of the eligibility criteria contained in the Joint Select Committee Legislation Framework and, as part of that process, has made some recommendations about the content of the eligibility criteria and the way in which they are structured.

Following its consultation and deliberations the Panel has also proposed that there are elements of the eligibility criteria that may be further refined to improve consistency and workability. The reasons for these refinements are outlined in the discussion sections that follow this overview.

Ministerial Expert Panel recommendation 2:

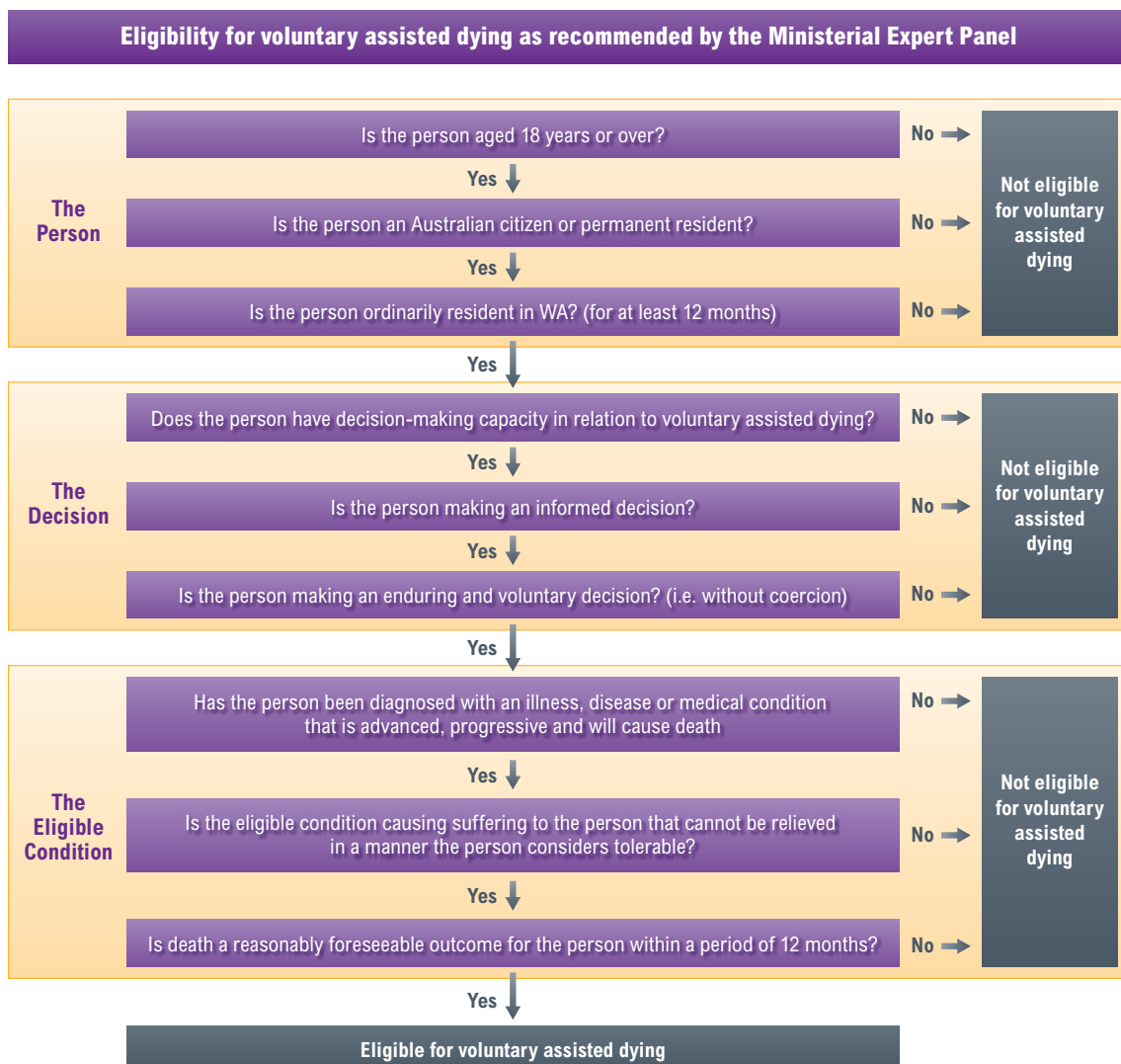
To access voluntary assisted dying, a person must meet all of the following eligibility criteria:

1. be an adult, aged 18 years or over; and,
2. be an Australian citizen or permanent resident and have been ordinarily resident in Western Australia for 12 months at the time of making the request; and,
3. have decision-making capacity in relation to a decision about voluntary assisted dying; and,
4. be diagnosed with an eligible condition, where an eligible condition is an illness, disease or medical condition that:
 - a. is advanced, progressive and will cause death; and,
 - b. is causing suffering to the person that cannot be relieved in a manner the person considers tolerable; and,
5. death is reasonably foreseeable for the person within a period of 12 months.

Policy intent:

To ensure that it is clear for whom voluntary assisted dying is intended.

To ensure that access to voluntary assisted dying is limited to those for whom it is intended.



The person

To access voluntary assisted dying, a person must meet all of the following eligibility criteria:

1. be an adult, aged 18 years or over; and,
2. be an Australian citizen or permanent resident and have been ordinarily resident in Western Australia for 12 months at the time of making the request; and,
3. have decision-making capacity in relation to a decision about voluntary assisted dying; and,
4. be diagnosed with an eligible condition, where an eligible condition is an illness, disease or medical condition that:
 - a. is advanced, progressive and will cause death; and,
 - b. is causing suffering to the person that cannot be relieved in a manner the person considers tolerable; and,
5. death is reasonably foreseeable for the person within a period of 12 months.

The Joint Select Committee

The Joint Select Committee recommended that voluntary assisted dying only be available to a person who is aged 18 years or older, and that eligibility requires ordinary residence in Western Australia and either Australian citizenship or permanent residency.

In Finding 52 of the *My Life, My Choice* report, the Joint Select Committee noted:

*'Individuals wishing to access voluntary assisted dying in Western Australia must be either a citizen or permanent resident of Australia ordinarily resident in Western Australia, as defined by the expert panel.'*³⁹

Consultation Findings

To define the concept of 'ordinarily resident', the Panel publicly consulted and sought expert advice on whether there should be a specific period of continuous residency to be 'ordinarily resident'.

The consultation demonstrated strong support for a requirement that a person be ordinarily resident, in Western Australia with either Australian citizenship or permanent residency.

As to 'ordinarily resident', opinion was fairly evenly divided on whether a timeframe should be stipulated and, if one were to be specified, whether it be 6 or 12 months. Some referred to the difficulties of applying a timeframe to some situations (for example a resident of Western Australia who has been working interstate and returns home after receiving a terminal diagnosis).

39 *'My Life, My Choice'* report of the Joint Select Committee on End of Life Choices, Parliament of Western Australia (August 2018).

Discussion

That voluntary assisted dying would only be available to adults aged 18 years or over is in alignment with the majority of jurisdictions that have legislated for voluntary assisted dying.⁴⁰ The Joint Select Committee also noted that this is 'consistent with the presumption of capacity at age 18 and with the community expectation of autonomy for adults'.⁴¹

'Ordinarily resident' is a term not infrequently used in Western Australian legislation. For the purposes of determining eligibility for voluntary assisted dying however, an assessing practitioner would benefit from having clear and objective guidance, as would a person seeking voluntary assisted dying.

The Panel is aware that some in the community have raised concerns over fears of so-called 'voluntary assisted dying tourism'. The requirement of ordinary residency in Western Australia, as well as having either Australian citizenship or permanent residency will address those concerns.

'A process for establishing residency in WA must be clear and specific to proposed voluntary assisted dying legislation to preclude 'voluntary assisted dying tourism.'

(Submission by the Australian Medical Association – WA)

The Panel recommends it be required that the person be ordinarily resident in Western Australia for not less than 12 months prior to the first request. This would serve the dual purpose of providing clear parameters for the assessing practitioner and ensuring access is limited to those ordinarily resident in Western Australia and is consistent with the approach taken in Victoria.⁴²

In most situations the assessing practitioner will be readily able to determine that a person meets these requirements. The Panel acknowledges however that there may be some circumstances where these strict requirements may result in unnecessary hardship and grief. For example, a person who may genuinely have moved to and established residency in Western Australia and is diagnosed with an eligible condition before 12 months have elapsed; or, a Western Australian who has been living interstate, is diagnosed with an eligible condition and wants to return home to be with family when they die. Western Australia also has a significant community of fly-in/fly-out workers who may have more than one legitimate 'ordinary residence'.

The Panel therefore recommends that there be provision to enable people to apply to the State Administrative Tribunal for relief from the strict requirements of residency, in exceptional circumstances, on compassionate grounds.

40 Australia (Victoria); Canada; US States (California, Colorado, District of Colombia, Hawaii, New Jersey, Oregon, Vermont, Washington State) (Refer Appendix 5).

41 'My Life, My Choice' report of the Joint Select Committee on End of Life Choices, Parliament of Western Australia (August 2018) 7.48.

42 *Voluntary Assisted Dying Act 2017* (Victoria).

Ministerial Expert Panel recommendation 3:

For access to voluntary assisted dying, the person must have been ordinarily resident in Western Australia for 12 months at the time of making the first request.

There should be provision for application to the State Administrative Tribunal for relief from the strict requirements of residency for 12 months in exceptional circumstances, on compassionate grounds.

Policy intent:

To provide clarity as to the meaning of 'ordinarily resident' for the purposes of access to voluntary assisted dying and to provide the opportunity for relief from the requirement for 12 months residency for exceptional circumstances.

Decision-making capacity

To access voluntary assisted dying, a person must meet all of the following eligibility criteria:

1. be an adult, aged 18 years or over; and,
2. be an Australian citizen or permanent resident and have been ordinarily resident in Western Australia for 12 months at the time of making the request; and,
3. **have decision-making capacity in relation to a decision about voluntary assisted dying; and,**
4. be diagnosed with an eligible condition, where an eligible condition is an illness, disease or medical condition that:
 - a. is advanced, progressive and will cause death; and,
 - b. is causing suffering to the person that cannot be relieved in a manner the person considers tolerable; and,
5. death is reasonably foreseeable for the person within a period of 12 months.

Decision-making capacity is a term used to describe whether or not someone is capable of making a decision. It is presumed that an adult is able to make decisions unless there is evidence to the contrary.⁴³

It is important to understand that capacity is specific, contextual and can vary over time. Someone may have the capacity to decide what to eat for breakfast but not have the capacity to make complex financial decisions. The crucial question is whether a person has capacity to make a valid decision about voluntary assisted dying.⁴⁴

⁴³ Ministerial Expert Panel on Voluntary Assisted Dying Discussion Paper, Department of Health, Western Australia (2019).

⁴⁴ Ibid.

For a decision to be valid it must be:

1. properly informed
2. voluntary
3. made by a person with capacity
4. current
5. specific to voluntary assisted dying.⁴⁵

Existing Western Australian legislation makes a legal presumption about a person's capacity ([refer to Appendix 6](#) for the actual legislation extracts):

- In relation to matters under the *Guardianship and Administration Act 1990*, it is clear that every person shall be presumed to be capable of looking after their own health and safety, managing their own affairs, and making reasonable judgements in respect of matters relating to themselves and to their estate. This legal presumption about a person's capacity applies until the State Administrative Tribunal deems otherwise.⁴⁶
- In relation to matters under the *Mental Health Act 2014* (such as psychiatric treatment), an adult is presumed to have the capacity to make a decision relating to themselves unless shown to not have that capacity.⁴⁷
- The *Mental Health Act 2014* sets out factors that must be demonstrated when assessing capacity under that Act ([refer Appendix 6](#)). These include that a person must be able to understand any information or advice about the decision, the matters involved in the decision and the effect of the decision. The person must also be able to weigh up these factors for the purpose of making the decision and communicate the decision in some way.⁴⁸

Questions about decision-making capacity are sometimes linked to a diagnosis of dementia. While dementia is often recognised as a terminal medical condition, people may live for many years with dementia. A person's decision-making capacity may change over time, noting that cognitive ability typically declines throughout the course of the disease.

The Joint Select Committee

The Joint Select Committee recommended that a person must have decision-making capacity in relation to a decision about voluntary assisted dying. It also recommended that 'each doctor must be independently satisfied that ... the request is made voluntarily, without coercion or duress' and that 'a person is not required to undergo consultant or specialist assessment except where either doctor is unable to determine... capacity, and/or the absence of coercion, in which case they must refer to a consultant psychiatrist or a consultant geriatrician as appropriate'.⁴⁹

45 Adapted from the WA Health Consent to Treatment Policy (2016) noting the Submission: Anglican Social Responsibilities Commission to the Ministerial Expert Panel on Voluntary Assisted Dying (2019).

46 *Guardianship and Administration Act 1990* s4(3).

47 *Mental Health Act 2014* s13(1).

48 *Ibid* s15.

49 'My Life, My Choice' report of the Joint Select Committee on End of Life Choices, Parliament of Western Australia (August 2018) 7.89.

Consultation Findings

Decision-making capacity, and the many complex circumstances surrounding this, was a significant topic of interest during the consultations.

The consultations demonstrated overwhelming support for a requirement that a person must have decision-making capacity to make an informed decision to request voluntary assisted dying.

The Panel found that, by and large, most were satisfied with the presumption of capacity in the absence of evidence otherwise and with the existing structure of determining capacity as outlined in the *Mental Health Act 2014*.

Where an assessing practitioner is unable to determine capacity, the consultations clearly supported a requirement for further assessment.

There was a strong focus in consultation on whether capacity assessment is solely in the domain of psychiatrists or not. The view of the Royal Australian and New Zealand College of Psychiatrists (outlined during stakeholder consultation) was that whoever is assessing capacity needs relevant expertise. This doesn't mean they need to be a specialist – it was noted that general practitioners (GPs) are capable of assessing capacity (with access to relevant information, which may include a report from a specialist).⁵⁰

*'Although psychiatrists have extended skills in capacity assessment as it relates to mental illness, the WA Branch recognises that in some circumstances other specialists may be better qualified to undertake capacity assessment... [there are] significant barriers to psychiatrists carrying out mandated assessments of all patients seeking access to PAS [VAD] in a timely way.'*⁵¹

It was noted that identifying specialists by type in the legislation may result in a delay to the process.

'A doctor should be able to refer to whichever doctor or other healthcare practitioner/s can appropriately assess a patient's capacity.'
(Submission by the Medical Insurance Group of Australia)

It was also noted by the Panel that there are access issues to these specialists for rural and remote communities. Medical practitioners in these communities already have functional referral pathways that may include disciplines other than psychiatrists and geriatricians.⁵²

In its submission to the Joint Select Committee on End of Life Choices, the WA Branch of the Royal Australian and New Zealand College of Psychiatrists suggested that training 'be provided to non-psychiatrically trained professionals by psychiatrists with relevant expertise.'⁵³ Refer to the section on Education and Training for recommendations in relation to training ([page 96](#)).

In considering to whom the practitioner should refer, the overall theme from consultation was that the referral should be based on expertise rather than specific medical specialty.

50 RANZCP representative to the Ministerial Expert Panel on Voluntary Assisted Dying Consultation Roundtable: Medical Practitioners (2019).

51 Submission by the Royal Australian and New Zealand College of Psychiatrists (WA Branch) to Joint Select Committee on End of Life Choices (18 October 2017).

52 Medical Workforce Report 2015/16: Medical Workforce Branch, Office of the Chief Medical Officer, Department of Health, Western Australia (2017).

53 Submission by the Royal Australian and New Zealand College of Psychiatrists (WA Branch) to Joint Select Committee on End of Life Choices (18 October 2017).

Strong community views were expressed about people who might be diagnosed with a condition such as dementia and who indicate early in the disease process a desire for voluntary assisted dying. Further concern was expressed that these people may have lost capacity by the time they might otherwise be eligible. Views were also expressed to the contrary that once the person had lost capacity they had also lost the ability to rescind a decision.⁵⁴

'We do not recommend consideration be given in the law to people who lose capacity after they commence the VAD process. As noted, decision-making capacity and enduring consent, including the ability to change one's mind and withdraw from the process at any stage, are key safeguards that ensure the VAD process remains transparent and self-determined throughout.'
(Submission by Go Gentle Australia)

This topic, and reference to the role of Advance Health Directives, is the subject of discussion in the section [Beyond the scope of the Panel](#).

The Panel also recognises that a person with an eligible condition may have decision-making capacity when making the first request, but progressively be at risk of losing that capacity due to the nature of the disease, the proximity to death, or the medication being taken. This issue is discussed in the section on [Process](#).

The Panel noted the point made in consultations that the disease itself should not preclude eligibility provided capacity is demonstrated. As the submission from Dementia Australia observes, *'it is unjust to assume that anyone with dementia at any specific stage does not have capacity to make decisions on their own behalf'*.⁵⁵

A clear message from consultation was that participants were very keen to ensure that the decision was voluntary and that the processes for voluntary assisted dying contained adequate safeguards to ensure that the person's decision is voluntary and valid.

Specific concerns raised included that a person may be coerced to opt for voluntary assisted dying or that more subtle forms of coercion may induce a person to feel like a burden and therefore request assisted dying. It was identified as imperative that vulnerable individuals in the community were protected from such situations.

Safeguards and processes to ensure that a person's decision is voluntary and valid were suggested by consultation participants.

These specifically included that the decision is well informed, that there is a requirement for more than one practitioner to be involved, that the practitioners are appropriately trained to detect risk of coercion or abuse (refer to the section on [Education and Training](#) for further information) and that there are multiple occasions in the process during which the person affirms their wishes.

'Bethesda is of the view that people participating in the provision of voluntary assisted dying services will require mandatory specialised and comprehensive training in the assessment of whether an individual's decision is voluntary'.
(Submission by Bethesda Health Care)

Some consultation respondents contended that developing adequate safeguards to ensure that decision-making is voluntary and valid would be challenging. Others noted that there was a need to have a good understanding of cultures that have a collectivist approach to decision-making and for practitioners to better understand how Aboriginal people may choose end-of-life care.

54 Submission: Alzheimer's Association WA to the Ministerial Expert Panel on Voluntary Assisted Dying (2019).

55 Submission: Dementia Australia to the Ministerial Expert Panel on Voluntary Assisted Dying (2019).

'Any guidelines or legislation for voluntary assisted dying must make it clear that autonomous, voluntary decision making for Aboriginal people is not precluded by a collectivist approach, and should be accepted'.

(Submission by the Aboriginal Health Council of Western Australia)

The importance of additional safeguards in the legislation for protection of people with a disability was raised, as was the need for specific training and appropriate referral.

'Particular focus should be to ensure the legislation protects people with disability from potential abuse-coercion'.

(Submission by the National Disability Services)

'Assessments of competence and undue influence are complex, and may require specific training for health care professionals. It is therefore sensible to make provision for the assessing medical practitioner to be able to refer to other health practitioners with specific expertise in assessing competence and undue influence. However, this should not unduly add to the length and complexity of the assessment process.'

(Submission by the Public Health Association of Australia)

Discussion

Most decisions, large or small, are made by people in the context of their usual life which includes family, friends and their community. People have the right to include or exclude whoever they choose in their deliberations on their decision and to seek support in their decision-making process. It is important to consider the needs of people from diverse backgrounds who may be from cultures that have a collectivist approach to decision-making.⁵⁶

That the person's decision is voluntary and valid is fundamental to the proposed model for voluntary assisted dying in Western Australia.⁵⁷ The Joint Select Committee recommended that the person must have decision-making capacity in relation to voluntary assisted dying throughout the entire process⁵⁸ and that it is appropriate that a general practitioner can usually determine capacity for the purposes of a person making a decision relating to voluntary assisted dying.⁵⁹

The Panel acknowledges and agrees with the position of the Joint Select Committee in this regard and notes that this is consistent with most other models of legalised voluntary assisted dying.⁶⁰ This is an important safeguard to ensure that the process remains self-determined (voluntary) throughout.⁶¹ This approach is consistent with the Guiding Principle *'People who may be vulnerable to coercion and abuse in relation to end of life choices and decisions should be protected'* (refer to the section on Guiding Principles).

56 Ministerial Expert Panel on Voluntary Assisted Dying Discussion Paper, Department of Health, Western Australia (2019).

57 Ibid.

58 *'My Life, My Choice'* report of the Joint Select Committee on End of Life Choices, Parliament of Western Australia (August 2018) 7.54.

59 *'My Life, My Choice'* report of the Joint Select Committee on End of Life Choices, Parliament of Western Australia (August 2018).

60 Australia (Victoria); Canada; US States (California, Colorado, District of Columbia, Hawaii, New Jersey, Oregon, Vermont, Washington State) (Refer Appendix 5).

61 Ministerial Expert Panel on Voluntary Assisted Dying Discussion Paper, Department of Health, Western Australia (2019).

The Panel observed that where voluntary assisted dying is practiced, systematic reviews have found that coercion is rare.⁶² Data from The Netherlands and Oregon show that ‘members of vulnerable groups are no more likely to receive assistance in dying ... with the sole exception of people with AIDS’.⁶³ The researchers concluded: ‘the available data ... shows that people who died with a physician’s assistance were more likely to be members of groups enjoying comparative social, economic, educational, professional and other privileges’.⁶⁴ Anecdotal reports suggest that coercion from relatives is more likely to take the form of an attempt to dissuade the person from voluntary assisted dying.⁶⁵

It is imperative that where either the co-ordinating or consulting practitioner believe that the person’s decision may not be voluntary or valid, that they refer to a health practitioner with relevant expertise for further assessment. These situations are expected to be rare.

The Panel notes that the Joint Select Committee Legislation Framework states that ‘if a doctor is unable to determine ... capacity, and/or the absence of coercion ... they must refer to a consultant psychiatrist or a consultant geriatrician as appropriate.’⁶⁶

The Panel has weighed up the points made throughout consultation about access to specialist practitioners, particularly in rural areas, the consequent risk of delaying decision-making and the experience and skills that health practitioners already have in assessing whether a person’s decision is voluntary and valid. The Panel has also noted the approach taken in Victoria where referral in this situation will be based on appropriate skills and training of the practitioner and is not be defined or limited to particular specialty types.⁶⁷

Based on this information, the Panel has formed the view that relevant experience and skills are more pertinent to this situation than specialist qualifications.

Therefore the Panel’s conclusion is that if either of the assessing practitioners is unclear about the voluntariness or validity of a person’s decision, they should refer to the appropriate health practitioner for the circumstances to undertake further assessment. If after further assessment there is still uncertainty about the nature of the person’s decision this should be referred to the State Administrative Tribunal.

The Panel recommends that each assessing practitioner, who must be properly qualified and experienced, undergo additional mandatory training to critically assess whether the decision of the person is voluntary and valid. Practitioners would have a responsibility to explicitly confirm these components of the assessment as well as being subject to formal oversight via the review process.

As detailed in the flowchart on [page 45](#) describing the Panel’s recommended process, the enduring nature of the person’s decision would be shown through several of the proposed process steps: the initial request, participation in the first assessment, participation in the second assessment, a written

62 Penney Lewis and Isra Black, ‘Adherence to the Request Criterion in Jurisdictions where Assisted Dying is Lawful? A review of the Criteria and Evidence in Netherlands, Belgium, Oregon and Switzerland’ (2013) 41(4) *Journal of Law, Medicine and Ethics* 885, 890; A van der Heide et al, ‘Euthanasie en andere medische beslissingen rond het levenseinde: Sterfgevallenonderzoek 2010’ [‘Euthanasia and other medical decisions at the end of life: Death certificate study 2010’] at table 2.6; Regional Euthanasia Review Committees (Netherlands), Annual Report 2017, <https://english.euthanasiecommissie.nl/the-committees/documents/publications/annual-reports/2002/annual-reports/annual-reports> p 47.

63 Battin et al. Legal physician-assisted dying in Oregon and the Netherlands: evidence concerning the impact on patients in ‘vulnerable’ groups (2007)33, *Journal of Medical Ethics* 591-7.

64 Ibid.

65 Ministerial Expert Panel on Voluntary Assisted Dying Consultation meeting with: Dr James Downar (Head, Division of Palliative Care, University of Ottawa) and Tanya Burr (Palliative Clinical Nurse Practitioner Lead, Central East, Local Health Integration Network, Ontario) (May 2019).

66 ‘My Life, My Choice’ report of the Joint Select Committee on End of Life Choices, Parliament of Western Australia (August 2018).

67 *Voluntary Assisted Dying Act 2017* (Victoria).

declaration of request, a third request that triggers the provision of the prescription and a request for administration of the medication (in the case of practitioner administration).

The Panel has also recommended that trained and independent navigators be available to assist a person requesting voluntary assisted dying (refer to the section on [Access](#)). The navigator would also play an important role in supporting confirmation that the person's decision was voluntary and valid.

The Panel acknowledges the position of the Joint Select Committee in relation to the requirement for the person to have decision-making capacity in relation to voluntary assisted dying and makes no further recommendation.

Ministerial Expert Panel recommendation 4:

Where the assessing practitioner is unable to determine that the person's decision is voluntary and valid, they should refer to a health practitioner with relevant expertise for further assessment.

That if, after further assessment, there is still uncertainty about whether the person's decision is voluntary and valid, such cases should be referred to the State Administrative Tribunal.

Policy intent:

To ensure that people are making a voluntary and valid decision to access voluntary assisted dying and that this decision is not subject to coercion.

To ensure that access to voluntary assisted dying is not unreasonably restricted through limiting referrals by specialist type.

A properly informed decision

It is usual practice for health practitioners to have discussions with people about end of life decisions, and this includes appropriately informing people of the relevant options currently available to them. For example, this may include discussions about palliative care, treatment initiation and withdrawal, Advance Health Directives and decision-making about Cardio Pulmonary Resuscitation (CPR). As well as informing the patient's decision, these discussions present another opportunity for the assessing practitioner and person to review the situation and ensure that everything (that is acceptable to the person) that can be done to relieve suffering is being done. These discussions form an important part of good patient care.⁶⁸

There are many factors to consider in relation to how people can be informed about voluntary assisted dying. Information needs to be accessible, understandable, translated and culturally appropriate.⁶⁹

In some communities, particularly more remote communities, an association with voluntary assisted dying may impact the community's trust in the local health practitioner or health service. There may be times where the use of an independent navigator would provide additional safety and space for a person to make a decision that reflects their personal choice (particularly if their viewpoint differs from that of their family or community).⁷⁰

68 Ministerial Expert Panel on Voluntary Assisted Dying Discussion Paper, Department of Health, Western Australia (2019).

69 Ibid.

70 Ibid.

The Joint Select Committee

The Joint Select Committee recommended that the assessing practitioner would be required to provide the person with information about the nature of their disease or illness, the prognosis, any curative or palliative treatments, information specific to voluntary assisted dying medications and also to inform them that they may withdraw their consent at any time.

The Joint Select Committee made recommendations in relation to the establishment of a telephone advice line, community education and resources.⁷¹ These types of initiatives may help to address the impacts outlined above. In Canada, a number of provinces and territories have set up centralised care co-ordination services that have specially trained medical doctors and nurse practitioners to assist the person to make an informed and supported decision as well as providing a navigator that can assist in working through the process.^{72,73} Victoria has also developed a care navigator service as part of implementation preparations.⁷⁴

Consultation Findings

It was evident to the Panel that education, information and informed decision-making are all very important to the Western Australian community. Feedback received has made it clear that all people must be able to access information in a language or manner suitable to them and that this information should be easily accessible.

Access to qualified interpreters was noted as important to support conversations with people who do not speak fluent English.⁷⁵ It was stressed that family members should not be used as interpreters as they may influence the nature of the information conveyed between the person and the health practitioner. It was also noted that assessments with people from culturally and linguistically diverse backgrounds may need longer to enable translation to occur.

Further to this there was context of particular relevance to Aboriginal people:

'There are English language terms which have no meaning for Aboriginal people and discussions around end of life care must take this into account. For example, even the term 'end of life' is not one that Aboriginal people would use or necessarily recognise as applying to them or their circumstances.' (Submission by the Aboriginal Health Council of WA)

The Panel heard overwhelming support for the concept of independent, culturally competent navigators and/or one central service that would specialise in voluntary assisted dying and provide support for the community and for health practitioners, particularly in relation to information, counselling and research.

There was support for the navigator's role being more than just their involvement in the voluntary assisted dying aspect of a person's care journey.

71 'My Life, My Choice' report of the Joint Select Committee on End of Life Choices, Parliament of Western Australia (August 2018) 7.89.

72 <http://www.health.alberta.ca/health-info/medical-assistance-dying.html>

73 Downie, J. 'Medical Assistance in dying: Lessons for Australia from Canada' (2017), *QUT Law Review*, vol. 17, Issue 1, pp. 127-146.

74 'Voluntary assisted dying care navigation service', Department of Health and Human Services, State of Victoria (2019). <https://www2.health.vic.gov.au/hospitals-and-health-services/patient-care/end-of-life-care/voluntary-assisted-dying/implementation-conference>.

75 WA Health System Language Services Policy, Department of Health, Western Australia (2017).

‘... navigators to work with palliative care services so that the journey is more streamlined for patients, i.e. they are part of the whole palliative care journey with the patient rather than a new person who is introduced only when voluntary assisted dying is needed.’

(Submission by the Society of Hospital Pharmacists – WA)

It was stressed that the navigator role would need to be carefully planned and implemented and should include thorough consultation with Aboriginal people, multicultural agencies and faith communities.

The role of health practitioners – including medical practitioners, nurse practitioners, nurses, counsellors and psychologists – in providing information to people to enable them to make informed decisions was a recurring theme throughout the consultation.

There was strong support for the education of all health practitioners to ensure they are able to appropriately provide accurate information to people (refer to the section on [Education and Training](#)).

Discussion

Provision of information should be included in the process for access to voluntary assisted dying, consistent with the recommendation in the Joint Select Committee Legislation Framework. The co-ordinating and consulting practitioners would be required to provide the person with information about the nature of their disease or illness, the prognosis, any curative or palliative treatments, information specific to voluntary assisted dying medications and also to inform them that the person's consent may be withdrawn at any time.

Legislating for the provision of this information is a key safeguard in the voluntary assisted dying process. The Panel recommends that the mandatory education and training of practitioners for voluntary assisted dying should cover information provision to the person, both in terms of content and delivery method. Where an interpreter is required, an additional legislated safeguard should be the requirement for the interpreter to be qualified, accredited, independent and not to stand to benefit from the death of the person. The legislation should also make it an offence to give false or misleading information in relation to all aspects of the voluntary assisted dying legislation and process as well as provide for protection of confidentiality.

The Panel agrees with the position of the Joint Select Committee that the person needs to be properly informed and that this can occur via a range of measures which need to be culturally and linguistically appropriate.

Ministerial Expert Panel recommendation 5:

Provision of information to the person by the co-ordinating and consulting practitioners must include: the nature of their disease or illness, the prognosis, any available curative treatments, any available palliative treatments, information specific to voluntary assisted dying medications and must also inform the person that they may withdraw their consent at any time.

This information must be provided in a language and format that the person understands.

Policy intent:

To ensure that people are provided with information sufficient to make fully informed decisions at end of life.

Raising the subject of voluntary assisted dying

Victoria is the only jurisdiction that prohibits health practitioners from starting a conversation about voluntary assisted dying.⁷⁶

Many health practitioners are reluctant to discuss end-of-life care with people. It is also known that up to 60% of Australians have low levels of individual health literacy.⁷⁷ This means that people may not have the knowledge or confidence to start discussions about specific treatments or options that have not already been raised by their health practitioner.⁷⁸

The Joint Select Committee

The Joint Select Committee specifically recommended that a prohibition on health practitioners starting a discussion about voluntary assisted dying was not adopted in Western Australia.⁷⁹ It follows that it should not be an offence or reportable disciplinary matter for health practitioners to start discussions about voluntary assisted dying with patients. This was consistent with a view that there should not be an attempt to censor the conversations that health practitioners have with patients.⁸⁰

Consultation Findings

The findings of the consultation demonstrate very strong opinion that legislation in Western Australia should not limit, impede or seek to censor the conversations that health practitioners appropriately conduct with patients. People were clear that they expect to be made aware of all the clinically suitable, legally available options to enable them to make fully informed decisions at end of life.

'Yes, (the) doctor should give (the) patient all of the information, like any treatment.'
(Participant at the Metro Central Public Forum)

'If the legislation is passed, voluntary assisted dying will be a legal, medical option, and it should form part of a medical practitioner's general discussion with their patients about end of life care. Without the medical practitioner raising it as an option, they cannot fulfil their obligation to the patient to provide them with all the relevant information, including treatment options, to make an informed decision and to provide valid consent.'
(Submission by Avant Mutual)

The Panel heard mixed views from health practitioners – there was some hesitancy on the basis of not wanting to be (or being seen to be) unduly influencing a patient but also acknowledgement that practitioners have responsibility in supporting informed patient choice.

Discussions that took place in the Kimberley raised issues in relation to self-harm and suicide and noted that even discussing palliative care with patients can be challenging in this context. There may be complexities surrounding concepts such as blame or 'pay back' in Aboriginal communities and potential implications if the family has a negative perception of the practitioner or health service because of involvement in voluntary assisted dying.

76 *Voluntary Assisted Dying Act 2017* (Victoria).

77 *Health Literacy: taking action to improve safety and quality*, Australian Commission on Safety and Quality in Health Care (August 2014).

78 Ministerial Expert Panel on Voluntary Assisted Dying Discussion Paper, Department of Health, Western Australia (2019).

79 *'My Life, My Choice'* report of the Joint Select Committee on End of Life Choices, Parliament of Western Australia (August 2018) 6.78 - 6.79.

80 *Ibid.*

‘High turnover of staff and GPs is a huge issue. For people to establish a relationship with their GP to even have a discussion about voluntary assisted dying is hard’.

(Consultation stakeholder meeting – Kimberley Palliative Care)

The complexity of medical terminology and the balance of power between health practitioner and patient was also identified as potentially challenging and would require thorough consideration during any implementation planning (including being part of practitioner education and training).

‘Clinicians often use complex medical terminology when discussing treatment options with Aboriginal people ... This results in the real risk that Aboriginal people may consent to something they don’t fully understand. There is also the issue of the disparity of power between a doctor and Aboriginal people; Aboriginal people will often agree with a doctor’s advice even if they are not happy with it as they can feel overpowered in the doctor-patient relationship’.

(Submission by the Aboriginal Health Council of Western Australia)

Some submissions noted practical challenges would arise if there was prohibition such as in Victoria.

‘The provision in the Victorian legislation may leave practitioners feeling unclear whether or not they are able to discuss voluntary assisted dying, depending on the precise wording of the question a patient asks’.

(Submission by the Public Health Association of Australia)

Discussion

The Panel carefully weighed the outcomes of the consultation and knowledge of other jurisdictions, with the unique cultural circumstances of Western Australia in its deliberations on this matter.

The Panel believes that health practitioners have a professional obligation to ensure that their patients are fully informed about their choices at end of life, including voluntary assisted dying.

The Panel acknowledges the position of the Joint Select Committee and agrees that health practitioners should not be restricted in their ability to have comprehensive end of life discussions with patients, including that there be no prohibition on health practitioners appropriately raising the subject of voluntary assisted dying.

Ministerial Expert Panel recommendation 6:

Health practitioners are able to appropriately raise the topic of voluntary assisted dying with a patient.

Policy intent:

To ensure that people are able to make fully informed decisions at end of life.

To ensure that access to voluntary assisted dying is not impeded by a health practitioner not discussing what would be a legal option at end of life for some people.

The eligible condition

To access voluntary assisted dying, a person must meet all of the following eligibility criteria:

1. be an adult, aged 18 years or over; and,
2. be an Australian citizen or permanent resident and have been ordinarily resident in Western Australia for 12 months at the time of making the request; and,
3. have decision-making capacity in relation to a decision about voluntary assisted dying; and,
4. **be diagnosed with an eligible condition, where an eligible condition is an illness, disease or medical condition that:**
 - a. **is advanced, progressive and will cause death; and,**
 - b. **is causing suffering to the person that cannot be relieved in a manner the person considers tolerable; and,**
5. death is reasonably foreseeable for the person within a period of 12 months.

The Joint Select Committee

The Joint Select Committee recommended that the person must be diagnosed with an eligible condition; which it defined as an advanced and progressive terminal, chronic or neurodegenerative condition for which death is reasonably foreseeable and is causing grievous and irremediable suffering to the person (that cannot be alleviated in a manner acceptable to the person).⁸¹

Consultation Findings

The question of what should constitute an ‘eligible condition’ was raised at public forums and in submissions to the Panel.

The term ‘chronic disease’ was found to be a source of significant confusion as possibly meaning that a person with a non-fatal chronic disease could access voluntary assisted dying or that it would be difficult to ascertain if or when a chronic disease became likely to cause death.

‘Large numbers of Aboriginal people live with chronic disease and it is conceivable under proposed legislation that they may be eligible for voluntary assisted dying. AHCWA and its member services recommend that careful consideration is given to the inclusion of chronic disease within the eligibility criteria for voluntary assisted dying, and that any legislation provides clear direction for doctors assessing the prognosis and suffering of a person living with chronic disease.’

(Submission by the Aboriginal Health Council of Western Australia)

‘Without a specified timeframe, voluntary assisted dying could be accessible for people living with chronic diseases like diabetes mellitus or renal failure for example, where death is reasonably foreseeable as a long term consequence of living with these conditions. The AMA (WA) strongly believes that this should never be the intention of such any proposed voluntary assisted dying regime.’

(Submission by the Australian Medical Association – WA)

81 ‘My Life, My Choice’ report of the Joint Select Committee on End of Life Choices, Parliament of Western Australia (August 2018) 7.89.

During consultation, the Panel explored the understanding and perspectives of the community in relation to how suffering relates to eligibility for access to voluntary assisted dying.

Many people at public forums expressed difficulty with the meaning of 'grievous' suffering. There were concerns that in order to meet the requirements of 'grievous and irremediable' suffering, people would have to reach and endure a high state of suffering. It was not surprising then that a majority of responses indicated that it should not be required that suffering be 'grievous' for a person to be eligible. There were similar comprehension issues with the term 'irremediable' and the perception that a flawed interpretation of the person's suffering could result.

On whether suffering must be related to the eligible condition, opinion was fairly evenly divided. It was recognised that co-morbidities and psychological, spiritual and existential suffering could co-exist with and contribute to the suffering related to the eligible condition.

'Yes, the suffering must be related, at least in part, to the eligible condition.'
(Submission by Doctors for Assisted Dying Choice)

Most agreed that suffering is subjective and that only the person can decide whether a certain level or type of suffering is intolerable. It was clear from the consultation that what constitutes suffering is a contentious and highly subjective issue that is influenced by a range of factors for each person and that there are multiple forms of suffering (physical, mental, emotional and existential). Some noted that suffering can be seen as redemptive or has other positive value in some cultures and religions.

'The concept of suffering as absolutely 'grievous and irremediable' would not make sense to many Christians. This is not because of the view that miracles from God, meaning restored health, are possible, but simply that for many Christians, suffering itself can be redemptive. This view may be held by the VAD patient, her or his family and faith community members. The tensions between these two, broad views should be clearly articulated and understood by all medical and support staff in the VAD process.'
(Submission by the Anglican Social Responsibilities Commission)

Discussion

Medical and health practitioners commonly use the word 'terminal' to describe a situation when an illness or disease is expected to lead to a foreseeable or imminent death. For some people in the general community the word 'terminal' may be given a specific interpretation, such as a person with cancer who is very close to death. This difference in interpretation of the word 'terminal' led, in part, to the specific inclusion of chronic illness or disease and neurodegenerative diseases in the eligibility criteria proposed by the Joint Select Committee, to help to make it clear that people with these illnesses and diseases may also be eligible for voluntary assisted dying.⁸²

Reflecting on the concerns exposed during the consultation process, the Panel deliberated about whether there should be specific reference to 'chronic illness or disease' and 'neurodegenerative illness or disease' in the eligibility criteria. The Panel looked to examples in other jurisdictions that have legislated for assisted dying and found reference to terminal disease or condition,⁸³ incurable illness or disease,⁸⁴ incurable condition⁸⁵ or medically futile condition⁸⁶ but none that specified particular types of disease (with the exception of the specification of neurodegenerative diseases in the Victorian *Voluntary Assisted*

82 Ministerial Expert Panel on Voluntary Assisted Dying Discussion Paper, Department of Health, Western Australia (2019).

83 US States (California, Colorado, District of Columbia, Hawaii, New Jersey, Oregon, Vermont, Washington State).

84 *Medical Assistance in Dying Act, Bill C-14 2016* (Canada).

85 *Law on the Right to Die with Dignity* (2009) (Luxembourg).

86 *Act on Euthanasia 2002* (Belgium).

*Dying Act 2017*⁸⁷ though that is noted to be a distinction on the basis of outlining the different eligibility timeframe).

The phrase ‘advanced and progressive’ means that the illness or disease is very serious and on a deteriorating trajectory.⁸⁸ This was clearly and consistently understood in the consultations.

The Panel considers that it is not helpful, and indeed may cause undue concern, to refer to specific disease types in the eligibility criteria and therefore recommends that there should not be a reference to a particular type of disease or illness.

Ministerial Expert Panel recommendation 7:

The eligibility criteria for voluntary assisted dying includes reference to an illness, disease or medical condition that is advanced, progressive and will cause death.

Policy Intent:

To clearly emphasise the terminal nature of the illness or disease as part of consideration as an eligible condition.

Suffering is an intensely personal experience and can take a variety of forms (physical, mental, emotional, social, spiritual or existential).

Not all jurisdictions include ‘suffering’ as a component of eligibility – the laws of the US states that have legislated for assisted dying are silent on this, and do not have a requirement that a person be suffering.⁸⁹

In Victoria, the eligibility criteria include that the eligible condition is causing suffering that *cannot be relieved in a manner acceptable to the person*.⁹⁰ This position was also taken by the Joint Select Committee and it further articulated that suffering be subjectively assessed – that is, from the person’s point of view. This is consistent with a person-centred approach to voluntary assisted dying.⁹¹

Jurisdictions that include suffering as a component of eligibility typically require the suffering to be very serious – described as ‘intolerable’ (Canada), ‘constant and unbearable’ (Belgium) or ‘lasting and unbearable’ (the Netherlands).⁹² However, the use of an adjective such as ‘grievous’ (or a more common term such as ‘very severe’) risks imparting a judgement on the suffering of the person and implies that the person needs to prove the severity of their suffering.⁹³

The Joint Select Committee also emphasised that suffering be subjectively assessed – that is, from the person’s point of view ‘only a subjective assessment of the relevant standard of suffering promotes the value of autonomy’.⁹⁴ This is consistent with a person-centred approach to voluntary assisted dying.⁹⁵

87 *Voluntary Assisted Dying Act 2017* (Victoria).

88 Ministerial Expert Panel on Voluntary Assisted Dying Discussion Paper, Department of Health, Western Australia (2019).

89 Appendix 5.

90 *Voluntary Assisted Dying Act 2017* (Victoria).

91 Ministerial Expert Panel on Voluntary Assisted Dying Discussion Paper, Department of Health, Western Australia (2019).

92 Appendix 5.

93 Ministerial Expert Panel on Voluntary Assisted Dying Discussion Paper, Department of Health, Western Australia (2019).

94 Professor Lindy Willmott and Professor Ben White at 7.46 ‘*My Life, My Choice*’ report of the Joint Select Committee on End of Life Choices, Parliament of Western Australia (August 2018).

95 Ministerial Expert Panel on Voluntary Assisted Dying Discussion Paper, Department of Health, Western Australia (2019).

The Panel considered whether the criteria for eligibility were enhanced in clarity or workability by the use of the terms 'grievous' and 'irremediable' as proposed by the Joint Select Committee. It concluded they were not. The Panel also felt that the terms 'grievous' and 'irremediable' could potentially compromise the compassionate intention of the legislation and lead to a possible interpretation that there should be an objective determination of the nature of the suffering.

'We agree that the person's suffering should be subjectively assessed. However, we believe that the phrase used in the Victorian legislation, "cannot be relieved in a manner acceptable to the person", is easier to understand for the person and the medical practitioners involved, compared with "grievous and irremediable".'

(Submission by Avant Mutual)

The Panel considered that it is sufficient that there be suffering related to the eligible condition (from the person's point of view) and that this suffering cannot be relieved in a manner acceptable to the person (hence irremediable). The Panel agreed that the provisions relating to suffering in the Victorian *Voluntary Assisted Dying Act 2017*⁹⁶ should be adopted for use in Western Australia.

Ministerial Expert Panel recommendation 8:

The eligibility criteria for voluntary assisted dying includes that the eligible condition 'is causing suffering to the person that cannot be relieved in a manner the person considers tolerable'.

Policy intent:

To ensure a compassionate person-centred approach to suffering in the eligibility criteria for voluntary assisted dying.

To ensure that it is not necessary for a person to prove the degree of their suffering which is, by definition, subjectively determined.

96 *Voluntary Assisted Dying Act 2017* (Victoria).

Timeframe to death

To access voluntary assisted dying, a person must meet all of the following eligibility criteria:

1. be an adult, aged 18 years or over; and,
2. be an Australian citizen or permanent resident and have been ordinarily resident in Western Australia for 12 months at the time of making the request; and,
3. have decision-making capacity in relation to a decision about voluntary assisted dying; and,
4. be diagnosed with an eligible condition, where an eligible condition is an illness, disease or medical condition that:
 - a. is advanced, progressive and will cause death; and,
 - b. is causing suffering to the person that cannot be relieved in a manner the person considers tolerable; and,
- 5. death is reasonably foreseeable for the person within a period of 12 months.**

Joint Select Committee

The Joint Select Committee recommended that death be reasonably foreseeable as a consequence of the condition (Recommendation 22) and incorporated this into its proposed Legislation Framework. The Joint Select Committee also found that ‘with regard to timeframes, whatever model of voluntary assisted dying is enacted in Western Australia should reflect the best possible clinical practice’ (Finding 45).⁹⁷

Consultation Findings

In considering this element of the eligibility criteria, the Panel noted that the Government has accepted Recommendation 22 of the Joint Select Committee.⁹⁸

The Panel consulted on how the requirement of a reasonably foreseeable death should be incorporated into legislation and whether a timeframe would improve clarity and strengthen safeguards. The Panel also sought emerging evidence from jurisdictions such as Canada about how the criterion of reasonably foreseeable has been implemented and interpreted in practice.

There were mixed views expressed through the consultation about the specification of a timeframe as part of eligibility. Those in support indicated that a timeframe would be useful and would provide guidance.

‘Quantitative criteria: a timeframe of twelve months.... If any mandatory timeframe were to be legislated, this one would be the most acceptable.’
(Submission by Doctors for Assisted Dying Choice).

Those not in support indicated that this should be the person’s decision, that this should be flexible and should reflect the person’s pain and suffering. Respondents noted that practitioners may have difficulty in assessing how long someone has to live and expressed concerns that a timeframe might impact negatively on a person’s autonomy or prolong unnecessary suffering and distress.

97 ‘My Life, My Choice’ report of the Joint Select Committee on End of Life Choices, Parliament of Western Australia (August 2018).

98 Western Australian Government response to the Joint Select Committee on End of Life Choices report, State of Western Australia (2018).

A majority of respondents indicated that they did not want a timeframe specified as part of eligibility criteria – many indicated that eligibility should be based on death being a reasonably foreseeable outcome for this person or a reasonably foreseeable outcome of the eligible condition.

‘Concept of reasonableness is something we work with all the time and has legal precedent.’
(Consultation stakeholder roundtable – Medical Practitioners)

‘Reasonably foreseeable for the person fits with the person-centred approach.’
(Consultation stakeholder roundtable – People with a disability)

‘On the assumption that terminally ill people have no desire to die, but when death is the inevitable outcome of their disease they want to die without pain and distress, there is no need to specify a timeframe... Best practice would be that, if the person has an eligible condition and is experiencing intolerable pain and distress, then their perspective on the right time to make a request should be respected’.
(Submission by Dying with Dignity – NSW)

Conversely, the Australian Medical Association (AMA) strongly advocated a timeframe, they believe that as a minimum safeguard:

‘Death must be imminent within 6 months, as the outcome of the medical condition. Further, all measures must have been exhausted to remediate the person’s suffering’.

Discussion

As already determined by the Government, the Panel worked from the basis that death is reasonably foreseeable as a consequence of the condition. The Panel considered this criterion in relation to how it applies to the person, consistent with the Panel’s Guiding Principles⁹⁹ and the Joint Select Committee’s Finding 45 ‘that with regard to timeframes, whatever model of assisted dying is enacted in Western Australia should reflect the best possible clinical practice’.¹⁰⁰

In line with Finding 45 the Panel consulted on and considered what, if any, role there was for a timeframe forming part of the eligibility criteria. The Panel took the view that specifying a timeframe may build a further safeguard into the eligibility criteria. It would also be a way to help ensure consistency of approach in implementation and provide guidance to assessing practitioners.

During its deliberations the Panel considered the experience of Canada in the implementation of medical assistance in dying (MAiD) and the interpretation of criterion 2(d) in that legislation: *‘natural death has become reasonably foreseeable, taking into account all of their medical circumstances, without a prognosis necessarily having been made as to the specific length of time that they have remaining’*.¹⁰¹ In relation to this requirement, the Canadian Association of MAiD Assessors and Providers (CAMAP) has noted that this criterion has caused ‘considerable difficulty to clinicians, particularly those carrying out assessments of eligibility for medical assistance in dying’.¹⁰² This was consistent with information the Panel received from discussions with relevant experts from Canada during the consultations.¹⁰³

99 Ministerial Expert Panel on Voluntary Assisted Dying Discussion Paper, Department of Health, Western Australia (2019).

100 *‘My Life, My Choice’* report of the Joint Select Committee on End of Life Choices, Parliament of Western Australia (August 2018).

101 *Medical Assistance in Dying Act, Bill C-14 2016* (Canada).

102 The clinical interpretation of ‘reasonably foreseeable’ Clinical Practice Guideline, Canadian Association of MAiD Assessors and Providers (June 2017) <https://camapcanada.ca/wp-content/uploads/2019/01/cpg1-1.pdf>.

103 Ministerial Expert Panel on Voluntary Assisted Dying Consultation meetings with: Drs Buckman and Blackmer (Canadian Medical Association) (April 2019); and, Dr James Downar (Head, Division of Palliative Care, University of Ottawa) and Tanya Burr (Palliative Clinical Nurse Practitioner Lead, Central East, Local Health Integration Network, Ontario) (May 2019).

The Panel noted that there have been legal challenges in Canada regarding the validity of the eligibility criteria,¹⁰⁴ including unresolved legal action awaiting judgement.¹⁰⁵

The Panel took the view that all eligible conditions must be clinically assessed in relation to their impact on the person. For example, death within a certain timeframe may be a reasonably foreseeable outcome of a condition for someone aged in their 90s but the prognosis may be very different for someone aged in their 40s.¹⁰⁶

Given the potential challenges in making consistent, reliable and unambiguous clinical assessments that death is reasonably foreseeable, the Panel considered the possible advantages of adding a timeframe.

It considered that a timeframe would be an important safeguard to ensure that eligibility for voluntary assisted dying remain restricted to those whose death is already imminent; that is, to maintain the distinction between this being a choice about the manner and timing of a person's death rather than a choice between life and death. This was particularly noted at the roundtable meeting held during the consultation regarding people with a disability.

The Panel reviewed best possible clinical practice in relation to timeframes and determined that there was evidence to support the prognostication of 12 months life expectancy.¹⁰⁷

This was based on the use of the Surprise Question ('Would I be surprised if this patient died in the next 12 months?') when combined with tools like the Supportive and Palliative Care Indicators Tool (SPICT).¹⁰⁸ New evidence released in 2019 reports that while not providing certainty, applying the Surprise Question and SPICT together in clinical practice can provide an accurate, yet conservative predictor of the risk of death within 12 months.¹⁰⁹ Other research shows that clinicians tend to overestimate survival times.¹¹⁰

A 12-month timeframe to expected death is referenced extensively in palliative care in Australia, often supported by the Surprise Question. It is consistent with existing end of life and palliative care policy documents such as the *National Consensus Statement: Essential elements for safe high quality end of life care*¹¹¹ and the *WA End-of-Life and Palliative Care Strategy 2018-2028*.¹¹²

With regard to the Joint Select Committee concern that specifying an expected time until death may unfairly exclude those people who would otherwise qualify for voluntary assisted dying,¹¹³ the Panel considered evidence that the majority of people who have accessed voluntary assisted dying in other

104 AB v Canada (Attorney General) 2017 ONSC 375; Lamb v Canada (Attorney General) 2017 BCSC 1802.

105 Jean Truchon and Nicole Gladu v Attorney General (Canada) and Attorney General (Quebec).

106 The clinical interpretation of 'reasonably foreseeable' Clinical Practice Guideline, Canadian Association of MAID Assessors and Providers (June 2017). <https://camapcanada.ca/wp-content/uploads/2019/01/cpg1-1.pdf>.

107 Kei Ouchi et al, 'The 'Surprise Question' Asked of Emergency Physicians May Predict 12 Month Mortality among Older Emergency Department Patients' (2018) 21(2) Journal of Palliative Medicine 236, 238; Jennings et al, 'The utility and value of the 'surprise question' for patients with serious illness' (2017) 189(33) CMAJ E1072.

108 While no screening tool will be able to provide absolute certainty that a person will die in a specified time, the Surprise Question and SPICT in combination have been shown to be useful clinical tools with acceptable accuracy across a range of settings and different medical conditions. Supportive and Palliative Care Indicators Tool – SPICT™ University of Edinburgh. <http://www.spict.org.uk>.

109 Woolfield et al, 'Predicting those who are at risk of dying within six to twelve months in primary care: A retrospective case-control General Practice chart analysis' (2019) Palliative Medicine.

110 Christakis NA, Lamont EB. 'Extent and determinants of error in doctors' prognoses in terminally ill patients: prospective cohort study' (2000) BMJ.320(7233):469-72.

111 National Consensus Statement: essential elements for safe and high quality end-of-life care, Australian Commission on Safety and Quality in Health Care, Sydney (2015).

112 WA End-of-Life and Palliative Care Strategy 2018-2028, Department of Health, Western Australia (2018).

113 'My Life, My Choice' report of the Joint Select Committee on End of Life Choices, Parliament of Western Australia (August 2018) 7.43.

jurisdictions could be reasonably expected to have a prognosis of 12 months or less.¹¹⁴ The requirement for this timeframe to include being reasonably foreseeable rather than a definitive prognosis also reduces the risk of unfairly excluding people who would otherwise qualify.

The Panel re-visited the consultation findings and the concern expressed by a number of respondents that a (prognostic) timeframe may hinder (appropriate) access to voluntary assisted dying, may negatively impact on a person's autonomy and may prolong unnecessary distress and suffering (for example until the person 'qualified' as meeting a prognostic timeframe). For this reason the Panel has further clarified that any such timeframe should be considered in the context of death being reasonably foreseeable for this person with these conditions rather than an absolute or certain prognosis.

The Panel has concluded that if there is a timeframe then there should only be one (that is, not 6 months for some conditions and 12 months for other conditions). The Panel's view was that it is difficult and potentially discriminatory to weight the suffering of one terminal diagnosis above other terminal diagnoses, especially since a person may be suffering from more than one terminal illness.

The Panel noted that the Victorian Ministerial Advisory Panel also found 'merit in the incorporation of a 12-month timeframe into the legislation'.¹¹⁵ It also noted that there is no clinical evidence to justify a shorter timeframe such as the six month timeframe in the US states (that have such legislation), and in Victoria. The use of a six month eligibility in jurisdictions such as Oregon is founded on the person's administrative eligibility for hospice care funding¹¹⁶ (NB: the term 'hospice care' in Oregon does not refer to a hospice as we know it here in Australia as a 'building' or 'place' but rather the funding for palliative care services to the person assessed as having less than six months to live).¹¹⁷ A time-based restriction on access to palliative care does not exist in Western Australia.

In Oregon where a six month timeframe is used, Dr David Grube reported around 50% of people who requested voluntary assisted dying and began the assessment process, died of their disease prior to the completion of the process.¹¹⁸ Interestingly, in The Netherlands, where there is no stipulated timeframe, 72% of voluntary assisted deaths are estimated to occur within a month of the expected natural death (36% ≤ 1 week, 36% 2-4 weeks, 19% 1-6 months, and 8% ≥ 6 months).¹¹⁹ This data indicates a 12-month timeframe would not be overly restrictive or exclude the types of people intended by the Joint Select Committee to be eligible for voluntary assisted dying.

The Panel closely considered the Joint Select Committee Legislation Framework (and Finding 45), experience in other jurisdictions, clinical evidence in prognosis or reasonable foreseeability of death and views expressed in consultations in concluding that there should be a timeframe of 12 months incorporated into the eligibility criteria.

114 Battin et al, 'Legal physician-assisted dying in Oregon and the Netherlands: evidence concerning the impact on patients in 'vulnerable' groups' (2007) *Journal of Medical Ethics* 33 pp. 591, 594.

115 Final Report of the Ministerial Advisory Panel on Voluntary Assisted Dying, State of Victoria, Department of Health and Human Services (2017).

116 Ibid.

117 Ministerial Expert Panel on Voluntary Assisted Dying Consultation meeting with: Dr David Grube (Medical Director Compassion and Choices; experienced assisted dying practitioner in Oregon, USA) (June 2019); 'What are palliative care and hospice care?', US Department of Health and Human Services. <https://www.nia.nih.gov/health/what-are-palliative-care-and-hospice-care#palliative-vs-hospice>

118 Ministerial Expert Panel on Voluntary Assisted Dying Consultation meeting with : Dr David Grube (Medical Director Compassion and Choices; experienced assisted dying practitioner in Oregon, USA) (June 2019).

119 Onwutea-Pilipsen BD et al. 'The third evaluation of the Termination of Life on Request and Assisted Suicide Act' ZonMw, the Hague, (2017).

A determination that ‘death is reasonably foreseeable for this person within a period of 12 months’, would be based on the best available clinical evidence being considered by the co-ordinating and consulting practitioners and their assessment being made in good faith. If a person assessed as eligible for voluntary assisted dying were to survive beyond 12 months that would not mean that the assessment made by the practitioner was not a genuine assessment made in good faith.¹²⁰

Ministerial Expert Panel recommendation 9:

The eligibility criteria for voluntary assisted dying specify that death is reasonably foreseeable for the person within a period of 12 months.

Policy intent:

To provide clarity for both the person and assessing practitioners regarding the eligibility for voluntary assisted dying.

Other considerations associated with eligibility

The Panel acknowledges and agrees with the position of the Joint Select Committee that:¹²¹

- A person with a mental illness who meets the eligibility criteria shall not be denied access to voluntary assisted dying;
- A person with a disability who meets the eligibility criteria shall not be denied access to voluntary assisted dying.

The Panel also acknowledges and agrees with the position that:

- Having a disability or mental health condition in itself would not be considered to meet the eligibility requirements.

Ministerial Expert Panel recommendation 10:

A person with a mental illness or disability who meets the eligibility criteria shall not be denied access to voluntary assisted dying.

Having a mental illness or disability, in itself, would not be considered to meet the eligibility requirements for voluntary assisted dying.

Policy intent:

To ensure that a person with a mental illness or disability is not discriminated against in seeking access to voluntary assisted dying but to also ensure clarity that a mental illness or disability on its own would not meet the eligibility criteria for voluntary assisted dying.

120 Final Report of the Ministerial Advisory Panel on Voluntary Assisted Dying, State of Victoria, Department of Health and Human Services (2017).

121 ‘My Life, My Choice’ report of the Joint Select Committee on End of Life Choices, Parliament of Western Australia (August 2018) 7.89.

Part B: Process



Process Overview

The Joint Select Committee on End of Life Choices outlined the following in relation to the process for voluntary assisted dying:

Joint Select Committee recommendation:

7.89 Voluntary Assisted Dying Legislation Framework

Assisted Dying

The legislation should provide for self-administration of lethal medication where an eligible person is physically able to self-administer. In cases where the person is eligible but physically incapable of self-administration, the legislation should permit a doctor to administer the lethal medication.

Assessment

Two doctors must assess the person. Either or both doctors can be a general practitioner and neither doctor is required to be a specialist regarding the person's disease or illness. Each doctor must be independently satisfied that:

- a. the person is aged 18 or over;
- b. the person is ordinarily resident in Western Australia;
- c. the request is voluntary, made without coercion or duress;
- d. the person has decision-making capacity in relation to a decision about voluntary assisted dying;
- e. the person has an advanced and progressive: terminal, chronic or neurodegenerative illness or disease;
- f. the person has grievous and irremediable suffering due to the disease or illness that cannot be alleviated in a manner acceptable to the person; and
- g. death is a reasonably foreseeable outcome of the condition.

Referral for specialist assessment

A person is not required to undergo consultant or specialist assessment except where either doctor is unable to determine:

- a. the precise nature of the disease or illness, in which case they must refer to a specialist in the relevant area of medicine.
- b. whether the disease is advanced and progressive, in which case they must refer to a specialist in the relevant area of medicine.
- c. whether death is reasonably foreseeable.
- d. capacity, and/or the absence of coercion, in which case they must refer to a consultant psychiatrist or consultant geriatrician as appropriate.

Procedure

A person must make an initial verbal request to a doctor to access assisted dying. A doctor must include a record that a verbal request has been made in the medical record. Following this request, providing that the doctor does not personally object to voluntary assisted dying, they must provide the person with information regarding:

- a. the nature of the disease or illness;
- b. the prognosis;
- c. any possible curative treatments;
- d. any available palliative treatments;
- e. the nature, effects and risks of the lethal medication that may be prescribed; and
- f. that the person's consent to assisted dying may be withdrawn at any time.

The person must provide the initial assessing doctor with a signed written request using a standard template. The written request must be filed with the oversight body.

The doctor should then carry out the assessment as described above. If satisfied that the person meets the assessment criteria, the doctor should complete a standard template referral to a second assessing doctor.

The second assessing doctor must then also carry out the assessment as described above. The second assessing doctor must then provide the initial doctor with written advice regarding the outcome of the assessment. The written advice must be filed with the oversight body.

The initial assessing doctor must inform the person of the results of the assessment. If both doctors concur that the person meets the assessment criteria, and the person makes a further verbal request to access assisted dying, the initial assessing doctor may provide the prescription for the lethal medication to the person and must provide instructions on the manner of use.

Timelines for each step in the process should be advised by the expert panel to ensure integrity in the process without unnecessary delay.

Reflection period

In order to provide a period of reflection a prescription for medication must not be filled sooner than prescribed under the legislation as determined by the expert panel.

Personal objection

At the time the patient makes the first verbal request, any doctor with a personal objection to providing assisted dying must inform the patient of the objection and offer to refer the patient to a doctor who is willing to provide assistance.

Where a person is an inpatient in a health service unwilling to provide assisted dying, that service must facilitate timely transfer to another service.

Non-discrimination

Mental Illness

A person with a mental illness who meets the eligibility criteria shall not be denied access to voluntary assisted dying.

Disability

A person with a disability who meets the eligibility criteria shall not be denied access to voluntary assisted dying.

Medication

The choice of lethal medication for voluntary assisted dying should remain a clinical decision based on the prescribed list of medications for this purpose. The WA Government should review current federal laws in relation to scheduling of medication in Australia, and negotiate with the Federal Government and the Therapeutic Goods Administration for the use of the best medication(s) for assisted dying.

Pharmacists dispensing lethal medication(s) must report the dispensing of the medication to the oversight body.

The process for accessing voluntary assisted dying in Western Australia should protect the person's fundamental right to make a voluntary and informed decision while also providing timely access across the state, building in essential safeguards and taking into account community and cultural beliefs and practices.¹²²

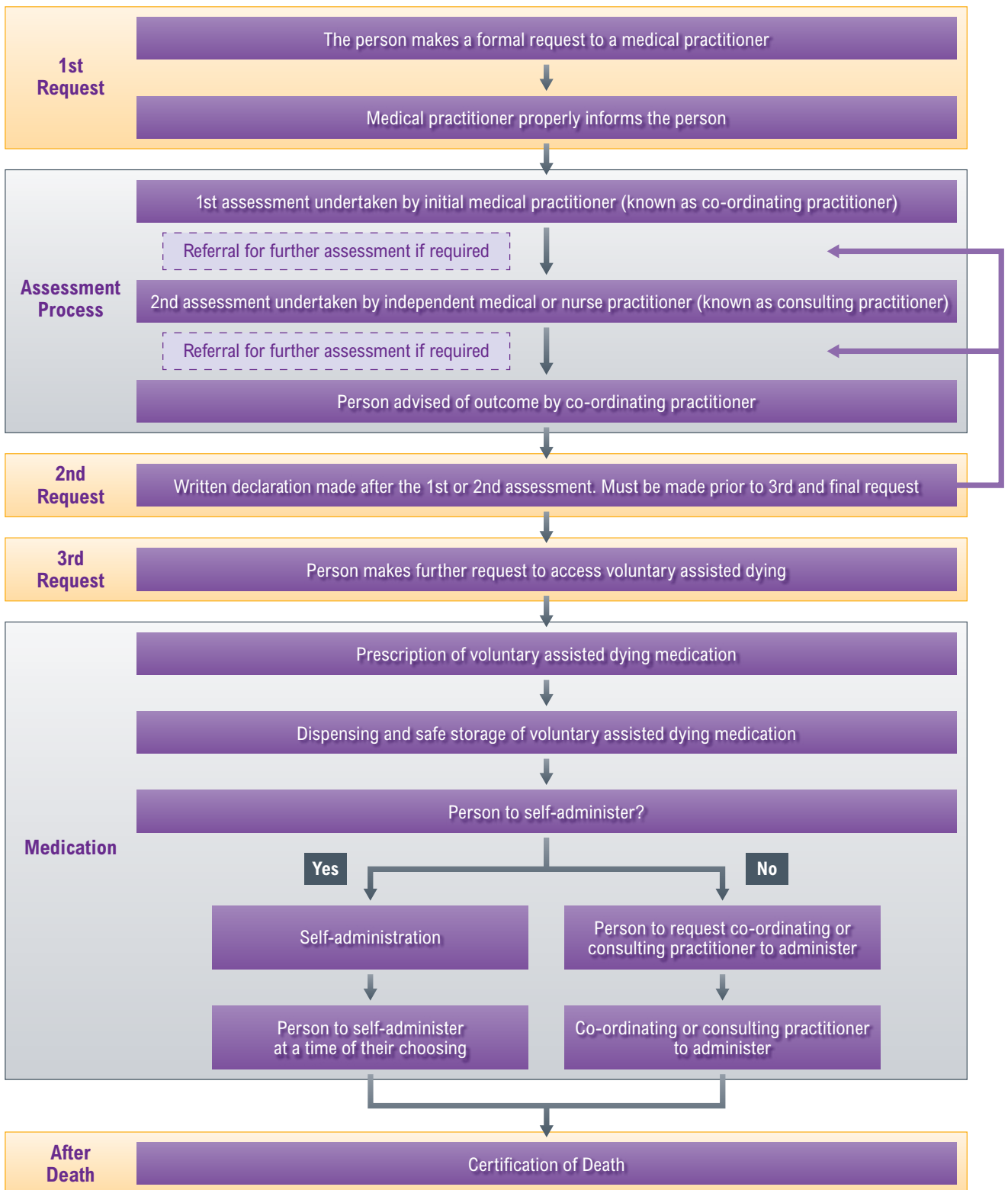
The process for voluntary assisted dying would need to ensure that linguistic and culturally specific considerations are appropriately integrated. It is recognised that there may be unintended impacts for individuals or communities through being involved in, or associated with, voluntary assisted dying.¹²³

For an overview of the recommended key steps in the process refer to the flow chart on the next page.

122 Ministerial Expert Panel on Voluntary Assisted Dying Discussion Paper, Department of Health, Western Australia (2019).

123 Ibid.

Process for voluntary assisted dying as recommended by the Ministerial Expert Panel



Access

As noted in the Panel's Discussion Paper, the formal request to access voluntary assisted dying must be made by the person seeking it. Ensuring people can source the information they need and then access a medical or nurse practitioner is essential. It will be necessary to work with Aboriginal communities and health services, the many culturally and linguistically diverse communities represented in Western Australia, and those who have alternative communication needs, to raise awareness and design safe, appropriate ways for individuals to access voluntary assisted dying.¹²⁴

The Joint Select Committee made a number of recommendations such as development of a telephone access line, community education and resources that would help to facilitate access and these were further consulted on and considered by the Panel.¹²⁵

Where required, the use of qualified interpreters or other communication methods that meet the needs of the person being assessed are essential to achieving equity of access. The person has the right to be supported during the assessment process and may choose to have a support person or an independent navigator present. Any other person who is present cannot make a voluntary assisted dying decision on the person's behalf.¹²⁶

Some individuals may wish to maintain confidentiality through all stages of the process. This is acknowledged, though also recognised to be challenging in some communities or individual situations. It may directly or indirectly impact a person's access to voluntary assisted dying.¹²⁷

The process must not disadvantage people living in rural and remote parts of Western Australia. The use of telehealth (a videoconferencing facility which is already integrated into many health services), as well as secure electronic information exchange, would assist to enable reliable and secure access for people across the state.¹²⁸

Consultation Findings

As part of public consultation on this topic, the Panel asked the question '*What other ways are there to appropriately enable access to voluntary assisted dying?*'.

The key themes identified in the responses related to this question were:

- education and community awareness processes; and
- ensuring health professionals are knowledgeable and can support people.

The importance of information that is user-friendly and easy to engage with was mentioned throughout the consultation. Several techniques were recommended; for example writing in plain language, using visual aids in written documents and ensuring information is available in multiple formats. The translation of information into a range of languages and the importance of using qualified interpreters were raised repeatedly in relation to meeting the needs of culturally and linguistically diverse communities and Aboriginal people (refer also to the section Making an informed decision).

124 Ibid.

125 '*My Life, My Choice*' report of the Joint Select Committee on End of Life Choices, Parliament of Western Australia (August 2018).

126 Ministerial Expert Panel on Voluntary Assisted Dying Discussion Paper, Department of Health, Western Australia (2019).

127 Ibid.

128 Ibid.

'Develop a telephone access line, community education and resources that would help to facilitate access to assisted dying.' (Submission by Dementia Australia)

In the public forums and submissions, the Panel frequently heard concerns surrounding access to medical practitioners for those who reside in regional, rural or remote areas, or for those with specific cultural and linguistic needs and practices.

Consultation with Aboriginal groups suggested that Aboriginal people who may seek voluntary assisted dying may want to return to Country before their death through voluntary assisted dying which may increase the rate of requests to Aboriginal Medical Services to take part in voluntary assisted dying.

'If Voluntary Assisted Dying is an option for an Aboriginal person, priority needs to be given to a patient journey which enables their preference for dying on country or in a health facility of their choice. For example, Aboriginal people who live in rural, regional or remote locations must not be compelled to travel to Perth.'

(Submission by the Aboriginal Health Council of Western Australia)

A number of respondents provided views on approaches or service models that might assist in supporting people who were considering voluntary assisted dying.

Palliative Care WA supported the concept of a highly accessible process for people to access information such as an 1800 number, navigator service and central register of providers.¹²⁹ Both Palliative Care WA and Catholic Homes noted that a navigator service should be available for all people at the end of life.¹³⁰

'Many Government processes are often difficult to navigate and it is likely that someone at the end of their life will experience a degree of confusion and frustration attempting to navigate the proposed process to access VAD or accessing suitable palliative care services. An independent navigator who can provide direction across all options for palliative care or VAD would be an invaluable asset, especially in remote and rural communities where genuine choice may be restricted.'

(Submission by Catholic Homes)

In its submission, the Aboriginal Health Council of WA (AHCWA) specifically supported the concept of a team of navigators to assist people in their end of life decision-making. AHCWA recommended that appropriate training and ongoing support be provided and that any navigator program should be planned, designed and implemented in a culturally appropriate manner.¹³¹

Several suggestions were made during the consultation that a government operated centrally located service that included a facility for the delivery of voluntary assisted dying, as well as an outreach service for patients in rural and regional areas, should be considered. The Panel considers that this is primarily a matter for implementation but notes the appropriateness of hub and spoke type service models across Western Australia.

There were suggestions that telehealth should have a role to play in addressing these access issues. Submissions and respondents stated that telehealth was an important element in enabling access statewide, particularly in rural areas and in towns where there was only one general practitioner (GP) or no medical service at all.

Others expressed concern that telehealth would not be appropriate.

129 Submission: Palliative Care WA to the Ministerial Expert Panel on Voluntary Assisted Dying (2019).

130 Submission: Palliative Care WA to the Ministerial Expert Panel on Voluntary Assisted Dying (2019); Submission: Catholic Homes to Ministerial Expert Panel on Voluntary Assisted Dying (2019).

131 Submission: Aboriginal Health Council of WA to the Ministerial Expert Panel on Voluntary Assisted Dying (2019).

'Assessments must be conducted face to face and the use of telehealth must not be permitted in the assessments of patient to provide voluntary assisted dying.'
(Submission by the Australian Medical Association – WA)

AHCWA also strongly recommended that all potential participants be provided with face-to-face advice to reduce the risk of misinformation, poor understanding and the potential for community backlash.¹³²

Discussion

In considering the needs of people who may seek access to voluntary assisted dying, the Panel agreed with the Joint Select Committee positions and many of the suggestions that were put forward during consultation.

The Panel particularly paid attention to the needs of culturally and linguistically diverse people, Aboriginal people and members of vulnerable population groups, as well as those living in rural and remote areas. The relevance and practical benefit of a navigator or navigation service that would provide people with reliable and accurate information on voluntary assisted dying in Western Australia was seen by the Panel as a very important suggestion for any implementation.

The Panel took account of the proposed service model in Victoria which includes the option of a voluntary assisted dying care navigator.¹³³ These navigators can provide support to people who want to access voluntary assisted dying and support and follow-up for their families, carers and friends. They can also support medical and health practitioners who are informing or supporting someone who has requested access to voluntary assisted dying. In addition to this they can provide information about access to voluntary assisted dying to those who request this.¹³⁴ Four positions of this type will be funded in Victoria.¹³⁵

Ministerial Expert Panel recommendation 11:

The Government should play a central role in providing information to the general public and health professionals about how to access voluntary assisted dying.

This information must be translated, culturally appropriate and accessible via multiple formats.¹³⁶

Policy intent:

To ensure that people who may seek to request voluntary assisted dying are provided with timely and appropriate information in a manner they understand that enables them to raise this question with their health professional.

132 Ibid.

133 Voluntary assisted dying model of care pathways, Department of Health and Human Services, Victoria (2019).

134 Ibid.

135 Victorian State Government, Voluntary assisted dying, www2.health.vic.gov.au/hospitals-and-health-services/patient-care/end-of-life-care/voluntary-assisted-dying.

136 WA Health System Language Services Policy, Department of Health, Western Australia (2017).

Ministerial Expert Panel recommendation 12:

The Government should develop a system of care navigators as part of any implementation of voluntary assisted dying in Western Australia.

Policy intent:

To ensure that people requesting voluntary assisted dying and their families, carers and health practitioners are provided with information, support and advice throughout the process.

In considering access to voluntary assisted dying, the Panel's deliberations particularly focused on the characteristics and needs of Western Australia; noting they are significantly different from Victoria.

The Panel took the view that designing an access process that would work safely in rural areas would also ensure appropriate and safe access in metropolitan areas.

Telehealth was noted throughout consultation as an important option for implementation. How telehealth is used in voluntary assisted dying will need to be clinically considered on a case by case basis i.e. 'for **this** person with **this** condition at **this** time and in **this** place'. The Panel noted that access opportunities provided by telehealth will need to be balanced with the need for an accurate and thorough assessment of the person against the eligibility criteria.

That telehealth has its place is indicated by the Royal Australian and New Zealand College of Psychiatrists who, in their submission to the Joint Select Committee advised that training resources be developed to include 'guidance on the appropriate use of telehealth, noting its potential to increase access but also to compromise the integrity of assessments'.¹³⁷

The Panel noted that access to telehealth is a question primarily for implementation but that there should be no impediment to this in the legislation.

¹³⁷ Submission by the Royal Australian and New Zealand College of Psychiatrists (WA Branch) to Joint Select Committee on End of Life Choices (2017).

Personal objection

The Joint Select Committee on End of Life Choices outlined the following in relation to personal objection to participation in voluntary assisted dying:

Joint Select Committee recommendations:

Recommendation 20

The Minister for Health should ensure that health professionals are not compelled to participate if any voluntary assisted dying framework is developed for Western Australia.

7.89 Voluntary Assisted Dying Legislation Framework

Personal objection

At the time the patient makes the first verbal request, any doctor with a personal objection to providing assisted dying must inform the patient of the objection and offer to refer the patient to a doctor who is willing to provide assistance.

Where a person is an inpatient in a health service unwilling to provide assisted dying, that service must facilitate timely transfer to another service.

The Joint Select Committee recommended that health practitioners have the right to not be compelled to participate in voluntary assisted dying.¹³⁸ This personal objection may be for many reasons but is often referred to as having a ‘conscientious objection’. This is a provision in all jurisdictions that have legislated for voluntary assisted dying (refer Appendix 5). The Panel noted that the Government has accepted Recommendation 20 of the Joint Select Committee outlined above and so personal objection itself was not a topic of consultation.¹³⁹

The Joint Select Committee further specified that if a doctor has a personal objection then they have a responsibility to offer to refer the person to another doctor for assistance (or facilitate transfer if the person is an inpatient of a health service unwilling to provide voluntary assisted dying). Victoria has not included this requirement in its voluntary assisted dying legislation.¹⁴⁰ Jurisdictions in the United States remain silent on the issue but require transfer of relevant medical records to the new provider if the patient transfers care.¹⁴¹

In Canada, there is no legislative obligation to refer¹⁴² (although the College of Physicians and Surgeons of Nova Scotia emphasises the responsibility of physicians to complete an ‘effective transfer of care’).¹⁴³

138 Ministerial Expert Panel on Voluntary Assisted Dying Discussion Paper, Department of Health, Western Australia (2019).

139 Western Australian Government response to the Joint Select Committee on End of Life Choices report, State of Western Australia (2018).

140 *Voluntary Assisted Dying Act 2017* (Victoria).

141 *Death with Dignity Act* (Oregon); *Death with Dignity Act* (District of Columbia).

142 *Medical Assistance in Dying, Bill C-14 2016* (Canada).

143 Professional Standard Regarding Medical Assistance in Dying, College of Physicians and Surgeons of Nova Scotia (December 2018).

The Panel noted the different positions taken by the Joint Select Committee, the Victorian Government and international jurisdictions and posed questions for consideration, particularly in relation to conscientious objection, in order to clarify its position on this topic.

However, in line with the person-centred nature of the Guiding Principles, the Panel also considered the timeframe in which a medical or nurse practitioner must accept or reject a request for voluntary assisted dying.

Consultation Findings

The consultation outcomes clearly demonstrated the expectation of the community that a practitioner with a conscientious objection should have an obligation to refer the patient to a practitioner or service that has no objection. Most responses to this question also indicated that information about services or practitioners who are willing to support voluntary assisted dying should be publicly available.

'Yes the doctor should be obliged to refer on.'

'The referral should be done with grace and compassion.'

(Participants at the Metro North Public Forum)

A small proportion of responses indicated that there should not be an obligation to refer on. This related to the rights of health practitioners and some identified that this would be ethically considered the same as actually participating in voluntary assisted dying.

'We note that many practitioners who have a conscientious objection to voluntary assisted dying will also find the process of referral to another practitioner or service very difficult, as by doing so they may feel complicit in the process that they object to.'

(Submission by the Australian & New Zealand Society of Palliative Medicine)

Issues of protection, privacy and confidentiality of a conscientious objector were also raised.

'It is imperative that any person or group exercising conscientious objection be afforded protection from discrimination or unfair treatment as a consequence.'

(Submission by St John of God Health Care)

Some submissions emphasised that while practitioners should not be forced to undertake actions that are not consistent with their beliefs, they still bear some responsibility to the person.

'Although physicians should not be forced to act outside their values and beliefs, they also should not disengage from patients holding different values and beliefs without ensuring that arrangements for ongoing care are in place.'

(Submission by the Royal Australasian College of Physicians)

There were also suggestions for ways that health practitioners could link people with referral pathways or a central information source (such as the Department of Health) that did not involve providing a direct referral. A number of respondents suggested that a central information source (such as a register of practitioners) could assist access but that any such register would need to be carefully managed to ensure protection for all involved.

Discussion

In considering its position on whether practitioners with a personal objection or services unwilling to provide voluntary assisted dying should be required to refer the person to another practitioner or health service, the Panel considered the very strong opposing views received in consultation.

Noting the deeply held ethical, moral and professional objections to voluntary assisted dying in parts of the community and amongst some practitioners, the Panel was not comfortable in requiring practitioners or services with a conscientious objection to refer on. The Panel particularly noted that a number of palliative care clinicians and services have publicly stated their objection to voluntary assisted dying. Being mindful that many requests for voluntary assisted dying are likely to come from people who are currently being cared for by a palliative care service, the Panel was keen to ensure that legislation did not place these clinicians and services in a difficult position by requiring them to refer the person on.

In its deliberations the Panel sought to balance protection for practitioners who have a personal objection with the need to facilitate timely and appropriate access for people who request voluntary assisted dying. In this regard the Panel referenced the Medical Board of Australia's *'Good medical practice: code of conduct for doctors in Australia'*.¹⁴⁴

- 2.4.6 Being aware of your right to not provide or directly participate in treatments to which you conscientiously object, informing your patients and, if relevant, colleagues, of your objection, and not using your objection to impede access to treatments that are legal.
- 2.4.7 Not allowing your moral or religious views to deny patients access to medical care, recognising that you are free to decline to personally provide or participate in that care.

In considering the feedback provided through consultation and in reaching its position on this topic the Panel was guided by the core principle that the person should be fully informed about voluntary assisted dying and all other options before formally requesting voluntary assisted dying.

If legislation is passed to enable voluntary assisted dying in Western Australia the panel noted the relevance of the principle that a person should not be impeded in accessing what would be a legal option at end of life. In the Panel's view however, it is not sufficient to simply not impede access. Given known issues with health literacy and challenges faced by some population groups, the Panel was clear that people should be provided with effective access to information. People from culturally and linguistically diverse backgrounds and others (for example those with low literacy levels or limited health literacy) may require additional help to access information in a manner they understand so that they can make informed choices.

In seeking to achieve a balance between these needs, the Panel determined that the most appropriate option was to recommend that practitioners and services that have a conscientious objection have an obligation to provide information to people seeking voluntary assisted dying but are not obliged to refer on. This would appear to be an acceptable 'middle ground'.

'Bethesda is of the view that an individual healthcare provider or organisation should not be obliged to refer a patient that wants to access voluntary assisted dying on to some other person or service that is prepared to help them.'

Note, however, that as part of our commitment to compassionate, patient-centred care, Bethesda (at this stage) would be prepared to provide the contact details for an appropriate co-ordination and navigation agency to patients if they request either information about voluntary assisted dying, or to access the process.'

(Submission by Bethesda Health Care).

144 Good medical practice: a code of conduct for doctors in Australia, Medical Board of Australia (2014).

The Panel is mindful that this is contrary to the Joint Select Committee recommendation that practitioners should be obliged to offer to make a referral.

As with any new legislation the Panel noted that particularly in the early stages of implementation, it will be very important to ensure that the person is proactively connected to information to enable access. The Panel was of the view that in order for people to be provided with information it will be necessary for the Government to be involved in this; it will not be sufficient for medical or health practitioners alone to address this need.

In reaching this decision the Panel noted that there are contemporary examples now available in Victoria and elsewhere of how information can be provided through central government agencies without requiring the direct involvement of a practitioner with a conscientious objection or an organisation unwilling to provide services. The Panel particularly noted the potential role of navigators and a central information hub in performing this function.

Ministerial Expert Panel recommendation 13:

A health practitioner or health service that is unwilling to be involved in the voluntary assisted dying process must provide information sufficient to enable the person to access information regarding voluntary assisted dying.

Policy intent:

To ensure that a person requesting voluntary assisted dying is able to be connected with information that meets their needs in a way that does not compromise the right of a health practitioner to conscientiously object to being involved in voluntary assisted dying.

In relation to the Joint Select Committee Legislation Framework request that timelines for each step in the process be advised by the Panel to ensure integrity in the process without delay,¹⁴⁵ the Panel considered the appropriate timeframe in which a practitioner must accept or refuse a request.

Most other jurisdictions do not specify a timeframe in which the practitioner must accept or refuse a request. Quebec legislation states that if a doctor refuses a request for Medical Assistance in Dying they must inform the executive director of the institution or health service as soon as possible so necessary steps can be taken to find a replacement physician who is willing to accept.¹⁴⁶ Note though, that this information must be provided after the request has been refused; the legislation does not place any timeframe on refusing the request itself. In Belgium, if a request is refused, the doctor must inform the patient in good time and provide reasons for the refusal.¹⁴⁷

145 'My Life, My Choice' report of the Joint Select Committee on End of Life Choices, Parliament of Western Australia (August 2018) 7.89.

146 *An Act Respecting End-Of-Life Care* (Quebec).

147 *Act on Euthanasia 2002* art 14 (Belgium).

The Medical Board of Australia's *'Good medical practice: code of conduct for doctors in Australia'* states that doctors should never use a conscientious objection to intentionally impede a patient's access to care.¹⁴⁸ The Australian Medical Association (AMA) *Position Statement on Conscientious Objection* states that when a doctor invokes a conscientious objection they should make **every effort in a timely manner** to minimise disruption to the delivery of health care.¹⁴⁹ It clarifies that a doctor should inform a patient of their objection preferably in advance or as soon as practicable.¹⁵⁰

Based on experience in other jurisdictions in relation to procedures like abortion, the Panel was concerned that doctors failing to accept or refuse a request in a reasonable timeframe could be used to delay referral until natural death or loss of decision-making capacity occurs. This potential disregard for both the law and the conscientious objection guidelines from the AMA and the Medical Board of Australia were considered to be sufficient reason to impose a timeframe in which the doctor must accept or refuse the request. Although the Panel thought this was a significant enough risk to require a timeframe be specified, it considered that any breach would be a professional conduct issue not an offence.

It was also recognised by the Panel that there may be other reasons why a practitioner is unable or unwilling to be a co-ordinating or consulting practitioner that may not relate to conscientious objection. For example the practitioner may be unwilling or unable to perform the role requested due to future availability, scheduling, not meeting qualification requirements or training concerns.

Ministerial Expert Panel recommendation 14:

If a medical or nurse practitioner is unwilling to participate in voluntary assisted dying the practitioner must inform the person immediately.

If the practitioner requires time to consider the request for some other reason the practitioner must inform the person of their decision within two working days.

Policy intent:

To ensure that a person requesting voluntary assisted dying is provided with a timely response about whether the medical or nurse practitioner can accept their request.

To provide the practitioner with time to check their availability, consider if they can undertake training or otherwise be able to fulfil the requirements of being a co-ordinating or consulting practitioner.

148 Good medical practice: a code of conduct for doctors in Australia, Medical Board of Australia (2014).

149 Position Statement on Conscientious Objection, Australian Medical Association (2019).

150 Ibid.

Assessment

The Joint Select Committee on End of Life Choices outlined the following in relation to assessment for voluntary assisted dying:

Joint Select Committee recommendation:

7.89 Voluntary Assisted Dying Legislation Framework

Assessment

Two doctors must assess the person. Either or both doctors can be a general practitioner and neither doctor is required to be specialists regarding the person's disease or illness. Each doctor must be independently satisfied that:

- a. the person is aged 18 or over;
- b. the person is ordinarily resident in Western Australia;
- c. the request is voluntary, made without coercion or duress;
- d. the person has decision-making capacity in relation to a decision about voluntary assisted dying;
- e. the person has an advanced and progressive: terminal, chronic or neurodegenerative illness or disease;
- f. the person has grievous and irremediable suffering due to the disease or illness that cannot be alleviated in a manner acceptable to the person; and
- g. death is a reasonably foreseeable outcome of the condition.

Referral for specialist assessment

A person is not required to undergo consultant or specialist assessment except where either doctor is unable to determine:

- a. the precise nature of the disease or illness, in which case they must refer to a specialist in the relevant area of medicine.
- b. whether the disease is advanced and progressive, in which case they must refer to a specialist in the relevant area of medicine.
- c. whether death is reasonably foreseeable.
- d. capacity, and/or the absence of coercion, in which case they must refer to a consultant psychiatrist or consultant geriatrician as appropriate.

A person seeking to access voluntary assisted dying must be assessed as eligible to do so. During the assessment process the enduring and voluntary nature of their decision would be confirmed and they would be able to withdraw at any stage.¹⁵¹

151 Ministerial Expert Panel on Voluntary Assisted Dying Discussion Paper, Department of Health, Western Australia (2019).

The requirement for two practitioners to independently assess that the person meets all eligibility criteria and is making a voluntary, competent and informed decision is a fundamental safeguard. It is a requirement in all jurisdictions that have legislated for voluntary assisted dying.¹⁵²

The Joint Select Committee Legislation Framework outlined that these mandatory first and second assessments would only be able to be undertaken by a registered medical practitioner who is a general practitioner (GP) or specialist.¹⁵³

In Victoria it is specified that at least one of the assessing medical practitioners must have practised as a registered medical practitioner for at least five years after completing their fellowship with a specialist medical college or becoming a vocationally registered GP.¹⁵⁴

In making recommendations on this topic the Panel has carefully considered the Joint Select Committee Legislation Framework and examples of legislation from other jurisdictions and how these might best apply to the geographical distribution of the West Australian medical workforce.

The Panel observes that the Joint Select Committee is effectively silent about the seniority or years of practice of the assessing medical practitioners, noting rather that they will be doctors, can both be general practitioners and that neither medical practitioner needs to be a specialist in the person's illness or disease.¹⁵⁵

Consultation Findings

The Panel's consultation specifically sought to test how the Victorian model of practitioner qualifications would apply in Western Australia.

In relation to the question of whether the assessing medical practitioners should have practised for at least five years after completing their fellowship or registering as a general practitioner, the majority of respondents indicated that this should apply to at least one of the assessing medical practitioners. However, there were others with reservations about an arbitrary time requirement.

'The practitioner may have 5 years' experience but that doesn't necessarily equate to competency and time is a poor surrogate for skills.'

'The practitioner should have informed knowledge, an appropriate skill set and core abilities to have discussions in a deep and meaningful way.'

'The time aspect of the process has been introduced for politicians to dissuade reservations from the community.'

(Stakeholder roundtable – Process, access, education and training)

'AMA (WA) notes that in the context of assessing capacity and decision-making, medical practitioners opting in to be involved in voluntary assisted dying should have a minimum of 5 years post-fellowship level experience in Australia with currency of clinical practice at a minimum of 0.5FTE equivalent.'

(Submission by the Australian Medical Association – WA)

152 [Appendix 5](#).

153 *'My Life, My Choice'* report of the Joint Select Committee on End of Life Choices, Parliament of Western Australia (August 2018) 7.89.

154 *Voluntary Assisted Dying Act 2017* (Victoria).

155 *'My Life, My Choice'* report of the Joint Select Committee on End of Life Choices, Parliament of Western Australia (August 2018).

There were significant concerns expressed about effective access for rural and remote Western Australians should there be restrictions on the type of medical practitioners able to be involved in the process for voluntary assisted dying.

'Access to a second medical practitioner may be problematic for some people, for example, those in rural and remote areas, or those with specific cultural or linguistic needs and practices.'

(Submission by the Public Health Association of Australia)

'If you lock out regional doctors without fellowship you lock out a large part of access to voluntary assisted dying in regional areas.'

'It is less of an issue of fellowship and more of an issue of competence. Minimum training is more important.'

'I see a big role for Nurse Practitioners in this particular area. This is partly due to limited access to medical practitioners and other services. ... One assessment could be made by a Nurse Practitioner.'

'People involved in assessments and support through this journey need a high level of expertise and understanding and knowledge. I would be anxious if these conversations could be had by people who are just passing through (locums). It is a big burden for them to have their head around this.'

(Consultation stakeholder meeting – Western Australian Country Health Service Board)

'We request, as we have in other States, that the Nurse Practitioner role be included in the process for Voluntary Assisted Dying in Western Australia. ... Participation may range from process navigation to being a coordinating practitioner or assisting practitioner.'

(Submission by Australian College of Nurse Practitioners)

Discussion

The types of practitioners that are able to undertake voluntary assisted dying will have significant implications for the workability of the legislation across the state of Western Australia.

Canada requires that the assessing practitioners are either a medical practitioner or nurse practitioner entitled to practise medicine or as a nurse practitioner respectively under the laws of the province.¹⁵⁶

In the United States, all jurisdictions that allow voluntary assisted dying refer to a physician (with some states further outlining that the physician is a doctor of medicine licensed to practise medicine by the state).¹⁵⁷ Other jurisdictions also refer to the physician without further qualification.¹⁵⁸

Victoria is the only jurisdiction that has legislated requirements for the qualifications of the assessing medical practitioners above and beyond what is required to be registered to practise medicine in Australia.

As noted previously in this Report, Western Australia differs significantly from Victoria in relation to geography, geographic distribution of the population, Aboriginal people and culturally and linguistically diverse communities.

¹⁵⁶ *Medical Assistance in Dying Act, Bill C-14 2016* (Canada).

¹⁵⁷ California, Colorado, District of Columbia, Hawaii, New Jersey, Montana, Oregon, Vermont, Washington State (USA) (refer [Appendix 5](#))

¹⁵⁸ Belgium; Netherlands (refer [Appendix 5](#)).

In putting the consultation findings into context, the Panel concluded that a requirement to have practised for at least five years as a Fellow or GP would significantly reduce the number of medical practitioners available to undertake assessments, particularly in rural and remote areas. This access issue would be further compounded in smaller centres and towns if a sole practitioner had a conscientious objection to voluntary assisted dying.

The Panel also noted that senior doctors in country hospitals and GPs who do not hold a fellowship are already able to perform functions such as ceasing life sustaining treatment where it is assessed as futile. The Panel placed value on the enduring relationship that these medical practitioners may have with their communities and considered this as a factor when weighing up their decision.

The Panel also noted strong feedback from the consultation that mandatory training on assessment was a significant factor in being able to undertake the voluntary assisted dying process well. The Panel also took into consideration that overseas trained doctors have met a relevant standard to practise in Australia.¹⁵⁹

In considering the question of medical practitioner qualifications and experience, the Panel was clear that this is not an appropriate task to be undertaken by junior medical practitioners or by medical practitioners in training. Being a co-ordinating or consulting practitioner for a person who has requested voluntary assisted dying is a significant responsibility and poses ethical and clinical practice considerations for these practitioners. This is not an appropriate responsibility to place on learning or inexperienced practitioners.

The Panel recommends that the medical practitioners involved in the voluntary assisted dying process should reflect the evidence of safe and effective voluntary assisted dying programs operating internationally as well as that which would best meet the needs of Western Australia.

To achieve this, the Panel sought further advice from the Western Australian Board of the Medical Board of Australia to be able to appropriately align the requirements of the medical practitioners with the National Registration and Accreditation Scheme.¹⁶⁰

The Panel therefore recommends that medical practitioners who may seek to become co-ordinating or consulting practitioners for the purposes of voluntary assisted dying must be:

1. Medical practitioners who currently hold **Specialist Registration** with AHPRA and have practised as a registered specialist for **at least one year**; or
2. Medical practitioners who currently hold **General Registration** with AHPRA and have practised as a generally registered medical practitioner for **ten or more years**.

Given the unique circumstances that exist in Western Australia, the Panel further recommends that consideration be given to the following category of medical practitioners (below) where it has been demonstrated that no local provider meets the requirements above. This would need to be reviewed on a case by case basis for each applicant to assess suitability.

159 Australian Health Practitioner Regulation Agency, Overseas Practitioners, <https://www.ahpra.gov.au/Registration/Registration-Process/Overseas-Practitioners.aspx>.

160 Personal communication with Professor Con Michael, Chair WA Board of the Medical Board of Australia (12 June 2019).

3. Internationally trained medical **specialists** who currently hold **Limited** or **Provisional Registration** for:
 - a. work in a gazetted Area of Need or as a sponsored provider within a health service in Western Australia; and,
 - b. who have undergone a formal assessment by the relevant Australian College; and,
 - c. for whom the relevant College has approved their specialist pathway and supervision program; and,
 - d. who have five years' experience as a specialist consultant; and,
 - e. have completed 12 months working in a supervised position within Western Australia.

As part of considering how access can safely and appropriately be provided for voluntary assisted dying across Western Australia the Panel also gave consideration to the role of nurse practitioners. Nurse practitioners are registered nurses with 'the experience and expertise to diagnose and treat people ... have completed additional university study at Master's degree level and are the most senior clinical nurses in our health care system'.¹⁶¹

The Panel examined existing examples of collaborative models of medical practitioners working with nurse practitioners, including examples in aged care and end of life settings.¹⁶² In Canada, this extends to inclusion in medical assistance in dying (MAiD) where nurse practitioners can be involved in all aspects of the process (including administration of intravenous medication¹⁶³ for the purposes of voluntary assisted dying) and accounts for 6-7% of all cases.¹⁶⁴

The Panel's view was that nurse practitioners' extensive training and scope of practice would enable them to function effectively in this role and would add to the provision of appropriate access to voluntary assisted dying across Western Australia.¹⁶⁵

The Panel reviewed the distribution of nurse practitioners across Western Australia – there are a total of 248 nurse practitioners with a significant number of these based outside hospital settings in community health, residential care facilities, in GP services and in Aboriginal Health Services. There are currently 43 nurse practitioners in WA Country Health Services working across a number of specialties.^{166, 167}

The Panel's view about the enduring relationship with medical practitioners also applied to nurse practitioners who are often key leaders in trusted roles in their workplaces and communities.¹⁶⁸

161 'What is a nurse practitioner?', Australian College of Nurse Practitioners <https://www.acnp.org.au/aboutnursepractitioners>.

162 Schadewaldt V et al, 'Experiences of nurse practitioners and medical practitioners working in collaborative practice models in primary healthcare in Australia: A multiple case study using mixed methods' (2016) *BMC Family Practice* 17(99), 1-16.

163 Experience internationally of the legalisation of assisted dying on the palliative care sector – Final Report, Palliative Care Australia (2018).

164 Fourth Interim Report on Medical Assistance in Dying in Canada, Health Canada (2019).

165 Nursing and Midwifery Board of Australia, Nurse Practitioner Standards for Practice <https://www.nursingmidwiferyboard.gov.au/codes-guidelines-statements/professional-standards/nurse-practitioner-standards-of-practice.aspx>.

166 National Health Workforce Dataset 2017 <https://hwd.health.gov.au/datatool.html>.

167 Personal communication with Robina Redknap, Chief Nurse and Midwifery Officer, WA Department of Health (7 June 2019).

168 Newhouse R et al, 'Advanced Practice Nurse Outcomes 1990-2008: A systematic review.' *Nursing Economics* (2011) 9(5) *Nursing Economics* 230-251.

Ultimately the Panel felt that the primary responsibility of being the co-ordinating practitioner needed to remain with a medical practitioner. The Panel determined that the role of consulting practitioner could be safely and appropriately performed by a nurse practitioner.

Ministerial Expert Panel recommendation 15:

Medical practitioners who may seek to become co-ordinating or consulting practitioners for the purposes of voluntary assisted dying must:

- 1. Currently hold Specialist Registration with AHPRA and have practised as a registered specialist for at least one year; or,**
- 2. Currently hold General Registration with AHPRA and have practised as a generally registered medical practitioner for 10 or more years; or,**
where it has been demonstrated that no local provider meets the above requirements, be:
- 3. An internationally trained medical specialist currently holding Limited or Provisional Registration for:**
 - a. work in a gazetted Area of Need or as a sponsored provider within a health service in Western Australia; and,**
 - b. who has undergone a formal assessment by the relevant Australian College; and,**
 - c. for whom the relevant College has approved their specialist pathway and supervision program; and,**
 - d. who has five years' experience as a specialist consultant; and,**
 - e. has completed 12 months working in a supervised position within Western Australia.**

Policy intent:

To ensure that the medical practitioners seeking to become co-ordinating or consulting practitioners for the purpose of voluntary assisted dying are only those that are appropriately qualified, skilled and experienced.

To ensure that there is appropriate access to voluntary assisted dying across the geographically diverse state of Western Australia.

To ensure that trainees or junior medical practitioners do not able to be either a co-ordinating or consulting practitioner for voluntary assisted dying.

Ministerial Expert Panel recommendation 16:

The co-ordinating practitioner must be a medical practitioner that meets the following qualification requirements:

- a. registered in Australia according to the medical practitioner qualification requirements for voluntary assisted dying previously specified; and,**
- b. must have successfully completed mandatory approved voluntary assisted dying training.**

The consulting practitioner:

- a. may be a medical practitioner (with same requirements as for co-ordinating practitioner); or,**
- b. may be a nurse practitioner registered in Australia on an ongoing basis; and,**
- c. must have successfully completed mandatory approved voluntary assisted dying training.**

Policy intent:

To ensure that only appropriately qualified, skilled practitioners and experienced are able to undertake voluntary assisted dying assessments.

To ensure that there is appropriate access to voluntary assisted dying across the geographically diverse state of Western Australia.

Mandatory training

Education, training and support for all health practitioners involved in voluntary assisted dying would be an important component of the implementation phase. This training should be developed to ensure that cultural context and competency is integrated with clinical and procedural education for voluntary assisted dying.¹⁶⁹

Victoria is the only jurisdiction that makes it compulsory for the assessing medical practitioners to have completed approved assessment training before undertaking assessments to determine eligibility for voluntary assisted dying.¹⁷⁰

Consultation Findings

There was a very strong endorsement from those consulted that completion of approved training be mandatory before a medical practitioner is able to undertake the process for voluntary assisted dying. It was further noted that the requirement should be premised on the attainment of competence, not simply completion of training.

'Undergoing training does not necessarily equal competence.'

(Consultation stakeholder meeting – Western Australian Country Health Service Board)

A number of organisational responses commented on the need for the training to be mandatory:

'All medical practitioners should be required to complete mandatory approved training before they are able to undertake the process for VAD.'

(Submission by Avant Mutual (Medical Indemnity Insurance Provider))

'We believe that approved training for voluntary assisted dying should be mandatory.'

(Submission by Palliative Care WA)

The Australian Medical Association (WA) also noted that if voluntary assisted dying were introduced in Western Australia it would be important to include education to all medical practitioners and medical students around end-of-life care and legislative issues.¹⁷¹ The consultation elicited rich feedback in relation to what should be included in the training. These aspects are addressed in the section on [Education and Training](#).

169 Ministerial Expert Panel on Voluntary Assisted Dying Discussion Paper, Department of Health, Western Australia (2019).

170 *Voluntary Assisted Dying Act 2017* (Victoria).

171 Submission: Australian Medical Association (WA) to the Ministerial Expert Panel on Voluntary Assisted Dying (2019).

Discussion

The Panel endorsed the findings from the consultation and agreed with the view that the training needed to include more than assessment and functions of the legislation.

The Panel observed that significant work has been done in Victoria to develop comprehensive training modules and that these would be an appropriate example to start from in developing Western Australian training.¹⁷²

More detail about the content and approach of training, including the need to provide a focus on cultural competence,¹⁷³ is provided in the section on [Education and Training](#).

Ministerial Expert Panel recommendation 17:

The co-ordinating practitioner must successfully complete approved voluntary assisted dying training before commencing the first assessment.

The consulting practitioner must successfully complete approved voluntary assisted dying training before commencing the second assessment.

Policy intent:

To ensure that all practitioners who undertake the process for voluntary assisted dying have successfully completed appropriate training for this purpose.

172 Victoria State Government, Voluntary assisted dying training for medical practitioners <https://www2.health.vic.gov.au/hospitals-and-health-services/patient-care/end-of-life-care/voluntary-assisted-dying/medical-practitioner-training>

173 'Cultural competence is the ability to participate ethically and effectively in personal and professional intercultural settings. It requires being aware of one's own cultural values and world view and their implications for making respectful, reflective and reasoned choices, including the capacity to imagine and collaborate across cultural boundaries.' National Centre for Cultural Competence, University of Sydney. <https://sydney.edu.au/nccc/about-us/what-is-cultural-competence.html>

At least two independent assessments

The Joint Select Committee on End of Life Choices outlined the following in relation to assessment for voluntary assisted dying:

Joint Select Committee recommendation:

7.89 Voluntary Assisted Dying Legislation Framework

Assessment

Two doctors must assess the person. Either or both doctors can be a general practitioner and neither doctor is required to be a specialist regarding the person's disease or illness. Each doctor must be **independently** satisfied that:

- a. the person is aged 18 or over;
- b. the person is ordinarily resident in Western Australia;
- c. the request is voluntary, made without coercion or duress;
- d. the person has decision-making capacity in relation to a decision about voluntary assisted dying;
- e. the person has an advanced and progressive: terminal, chronic or neurodegenerative illness or disease;
- f. the person has grievous and irremediable suffering due to the disease or illness that cannot be alleviated in a manner acceptable to the person; and
- g. death is a reasonably foreseeable outcome of the condition.

Referral for specialist assessment

A person is not required to undergo consultant or specialist assessment except where either doctor is unable to determine:

- e. the precise nature of the disease or illness, in which case they must refer to a specialist in the relevant area of medicine.
- f. whether the disease is advanced and progressive, in which case they must refer to a specialist in the relevant area of medicine.
- g. whether death is reasonably foreseeable.
- h. capacity, and/or the absence of coercion, in which case they must refer to a consultant psychiatrist or consultant geriatrician as appropriate.

Although not a direct point for consultation, points were raised in relation to the independence of the assessing practitioners. Whilst not explicitly precluded, if the assessing practitioners are from the same practice (for example) it may be difficult to determine that each practitioner is truly independent of the other. There is a risk that a consulting practitioner may feel implicit pressure to concur with the first assessment findings. The Panel particularly notes that in assuring independence it is important that neither practitioner is in a supervisory or employing role in relation to the other. Each practitioner is responsible for arriving at their own conclusion and must provide an independent assessment.

Additional feedback from some practitioners indicated that it would be useful to have an independent clinician available for medical/legal advice throughout the process. This is a function that would need to be considered during implementation and may be appropriate as part of any navigator or hub service.

The Panel agrees with the Joint Select Committee that at least two independent practitioners must assess the person and be satisfied that the person meets the eligibility criteria.

Purpose and timing of the written declaration

The Joint Select Committee on End of Life Choices outlined the following in relation to the written request for voluntary assisted dying:

Joint Select Committee recommendation:

7.89 Voluntary Assisted Dying Legislation Framework

Procedure

The person must provide the initial assessing doctor with a signed written request using a standard template. The written request must be filed with the oversight body.

The doctor should then carry out the [first] assessment as described above.

The Joint Select Committee also made the following commentary:

7.63

Timelines for each step in the process should be advised by the expert panel to ensure integrity in the process without unnecessary delay.

The Panel consulted specifically on the purpose and timing of the written declaration because the Joint Select Committee proposed a different process to that outlined in the Victorian *Voluntary Assisted Dying Act 2017* and therefore a position needed to be established regarding what would be appropriate for Western Australia.

The Joint Select Committee proposed that the written declaration be provided after the first verbal request but before the first assessment. In Victoria the written declaration is completed after the person has completed both assessments and has been deemed eligible for voluntary assisted dying.

Ahead of consideration of timing, it is the purpose of the written declaration that needs to be defined and that will then guide its placement in the voluntary assisted dying process.

Consultation Findings

The majority of respondents considered that the purpose of the written declaration was to formalise the person's request once the person has been fully informed and assessed as eligible for voluntary assisted dying.

Some roundtables/meetings noted the opportunity for reflection that the written declaration provides.

Although support was strongly for the written declaration being formalised after the assessments, there were also views raised around its purpose and timing. The Process, Access and Education roundtable noted mixed views depending on whether the purpose was assurance surrounding the initial request or confirmation of the decision at the end; participants felt that both had merit.

Respondents also advised that the written declaration should be an understandable document and needs to consider the literacy level of the person, not the ‘complicated language used by doctors.’¹⁷⁴

Other feedback was that some people who may wish to access voluntary assisted dying may be unable to sign a physical document themselves and that the process should ensure suitable alternatives.

‘People with decision-making capacity should be entitled to make a valid request irrespective of how they can communicate that request.’

(Submission by the Equal Opportunity Commission)

Discussion

Following consultation, the Panel considered that the written declaration demonstrated the person’s enduring request for voluntary assisted dying and that it be completed by the person after the first assessment but before the third request (refer to the flow chart on [page 45](#)). This timing also ensures that the written declaration formalises the request once a person has been fully informed and assessed as eligible by at least one practitioner.

The Panel took particular note of the submission from the Equal Opportunity Commissioner that there needs to be particular provisions made for those that cannot write, either due to literacy issues or as a result of the effects of their diagnosis. The Victorian legislation provides an example of such a provision by detailing that a person who cannot sign the written declaration themselves can direct another person to sign on their behalf (this person cannot also be a witness to the written declaration).¹⁷⁵

In relation to witnessing provisions, the Panel noted advice from Victoria that their provisions were potentially complex in implementation and that Western Australia should aim to strike a balance between safeguards and practicality in this regard and wherever possible to base these provisions on an existing practice.¹⁷⁶

The Panel determined that the written declaration should be witnessed by two witnesses to attest that the person requesting voluntary assisted dying signed the declaration voluntarily. The witnesses would be people who are aged 18 or over and have no reasonable grounds for belief that they will benefit financially from the person’s death.

The Panel also gave consideration to how the timing of the written statement and the role of witnesses could be structured in a person-centred and time-sensitive way, given that many people seeking voluntary assisted dying would be very unwell by this stage.

The Panel recommended that the person could return the completed declaration prior to the second assessment (rather than having to wait until afterwards as in Victoria).¹⁷⁷ This would give the person a wider window of calendar time in which to organise witnesses and signing but still occur after they have been informed and had at least one assessment completed. This is demonstrated in the flow chart on [page 45](#). In regards to the written declaration, the Panel determined that the two witnesses did not necessarily need to witness the declaration in the presence of the co-ordinating practitioner – this was not seen to add meaningful oversight and would likely add significant burden to the person.

174 Ministerial Expert Panel on Voluntary Assisted Dying Consultation Stakeholder Roundtable: Process, Access and Education (2019).

175 *Voluntary Assisted Dying Act 2017* (Victoria).

176 Verbal presentation by Ms J Kearney and Mr J Cameron (Department of Health and Human Services, State Government of Victoria), Ministerial Expert Panel meeting (May 2019).

177 *Voluntary Assisted Dying Act 2017* (Victoria).

Ministerial Expert Panel recommendation 18:

The written request is a declaration of the person's considered and enduring request for voluntary assisted dying.

The written declaration must be completed after the first assessment and before the third request.

Where the person is unable to sign the written declaration of request, the person may direct another person to sign on their behalf (where that person is not also a witness).

The written declaration of request will be witnessed by two witnesses to establish that the person requesting voluntary assisted dying signed the declaration voluntarily. The witnesses will be people who are aged 18 or over and have no reasonable grounds for belief that they will financially benefit from the person's death. Neither the co-ordinating nor consulting practitioner may be a witness for the person.

Policy intent:

To ensure that the request is formalised after the person has received information about all of their options and been assessed as eligible by at least one practitioner.

To ensure that the witnessing of the written declaration of request does not unduly delay the process.

To ensure that the purpose of witnessing the written declaration of request is clear. To ensure that the written declaration of request is witnessed in a safe and responsible way.

To ensure that a person who is unable to sign the written declaration of request is able to have the written declaration of request completed in a manner that fulfils the requirement under the legislation.

Reflecting on the decision

The Joint Select Committee on End of Life Choices outlined the following in relation to the reflection period for voluntary assisted dying:

Joint Select Committee recommendation:

7.89 Voluntary Assisted Dying Legislation Framework

Procedure

The person's consent to assisted dying may be withdrawn at any time.

Reflection period

In order to provide a period of reflection a prescription for medication must not be filled sooner than prescribed under the legislation as determined by the expert panel.

The Joint Select Committee also made the following commentary:

7.63

Timelines for each step in the process should be advised by the expert panel to ensure integrity in the process without unnecessary delay.

The time between each step in the process would, of itself, provide some period for reflection. The person would always have the protection of being able to withdraw from the process at any stage.¹⁷⁸

That a person's decision is enduring would be shown through several of the proposed process steps: the initial request, participation in the first assessment, the written declaration, participation in the second assessment, the request that triggers the provision of the prescription and the request for administration of the medication (if not self-administering) (refer to the flow chart on [page 45](#)).¹⁷⁹

In most jurisdictions there is some form of prescribed waiting period of anywhere from 9-17 days ([refer Appendix 5](#)). The Joint Select Committee was clear that the process ought to enable a person to have proper reflection but also that access should not be unnecessarily delayed.

In Victoria the minimum nine day waiting period between the first and final request can be reduced to not less than one day if the opinion of both medical practitioners is that the person is likely to die before the end of the nine day waiting period.¹⁸⁰

In Canada there must be 10 days between the signing of the written request (which is done after the first assessment) and the day on which medical assistance in dying (MAiD) is provided.¹⁸¹ The timeframe can be reduced if both assessing practitioners are of the opinion that death or loss of capacity is imminent.

178 Ministerial Expert Panel on Voluntary Assisted Dying Discussion Paper, Department of Health, Western Australia (2019).

179 Ibid.

180 *Voluntary Assisted Dying Act 2017* (Victoria).

181 *Medical Assistance in Dying Act, Bill C-14 2016* (Canada).

The Joint Select Committee proposed a minimum time period between the first formal request and the filling of the prescription for the medication. This would require the pharmacist to be reliably informed of the date of the first formal request and would shift responsibility for compliance from the practitioner to the pharmacist.

Consultation Findings

Consultation respondents were generally in support of a minimum timeframe to enable reflection on the decision to access voluntary assisted dying, and noted that time for reflection without the weight and pressure of the request and assessment process influencing their decision would be essential.

'It is generally agreed that there should be a cooling off period to permit proper reflection before a person should be given the opportunity of making a final request that will have the effect of ending their life.'

(Submission by Doctors for Assisted Dying Choice)

Consultation respondents were also generally in support of there being the option to waive or reduce the minimum timeframe in certain circumstances. Mostly this was considered in relation to death being imminent.

'...perhaps with the ability to reduce times if the patient is undergoing excruciating pain that cannot be relieved or death is imminent within that period.'

(Submission by the Anglican Social Responsibilities Commission)

'Bethesda is of the view that it is reasonable to waive the waiting period if in the opinion of two medical practitioners that the person will die before the waiting period has elapsed (as in Victoria).'

(Submission by Bethesda Health Care)

There were multiple viewpoints in relation to how the reflection period should be measured: between the first and second requests; between the second and third requests, or between the third request and the administration of medication.

Discussion

The Panel considered the importance of the time period for reflection in balance with a compassionate, person-centred approach to voluntary assisted dying. This was consistent with commentary of the Joint Select Committee that:

*'An individual should not be forced to continue to experience prolonged grievous and irremediable suffering that cannot be alleviated in a manner acceptable to the person. Therefore, any final period for reflection should accommodate proper reflection and not be unnecessarily delayed.'*¹⁸²

Following deliberation, the Panel determined that the timeframe for reflection should be at least nine days from the time of the first request to the third request for voluntary assisted dying – this approach is consistent with Victoria.¹⁸³

182 'My Life, My Choice' report of the Joint Select Committee on End of Life Choices, Parliament of Western Australia (August 2018) 7.65.

183 *Voluntary Assisted Dying Act 2017* (Victoria) and *Medical Assistance in Dying Act, Bill C-14* (Canada).

The Panel also considered the provisions in Victoria and Canada for the reduction of the waiting period in certain circumstances – if death is likely to occur before the expiry of the waiting period (Victoria and Canada)¹⁸⁴ or if the loss of capacity to provide informed consent is imminent (Canada).¹⁸⁵

The Panel found that there was merit for the inclusion of both these criteria in the ability to reduce the timeframe to not less than one day after the day on which the second assessment is completed. The Panel made this determination based on the increased suffering the person could experience through fear of losing capacity (for example by ceasing pain medications because they are worried it might cause them to lose capacity). Note that the Panel emphasised that the person must still have decision-making capacity at all points in the process for voluntary assisted dying.

Ministerial Expert Panel recommendation 19:

The time period for reflection be defined as the person’s third request to be made at least nine days after the day on which the person made the first request.

The voluntary assisted dying medication must not be prescribed before the third request.

Policy Intent:

To ensure that the process affords the person an adequate time for reflection and demonstrates the enduring nature of their decision but does not unduly delay their access to voluntary assisted dying.

Ministerial Expert Panel recommendation 20:

Where the co-ordinating practitioner is of the opinion that the person’s death is likely to occur before the expiry of the reflection period or that the person is likely to lose decision-making capacity before the expiry of the reflection period, and that this opinion is consistent with the assessment by the consulting practitioner, then the reflection period may be reduced to not less than one day after the consulting assessment.

Policy Intent:

To provide clear direction to the co-ordinating practitioner regarding when the time period may be reduced.

184 *Voluntary Assisted Dying Act 2017* (Victoria).

185 *Medical Assistance in Dying Act, Bill C-14 2016* (Canada).

Approval

The Joint Select Committee on End of Life Choices outlined the following in relation to approval for voluntary assisted dying:

Joint Select Committee commentary:

6.84

Some elements of the Victorian law are not commonly replicated in other jurisdictions. This includes the role of a senior bureaucrat in providing the final approval for a patient's decision to choose to end their own life. It is difficult to contemplate any other scenario where it would be appropriate for the government to insert itself into the private medical decisions made by a patient in consultation with their doctors.

Indeed, such intervention is not currently required for other end of life options open to patients – government permission is not required, for example, for a person to receive terminal sedation, or to refuse artificial food and hydration.

No permit system

In Victoria, the Department of Health and Human Services must approve and provide an authorisation permit prior to the medical practitioner prescribing the person a voluntary assisted dying medication. This is a third tier of approval, separate and independent from the first two approvals given by medical practitioners. This was included as an additional check point to ensure the process has been completed correctly prior to prescription.

Consultation Findings

During consultations with the public, stakeholders and key experts, one of the questions posed by the Panel was *'Should there be a separate approval and permit for voluntary assisted dying (over and above any that may relate to the prescription of the medication)?'*

The majority of responses suggested that an additional approval and permit process would add an additional, unnecessary layer of bureaucracy and 'red tape'. Other responses suggested some support for additional processes or permits as an important safeguard.

At the Medication and Approval roundtable general consensus was that there are other means already available in Western Australia to ensure appropriate governance of voluntary assisted dying medications without resorting to an additional permit system. It was agreed that there is a need to track voluntary assisted dying medication at every point in the process and existing systems for tracking medicines could be enhanced to provide assurance that correct processes have been followed prior to prescribing.

The Society of Hospital Pharmacists (WA Branch) (SHPA WA) submission put forward that a permit process is not necessary and that the requirement for a permit for issue of the prescription itself would cause an administrative burden at the wrong point in the voluntary assisted dying process. Instead SHPA WA recommended an approval authorisation and notification process, potentially in the form of an online portal for which credentialed practitioners could have access; allowing effective communication for those involved.

Discussion

The Joint Select Committee's commentary noted above clearly indicates its position on the matter of permits and recommended that the Victorian requirement of departmental approval and the associated permit system for voluntary assisted dying not be a feature of the model for Western Australia.

The Victorian permit system is to be implemented based on the pre-existing Victorian medication authorisation system.¹⁸⁶ However, the framing of the legislation to require a specific permit does not mandate a streamlined approach using existing mechanisms and risks a more cumbersome approach being adopted.

In Western Australia the *Medicines and Poisons Act 2014* stipulates that certain controlled medications require notification to, or authorisation from, the Department of Health prior to prescription in certain situations.

This notification or authorisation of voluntary assisted dying medications can provide an avenue for oversight and approval without the need for an additional legislated approval and permit process.¹⁸⁷

Online authorisation and notification systems that enable communication between health practitioners about some 'high risk' medicines already exist. Similar programs could be created for voluntary assisted dying that track the steps and status of voluntary assisted dying requests. This would ensure a real-time method of communication about voluntary assisted dying and offer a 'closed loop' to account for all steps of the process, from approval to dispensing to use or return of the medicines and documentation about actual deaths versus withdrawn requests and approvals.

In Western Australia an oversight body would provide additional safeguard measures by undertaking retrospective review of voluntary assisted dying deaths and other reporting points in the voluntary assisted dying process pathway.

Ministerial Expert Panel recommendation 21:

There be no legislated requirement for an additional permit approval system in Western Australia.

Policy intent:

To ensure that the voluntary assisted dying process is not burdened by bureaucratic oversight that may not materially add to the safety of the process.

Ministerial Expert Panel recommendation 22:

Authorisation for prescription of voluntary assisted dying medication be managed through existing mechanisms under the *Medicines and Poisons Act 2014*.

Policy intent:

To provide clarity that appropriate authorisation of the prescription of voluntary assisted dying medication can be controlled under existing Western Australian legislation.

186 Personal communication with Mr Jarrod McMaugh, Chair of the Victorian Voluntary Assisted Dying Implementation Taskforce Working Group for voluntary assisted dying medication review and protocol development (June 2019).

187 Ministerial Expert Panel on Voluntary Assisted Dying Discussion Paper (May 2019).

Medication

The Joint Select Committee on End of Life Choices outlined the following in relation to the medication for voluntary assisted dying:

Joint Select Committee recommendations:

7.89 Voluntary Assisted Dying Legislation Framework

Medication

The choice of lethal medication for voluntary assisted dying should remain a clinical decision based on the prescribed list of medications for this purpose. The WA Government should review current federal laws in relation to scheduling of medication in Australia, and negotiate with the Federal Government and the Therapeutic Goods Administration for the use of the best medication(s) for assisted dying.

Pharmacists dispensing lethal medication(s) must report the dispensing of the medication to the oversight body.

Assisted dying

The legislation should provide for self-administration of lethal medication where an eligible person is physically able to self-administer. In cases where the person is eligible but physically incapable of self-administration, the legislation should permit a doctor to administer the lethal medication.

Medication as a clinical decision

Discussion

In considering this element of the Joint Select Committee Legislation Framework, the Panel noted that the Government has accepted the recommendation of the Joint Select Committee on this topic.¹⁸⁸

The Panel agrees with the Joint Select Committee's recommendation that the choice of lethal medication should remain a clinical treatment decision, based on the prescribed list of medications.

The choice of lethal medication being a clinical treatment decision ensures that the medical practitioner, in consultation with the person, can determine the most clinically appropriate option as per usual practice. The decision about the most appropriate medication regime occurs ahead of the decision about whether the patient is physically capable of self-administration of that regime. For example an intravenous regime may be the most clinically appropriate option even for a patient who could physically self-administer oral medication.

From a practical perspective there might be a range of alternative medications to circumvent potential supply problems and different formulations (i.e. oral liquid, tablet or capsules or intravenous agents) according to patient and prescriber preferences.

188 Western Australian Government response to the Joint Select Committee on End of Life Choices report, State of Western Australia (2018).

Medication administration method

The Joint Select Committee Legislation Framework provides for self-administration of voluntary assisted dying medication except in cases where the person is physically incapable, in which case a doctor could administer the lethal medication to an eligible person. This is in line with the Victorian *Voluntary Assisted Dying Act 2017*.

In considering this element of the process, the Panel noted that the Government has accepted the recommendation of the Joint Select Committee.¹⁸⁹

Consultation Findings

During consultations with the public, stakeholders and key experts, one of the questions posed by the Panel was *‘Should a medical practitioner only be permitted to administer the medication if the person is physically incapable of self-administration?’*.

Views about this were varied. Whilst most responses indicated that medical administration should be an option, there were also concerns that administration by a medical practitioner may inadvertently limit access to voluntary assisted dying (for example a practitioner may be willing to prescribe voluntary assisted dying medications for self-administration but not to administer the medication to the person).

The submission by Brightwater Care Group suggested that some people may feel more comfortable with the medical practitioner administering the medication even if they are physically capable: *‘This may assist with family healing and support’*.¹⁹⁰

Other suggestions related to provision for intervention by medical practitioners for self-administered oral medication failures (noting that a different permit is required to be applied for this under the Victorian system).¹⁹¹

‘However, there should be an escape clause that would allow the physician to use an intravenous injection if the process following ingestion is prolonged or complicated, in any way’.

(Individual Submission)

The Society of Hospital Pharmacists of Australia (WA Branch) (SHPA WA) stated that it should not be legislated that the doctor can only administer the medication if the person is unable to and that there should be more room for discussion of options and choice on the part of the person and the doctor.

The Australian Medical Association (WA) (AMA WA) submission also did not support the option of health practitioner administration.

‘One of the main drivers behind voluntary assisted dying is the concept of patient autonomy. Therefore, a person should, where possible, personally administer the medication and not involve a health practitioner or family member in the process of administration’.

(Submission by the Australian Medical Association – WA)

The consultation also raised considerations in relation to the types of practitioners that may have a role in administration of voluntary assisted dying medication.

189 Western Australian Government response to the Joint Select Committee on End of Life Choices report, State of Western Australia (2018).

190 Submission: Brightwater Care Group to the Ministerial Expert Panel on Voluntary Assisted Dying (2019).

191 *Voluntary Assisted Dying Act 2017* (Victoria).

At the Medication and Approval roundtable there was discussion surrounding the possible medication regimes as they relate to who could or should administer voluntary assisted dying medications and in what circumstances.

Maybe others should be allowed to administer the medication, for example a nurse.'
(Consultation stakeholder roundtable – Medication and Approval)

A similar view was explored in the submission by the AMA (WA):

*'The AMA (WA) contends that doctors do not necessarily need to be involved in the administration of lethal medication and where self-administration is not possible, another nominated person or health practitioner could administer the medication.'*¹⁹²

Responses from other groups also advocated that where necessary, administration should not be limited to medical practitioners. At the WA Primary Health Alliance (Kimberley) consultation meeting it was raised that for some rural and remote areas it will be important to be able to utilise other health professionals such as nurses for the administration of medication to ensure access.

There were other submissions that firmly held the opinion that only medical practitioners should be able to administer the medication.

'Administering voluntary assisted dying medication is, and should remain, outside the scope of practice of other healthcare professions, and should be restricted to medical practitioners who have been specially trained in the provision of voluntary assisted dying services.'
(Submission by Bethesda Health Care)

Another theme that emerged during consultations was the presence of a health practitioner when the person self-administers voluntary assisted dying medication.

The SHPA WA made the following points with regards to whether or not a health practitioner should be present during medication administration:

'Ideally, the doctor would be present with the person at the time of administration of the medicine. There are potentially numerous benefits of having medically/health practitioner-witnessed voluntary assisted dying, including having closure for the process for both person and doctor and having the practitioner provide assistance if something goes wrong. For example, what to do in the case where the oral medicine is vomited up or not effective and a backup regime is needed, the practitioner being able to certify the death, etc. Ideally, there would be enough practitioners who are willing to assist the individual in the final act of voluntary assisted dying and there are enough resources to do so.'

'If it is legislated that a health practitioner does not need to be present during voluntary assisted dying, then there needs to be careful consideration of the medicines and regimens chosen, including back up medicines, what information the person and contact person are given about how to use the medicines and what to do if something goes wrong. Safeguards would need to be in place to help the person and witnesses in managing the event of final voluntary assisted dying medicine administration if a practitioner is not mandated to be present. It would be unfortunate if a person were to access voluntary assisted dying medications and not have the support needed at the time of medication administration. Perhaps this could be the role of navigators if doctors do not wish to participate in the final voluntary assisted dying event, or if there is not enough resourcing to do so.'
(Submission by the Society of Hospital Pharmacists of Australia – WA Branch)

192 Submission: The Australian Medical Association (WA) to the Ministerial Expert Panel on Voluntary Assisted Dying (2019).

Consultations also noted that for people from culturally and linguistically diverse or Aboriginal backgrounds the location of where the voluntary assisted dying medication is ingested is important. Representatives from these groups indicated that it may be safer for medication to be administered in hospital rather than at home for a range of different reasons related to family structure, decision-making and the risk of payback or blame.

Discussion

As noted previously, the view of the Joint Select Committee (in alignment with the approach in Victoria) is that the legislation should provide for self-administration of lethal medication where an eligible person is physically able to self-administer and in cases where the person is eligible but physically incapable of self-administration, the legislation should permit a doctor to administer the lethal medication. This decision was considered to strike the right balance between autonomy, access and safety.

There is no mention in the Joint Select Committee Report of why self-administration is preferable to administration by a medical practitioner or any commentary on there being an option for people who are physically able to self-administer but who would prefer that a practitioner administer the medication.

There is no requirement in the Victorian legislation for a health practitioner to be present when the person self-administers the medication and the Joint Select Committee makes no recommendation in this regard.

Given the consultation findings, the Panel considered whether patients should be offered the choice between self-administration and practitioner administration.

Internationally there are a variety of ways in which voluntary assisted dying medications are administered and whether or not health practitioners are in attendance at the time the medication is administered.

In Canada where a person has the option to either self-administer or have a medical practitioner administer the medication, the vast majority of voluntary assisted deaths have been via practitioner administration.¹⁹³

In all US states that allow voluntary assisted dying, the medication must be self-administered with no option for physician administration.¹⁹⁴

From a quality and safety perspective there is only a small amount of evidence that practitioner administration may be safer than self-administration.¹⁹⁵

The argument often put in favour of mandatory self-administration (subject to administration by a doctor if the person is physically incapable of self-administration) is that the act of self-administration ensures that the person's decision remains consistent throughout the process. It is also thought to allow people to have more choice in the manner and timing of their death.

193 Ministerial Expert Panel on Voluntary Assisted Dying Consultation meeting with Dr Buchman (President-Elect of Canadian Medical Association) and Dr Blackmer (physician and Vice President International Health Canadian Medical Association), April 2019.

194 Ezekiel Emanuel et al, 'Attitudes and Practice of Euthanasia and Physician-Assisted Suicide in the United States, Canada and Europe' (2016) 315(1) JAMA 79-90.

195 Canadian Association of MAiD Assessor and Providers: Failed MAiD in the Community <https://camapcanada.ca/publications/>; Groenewoud et al, 'Clinical problems with the performance of euthanasia and physician-assisted suicide in the Netherlands' (2000) 342(8) New England Journal of Medicine 551-556; The Oral MAiD Option in Canada Part 2 (2018) <https://camapcanada.ca/publications/>.

However, that proposition implies that in the case of practitioner administration, the administration might go ahead without the health practitioner being satisfied that the person wishes to proceed. The Panel deemed this to be highly unlikely; and if there is to be an exception allowing administration by a health practitioner where the person concerned is physically incapable of self-administration, then the argument becomes logically flawed.¹⁹⁶

Although practitioners may be willing to prescribe voluntary assisted dying medications, some may be reluctant to administer lethal medications to patients – that is to say there may be a scale of practitioner willingness of involvement.

There is growing commentary that calls for a medical practitioner to be present in all cases of voluntary assisted dying, including oral self-administration, to ensure the highest standard of quality care is provided and to reduce any perceived risk of assisted dying medications being present in the community.

^{197, 198, 199}

People self-administering voluntary assisted dying medication may want to choose to have a health practitioner present. In Oregon in 2016, health practitioners reported being present 41% of the time when the lethal dose of medication was self-administered.²⁰⁰ In Washington there was a medical practitioner present in 75% of cases in 2015.²⁰¹

The presence of a health practitioner during self-administered voluntary assisted dying would provide benefits in terms of clinical support, ensuring appropriate administration, and governance of medications.

There may be some people undertaking voluntary assisted dying however, who may wish for complete independence and privacy at this time – thus the presence of a health practitioner should be a decision between the practitioner and the person.

In its final deliberation, the Panel concurred with the Joint Select Committee that self-administration of a lethal dose of medication demonstrates that the person is acting autonomously and that self-administration is the preferred model except where there is a clinical determination that self-administration is not suitable for the person.

In extending the recommendation of the Joint Select Committee, the Panel acknowledged that there are clinical circumstances in which self-administration is not appropriate and administration of the voluntary assisted dying medication may be via practitioner administration.

196 Ministerial Expert Panel on Voluntary Assisted Dying consultation briefing prepared by Professor Ben White and Professor Lindy Willmott (2019).

197 Christopher Harty et al, 'Oral medical assistance in dying (MAiD): informing practice to enhance utilisation in Canada' (2019) *Canadian Journal of Anesthesia* (published online); Canadian Association of MAiD Assessor and Providers. The Oral MAiD Options in Canada. Part 2: Processes for Providing [Clinical Practice Guideline] (2018) <https://camapcanada.ca/publications/>.

198 Sean Riley. 'Navigating the new era of assisted suicide and execution drugs' (2017) *Journal of Law and the Biosciences* 424, 434.

199 Ben White and Lindy Willmott, 'Voluntary Assisted Dying Bill 2019' (2019) <https://eprints.qut.edu.au/128753/> Submission to the Queensland Inquiry into aged care, end-of-life and palliative care and voluntary assisted dying 2019, Explanatory Notes, p 2-3.

200 Oregon Public Health Division, Center for Health Statistics, Oregon Health Authority (2017), Oregon Death with Dignity Act: data summary 2016, State of Oregon, Portland <http://www.oregon.gov/oha/PH/ProviderPartnerResources/EvaluationResearch/DeathwithDignityAct/Pages/ar-index.aspx>.

201 Washington State Department of Health (2016), Washington State Department of Health 2015 Death with Dignity Act report, Washington State <http://www.doh.wa.gov/YouandYourFamily/IllnessandDisease/DeathwithDignityAct/DeathwithDignityData>.

Having reached this position the Panel also considered the roles of the co-ordinating practitioner and the consulting practitioner in relation to medication administration if the person is unable to self-administer. In order to establish a model in which the needs of a person who is unable to self-administer can be met in a timely way the Panel determined that it would be necessary for the consulting practitioner to also administer medication, under the direction of the co-ordinating practitioner.

Ministerial Expert Panel recommendation 23:

- 1. Administration of the voluntary assisted dying medication should usually be by self-administration.**
- 2. Administration of the voluntary assisted dying medication may be by practitioner administration as a result of a clinical determination where consideration has been given to:**
 - a. the person's ability to self-administer, including concerns regarding self-administration;**
 - b. the administration method(s) that are suitable for the person;**
 - c. the voluntary assisted dying medication that is suitable for the person; or**
 - d. other matters that the clinician or person may see as necessary to the decision-making.**

Policy intent:

To ensure it is clear in the first instance that voluntary assisted dying medication should be self-administered.

To ensure that people who are otherwise not able to self-administer can have voluntary assisted dying medication administered by a practitioner.

Medication safety

The Joint Select Committee recommended that pharmacists dispensing lethal medications must report the dispensing of the medication to the oversight body.²⁰² In the Ministerial Expert Panel Discussion Paper on voluntary assisted dying it was proposed that pharmacists would be required to provide relevant information at the time of dispensing and to notify the oversight body when medication is dispensed.²⁰³ As with all medication, it is essential that it be stored safely. The Discussion Paper also noted that the appointment of a contact person who would be responsible for return of unused medication to the pharmacist, as in Victoria, would be a further safeguard.

In considering this element of the process, the Panel noted that the Government has accepted the recommendation of the Joint Select Committee.²⁰⁴

Consultation Findings

During consultations with the public, stakeholders and key experts, the Panel further investigated issues relating to medication safety including ensuring return of any unused medication and other safeguards to protect the public from the loss, misuse or misdirection of the medication.

202 'My Life, My Choice' report of the Joint Select Committee on End of Life Choices, Parliament of Western Australia (August 2018).

203 Ministerial Expert Panel on Voluntary Assisted Dying Discussion Paper (May 2019).

204 Western Australian Government response to the Joint Select Committee on End of Life Choices report, State of Western Australia (2018).

Tracking medication

The Australian Medical Association (WA) (AMA WA) advocated for a centrally co-ordinated service, including a dispensing facility and navigators as well as ‘Directly Observed Therapy’ to minimise the chance of misuse or diversion of medications.²⁰⁵

Other groups also recommended a single central dispensing, dispatch and returns pharmacy service.

‘All medications should be dispensed from a single, central hospital pharmacy. The coordinating medical practitioner should either collect the medications from this location, or sign that they have received the medications from a courier (for peri-urban and country patients), and then sign a declaration that they have administered the medications and are returning any unused medications’.

(Submission by Bethesda Health Care)

The Society of Hospital Pharmacists (WA Branch) (SHPA WA) considered that the supply of voluntary assisted dying medicines from a single centre, as in the case of Victoria, may not be feasible for Western Australia given geographical challenges, but that an agreement between all public hospitals or a network of community pharmacies may work to safeguard supply by restricting supply to a known set of approved sites. This would help with accountability for supply, dispensing and tracking the whereabouts of medicines, including returns.²⁰⁶

Instead the SHPA WA recommended an approval and notification process which tracks the voluntary assisted dying process and communicates information in real-time for all practitioners involved. Programs that utilise online portals for communicating information about other ‘high risk’ medicines in the community already exist and the SHPA WA proposed that a similar program could be created which would track and communicate the steps and status of voluntary assisted dying requests.²⁰⁷

Medication storage

During the Panel’s consultation concerns were raised about storage of voluntary assisted dying medications in the home.

‘As Aboriginal families often live together, with multiple generations sharing the same house, there is a safety concern about the unregulated presence of highly harmful medication in the home. Careful consideration about potential safeguards for this is essential’.

(Submission by Aboriginal Health Council of Western Australia)

Participants at the Medication and Approval roundtable consultation session raised concerns about medication stability and how long voluntary assisted dying medicines can be safely kept in the community due to the unique climate effects of heat and humidity in some parts of Western Australia.

The SHPA WA suggested that locked boxes are an option for safe transfer, storage and return of any unused medicines. The SHPA WA noted the following beneficial features of locked boxes:

‘Medicines which are dispensed generally are capable of causing death if improperly used however medicines for voluntary assisted dying need to look different to regular medicines. Medicines for voluntary assisted dying are intended to cause death, where regular medicines are not. Hence, having the medicines presented in a way which looks very different from regular medicines is important – this is important also for community perception of danger’.

205 Submission: by the Australian Medical Association (WA) to the Ministerial Expert Panel on Voluntary Assisted Dying (2019).

206 Submission: by the Society of Hospital Pharmacists (WA Branch) to the Ministerial Expert Panel on Voluntary Assisted Dying (2019).

207 Ibid.

and safeguards around VAD medicines. All medicines have the Keep Out of Reach of Children warning on the label, but a physical locked box would hinder access by children, pets and people with cognitive impairment.

The locked box would need to be provided by the dispensing pharmacy and is not up to the individual or contact person to supply their own locked box.

A locked box would need to show evidence of it being opened. This is in the form of a tamper-proof seal to advanced technologies such as electronic codes sent to mobile phones or fingerprint technology – all depends on funding.

A locked box would help keep the medicines together if there is more than one item and allow for easier storage and the eventual return of the medicines.’²⁰⁸

Other themes identified in the consultations were:

- ensuring it is very difficult for the voluntary assisted dying medication to be mistaken for other medication or used for other purposes (for example different packaging, multiple layers to open, short shelf life)
- ensuring a second person is present for the administration of the medicine
- ensuring that labelling of medications includes appropriate warnings and symbols for culturally and linguistically diverse populations.

Safe return of unused medication

For oral self-administered medications the exact lethal quantity of medicine would normally be prescribed for each person; thus if the voluntary assisted dying medication is used as prescribed there would be no medication ‘left over’. Circumstances where there might be unused medication requiring safe disposal include: medication remaining after death should the person die from natural causes prior to administration of the medication, in the event of the person losing decision-making capacity to self-administer or changing their mind, or the medication expiring. During consultation the geographic size of Western Australia was noted to create particular practical constraints for the return of unused medicines. At the Medication and Approval roundtable there was discussion surrounding the need for local return options and the value of a closed loop system for recording any unused medication.

The AMA (WA) had concerns about the release of lethal medications into the community and recommended ‘Direct Observed Therapy’ either in the home or healthcare facility which would control the return of any unused medication.²⁰⁹ The AMA (WA) submission also suggested that there may be issues with patients who decide not to proceed with voluntary assisted dying retaining the medication.

The SHPA WA recommended that all voluntary assisted dying medicines should ideally be returned to pharmacies and that this should include hospital and community pharmacies (including in rural and remote areas). Where return to a pharmacy is not practicable, it may be appropriate for voluntary assisted dying medicines to be destroyed on site at a residential aged care facility, hospital or in the person’s home (noting there should be clear guidelines regarding this responsibility and instruction on the destruction method). Assigning a nominated contact person would be a reasonably safe approach for ensuring return of any unused medicines.²¹⁰

208 Submission: by the Society of Hospital Pharmacists (WA Branch) to the Ministerial Expert Panel on Voluntary Assisted Dying (2019).

209 Submission: by the Australian Medical Association (WA) to the Ministerial Expert Panel on Voluntary Assisted Dying (2019).

210 Submission: by the Society of Hospital Pharmacists (WA Branch) to the Ministerial Expert Panel on Voluntary Assisted Dying (2019).

Discussion

In Oregon the voluntary assisted dying medication prescription is provided to the person, and they have the medication dispensed when they choose. In Victoria the prescription is sent directly to the central pharmacy service located at the Alfred Hospital and the medication is dispensed when the person requests it.

Canada differs, in that most policies and practice guidelines recommend that the medication is dispensed directly to the prescriber, rather than to the patient, eliminating any concerns about the medication being in the community.²¹¹ Further, there is a recommendation that the practitioner in Canada obtains final consent just prior to the administration of medical assistance in dying (MAiD) potentially implying they would be present immediately before the person self-administers.²¹²

While concerns have been raised in other jurisdictions with respect to the types of medications that are used for oral voluntary assisted dying and whether they are appropriate,²¹³ there has been almost no concern raised by medical practitioners or pharmacists with respect to the misuse of the voluntary assisted dying medication by people other than the patient who has been deemed eligible.²¹⁴ Further, there have been no reported cases of intentional or accidental misuse of voluntary assisted dying medications.

The Victorian *Voluntary Assisted Dying Act 2017* specifically legislates for locked boxes.²¹⁵ Whilst locked boxes may be an element of other jurisdictions' voluntary assisted dying processes, no other jurisdictions legislate for this.

In March this year, the Canadian Association of MAiD Assessors and Providers published '*Complications with Medical Assistance in Dying (MAiD) in the Community in Canada*' in which there is no mention of medication being misused or any mention of a risk of it being misused.²¹⁶

Despite the concerns raised in the consultation, the Panel noted there is no evidence of misuse with voluntary assisted dying medications elsewhere in the world.

The Panel considers that it is very important to have in place a regulatory regime that provides for the safe dispensing, storage, return and general management of the voluntary assisted dying medication. That regime will need to address the various issues referred to in this section. Determining the precise details of the regulatory regime is beyond the scope of the work of the Panel, and will depend upon a number of factors including the nature of the medications that are prescribed and whether more than one pharmacy will be able to dispense the medication. The Panel therefore recommends that further consideration be given to the precise details of the regulatory regime by the Department of Health as part of the implementation phase.

211 Canadian Association of MAiD Assessor and Providers. The Oral MAiD Options in Canada. Part 2: Processes for Providing [Clinical Practice Guideline] (2018) <https://camapcanada.ca/publications/>.

212 Ibid.

213 Particularly in Canada where some medications used in other jurisdictions were not available. The Canadian Association of MAiD Assessors and Providers (CAMAP) has since released a medication protocol to offer evidence based advice on which medications are best <https://camapcanada.ca/publications/>.

214 Lee Verweel, et al, 'Medical assistance in dying: Examining Canadian pharmacy perspectives using a mixed methods approach' (2018) 151(2) *Canadian Pharmacists Journal* 121.

215 *Voluntary Assisted Dying Act 2017* (Victoria).

216 Canadian Association of MAiD Assessors and Providers, *Complications with Medical Assistance in Dying in the Community in Canada 2019* <https://camapcanada.ca/wp-content/uploads/2019/05/Failed-MAID-in-Community-FINAL-CAMAP-Revised.pdf>.

Ministerial Expert Panel recommendation 24:

The Government should establish regulatory processes for the secure prescription, dispensing, handling, administration and disposal of voluntary assisted dying medication.

Policy intent:

To ensure the safe and secure management of voluntary assisted dying medication.

To ensure that there are clear roles and responsibilities for the person, their family, the contact person and health professionals for medication used in voluntary assisted dying.

Death Certification

The Joint Select Committee on End of Life Choices outlined the following in relation to death certification for voluntary assisted dying:

Joint Select Committee recommendation:

7.89 Voluntary Assisted Dying Legislation Framework

Death certification

Where an assisted death takes place it must be noted on death certification documents. The WA Government should amend the:

- a. Medical Certificate Cause of Death – completed by the doctor certifying cause of death;
- b. Manual Death Registration Form – completed by the funeral director to register a death; and,
- c. Death Certificate – issued by the Registrar of Births Deaths and Marriages,

to make provisions for the inclusion of voluntary assisted dying as a contributing cause of death, and to provide guidance for doctors and others who complete each of the documents.

The Joint Select Committee also made the following commentary:

7.87

For the purposes of the *Coroners Act 1996*, the death would be a foreseeable death and specifically regulated in accordance with voluntary assisted dying legislation. [...] in the Committee's view an assisted dying death should not be automatically reportable to the Coroner. [...] there should be mandatory reporting to the oversight body established to review and regulate voluntary assisted deaths.

Joint Select Committee

In Western Australia there are three key documents which record details regarding the death of an individual:

1. The Medical Certificate Cause of Death:

This form is completed by the medical practitioner when a person dies (except if the death is a reportable death under the *Coroners Act 1996* in which case the medical practitioner does not complete this form). The form requires the medical practitioner to define the disease or condition directly leading to the death, and other causes or conditions that contributed to their death. These details inform what is on the Death Certificate and also data collected at state and national levels. This form is forwarded to the funeral director and then to the Registrar of Births Deaths and Marriages.

2. The Manual Death Registration Form:

This form is completed by the funeral director and forwarded to the Registrar of Births Deaths and Marriages.

3. The Death Certificate:

This certificate is issued by the Registrar of Births Deaths and Marriages to the funeral director or family of the person who has died.

The Joint Select Committee Legislation Framework states that an assisted death must be noted on death certification documents, with all of the above three documents being amended to make provision for inclusion of voluntary assisted dying as a contributing cause of death.

There are several aspects to be considered in relation to the Joint Select Committee proposal to list voluntary assisted dying on death certification documents. At the core of the discussion is the balance between privacy and confidentiality of the person, and the need to ensure accuracy and collect information about voluntary assisted dying. In some communities there may be significant impact on the extended family of a person who has died through accessing voluntary assisted dying.

The Panel invited community feedback on these issues.

Closely associated with this topic, is the question of whether a death caused by voluntary assisted dying should be reported to the Coroner. Currently, under the *Coroners Act 1996*, certain categories of deaths (known as reportable deaths²¹⁷) are required to be reported to the Coroner.²¹⁸ In most cases,²¹⁹ the Coroner is then required to engage in an investigation of that death and make findings as to the identity of the deceased, the cause of death, the particulars needed to register the death under the *Births, Deaths and Marriages Registration Act 1998* and (with some exceptions) how death occurred.²²⁰ In so doing, a post mortem examination is likely to be carried out and an inquest may (but not must)²²¹ be held.

A death caused by voluntary assisted dying would fall within the definition of a reportable death unless consequential amendments were made to the *Coroners Act 1996*.

The Joint Select Committee did not make a recommendation or finding about whether a death that had occurred as a result of voluntary assisted dying should be a reportable death under the *Coroners Act 1996*. However it did make a statement to the effect that such a death should not be reportable (see previous page).

In the Victorian *Voluntary Assisted Dying Act 2017* the death of a person who has been administered or self-administered a voluntary assisted dying substance is notifiable to the Coroner but is not a reportable death²²² – the category of notifiable deaths was created by a House Amendment in the legislation.²²³ In Western Australia there is not a separate category of deaths that are notifiable (but not reportable) to the Coroner.²²⁴

The Panel also invited expert stakeholder feedback on the question of whether a voluntary dying death should be a reportable death under the *Coroners Act 1996*.

217 See the definition of 'reportable death' in the *Coroners Act 1996* s3.

218 *Coroners Act 1996* s17.

219 See the exceptions contained in of the *Coroners Act 1996* s9A.

220 *Coroners Act 1996* s25

221 Ibid s22.

222 *Voluntary Assisted Dying Act 2017* (Victoria).

223 House Amendment (Jennings 141117) Voluntary Assisted Dying Bill 2017 (Victoria). http://www.legislation.vic.gov.au/domino/Web_Notes/LDMS/PubPDocs_Arch.nsf/5da7442d8f61e92bca256de50013d008/ca257cca00177a46ca2581a1007a8903!OpenDocument.

224 Coroner's Court of Western Australia <https://www.coronerscourt.wa.gov.au/>.

Consultation Findings

Inclusion of voluntary assisted dying on death certification documents

The consultation feedback revealed strong support for the inclusion of voluntary assisted dying on the Medical Certificate Cause of Death, but not on the Death Certificate issued by the Registrar of Births Deaths and Marriages.

There was general support for the position that there ought to be an approach that balances the need for accurate information regarding the cause of death and the fact that the person accessed voluntary assisted dying, with the need to give consideration to the privacy of both the individual and family.

'GGA supports the requirement that VAD be listed as a contributing cause of death only on the Medical Certificate Cause of Death, and only if this information remains publicly unavailable.'

'Death certificates are used for a range of purposes, and there is no reason to include information about voluntary assisted dying on such a public document. To preserve the privacy of the person, their family, and health practitioners, information about voluntary assisted dying also should not be included.'

(Submission by Go Gentle Australia)

'At the centre of the discussion is the balance between privacy and confidentiality of the person, and the need to collect information about voluntary assisted dying. In some communities there may be significant impact on extended family of a person who has died through accessing voluntary assisted dying.'

(Submission by the National Disability Services)

The Panel also received feedback raising concerns about third parties (such as funeral directors) who have links to the person and their family or community becoming aware that a death has occurred through voluntary assisted dying. There was concern that if it became known in those communities that the person had accessed voluntary assisted dying, the family may be exposed to negative treatment.

'From the perspective of faith communities, most would denounce any form of VAD and therefore have concerns about what is made public and that having VAD detail on the Death Certificate would be problematic.'

(Consultation stakeholder roundtable – Death Certification)

'The SRC view is that the approach to the certification of death should match that concerning death itself; sanctity and respect. VAD death certification should be as respectful and confidential as possible to ensure it cannot be used for any religious or political agenda of any faith or secular group.'

'From a Christian point of view, the SRC believes that [it] is both practical and respectful if the medical practitioner overseeing the death, having a personal connection with the deceased, directly contact the VAD oversight body with VAD details.'

'Care should be taken to develop procedures that third parties, such as funeral directors, do not automatically become aware of the deceased's access to VAD. Families of people accessing VAD may have further pain caused to them if their faith communities become aware of the use of VAD.'

(Submission by the Anglican Social Responsibilities Commission)

However, contrary views were also received, with some submissions supporting the inclusion of voluntary assisted dying on the Death Certificate in order to ensure accurate information is recorded:

'AMA (WA) proposes for completion of death certificates:

- *The cause of death would be the underlying condition for which a patient has sought assisted dying*
 - *The mechanism of death would be voluntary assisted dying, either:*
 - *Self-administered*
 - *Assisted by a third party including health practitioner'*
- (Submission by the Australian Medical Association – WA)

'The Law Society understands that concerns have been raised that this may cause distress to family members of the deceased. However, in cases of self-inflicted death or homicide the cause of death is shown as such on the death certificate. The cause of death of VAD should be consistent with that practice and VAD should be shown on the death certificate, as recommended by the Joint Select Committee.'

(Submission by the Law Society of Western Australia)

Reporting voluntary assisted dying deaths to the Coroner

The question of whether a death caused by voluntary assisted dying should be a reportable death was discussed at a consultation stakeholder roundtable with representatives from organisations including the Coroner's Court, Western Australia Police, the Public Advocate, the State Solicitor's Office and other health and legal representatives.

The Principal Registrar from the Coroner's Court identified a number of reasons why a death caused by voluntary assisted dying should be a reportable death, including that the Coroner already had in place the systems to ensure an investigation could take place, and that steps could be taken quickly to ensure any necessary post mortem investigations were undertaken promptly.

The Principal Registrar was also of the view that the Coroner could ensure that an investigation was carried out in such a manner as to minimise distress to the family.

However, the Panel also received feedback during the meeting that it would not be desirable for all deaths caused by voluntary assisted dying to be the subject of an investigation by the Coroner.

Concerns were expressed regarding the distress this may cause to the family and that in most cases the extensive process that had been followed would make an investigation by the Coroner unnecessary.

Feedback was also received that a voluntary assisted dying oversight body would be receiving information at key points in the process and that the oversight body would be in the best position to provide scrutiny of voluntary assisted dying deaths. A requirement for the oversight body to have the power to refer any deaths of concern to the Coroner for investigation was also raised in consultations.

Discussion

Medical Certificate Cause of Death

The Medical Certificate Cause of Death is completed by the doctor who was responsible for the person's medical care immediately before death, or who examined the deceased person's body.²²⁵ However, a Medical Certificate Cause of Death is not completed by the doctor if the death is a reportable death for the purposes of the *Coroners Act 1996*.

²²⁵ *Births, Deaths and Marriages Act 1998* s1.

The Medical Certificate Cause of Death is forwarded to the funeral director, who in turn provides it to the Registrar of Births Deaths and Marriages.

The Medical Certificate Cause of Death contains information regarding the cause of the person's death. As the submission from Doctors for Assisted Dying Choice explained:

'The Medical Certificate of Cause of Death (MCCD) is recommended by the World Health Organisation (WHO) for international use. All Australian states and territories have very similar versions. After the information has been abstracted from the MCCD for the purpose of registering the death, it is sent to the Australian Bureau of Statistics, along with comparable data from all other States and Territories, for the coding of causes of death throughout the country to an international standard, called the International Statistical Classification of Diseases and Related Health Problems (ICD).

All agencies involved with MCCDs endorse the WHO recommendations for completing them and coding the data from them.'

(Submission by Doctors for Assisted Dying Choice)

The Panel understands that it is therefore important that the Medical Certificate Cause of Death is completed in a manner which is consistent with the World Health Organisation recommendations in order to ensure accurate and consistent data collection. The Panel has received feedback that in the context of voluntary assisted dying, this would involve recording of the cause of death as 'Voluntary Assisted Dying' at Part 1(a) of the Medical Certificate Cause of Death, with other antecedent causes listed in Part 1(b)-(e) with the underlying condition listed last.

The Panel acknowledges the importance of data collection at both the state and national level in relation to the underlying disease or illness. The Panel agrees that it is important that such data collection is not adversely impacted by the introduction of voluntary assisted dying. Ensuring that the underlying disease or illness continues to be recorded on the Medical Certificate Cause of Death as the underlying condition (last in the list of antecedent causes) would satisfy this requirement.

However, the Panel is mindful of the feedback it has received regarding concerns about third parties (such as funeral directors) who have links to the person's (and their family's) community becoming aware that a death has occurred through voluntary assisted dying and exposing the family to negative treatment. This feedback is applicable to the Medical Certificate Cause of Death, because this document is seen by third parties such as funeral directors.

In light of these concerns, the Panel recommends that in the case of a person whose death is caused by voluntary assisted dying, a separate reporting mechanism for this information be considered. The Panel recommends that the medical practitioner report this information directly to the oversight body, who in turn can report this information to the Registrar of Births Deaths and Marriages.

The Panel received feedback from the Registrar that he would have concerns about such a mechanism because reporting from different sources brings with it a high risk that the information from the two separate sources would be mismatched. However, the Panel is concerned that the family of the individual do not suffer any adverse treatment as a result of an individual's lawful decision to access voluntary assisted dying.

There were a range of views on this topic in the Panel. Ultimately the Panel has prioritised the importance of maintaining a family's privacy and therefore recommends that voluntary assisted dying not be recorded as the cause of death on the Medical Certificate Cause of Death.

Manual Death Registration Form

The Panel understands that the Manual Death Registration Form is completed by the funeral director and forwarded to the Registrar of Births Deaths and Marriages.

The Panel has been advised by the Registrar that 85% of death notifications by funeral directors are received via an on-line portal and the remaining 15% of death notifications are provided via the manual form.

The Manual Death Registration Form (including the on-line portal version) do not currently require the cause of death to be specified. Accordingly, the Panel does not recommend any changes be made to this form as a consequence of a person accessing voluntary assisted dying.

Death Certificate

Whilst the Panel received a variety of feedback on the question of whether voluntary assisted dying should be recorded on the Death Certificate issued by the Registrar of Births Deaths and Marriages, the majority of that feedback supported not including this information on the Death Certificate. Whilst there was some feedback that this information should be recorded for accuracy reasons, there were other submissions that this information should not be recorded so as to protect the privacy of the individual and their family.

The Panel received submissions that inclusion of this information in a document that is received by the individual's family may cause the family some difficulty and distress in circumstances where they were unaware that their family member accessed voluntary assisted dying. In other instances, concern was expressed that the inclusion of this information on the Death Certificate may cause some difficulty for family members in communities where voluntary assisted dying is not acceptable.

Whilst the Death Certificate is only initially provided to the funeral director or the designated family member, the Panel understands that the Death Certificate may be required to be provided to a number of different people and organisations following a person's death, as part of dealing with the estate of the person.

In Victoria, voluntary assisted dying is not listed on the publicly available extract from the Births, Deaths and Marriages Register (also known as the Death Certificate).

Having considered the various matters raised during the consultation period, the Panel is of the view that voluntary assisted dying should not be included in the Death Certificate by the Registrar of Births Deaths and Marriages as a cause of death. Rather, the underlying illness or medical condition should instead be recorded. The Panel considers that this will protect the privacy of the individual concerned, and also record the fact that the person was diagnosed with an illness or medical condition that would have caused the death of the individual, and was the underlying cause of their death.

The Panel also notes that there are other reporting mechanisms in the proposed framework which will ensure that there is an accurate record of the fact that the person accessed voluntary assisted dying.

Reporting Voluntary Assisted Dying Deaths to the Coroner

The Panel is of the view that a death caused by voluntary assisted dying should not be a reportable death for the purposes of the *Coroners Act 1996*, and an amendment to that effect should be made.

The Panel was mindful of avoiding distress and anxiety to family members, including through the need for a post mortem examination and an investigation into the circumstances surrounding the death.

The Panel was of the view that a death which has occurred through the lawful process of voluntary assisted dying should not constitute a death that requires an investigation by the Coroner. However, the Panel agrees that it is important that there be a mechanism for oversight and review of deaths in circumstances where there is concern that the correct process has not been followed in some manner. The Panel recommends that the voluntary assisted dying oversight body has the authority to refer any such cases to the Coroner for investigation. This will require the oversight body to have real-time access to information regarding applications for voluntary assisted dying, and be in a position to consider and make referrals quickly following a person's death, in order to ensure maximum opportunity for the Coroner to take all necessary steps to conduct an investigation.

Ministerial Expert Panel recommendation 25:

Voluntary assisted dying not be recorded by the medical practitioner as the cause of death in Part 1(a) of the Medical Certificate Cause of Death or reported on the Death Certificate issued by the Registrar of Births Deaths and Marriages.

A separate reporting system should be established requiring the medical practitioner to inform the voluntary assisted dying oversight body when voluntary assisted dying is the cause of death of a person and requiring the voluntary assisted dying oversight body to inform the Registrar of Births Deaths and Marriages.

Policy intent:

To ensure the need for data collection and accurate recording keeping surrounding voluntary assisted dying and the underlying illness or medical condition is met, and to ensure the community's expectations for privacy and confidentiality are fulfilled.

Ministerial Expert Panel recommendation 26:

A death that occurs through voluntary assisted dying should not be a reportable death for the purposes of the *Coroners Act 1996* unless the death is referred to the Coroner by the voluntary assisted dying oversight body.

Policy intent:

To ensure that an appropriate mechanism is in place to report any concerns regarding deaths occurring through voluntary assisted dying to the Coroner for investigation, without otherwise lawful deaths occurring through voluntary assisted dying being the subject of an unnecessary investigation.

Part C: Oversight

Oversight

The Joint Select Committee on End of Life Choices outlined the following in relation to oversight of voluntary assisted dying:

Joint Select Committee recommendation:

7.89 Voluntary Assisted Dying Legislation Framework

Oversight

An oversight body must be established to:

- a. provide policy and strategic direction for the State of Western Australia;
- b. review all voluntary assisted dying deaths;
- c. provide community education and resources;
- d. provide health professional education and resources, including counselling and advice for practitioners;
- e. provide a telephone advice line;
- f. maintain a database of all relevant statistics related to assisted dying; and,
- g. provide an annual report to Parliament.

The Joint Select Committee

The Joint Select Committee recommended that there be appropriate oversight of voluntary assisted dying. It proposed an oversight body should be authorised and resourced to undertake a number of specific functions (as outlined above).²²⁶

Consultation Findings

In support of the Joint Select Committee recommendation for oversight, the Panel publicly consulted and sought expert stakeholder advice on how appropriate oversight may best be achieved in the Western Australian context. This included exploration of themes associated with oversight such as structure, membership, data and information, voluntary assisted dying review and complaints management.

Feedback from the consultation regarding the membership of an oversight body (such as a Board) was strongly in favour of there being representation from medical, health, mental health and legal practitioners as well as community members.

'Suggestion that listed membership should be consistent with the decisions being made: medical practitioners, legal practitioners (with experience in health, guardianship), pharmacist, members of the community'.

(Consultation stakeholder roundtable – Oversight)

226 'My Life, My Choice' report of the Joint Select Committee on End of Life Choices, Parliament of Western Australia (August 2018) 7.86.

The importance of data collection and information evaluation was evident from the consultations. It was recognised that this would serve a number of purposes including monitoring, evaluation and understanding the place and context of voluntary assisted dying. That this reporting and monitoring would also have a safeguard function was also emphasised.

'In considering what data to collect, it would be extremely valuable to collect information around reasons why people have chosen VAD. Understanding what has prompted a person to make this choice could facilitate improvements to models of care and care delivery.'

(Submission by the Australian College of Nursing)

'Data must be collected, monitored and reported in a manner that can pinpoint abuse at an individual and population level.'

(Submission by the Royal Australasian College of Physicians)

The consultation raised the need for clear complaints processes and included commentary that this ought to be handled through existing mechanisms where possible.

'...as for other complaints against doctors and healthcare providers involving issues of clinical judgement and compliance with laws and professional standards, these should be handled within existing mechanisms'.

(Submission by the Medical Insurance Group of Australia)

'We highlight that the National Scheme provides a well-established notification and complaint system for registered health practitioners'.

(Submission by the Australian Health Practitioner Regulation Agency)

Consultation feedback in relation to aspects associated with training, education and information for the community and for health professionals (and associated care staff) has been addressed in other sections of this Report – refer to the section on Process (particularly [Access](#)) and the section on [Education and Training](#).

Discussion

The Joint Select Committee recommendation for an oversight body with a retrospective review and reporting function is consistent with many jurisdictions that have legislated for a form of voluntary assisted dying (refer [Appendix 5](#)). In the Netherlands the review panel consists of a medical physician, a lawyer and an ethicist.²²⁷ In Victoria, the members of the oversight Board are appointed as deemed appropriate by the Minister – the Act does not specify qualifications or number of members.²²⁸

The Panel has carefully considered the Joint Select Committee's Framework, the consultation findings and evidence associated with oversight in other jurisdictions.

The Panel acknowledges that there is a place for good oversight and the functions listed in the Joint Select Committee Legislation Framework. It is noted that each of these functions would need to be carried out by an appropriate body (for example, some functions would sit well with a statutory body such as a Board and others with the Department of Health).

227 Regional Euthanasia Review Committees, <https://english.euthanasiecommissie.nl/the-committees/the-committees>.

228 *Voluntary Assisted Dying Act 2017* (Victoria).

The creation of a statutory body such as a Board to review and monitor voluntary assisted dying in Western Australia would be both a key safeguard and a practical source of advice or recommendations to Government. It would be expected that the oversight body would receive relevant forms from the practitioners involved in the voluntary assisted dying process to enable review, analysis and reporting (including reporting to Parliament). The oversight body may seek further information as needed and could refer matters to other relevant authorities if required (for example compliance or professional misconduct issues).²²⁹

In regards to membership of an oversight body, the Panel considered that any such body would be best served by members that not only reflected the requirements of the voluntary assisted dying process but also the citizens of the state of Western Australia (for example in cultural, gender and geographic diversity). Membership should include appropriately skilled and experienced medical, legal, pharmacy and community representatives.

Ministerial Expert Panel recommendation 27:

The membership of the voluntary assisted dying oversight body should comprise a suitable mix of appropriate and relevant medical, legal and pharmacy expertise related to voluntary assisted dying as well as community representation and be reflective of the citizens of Western Australia.

Policy intent:

To ensure that the oversight body is able to appropriately and effectively undertake its functions and responsibilities.

To ensure that the oversight body is contemporary and representative of the citizens of Western Australia.

There are already pathways and processes that exist for people to raise concerns in relation to health and medical treatment or services. The Health and Disability Services Complaints Office (HaDSCO) operates as an impartial complaints resolution service for Western Australian health, disability and mental health services.²³⁰ The Australian Health Practitioner Regulation Agency (AHPRA) has a primary consideration in protecting the public and works with the National Health Practitioner Boards (each of which has a Code of Conduct by which registered practitioners are obliged to abide).²³¹

The Panel acknowledges the Joint Select Committee Legislation Framework recommendation in relation to maintaining a database of all relevant statistics related to voluntary assisted dying. There would need to be consideration given to the type of data collected about voluntary assisted dying to ensure that it is comprehensive enough to meet the reporting requirements of the oversight body as well as deepening knowledge about voluntary assisted dying.

229 Ministerial Expert Panel on Voluntary Assisted Dying Discussion Paper, Department of Health, Western Australia (2019).

230 Health and Disability Services Complaints Office <https://www.hadSCO.wa.gov.au/home/>.

231 Australian Health Practitioner Regulation Agency, Regulatory principles for the National Scheme <https://www.ahpra.gov.au/About-AHPRA/Regulatory-principles.aspx>.

Noting that many jurisdictions undertake reporting in relation to assisted dying,²³² the Panel was particularly interested to learn of the approach to data collection now being undertaken in Canada. In his meeting with the Panel,²³³ Dr James Downar described that since November 2018, a new federal approach to data collection has been adopted that includes data elements beyond those solely relating to the voluntary assisted dying process (for example whether or not the person was receiving palliative care?; if so, for how long?; if not, was palliative care accessible for the person? etc).²³⁴

From these examples the Panel considers that data collection by the oversight body should include elements such as:

- aspects related to the person (demographics, medical condition/s, vulnerable population group)
- aspects related to the care status of the person (palliative care, other support services involved)
- aspects related to the practitioners involved (type, location)
- voluntary assisted dying eligibility / ineligibility status (and reasons)
- voluntary assisted dying procedural data and benchmarks
- aspects related to medication prescription
- aspects related to medication administration (planned and actual, location)

The Panel acknowledges, there are leading end of life researchers in Western Australia that could contribute to the development of these data requirements. The Panel further acknowledges the importance of balancing data collection with not unduly creating administrative burden.

Ministerial Expert Panel recommendation 28:

Data collection in relation to voluntary assisted dying should include all aspects of the process of voluntary assisted dying and comprehensive information relating to the person accessing voluntary assisted dying.

Policy intent:

To enhance current and future knowledge and understanding of voluntary assisted dying in the broader context of end of life.

232 Final Report of the Ministerial Advisory Panel on Voluntary Assisted Dying, State of Victoria, Department of Health and Human Services (2017).

233 Panel meetings with Dr James Downar (Head, Division of Palliative Care, University of Ottawa) and Tanya Burr (Palliative Clinical Nurse Practitioner Lead, Central East, Local Health Integration Network, Ontario (May 2019).

234 'Regulations for the Monitoring of Medical Assistance in Dying', Government of Canada (2018).

Education and Training

The Joint Select Committee on End of Life Choices outlined the following in relation to education and training in relation to voluntary assisted dying:

Joint Select Committee recommendation:

7.89 Voluntary Assisted Dying Legislation Framework

An oversight body must be established to:

- a. provide policy and strategic direction for the State of Western Australia;
- b. review all voluntary assisted dying deaths;
- c. provide community education and resources;**
- d. provide health professional education and resources, including counselling and advice for practitioners;**
- e. provide a telephone advice line;
- f. maintain a database of all relevant statistics related to assisted dying; and,
- g. provide an annual report to Parliament.

The Joint Select Committee

The Joint Select Committee recommended that the oversight body provide education and resources for both the community and health practitioners. While this is primarily an area for implementation the Panel acknowledges the importance of education and training in ensuring safe and compassionate processes for voluntary assisted dying.

Consultation Findings

The importance of education and training for medical practitioners, other health practitioners and the wider community was a consistent theme throughout the consultation. The richness of information received from forums, roundtable discussions and submissions will be an invaluable resource during the implementation period when the specific components of the training would be developed.

Co-ordinating and consulting practitioners

The consultation demonstrated strong backing for approved training being mandatory before a medical or nurse practitioner is able to undertake the process for voluntary assisted dying. Several submissions identified that a core component of this mandatory training would need to be an assessment to ensure competency prior to endorsement.

Submissions to the Panel highlighted many aspects for inclusion in the training for medical or nurse practitioners involved in the voluntary assisted dying process.

The Panel heard that there should be an emphasis on communication training to ensure that the practitioner feels confident and is skilled in having difficult conversations about death and dying in a culturally competent manner. Further to this, support for the integration of competencies relating to working with people from culturally and linguistically diverse communities with the requisite clinical and procedural education was raised during consultation.

‘Training is essential for those who provide voluntary assisted dying particularly in communication skills and eliciting and responding to suffering and distress.’
(Submission by Palliative Care WA)

Consistent feedback was received that training would need to include relevant skills for assessment of eligibility for voluntary assisted dying with a strong focus on assessment of decision-making capacity, voluntariness and when to refer to other health practitioners.

‘The WA Branch [of Royal Australian and New Zealand College of Psychiatrists] suggests that training be provided to non-psychiatrically trained professionals by psychiatrists with relevant expertise, and that resources be developed covering:

- *Screening tools for mental disorders and neuropsychiatric conditions*
- *Other risk factors to look out for, including vulnerable populations, such as older, isolated women, who may seek access to PAS [VAD] more often*
- *Guidance on the appropriate use of telehealth, noting its potential to increase access but also to compromise the integrity of assessments*
- *How to interact with families/carers, and what to do when a patient does not wish to involve their family.’*²³⁵

Practitioners would also need to be able to provide accurate information about all relevant end-of-life care options for the person, including palliative care.

‘Communication with people at end of life, their families and caregivers, including during bereavement requires specific competencies... This should form part of any mandatory training before a medical practitioner is able to undertake the process for voluntary assisted dying.’ (Submission by the Australian and New Zealand Society of Palliative Medicine)

The Panel also received recommendations that training should develop the skills and knowledge of practitioners to enable greater engagement with people with disabilities and other population groups.

The need for support for practitioners involved in the process was raised by both medical practitioners and community members:

‘In the event that a system of voluntary assisted dying is introduced, there must be counselling services and psychological support for any individual involved in the provision of voluntary assisted dying services.’ (Submission by the Australian Medical Association – WA)

Suggested key competencies for the mandatory training for medical and nurse practitioners included:

- an overview of the Act and its ethical and legal implications for practitioners
- knowledge of evidence for best practice palliative care
- cultural competency (including understanding the perspectives of people from different beliefs and faiths)
- guidelines for end of life discussions
- support for families or where to refer them to for support
- details of the voluntary assisted dying process including the obligations of the practitioner at each stage
- assessment including eligibility, decision-making capacity, voluntariness and identifying coercion (particularly as relates to groups such as people with disability or mental health issues)

²³⁵ Submission: by the Royal Australian and New Zealand College of Psychiatrists (WA Branch) to Joint Select Committee on End of Life Choices (18 October 2017).

- pharmacology and administration of the voluntary assisted dying substance
- documentation and reporting requirements
- death certification
- access psychological and peer / mentoring support

The consultation emphasised to the Panel that training must be easily accessible so that it does not become a barrier to access, particularly for rural and remote areas of Western Australia. Furthermore, training must be widely available and not overly time consuming to enable a practitioner to be trained within a timely manner to respond to a request from a person. Several submissions looked to the Victorian model of online training as an appropriate format for Western Australia.

There was strong opinion that in the long term, education about the ethical, legal and practical aspects of voluntary assisted dying should be incorporated into tertiary education curriculums and continuing professional development. This should not be seen to replace, but rather complement, the mandatory training program for medical and nurse practitioners directly involved in the process.

Pharmacists

For those pharmacists involved in the voluntary assisted dying process, specific education and training would need to be designed and implemented.

Other health practitioners

It was raised in several submissions and in discussions with stakeholders that training should be available for all those involved in the care of people at end of life including, but not limited to, nurses, allied health professionals and care workers.

Although not formally part of the voluntary assisted dying process they would continue to play a key role in the support and care of those who would likely request access.

'It is very likely that nurses will be asked about VAD by both patients and their families, and it is necessary that they have a comprehensive understanding of the process, the legal implications and how to appropriately discuss VAD... It is imperative that nurses are adequately informed about VAD, their professional obligations and role and the nexus with their scope of practice. It is equally essential that nurses are educated about how they can support patients who request VAD and can continue to provide care.'

(Submission by the Australian College of Nursing)

Feedback from roundtable discussions, organisational and community submissions also identified the need for counselling services and peer support for all health practitioners involved in the voluntary assisted dying process.

Community education

Community education was raised primarily in the context of enabling access to voluntary assisted dying (refer to the section on [Access](#)).

It was recommended that community information and education be provided by 'a limited number of specialised organisations'²³⁶ and be disseminated to the community via health professionals, health care facilities and online. The Panel heard support for providing community information in a range of accessible formats and in languages other than English. It was also noted that information should

236 Submission: by the Disability Health Network (Department of Health) to the Ministerial Expert Panel on Voluntary Assisted Dying (2019).

be provided in accessible plain language given approximately 60% of Australians have low levels of individual health literacy.²³⁷

Some submissions highlighted that appropriately informing the community would need to be done with care and consideration for the complexity of decisions about end of life.

'If assisted dying becomes law in Western Australia there will need to be adequate public education and awareness about its availability... [this] should be communicated concurrently with information about palliative care, and needs to be strictly controlled to ensure that assisted dying is not, whether explicitly or subtly, promoted in a way that risks positioning assisted dying as the community's expectation for people with terminal illnesses...'
(Submission by the Cancer Council – WA)

Discussion

Education of health professionals would be vital to ensuring the voluntary assisted dying process is undertaken appropriately and safely.²³⁸ As such investment in the preparation of education and training programs would be paramount.

Evidence from Canada illustrates the importance of establishing these programs early – the Canadians were 'playing catch-up' with infrastructure for training and education for some time after the laws changed in 2016.²³⁹ In contrast, during the 18 month implementation period in Victoria, training modules for medical practitioners have been developed by the Department of Health and Human Services and made available online for medical practitioners to complete in advance of commencement of the Victorian *Voluntary Assisted Dying Act 2017* in June this year.²⁴⁰ Community and consumer information has been developed in parallel and can also be accessed via the Victorian Department of Health and Human Services website.²⁴¹

The Panel recommends that any implementation taskforce should seek to learn from the Victorian approach to ensure best practice preparation in Western Australia. Training and education programs for health practitioners should be developed in collaboration with peak professional bodies with a particular focus on cultural context and culturally competent practice given the diversity of the Western Australian population. Community information should be developed in consultation with health practitioners, consumer groups and members of different culturally and linguistically diverse communities.

The Panel believes that best practice preparation coupled with the requirement of online mandatory training for those practitioners directly involved in the voluntary assisted dying would be a key safeguard in an accessible and workable voluntary assisted dying process for Western Australia. The availability of optional training for those health professionals who provide care for people most likely to seek access to voluntary assisted dying would enable well-informed and supported discussions to take place.

237 *Health Literacy: taking action to improve safety and quality*, Australian Commission on Safety and Quality in Health Care (August 2014).

238 Ministerial Expert Panel on Voluntary Assisted Dying Discussion Paper, Department of Health, Western Australia (2019).

239 Downie J, 'Medical Assistance in Dying: Lessons for Australia from Canada' (2017) QUT Law Review, vol. 17, Issue 1, pp. 127-146.

240 Victoria State Government, Voluntary assisted dying training for medical practitioners <https://www2.health.vic.gov.au/hospitals-and-health-services/patient-care/end-of-life-care/voluntary-assisted-dying/medical-practitioner-training>.

241 Victoria State Government, Community and consumer information <https://www2.health.vic.gov.au/hospitals-and-health-services/patient-care/end-of-life-care/voluntary-assisted-dying/community-and-consumers>.

The Panel considered evidence from other jurisdictions such as Oregon and Canada indicating that mentoring and support for those working with voluntary assisted dying is essential.²⁴² Whilst the Panel acknowledges that peer support networks and mentoring programs evolve with time, it recommends that any implementation taskforce recognise the importance of establishing a framework that not only enables but encourages these networks to develop.

Ministerial Expert Panel recommendation 29:

Mandatory training and education provided to those seeking to become co-ordinating and consulting practitioners for voluntary assisted dying should be informed by the Panel's consultation.

Voluntary assisted dying mandatory training for co-ordinating and consulting practitioners must include a focus on ensuring the voluntary and valid decision of the person.

All training in relation to voluntary assisted dying must promote culturally competent practice in relation to voluntary assisted dying.

Policy intent:

To ensure that the mandatory training and education is effective in promoting the competencies required by practitioners to complete the voluntary assisted dying process in a way that is safe, effective and culturally appropriate.

242 Ministerial Expert Panel on Voluntary Assisted Dying Consultation meeting with: Dr James Downar (Head, Division of Palliative Care, University of Ottawa) and Tanya Burr (Palliative Clinical Nurse Practitioner Lead, Central East, Local Health Integration Network, Ontario) (May 2019); and Dr David Grube (Medical Director Compassion and Choices; experienced assisted dying practitioner in Oregon, USA) (June 2019).

Part D: Implementation

Implementation

The Panel was cognisant of the need for workable legislation throughout its considerations. The Victorian implementation phase is due to conclude in mid-June 2019; from this time people will be able to request access to voluntary assisted dying. Lessons learnt as part of Victorian implementation will be invaluable for Western Australia and will help to guide planning for any implementation period required. It should be noted, however, that the uniqueness of Western Australia in its geography and great diversity of cultures and languages will present its own challenges for implementation and as such the Victorian process cannot be followed indiscriminately.

The richness of the consultation findings outlined in this report should be used as a solid foundation for the implementation taskforce to work from. Despite this, an adequate period of time – at least 18 months – will be required to enable Government and health services to plan, consult on and develop guidelines and protocols to ensure that the legislation is translated safely, effectively and appropriately for Western Australia.

It is imperative that the legislation be reviewed at regular intervals in the future. Initially it will be important to identify any issues with the voluntary assisted dying legislation and to review whether it has been enacted and implemented appropriately. The Panel recommends that this occurs three years from the commencement of the legislation. Reviews every five years thereafter would be sufficient to ensure that the legislation remains in line with contemporary views and practices.

Ministerial Expert Panel recommendation 30:

There should be at least an 18 month period between passage and commencement of voluntary assisted dying legislation.

Policy intent:

To enable sufficient time to plan, consult on and develop guidelines and protocols to ensure that the legislation is translated safely, effectively and appropriately for Western Australia.

Ministerial Expert Panel recommendation 31:

The legislation should initially be reviewed three years after the date of operation of the legislation, and every five years thereafter.

Policy intent:

To ensure that the legislation remains in line with contemporary views and practices.

Part E: Beyond the Scope of the Panel



Beyond the Scope of the Panel

Background

This section of the Report explores concerns that were raised during the Panel's consultation that were not within the terms of reference of the Panel to address.

More specifically these relate to the issues and complexities of people who have lost, or may lose, decision-making capacity in relation to access to voluntary assisted dying.

There were two main themes that emerged during the consultation:

1. the community expectation of being able to access voluntary assisted dying when dementia is present; and,
2. the expressed wish for being able to add voluntary assisted dying to an Advance Health Directive in the event that the person might develop dementia (or in the early stages of having dementia before decision-making capacity is lost).

The Panel acknowledges the depth and breadth of such views expressed during consultation. The Panel also acknowledges the intensity of feeling that accompanied many of these expressed views.

All of this has been heard, understood and discussed at length by the Panel.

Dementia and requests for voluntary assisted dying

Consultation Findings

A significant theme emerging from the general community during consultation was consideration for people who have a disease, such as dementia, where they may have decision-making capacity in the early stages of the disease process but have lost decision-making capacity once the disease has reached an advanced stage.

The Panel heard first-hand from people who had experience of dementia; some of whom were living with the early stages of dementia, some of whom were caring for or working with people with dementia. The distressing and challenging nature of the disease and its impact on the person, their family and friends was evident and the Panel wishes to acknowledge the honesty and willingness of those people in sharing their experiences.

The Panel acknowledges that there are many differing views on this topic.

Concern was expressed by individual members of the public that people living with dementia would not be able to access voluntary assisted dying and that this was inconsistent with what they thought should be the case.

'My original decision should be honoured.'
(Participant at the Bunbury Public Forum)

Conversely, many were firmly committed to the principle that decision-making capacity was imperative at every stage in the voluntary assisted dying process and that once decision-making capacity was lost you couldn't really know for sure what decision the person would make.

‘a patient who loses capacity should not be eligible for voluntary assisted dying’.
(Submission by the Australian Medical Association – WA)

‘The process should be stopped forthwith.’
(Participant at the Metro North Public Forum)

Discussion

The Joint Select Committee recommended that the person must have decision-making capacity in relation to voluntary assisted dying throughout the process.²⁴³ The Panel acknowledges and agrees with this recommendation (refer to the section on [Eligibility](#)).

The requirement for decision-making capacity in relation to a decision about voluntary assisted dying is consistent with the Guiding Principle ‘People who may be vulnerable should be protected from coercion and abuse in relation to end of life choices and decisions’ (refer to the section on Guiding Principles).

The Panel notes that while dementia is recognised as a terminal medical condition, and is the second leading cause of death in Australia, people may live for many years with dementia and a person’s decision-making capacity will change over time with cognitive ability typically declining throughout the course of the disease.²⁴⁴

The voluntary assisted dying eligibility criterion which requires the person’s terminal illness or disease to be ‘advanced and progressive’ (refer to the section on [Eligibility](#)) would usually mean that a person with dementia does not have decision-making capacity at that stage of the disease process. There may be rare occasions where a person with dementia meets all aspects of the eligibility criteria.

Some people are of the opinion that this discriminates against people living with dementia, or against people who may develop dementia in the future. The Panel is sympathetic to, and understands the community’s concerns on this topic.

The Panel is clear in its view, however, that in order to provide fundamental safeguards, protect individual autonomy and maintain the integrity of the voluntary assisted dying process, a person must have decision-making capacity at all stages in the process. The person must have decision-making capacity in order to make a choice or request to administer or be administered the lethal dose of medication.

For people who have lost decision-making capacity, it is not possible to validly confirm that they want to proceed with administering the lethal dose of medication. These decisions would require the subjective judgement of a third party, thus negating the voluntary nature of the decision and over-riding a fundamental safeguard.

The issue was well expressed by Alzheimer’s WA and serves to illustrate the difficulty with this scenario:

‘In contemplating how to create provisions regarding capacity to provide access to a choice regarding VAD for those with dementia, the matter is further complicated by the person with dementia’s inability to rescind a decision throughout or later in the decision-making process’.
(Submission by Alzheimer’s WA)

243 *‘My Life, My Choice’* report of the Joint Select Committee on End of Life Choices, Parliament of Western Australia (August 2018).

244 Deaths in Australia, Australian Institute of Health and Welfare (July 2018) <https://www.aihw.gov.au/reports/life-expectancy-death/deaths-in-australia/contents/leading-causes-of-death>.

Requesting voluntary assisted dying in Advance Health Directives

Consultation Findings

Closely related to the issues surrounding access to voluntary assisted dying for someone with dementia were the strong views expressed in relation to being able to include voluntary assisted dying in an Advance Health Directive.

The Panel frequently heard from people that they felt this would be a useful function for managing situations at end of life that they imagined would bring significant suffering.

Discussion

The purpose of an Advance Health Directive is to outline a person's treatment decisions for a time in the future when they are not able to make or communicate their own decisions.²⁴⁵

There are many issues in relation to a request for voluntary assisted dying in an Advance Health Directive or as an advance request. The person would need to identify the precise point at which they would wish to die in advance of reaching that point – this may be highly unreliable as the person may identify a situation that their future self does not indeed find intolerable and may actively refuse. A third party would be required to interpret the patient's current state of health and suffering and anticipate their wishes to proceed or not with assisted dying; this would potentially place a significant burden on that third party.

These are but a few of the myriad concerns in relation to advance requests for voluntary assisted dying. Throughout the consultation, it became evident that there are differing views regarding whether voluntary assisted dying is a treatment or not. The position of the Western Australian Public Advocate is that voluntary assisted dying would not be considered a treatment under the *Guardianship and Administration Act 1990*.²⁴⁶

Whilst the Panel acknowledges the perspectives of those that indicated preference for a system that would allow advance request of assisted dying, it is beyond the scope of this Panel to consider at this point in time.

Impact of voluntary assisted dying on insurance provisions

During the consultation process, the Panel frequently heard from members of the community who were concerned that a death from voluntary assisted dying may have an adverse impact on life insurance, in a similar way that an act of suicide may have an impact on life insurance.

Discussion

The impact of voluntary assisted dying on insurance provisions was explored in South Australia when the *Death with Dignity Bill 2016* was introduced into Parliament.

245 Government of Western Australia, Office of the Public Advocate https://www.publicadvocate.wa.gov.au/A/advance_health_directives.aspx.

246 Ministerial Expert Panel on Voluntary Assisted Dying Consultation Stakeholder Roundtable: People with a disability (2019).

Clause 30 of the *Death with Dignity Bill 2016* (South Australia)²⁴⁷ provided as follows:

1. An insurer is not entitled to refuse to make a payment that is payable under a life insurance policy on the death of the insured on the ground that the death resulted from the administration of voluntary euthanasia (and any clause in a life insurance policy that is inconsistent with this subsection will be taken to be void and of no effect).
2. This section applies despite an agreement between a person and an insurer to the contrary.

Anecdotal evidence indicates that the Financial Services Council (representing the life insurance industry) was critical of this clause.

Under section 51 (xiv) of the Constitution of the Commonwealth, the Commonwealth has legislative power with respect to 'Insurance, other than State insurance; also State insurance extending beyond the limits of the State concerned'.²⁴⁸ This is not an exclusive power but a Commonwealth law would override any inconsistent State laws. The *Insurance Act 1973* (Cth), the *Insurance Contracts Act 1984* (Cth) and the *Terrorism Insurance Act 2003* (Cth) are examples of Commonwealth legislation relating to insurance. If consideration is given to the inclusion of a clause in the Bill which is similar to clause 30 of the South Australian Bill, then it would be important to ensure that the clause is not inconsistent with any Commonwealth legislation.

Furthermore, insurance policy terms and conditions are a private contractual matter between the person and the insurance company. Life insurance policies vary, and individual circumstances vary regarding policy coverage. If a person has a pre-existing life insurance policy with an insurer, the issue of whether the person is covered for voluntary assisted dying depends on the terms of the insurance policy. It is open to an insurer to refuse to provide life insurance cover to any person.

It is worthy of noting that life insurance policies commonly include terminal illness cover. This means that in the event that a person is diagnosed with a terminal illness and is not expected to live more than a specified period (for example 12 months) they will be entitled to receive their benefits in full prior to their death. This aligns with the Panel's recommendation regarding eligibility criteria for voluntary assisted dying in respect to time to death: *That death is a reasonably foreseeable outcome for the person within a period of 12 months* (refer to the section on Eligibility). Some life insurance policies provide coverage for intentional self-inflicted acts. However, there is generally an exclusion period before the insurer is liable to pay a monetary benefit on the occurrence of such an event.

The Panel understands the community's concern about the potential impact of voluntary assisted dying on insurance provisions; however, it is outside of the Panel's Terms of Reference to make recommendations on this point.

²⁴⁷ *Death with Dignity Bill 2016* (South Australia).

²⁴⁸ Australian Constitution.

Appendix 1: Joint Select Committee Voluntary Assisted Dying Legislation Framework²⁴⁹

7.89 Voluntary Assisted Dying Legislation Framework

Preamble

The Government should introduce legislation to provide for voluntary assisted dying.

The legislation should not merely provide a criminal defence to those assisting an eligible person to die. Nor should it merely provide for a change to prosecution guidelines relating to the prosecution of those assisting an eligible person to die. Rather, the legislation should reform the law with a standalone Act that permits voluntary assisted dying to eligible people in accordance with strict criteria.

The WA Government should establish a panel of experts to consider the implementation of legislation for voluntary assisted dying, based on the elements contained in this framework.

Assisted dying

The legislation should provide for self-administration of lethal medication where an eligible person is physically able to self-administer. In cases where the person is eligible but physically incapable of self-administration, the legislation should permit a doctor to administer the lethal medication.

Eligibility

Eligible Conditions

The legislation is intended to provide assisted dying for those for whom death is a reasonably foreseeable outcome as a result of an eligible condition.

An eligible condition is an advanced and progressive:

- a. terminal illness or disease;
- b. chronic illness or disease; or
- c. neurodegenerative illness or disease,

where death is a reasonably foreseeable outcome of the condition.

The person's suffering

The person's suffering must not be temporary nor able to be treated or remedied in a manner acceptable to the person. The suffering:

- a. must be related to an eligible condition;
- b. must be grievous and irremediable;
- c. cannot be alleviated in a manner acceptable to the person; and
- d. must be subjectively assessed – that is, from the person's point of view.

²⁴⁹ 'My Life, My Choice' report of the Joint Select Committee on End of Life Choices, Parliament of Western Australia (August 2018).

Age

The person must be aged 18 years or over.

Capacity

In order to request assisted dying the person must have decision-making capacity in relation to a decision about voluntary assisted dying.

Residency

Eligibility requires ordinary residence in Western Australia and either Australian citizenship or permanent residency.

Assessment

Two doctors must assess the person. Either or both doctors can be a general practitioner and neither doctor is required to be a specialist regarding the person's disease or illness. Each doctor must be independently satisfied that:

- a. the person is aged 18 or over;
- b. the person is ordinarily resident in Western Australia;
- c. the request is voluntary, made without coercion or duress;
- d. the person has decision-making capacity in relation to a decision about voluntary assisted dying;
- e. the person has an advanced and progressive: terminal, chronic or neurodegenerative illness or disease;
- f. the person has grievous and irremediable suffering due to the disease or illness that cannot be alleviated in a manner acceptable to the person; and
- g. death is a reasonable foreseeable outcome of the condition.

Referral for specialist assessment

A person is not required to undergo consultant or specialist assessment except where either doctor is unable to determine:

- a. the precise nature of the disease or illness, in which case they must refer to a specialist in the relevant area of medicine.
- b. whether the disease or illness is advanced and progressive, in which case they must refer to a specialist in the relevant area of medicine.
- c. whether death is reasonably foreseeable.
- d. capacity, and/or absence of coercion, in which case they must refer to a consultant psychiatrist or a consultant geriatrician as appropriate.

Procedure

A person must make an initial verbal request to a doctor to access assisted dying. A doctor must include a record that a verbal request has been made in a medical record. Following this request, providing that the doctor does not personally object to voluntary assisted dying, they must provide the person with information regarding:

- a. the nature of the disease or illness;
- b. the prognosis;
- c. any possible curative treatments;
- d. any available palliative treatments;
- e. the nature, effects and risks of the lethal medication that may be prescribed; and
- f. that the person's consent to assisted dying may be withdrawn at any time.

The person must provide the initial assessing doctor with a signed written request using a standard template. The written request must be filed with the oversight body.

The doctor should then carry out the assessment as described above. If satisfied that the person meets the assessment criteria, the doctor should complete a standard template referral to a second assessing doctor.

The second assessing doctor must then also carry out the assessment as described above. The second assessing doctor must then provide the initial doctor with written advice regarding the outcome of the assessment. The written advice must be filed with the oversight body.

The initial assessing doctor must inform the person of the results of the assessment. If both doctors concur that the person meets the assessment criteria, and the person makes a further verbal request to access assisted dying, the initial assessing doctor may provide the prescription for the lethal medication to the person and must provide instructions on the manner of use.

Timelines for each step in the process should be advised by the expert panel to ensure integrity in the process without unnecessary delay.

Reflection period

In order to provide a period of reflection a prescription for medication must not be filled sooner than prescribed under the legislation as determined by the expert panel.

Personal objection

At the time the patient makes the first verbal request, any doctor with a personal objection to providing assisted dying must inform the patient of the objection and offer to refer the patient to a doctor who is willing to provide assistance.

Where a person is an inpatient in a health service unwilling to provide assisted dying, that service must facilitate timely transfer to another service.

Non-discrimination

Mental Illness

A person with a mental illness who meets the eligibility criteria shall not be denied access to voluntary assisted dying.

Disability

A person with a disability who meets the eligibility criteria shall not be denied access to voluntary assisted dying.

Medication

The choice of lethal medication for voluntary assisted dying should remain a clinical decision based on the prescribed list of medications for this purpose. The WA Government should review current federal laws in relation to scheduling of medication in Australia, and negotiate with the Federal Government and the Therapeutic Goods Administration for the use of the best medication(s) for assisted dying.

Pharmacists dispensing lethal medication(s) must report the dispensing of the medication to the oversight body.

Death Certification

Where an assisted death takes place it must be noted on death certification documents.

The WA Government should amend the:

- a. Medical Certificate Cause of Death – completed by the doctor certifying cause of death;
- b. Manual Death Registration Form – completed by the funeral director to register a death; and
- c. the Death Certificate – issued by the Registrar of Births Deaths and Marriages,

to make provision for the inclusion of voluntary assisted dying as a contributing cause of death, and to provide guidance for doctors and others who complete each of the documents.

Oversight

An oversight body must be established to:

- a. provide policy and strategic direction for the State of Western Australia;
- b. review all voluntary assisted dying deaths;
- c. provide community education and resources;
- d. provide health professional education and resources, including counselling and advice for practitioners;
- e. provide a telephone advice line;
- f. maintain a database of all relevant statistics related to assisted dying; and
- g. provide an annual report to Parliament.

Appendix 2: Ministerial Expert Panel on Voluntary Assisted Dying Terms of Reference

Terms of Reference

1. Purpose

The Voluntary Assisted Dying Ministerial Expert Panel (**MEP**) will provide advice to the WA Government to assist in the development, consultation and implementation of new legislation for Voluntary Assisted Dying in Western Australia.

2. Background

As a result of the inquiry into the need for laws in Western Australia to allow citizens to make informed decisions regarding their own end of life choices, the report of the Parliamentary Joint Select Committee (**Committee**) on End of Life Choices *'My Life, My Choice'* was released in August 2018.

The Committee made 24 recommendations. 12 of the recommendations relate to the provision of palliative care; 6 relate to advance care planning and the need for statutory recognition of Advance Health Directives; and 6 relate to voluntary assisted dying.

Recommendations 19 - 24 relate to the introduction, by Government, of a legal framework for voluntary assisted dying in Western Australia. Recommendation 21 specifically recommends the establishment of a Ministerial Expert Panel (MEP) to undertake consultation and develop legislation for voluntary assisted dying in Western Australia.

Importantly, the development and introduction of the voluntary assisted dying legislation is being progressed in parallel to the End-of-Life Care program which is designed to improve access to end-of-life and palliative care services, as well as improved policy and practice, governance, and education for health professionals and the wider community on advance care planning and Advance Health Directives.

3. Role

The MEP will provide advice to government to assist in the development, consultation and implementation of new legislation for voluntary assisted dying.

The MEP will take the findings and recommendations of the JSC report *'My Life, My Choice'* including consideration of the recommended voluntary assisted dying framework, and consider the detail of how voluntary assisted dying legislation could be implemented safely and compassionately in Western Australia.²⁵⁰

As such, the MEP's remit is to consider the 'how' of voluntary assisted dying, using the context of the Victorian Legislation as a starting point and proposing amendments that reflect the Joint Select Committee's findings and recommendations and to meet the needs of the Western Australian community.

250 *'My Life, My Choice'* report, Joint Select Committee on End of Life Choices Parliament of Western Australia, Perth (August 2018), recommendations 19-24 and key findings 37-52.

The MEP will do this by:

- a. Seeking expert advice on specific elements of voluntary assisted dying Legislation, and
- b. Undertaking public consultation on specific topics and clauses in the Bill.

This consultation will be based on key topics identified by the MEP, the Minister for Health, the Premier, Department of Health and Department of Justice.

The MEP will communicate and engage with stakeholders with a range of perspectives, harnessing their expertise and experience to develop advice on the access, safeguards, and practical considerations required to establish compassionate and safe voluntary assisted dying.

The MEP will consult with the following groups (including but not limited to):

- Medical, nursing and allied health professionals
- Consumer and carer groups
- Aboriginal and Torres Strait Islander advocacy groups
- Disability advocacy groups
- Legal organisations
- Mental health providers
- Health administrators
- Culturally and linguistically diverse advocacy groups
- Other subject matter experts

The MEP will develop and endorse policy positions and recommendations on specific elements for voluntary assisted dying legislation which will be used by Government to develop instructions for the final Bill.

The MEP should, at all times, apply the best interests of the WA community to all discussions and decisions over and above their own personal interests.

The role of the MEP is not to:

- a. replicate the consultations undertaken by the Committee Inquiry into End-of-Life Choices.
- b. consider the argument 'for' or 'against' for voluntary assisted dying.
- c. focus on the detail of any implementation required for the voluntary assisted dying legislation
- d. draft legislation – legislation will be drafted by the Parliamentary Counsel's Office based on the Government's final policy positions.

4. Membership

4.1. Chair

The Independent Chair will be appointed by Cabinet, on the recommendation of the Minister for Health.

The role of the Chair is to:

- Provide clear direction to facilitate a rigorous and timely decision-making process;
- Brief members on issues arising between meetings;
- Determine any items that require out-of-session consideration by the MEP;

- Act as the lead liaison between the MEP and Minister for Health;
- Lead the consultation process, including facilitating one-on-one consultation sessions with key stakeholders as required;
- Lead the development of policy positions and legislative recommendations;
- Be the representative of the MEP for media requests and inquiries,
- Ensure the MEP Terms of Reference are applied throughout the term of the MEP; and
- Provide ownership of the agenda.

The Deputy Chair will be appointed by Cabinet, on the recommendation of the Minister for Health, and will act as Chair in his or her absence.

4.2. Members

The role of a Member is to:

- Contribute to constructive debate on issues raised;
- Participate in targeted consultation as required;
- Provide advice to the Chair on all matters;
- Consider and review documents / issues out of session as required;
- Provide advice and endorsement of policy positions and legislative recommendations.

Membership consists of:

- Mr Malcolm McCusker AC QC (Chairman)
- Dr Penny Flett AO (Deputy Chair)
- Associate Professor Kirsten Auret
- Dr Scott Blackwell
- Dr Elissa Campbell
- Professor Phillip Della
- Ms Noreen Fynn
- Ms Kate George
- Dr Roger Hunt
- Ms Samantha Jenkinson
- Ms Maria Osman
- Ms Fiona Seaward
- Dr Simon Towler

4.3. Attendees

The Chair may invite non-members to participate if they are considered to be directly involved in the matter/s at hand, or have expertise to assist in advising on matters as required.

4.4. Accountability

The MEP will report to the Minister for Health as required.

4.5. Proxy Membership

All members are expected to attend all formal MEP meetings wherever possible.

5. Resources

The MEP will be supported by staff in the Minister for Health's office and the Department of Health who will:

- Undertake a secretariat role including compilation of agendas, document distribution and other coordination functions.
- Provide research, analysis and evaluation, including the identification and management of emerging issues, risks and trends at local, national and international levels and develop policy proposals and options to support the work of the MEP.
- Prepare reports, briefs and submissions (such as Cabinet and Parliament documents, Ministerial Briefs and correspondence, and discussion papers) on the legislative, regulatory and policy issues related to assisted dying.
- Coordinate and support stakeholder consultations and seek advice to resolve key issues and provide advice and input into the development of legislation and regulation.

6. Operating Procedures

6.1. Meeting Frequency

- Meetings will be held at a minimum of one meeting every month for one hour.
- The Minister or the Chair may convene additional meetings on an as needs basis.

6.2. Quorum

A quorum will consist of at least seven MEP members.

6.3. Meeting Documentation

- All meeting documentation intended for the MEP's consideration (including but not limited to reports, presentations, briefing notes) are to be provided to the Secretariat a minimum of five working days prior to the meeting.
- Late papers will only be circulated with approval from the Secretariat and Chair.
- At the discretion of the Chair, items may be considered out of session if deemed appropriate to review and/or requiring immediate attention in advance of a scheduled meeting.

6.4. Records

A decision and action log will be maintained by the Secretariat.

7. Term

The MEP will operate from November 2018 to July 2019 – or until such time as the Minister for Health determines the Panel has completed its purpose.

8. Conflict of Interest

A declaration of conflict of interest is required where a member has competing professional or personal interests. In this instance and on advice from the Chair, the member will either refrain from voting/participating in consensus decision-making or retire from the room for that Agenda Item. All declarations of conflicts of interest will be recorded in the minutes.

9. Confidentiality

MEP members will be in receipt of information that is regarded as confidential. Members acknowledge their responsibility to maintain confidentiality of all information that is not in the public domain, and will maintain all documents in a confidential manner separate from any other business or responsibilities.

10. Change Log

Version	Date	Commentary
1.0	Dec 2018	
2.0	Jan 2019	<ul style="list-style-type: none">• Removal of Cabinet-in-Confidence status• Addition of Appendix 1: MEP Guiding Principles• Submission of draft v2.0 to MEP meeting 14/01/2019• Addition of Nursing Rep and CALD rep• Addition of Guiding Principles amendments
3.0	Feb 2019	<ul style="list-style-type: none">• Amendment to proxy membership• Addition of Aboriginal and CALD groups for consultation

11. Endorsement

Date	Approver	Signed
05/12/2018	V1.0 Endorsed at MEP meeting	

Terms of Reference

Appendix 1: Ministerial Expert Panel Guiding Principles

Background

The Ministerial Expert Panel (MEP) proposed adopting a set of fundamental principles to guide the voluntary assisted dying legislation development and consultation process. The guiding principles are drawn from the Final Report of the Victorian Ministerial Advisory Panel on Voluntary Assisted Dying (July 2017).²⁵¹ The Guiding Principles are consistent with the values identified in the Joint Select Committee on End of Life Choices 'My Life, My Choice' report (August 2018) and the WA Health Code of Conduct.^{252,253}

MEP Guiding Principles

- Every human life has equal value.
- A person's autonomy should be respected.
- A person has the right to be supported in making informed decisions about their medical treatment, and should be given, in a manner the person understands, information about medical treatment options, including comfort and palliative care.
- Every person approaching the end of life should be provided with quality care to minimise their suffering and maximise their quality of life.
- A therapeutic relationship between a person and their health practitioner should, wherever possible, be supported and maintained.
- People should be encouraged to openly discuss death and dying and the person's preferences and values should be encouraged and promoted.
- The person should be supported in conversations with their health practitioners, family, carers and community about treatment and care preferences.
- The person should be supported in their right to privacy and confidentiality in relation to their choices about treatment and care preferences.
- People are entitled to genuine choices regarding their treatment and care.
- There is a need to protect people who may be vulnerable in relation to end-of-life choices and decisions.
- All people, including health practitioners, have the right to be shown respect for their culture, beliefs, values and personal characteristics

Note: These Guiding Principles were adopted by the Ministerial Expert Panel as part of the Terms of Reference; they became a starting point for the Guiding Principles that went on to form Recommendation 1.

251 Ministerial Advisory Panel on Voluntary Assisted Dying Final Report, State of Victoria, Department of Health and Human Services (July 2017).

252 'My Life, My Choice' report, Joint Select Committee on End of Life Choices Parliament of Western Australia, Perth (August 2018) 7.14.

253 WA Health Code of Conduct, MP0031/16 v2.0, (Sept 2017).

Appendix 3: Glossary

Advance Health Directive

An Advance Health Directive (AHD) is a legal document that enables a person to make decisions now about the treatment they would want – or not want – to receive if they ever became sick or injured and were incapable of communicating their wishes. In such circumstances, their AHD would effectively become their voice.²⁵⁴

Chronic disease

'Term applied to a diverse group of diseases, such as heart disease, cancer and arthritis that tend to be long-lasting and persistent in their symptoms and development. Although these features apply to some communicable diseases (infections), the term is usually confined to non-communicable diseases.'²⁵⁵

Controlled drugs

These are substances which require restriction of manufacture, supply, distribution, possession and use to reduce abuse, misuse and physical or psychological dependence.²⁵⁶ Also known as Schedule 8 (S8) drugs.

Decision-making capacity

This refers to the ability of a person to make a decision. Capacity is decision specific – a person can have the ability to make one type of decision but not another. A person may have a disease, illness, brain injury or disability that impacts the ability to make some decisions but not all decisions – it cannot be assumed that someone does not have capacity just because they have one of these conditions. Capacity can fluctuate or vary depending on other factors such as stress, medication or infection.²⁵⁷

Departmental approval

This means approval by a government department or someone acting on behalf of a government department.

End of life

End of life is the timeframe during which a person lives with, and is impaired by, a life-limiting/ fatal condition, even if the prognosis is ambiguous or unknown. Those approaching end of life will be considered likely to die during the next 12 months.²⁵⁸

Grievous

(Of something bad) very severe or serious.²⁵⁹

254 Government of Western Australia, Office of the Public Advocate https://www.publicadvocate.wa.gov.au/A/advance_health_directives.aspx.

255 Australia's Health 2012: The thirteenth biennial health report of the Australian Institute of Health and Welfare, Australian Institute of Health and Welfare, Canberra (2012).

256 *Medicines and Poisons Act 2014*.

257 Capacity Australia, About Decision Making Capacity <http://capacityaustralia.org.au/about-decision-making-capacity/>.

258 WA End-of-life and Palliative Care Strategy 2018-2028, Department of Health, Western Australia.

259 Oxford Dictionary <https://en.oxforddictionaries.com>.

Irremediable

Impossible to cure or put right.²⁶⁰

Joint Select Committee

The Joint Select Committee refers to a parliamentary committee that was established on 23 August 2017 to look into end of life choices in Western Australia. The Joint Select Committee was chaired by Ms Amber-Jade Sanderson MLA and consisted of four members of the Legislative Council and four members of the Legislative Assembly. The Joint Select Committee tabled its report, *'My Life, My Choice'*, on 23 August 2018.

Medical practitioner

Medical practitioner refers to a medical doctor registered with the Australian Health Practitioner Regulation Agency (refer also: Registered Health Practitioner).

Navigator

A navigator is a person who helps and supports another person to understand their way through a system (such as the health system).

Neurodegenerative conditions

Resulting in, or characterised by degeneration of the nervous system, especially the neurons in the brain.²⁶¹ Examples include: motor neurone disease, Parkinson's disease, Huntington's disease and dementia.

Nurse practitioner

A nurse practitioner is a registered nurse educated and authorised to function autonomously and collaboratively in an advanced and extended clinical role.²⁶² A nurse practitioner must be registered with the Australian Health Practitioner Regulation Agency to practice.

Registered health practitioner

Registered health practitioner refers to a person registered under the Health Practitioner Regulation National Law (Western Australia) to practice a health profession (other than as a student).

This includes: Aboriginal and Torres Strait Islander health practitioners, Chinese medicine practitioner, chiropractors, dental practitioners, medical practitioners, medical radiation practitioners, nurses and midwives, occupational therapists, optometrists, osteopaths, paramedics, pharmacists, physiotherapists, podiatrists and psychologists.

(It should also be acknowledged that a term such as allied health professional would more broadly include self-regulated professions such as social work and speech pathology, but that these professions are not registered).

The Panel

The Panel refers to the Ministerial Expert Panel on Voluntary Assisted Dying established by the Minister for Health, Hon. Roger Cook MLA.

Victoria

References to Victoria in this Report refer to the state of Victoria in Australia and not Victoria the capital city of British Columbia in Canada.

²⁶⁰ Ibid.

²⁶¹ Ibid.

²⁶² Australian Nursing and Midwifery Accreditation Council <https://www.anmac.org.au/>.

Appendix 4: Consultation summary

This section outlines details of the Ministerial Expert Panel consultation on voluntary assisted dying legislation conducted between 19 March and 24 May 2019.

4.1 Consultation questions²⁶³

Topic	Sub-topic	Page No. *	Question
Guiding Principles		15	Are there other guiding principles that should be considered for the Bill?
The Person		20	Should there be a specific period during which someone has to be continuously living in Western Australia in order to be considered 'ordinarily resident'? If so, what period?
The Decision	A voluntary decision	22	What safeguards should there be to ensure that a request is voluntary?
The Decision	A voluntary decision	22	Should the assessing medical practitioner be able to refer to other health practitioners with relevant competency to assess that the decision is voluntary?
The Decision	An informed decision	23	Should health practitioners be able to discuss voluntary assisted dying with their patients in the same way they raise and discuss other health or medical decisions and care options?
The Decision	An informed decision	23	What are the cultural and linguistic considerations in relation to how people may be informed about voluntary assisted dying?
The Decision	An informed decision	23	What, if any, additional initiatives should be considered to ensure people are properly informed about voluntary assisted dying and supported in the decision-making process? For example, should there be a role for navigators?
The Decision	Decision-making capacity	25	How should capacity be determined? Is the way in which this is done in existing WA law sufficient?
The Decision	Decision-making capacity	25	Should the assessing medical practitioner be able to refer to other health practitioners with relevant competency in capacity assessment (e.g. a neuropsychologist) instead of a consultant psychiatrist or consultant geriatrician?

263 Ministerial Expert Panel on Voluntary Assisted Dying Discussion Paper, Department of Health, Western Australia (2019).

Topic	Sub-topic	Page No. *	Question
The Decision	Decision-making capacity	25	Should there be particular consideration given to people who lose capacity after they have started the process?
The Decision	Reflecting on the decision	26	Should there be a minimum timeframe to enable reflection on the decision to access voluntary assisted dying? If so, should this be able to be waived? Under what conditions?
The Decision	Reflecting on the decision	26	Between which points in the process should the minimum timeframe be measured?
The Decision	Reflecting on the decision	26	What should the minimum timeframe be?
Eligible Conditions		30	If voluntary assisted dying only applies to an illness or disease that is terminal, is specification of a timeframe either desirable or necessary?
Eligible Conditions		30	Would a timeframe help or hinder access to voluntary assisted dying? From the perspective of the person? Or medical practitioner?
Eligible Conditions		30	If a timeframe is to be specified should it be defined as: <ul style="list-style-type: none"> reasonably foreseeable outcome of the eligible condition? reasonably foreseeable outcome for this person? 6 months? (with 12 months for neurodegenerative disorders) 12 months? other?
Eligible Conditions		30	Must a person's suffering be 'grievous and irremediable' to be eligible?
Eligible Conditions		30	Must the person's suffering be related to the eligible condition?
The process		31	How should the process take community, linguistic and cultural beliefs and practices into account while also ensuring human rights, personal autonomy, privacy and choice? What approaches or initiatives would assist in achieving this balance?
The process	Access	31	What other ways are there to appropriately enable access to voluntary assisted dying?
The process	Assessment	34	Should a medical practitioner or health service that conscientiously objects have an obligation to refer the patient to a practitioner or service that has no objection? If so, how should the medical practitioner find out which doctors are willing to provide voluntary assisted dying?

Topic	Sub-topic	Page No. *	Question
The process	Assessment	34	<p>What should the purpose and timing of the written statement be?</p> <ul style="list-style-type: none"> to formalise the initial request (and thus occur before the assessments)? or to formalise the request once the person has been informed of all of their options, including palliative care, and is approved as eligible (and thus occur after the assessments)?
The process	Assessment	34	<p>Should the assessing medical practitioners have practised for at least five years after completing their fellowship or registering as a GP? Should this be required for both medical practitioners or at least one (as in Victoria)?</p>
The process	Assessment	34	<p>What should be included in the training for health practitioners involved in voluntary assisted dying?</p>
The process	Assessment	34	<p>Should the completion of approved training be mandatory before a medical practitioner is able to undertake the process for voluntary assisted dying?</p>
The process	Approval	35	<p>Should there be a separate approval and permit process for voluntary assisted dying (over and above any that may relate to the prescription of the medication)?</p>
The process	Medication	37	<p>Should a medical practitioner only be permitted to administer the medication if the person is physically incapable of self-administration?</p>
The process	Medication	37	<p>What is the safest approach to returning any unused medication after death?</p>
The process	Medication	37	<p>How should the public be protected from the loss, misuse or misdirection of medication?</p>
The process	Medication	37	<p>Are there other safeguards to consider in relation to medication?</p>
Death certification		38	<p>Should it be required that voluntary assisted dying is listed as a contributing cause of death on:</p> <ul style="list-style-type: none"> the Medical Certificate Cause of Death? the publicly available Death Certificate?
Oversight		40	<p>What types of members should form the oversight body? (e.g. qualifications, relevant experience)</p>
Oversight		40	<p>What information should health practitioners be required to report to the oversight body?</p>

Topic	Sub-topic	Page No. *	Question
Oversight		40	What data should be collected about voluntary assisted dying?
Oversight		40	How should community information and education be provided?
Oversight		40	How should health practitioner training and education be provided?
Oversight		40	How should complaints about voluntary assisted dying be handled?
Conclusion		41	Are there any further issues related to the Joint Select Committee's recommended framework that require the Ministerial Expert Panel's consideration?

*Discussion Paper page reference.

4.2 Public Forums

Table 1. Voluntary assisted dying consultation public forum dates, locations and attendees

Date	Regional or metro	Region	Town/locality	Attendees
05/04/2019	Regional	Goldfields	Kalgoorlie	24
08/04/2019	Regional	Midwest	Geraldton	56
12/04/2019	Metro	North	Joondalup	40
15/04/2019	Metro	Central	Maylands	59
29/04/2019	Metro	South	Murdoch	81
29/04/2019	Webinar	(South)	Webinar	8
02/05/2019	Regional	Kimberley	Broome	10
06/05/2019	Regional	South West	Bunbury	86
13/05/2019	Regional	Peel	Mandurah	85
20/05/2019	Regional	Wheatbelt	Northam	13
21/05/2019	Webinar	Community Resource Centres (CRCs)	Webinar	62*
23/05/2019	Regional	Pilbara	Karratha	15
23/05/2019	Regional	Gascoyne	Carnavon	18

*14 CRCs (49 people), 13 individuals participated

4.3 Stakeholder roundtables

Table 2. Voluntary assisted dying consultation stakeholder roundtables by topic/group, region, locality and number of attendees

Date	Topic or Group	Region	Town/locality	Attendees
18/04/2019	Medication/approval & permit process	Metro	Perth	8
18/04/2019	Oversight	Metro	Perth	11
18/04/2019	Death Certification	Metro	Perth	9
26/04/2019	Multicultural Affairs Multicultural Advisory Group	Metro	Perth	7
30/04/2019	Aboriginal Health Council WA CEOs Network	Metro	Perth	11
09/05/2019	People with a disability	Metro	Perth	6
15/05/2019	Process and Access (inc rural/remote)	Metro	Perth	27
15/05/2019	Education, training and workforce *	Metro	Perth	Included above
15/05/2019	Health Professionals - Nursing *	Metro	Perth	Included above
15/05/2019	Health Professionals - Allied Health *	Metro	Perth	Included above
15/05/2019	Health Professionals - Medical	Metro	Perth	7

*Some planned roundtables merged

4.4 Stakeholder meetings

Table 3. Voluntary assisted dying consultation stakeholder meetings by group, region, locality and number of attendees

Date	Group	Region	Town/locality	Attendees
04/04/2019	Spinifex Health Services	Regional	Kalgoorlie	4
05/04/2019	Kalgoorlie General Practitioners	Regional	Kalgoorlie	3
05/04/2019	WA Country Health Services - Goldfields	Regional	Kalgoorlie	10
08/04/2019	WA Country Health Services - Midwest	Regional	Geraldton	4

Date	Group	Region	Town/locality	Attendees
11/04/2019	Health Networks Leadership Forum	Metro	Perth	17
18/04/2019	NMHS - Board	Metro	Nedlands	12
29/04/2019	SMHS - Board	Metro	Murdoch	12
30/04/2019	EMHS - Board	Metro	Perth	15
02/05/2019	Kimberley Palliative Care team	Regional	Broome	3
03/05/2019	WA Primary Health Alliance - Kimberley	Regional	Broome	2
03/05/2019	WA Country Health Services - Kimberley	Regional	Broome	6
24/05/2019	WACHS - Board	Metro	Perth	15

4.5 Information sessions

Table 4. Voluntary assisted dying information sessions held by Associate Professor Kirsten Auret by group, region, locality and number of attendees

Date	Group	Region	Town/locality	Attendees
16/04/2019	Pioneer Health GP	Regional	Albany	6
02/05/2019	City of Albany	Regional	Albany	31
08/05/2019	Albany Hospital: Executive and Heads of Department	Regional	Albany	7
09/05/2019	Albany Community Hospice	Regional	Albany	28
10/05/2019	University of 3rd Age	Regional	Albany	31
17/05/2019	Clarence Estate RACF	Regional	Albany	13

4.6 Meetings with International Experts

Table 5. Ministerial Expert Panel meetings with international experts

Date		Mode	Experts
10/04/2019	Canadian Medical Association Dr Buchman Dr Blackmer	Videoconference	2
07/05/2019	Canada Dr James Downar Tanya Burr (Nurse Practitioner)	In person	2
03/06/2019	USA – Oregon Dr David Grube	Teleconference	1

4.7 Direct submissions received

Table 6. Voluntary assisted dying submissions received online via Citizen Space, by email and mail

Date	Mode	Total
As at 24/05/2019	Citizen Space (Online)	417
As at 31/05/2019*	Email	110
As at 24/05/2019	Mail	14

*Includes organisational submissions granted extension of deadline until 31/05/2019

4.8 Citizen Space demographics

There were a total of 417 responses to Citizen Space. Key demographics of this cohort were:

- there was a marked pick up in responses late in the consultation process
- there were 5 responses from a group/organisation and 412 responses from individuals.
- majority of respondents were female (295 of 417)
- most common age range of respondents was 65 to 74 years (94 of 417)
- majority of respondents were providing their views as a private citizen (326 of 417)
- majority of respondents did not identify as coming from a culturally and linguistically diverse background (373 of 417)
- majority of respondents normally resided in Western Australia (377 of 417)

Figure 1. Responses to Citizen Space by day

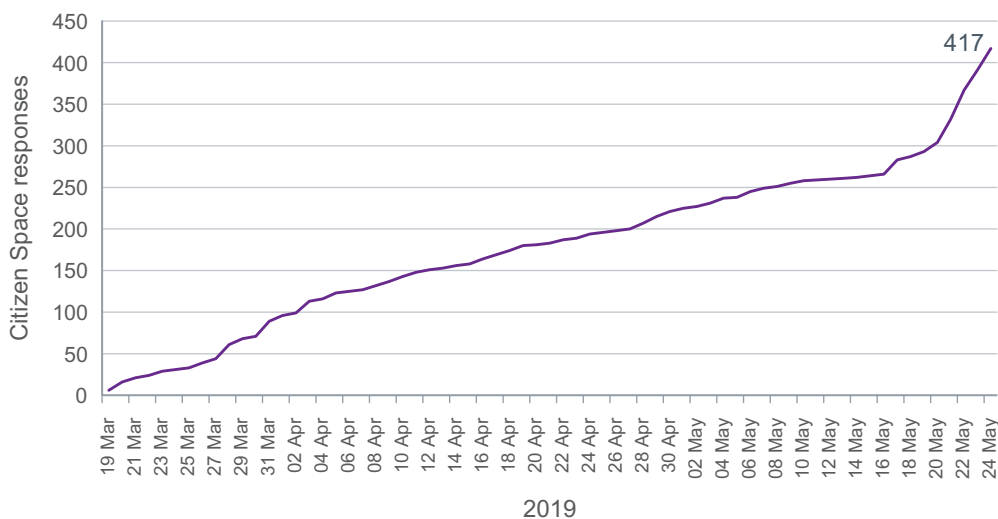


Figure 2. Citizen Space responses by gender

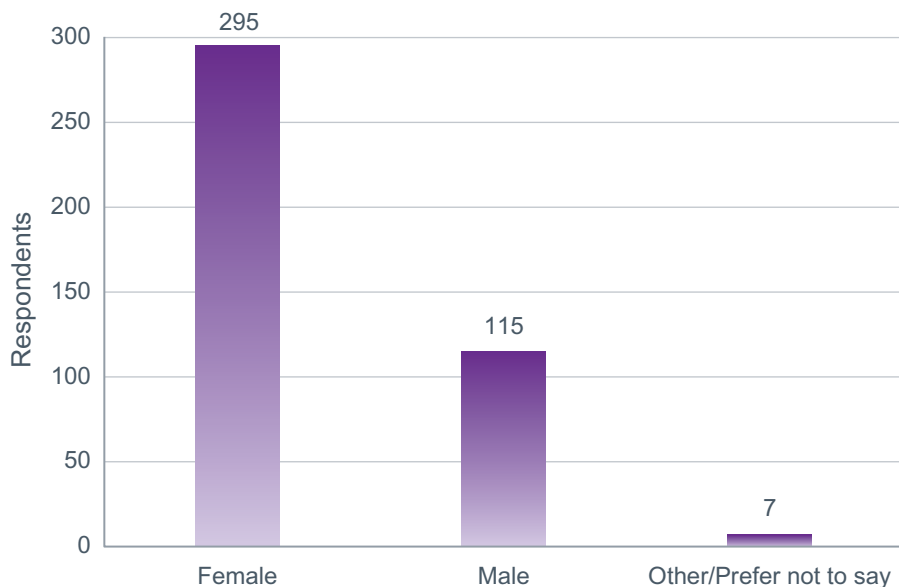


Figure 3. Citizen Space responses by age range

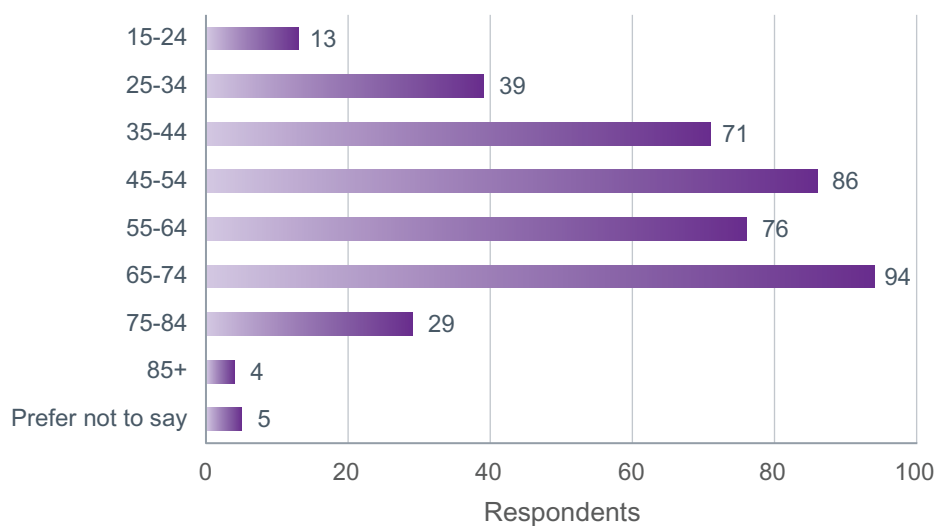


Figure 4. Citizen Space responses by circumstances

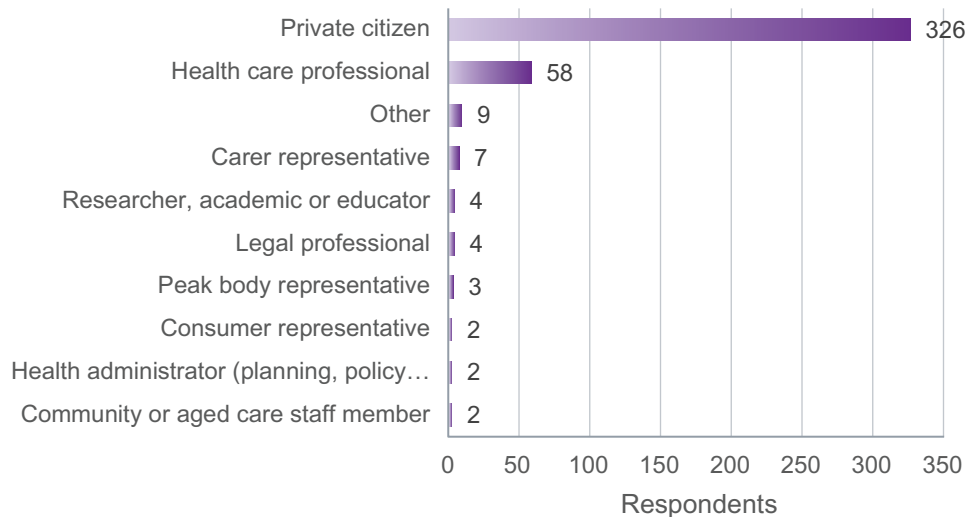


Table 7. Citizen Space responses by identifying with an Aboriginal or Torres Strait Islander or culturally and linguistically diverse background

Citizen Space response	Count	Percentage
having a culturally and linguistically diverse background (please specify below)	39	9%
having an Aboriginal or Torres Strait Islander background	5	1%
None of the above	352	84%
Prefer not to say	21	5%
Grand Total	417	100%

Table 8. Citizen Space responses by respondent's normal residence

Citizen Space response	Count	Percentage
New South Wales	19	5%
Queensland	4	1%
Victoria	12	3%
Northern Territory	1	<1%
Tasmania	1	<1%
Prefer not to say	2	<1%
In another country (ie. Not in Australia)	1	<1%
Western Australia	377	90%
Grand Total	417	100%

4.9 Organisations consulted

Aboriginal Health Council of Western Australia
Anglican Social Responsibilities Commission
ANZ Society of Palliative Medicine
Armada Kalamunda Group – East Metropolitan Health Service
Australian Care Alliance
Australian Christian Lobby
The Australian Clinical Psychology Association
Australian College of Nursing
Australian College of Nurse Practitioners
Australian Health Practitioner Regulation Agency
Australian Medical Association – WA
Avant Mutual Group Ltd.
Bethesda Health Care
Brightwater Care Group Ltd.
Cancer Council WA
Catholic Homes
Chief Health Professions Office, Department of Health
Citizens Advice Bureau
Coroner's Court
Council on the Ageing WA
Dementia Australia
Department of Communities
Department of Justice
Dignitas
Disability Health Network, Department of Health
Doctors 4 Assisted Dying Choice
Dying with Dignity (NSW)
Dying with Dignity (WA)
East Metropolitan Health Service Board and Executive
Edith Cowan University
Equal Opportunity Commission
Ethnic Communities Council of Western Australia
Go Gentle Australia
Health and Disability Services Complaints Office
Health Consumers' Council (WA)
Health Professionals Say No
Kimberley Palliative Care Team (WA Country Health Service)
Law Society of Western Australia
Legal Aid WA
LJ Goody Bioethics Centre
Medical Insurance Australia Pty Ltd
National Disability Services
North Metropolitan Health Service Board and Executive
Nursing and Midwifery Office, Department of Health
Office for Multicultural Interests
Office of the Chief Medical Officer, Department of Health
Office of the Chief Pharmacist, Department of Health

Office of the Chief Psychiatrist, Department of Health
Office of the Public Advocate, Department of Justice
Palliative Care Nurses Australia
Palliative Care WA
Patient Safety and Clinical Quality, Department of Health
People With disabilities WA
Pharmaceutical Society of Australia
The Pharmacy Guild of WA
Primary Care Integration Health Network, Department of Health
Public Health Association Australia
Rationalist Society of Australia
Royal Australian and New Zealand College of Psychiatrists
Royal Australian College of General Practitioners
Royal Australasian College of Physicians
Silver Chain
Society of Hospital Pharmacists – WA Branch
South Metropolitan Health Service Board and Executive
Spinifex Health Services
St John Ambulance
St John of God Health Care
State Administrative Tribunal
State Solicitor's Office, Department of Justice
WA Country Health Service Board and Executive
WA Country Health Service, Geraldton
WA Country Health Service, Goldfields Region
WA Country Health Service, Kimberley
WA Primary Health Alliance
WA Police Force

2 organisations requested submissions to remain confidential

Appendix 5: Voluntary Assisted Dying in other jurisdictions

Disclaimer: Every reasonable effort has been made to ensure that the information in this Appendix is complete and accurate. However the information relied upon from other jurisdictions is subject to change and interpretation, and the content of this appendix is for comparative purposes only.

Australia

Victoria: *Voluntary Assisted Dying Act 2017*

Belgium

Act on Euthanasia 2002

Canada

Provinces and territories of Canada (excl. Quebec): *An Act to Amend the Criminal Code and to make related amendments to other Acts (Medical Assistance in Dying), Bill C-14 2016*

*NB: for ease of reference, in this Report the Canadian Federal Legislation is referred to as: Medical Assistance in Dying Act, Bill C-14 (Canada).

Quebec: *An Act Respecting End of Life Care 2015*

Colombia

In 1997, the Colombian Constitutional Court ruled that a physician should not be prosecuted for ending life at the repeated request of a terminally ill patient. No progress was made in Congress. In 2014, the Constitutional Court ordered the Ministry of Health to set up a national expert committee who established a Resolution permitting euthanasia which came into force in 2015.²⁶⁴

Germany

There is no stand-alone act in Germany. Euthanasia is not permitted, but assisted suicide was never illegal in Germany. A case in 2017 (Bundesverwaltungsgericht 3 C 19.15) found that patients who suffer unbearably and are incurably ill, who have a well-considered and voluntary wish to die, should be able to access prescribed medication to end their life. Despite this German citizens are having difficulties with access.

Luxembourg

Law on Euthanasia and Assisted Suicide 2009

The Netherlands

Termination of Life on Request and Assisted Suicide (Review procedures) Act 2001

264 Submission: by Professor Penney Lewis, Co-Director Centre of Medical Law and Ethics, Dickson Poon School of Law, King's College London to the Ministerial Expert Panel on Voluntary Assisted Dying (2019).

Switzerland

There is no legislation which decriminalises assisted dying. It is a criminal offence to assist suicide only when the assister has a selfish motive (Criminal Code 1942).

United States of America

California: *End of Life Option Act 2015*

Colorado: *End of Life Options Act 2016*

District of Columbia: *D.C. Death with Dignity Act 2016*

Hawaii: *Our Care, Our Choice Act 2018*

Maine: *Death with Dignity Act 2019* passed on Wednesday 12 June 2019. This legislation was not considered by the Panel as part of its deliberations as it was not passed at that time.

Montana: No current statute safeguarding physician-assisted death.

In 2009, Montana's Supreme Court ruled nothing in the state law prohibited a physician from honouring a terminally ill, mentally competent patient's request by prescribing medication to hasten the patient's death.

New Jersey: *Aid in Dying for the Terminally Ill Act 2019*

Oregon: *Oregon Death with Dignity Act 1994*

Vermont: *Patient Choice and Control at the End of Life Act 2013*

Washington: *Washington Death with Dignity Act 2008*

Voluntary assisted dying in other jurisdictions²⁶⁵

Victoria	Canada	Oregon	Washington State	Vermont	California ²⁶⁶	Belgium	Netherlands
Eligibility							
At least 18 years of age, resident in Victoria for at least 12 months (must be Australian citizen or permanent resident) and has decision-making capacity. Has advanced disease that is expected to cause death within six months (or within 12 months for neurodegenerative diseases). Disease is causing suffering that cannot be alleviated in a manner that is tolerable for the person. Cannot qualify solely because of mental illness or disability.	At least 18 years of age and capable of making decisions and with a grievous and irremediable medical condition. Condition is serious and incurable illness, disease or disability; in an advanced state of irreversible decline; causing enduring suffering that is intolerable. Natural death has become reasonably foreseeable.	Capable adult resident suffering from a terminal disease as determined by physician. Disease will produce death within six months. Cannot qualify solely because of age or disability.	Competent adult resident determined by physician to be suffering from a terminal disease which will produce death within six months. Person does not qualify solely because of age or disability.	Capable resident at least 18 years of age, suffering from a terminal condition, which means incurable and irreversible disease that would result in death within six months.	Competent resident 18 years of age or older with terminal disease which will result in death within six months. Person does not qualify solely because of age or disability.	Limited to those in a medically desperate state with constant and unbearable suffering that cannot be alleviated. The suffering can be physical or psychological and must be the result of a serious and incurable disease or an accident-induced condition. Not limited to people at the end of their life. Adults and emancipated minors can access but must be legally competent at time of request.	Must be lasting and unbearable suffering (in view of physician). No reference to condition. Not limited to people at the end of their life. The Act applies for patients aged 12 and over (with certain requirements for parental involvement).

²⁶⁵ Adapted from Ministerial Advisory Panel on Voluntary Assisted Dying Final Report, Department of Health and Human Services, State of Victoria (July 2017).

²⁶⁶ Voluntary assisted dying has also been legislated for in the US states of Hawaii, Colorado, New Jersey and District of Columbia. The statutes in these states are very similar to those US states listed in the table.

Victoria	Canada	Oregon	Washington State	Vermont	California	Belgium	Netherlands
Request							
<p>Patient must make a first verbal request, followed by a written request, witnessed by two independent individuals, and a final verbal request. The final request must be made at least nine days after the first request. The final request may not be made on the same day as the second independent assessment. If medication is practitioner administered there must be a fourth request which can be immediately prior, can be verbal and must be witnessed.</p> <p>Waiting period can be reduced if death is likely to occur before expiry of the waiting period.</p>	<p>Request is written and witnessed by two individuals. 10 days between written request and the day on which medical assistance in dying is provided. Supports those with communication difficulties.</p> <p>Waiting periods can be reduced if death or loss of capacity is imminent.</p>	<p>Request is written and witnessed by two independent individuals.</p> <p>Requests repeated with 15 days waiting period between two oral requests.</p>	<p>Request written and witnessed by two independent individuals.</p> <p>Second oral request reiterated at least 15 days after initial oral request.</p> <p>Prescription at least 48 hours after written request.</p>	<p>Written request in presence of two independent witnesses.</p> <p>Requests repeated with 15 days waiting period between two oral requests.</p> <p>Prescription at least 48 hours after whichever event occurred last.</p>	<p>Two oral requests 15 days apart and a written request, witnessed by two individuals.</p>	<p>Request must be voluntary, well-considered and repeated. Request in writing. May be included in an advance directive. No specified waiting periods but the doctor and person need to have had several conversations over a reasonable period of time.</p>	<p>Request must be voluntary and well-considered.</p> <p>No written request required.</p>

Victoria	Canada	Oregon	Washington State	Vermont	California	Belgium	Netherlands
Assessment							
Both the co-ordinating practitioner and consulting practitioner independently assess eligibility, that the request is voluntary and inform the person. Referral for specialist assessment if doubt about decision-making capacity.	Assessment undertaken by medical or nurse practitioner, who must also ensure another independent practitioner has given written confirmation of person meeting criteria.	Attending physician assesses eligibility and informs patient. Consulting physician confirms and verifies. Counselling referral if suffering from psychiatric or psychological disorder or depression causing impaired judgement.	Attending physician assesses eligibility and informs patient. Refers to consulting physician for confirmation of diagnosis and verification that patient is competent and acting voluntarily. Counselling referral if suffering from psychiatric or psychological disorder or depression causing impaired judgement.	Physician assesses eligibility and informs patient. Refers patient to second physician for medical confirmation. Verifies judgement not impaired or referred for evaluation.	Attending physician assesses eligibility and informs patient. Refers if indication of mental disorder. Consulting physician conducts second assessment, and referral if required.	Assessment is undertaken by one physician, who consults an independent physician about the disorder. If the person is not expected to die in the near future, a psychiatrist or specialist in the disorder must conduct a second assessment and confirm the suffering cannot be alleviated and that the request is voluntary, considered and repeated.	Assessment undertaken by one physician who has consulted with one other independent physician who has seen the person and given a written opinion that the person has fulfilled the eligibility criteria.
Practitioner							
Participation is voluntary. Protection if participating in good faith.	No one is compelled to provide or assist in dying. Protection for those who participate.	Protection if participating in good faith compliance. No health care provider may be under a duty to participate.	Only willing health care providers shall participate. Protection if participating in good faith.	Physician or other person not under any duty to participate. Physician not subject to liability if complies with requirements.	Participation is voluntary. Protection if participating in good faith.	No physician compelled to participate.	Act is ground for exemption from criminal liability for physician who observes requirements.

Victoria	Canada	Oregon	Washington State	Vermont	California	Belgium	Netherlands
Medication Management							
Prescription requires authorisation permit by Department of Health and Human Services. Any medication not used must be returned to dispensing pharmacist by contact person.	Medical practitioner informs dispensing pharmacist of purpose of medication. Silent about unused medication.	Dispensing record filed with authority. Silent about unused medication.	Any medication not used must be disposed of by lawful means.	Department of Health shall adopt rules for safe disposal of unused medications.	Unused medication personally delivered to facility or disposed of by lawful means.	Legislation is silent on medication management.	Legislation is silent on medication management.
Medication Administration							
If the person cannot self-administer, the co-ordinating practitioner may administer with a witness present and additional certification.	Medication may be self-administered or administered by medical or nurse practitioner. * In Quebec, there is different legislation for assisted dying and only practitioner is permitted.	Medication must be self-administered. No option for physician administration of medication.	Medication must be self-administered. No option for physician administration of medication.	Medication must be self-administered. No option for physician administration of medication.	Medication must be self-administered. Requires form 48 hours before self-administration. No option for physician administration of medication.	Legislation provides for physician administration (viz 'physician who performs euthanasia') though the oversight agency has accepted cases of assisted suicide as falling under the law. ²⁶⁷	Physician may administer or assist in self-administration.

267 Analysis of the Seventh Report of the Federal Commission for Euthanasia Control and Evaluation to the Legislative Chambers (for the years 2014 and 2015), Institut Européen de Bioéthique, Brussels (2016).

Victoria	Canada	Oregon	Washington State	Vermont	California	Belgium	Netherlands
Mandatory Reporting							
Mandatory reporting to Review Board within seven days of completion of first assessment, completion of second assessment, completion of certification for authorisation and administration by medical practitioner.	Minister for Health makes regulations for provision and collection of information.	Request form is included in legislation. Details of request and assessment only filed in patient's medical record. Health care provider files copy of dispensing record with authority. Authority conducts annual review of a sample of records.	Administratively required documentation and a copy of dispensing record filed with Department of Health. Department conducts annual review of all records.	Physician to file a report with Department of Health documenting completion of all the requirements.	Request form is included in legislation. Physician documents information in individual's medical record. Dispensing record filed with Department. Department conducts annual review of a sample of records.	Oversight body sets out a registration form that must be filled in by physician whenever lethal dose of medication is administered. Must be submitted within four days of administration.	Physician notifies municipal autopsist via form and provides report on observance of due care requirements.
Oversight							
Voluntary Assisted Dying Review Board has multiple functions relating to reporting, monitoring, referral of issues, continuous improvement, analysis, research and provision of information and advice.	Minister for Health to make regulations for the collection of information for monitoring. Provides for five year review of legislation.	The law requires the Public Health Division of the Oregon Health Authority (OHA) to monitor compliance with the law and issue an annual report.	Department of Health annually reviews all records maintained. Department adopts rules to facilitate collection of information regarding compliance. Department must publish annual report.	Department of Health shall adopt rules to facilitate collection of information regarding compliance. Department generates a biennial statistical report.	Department of Public Health collects and reviews a sample of records. Department publishes a statistical report every year.	Establishes a Commission that reviews reporting forms to determine if there has been compliance. Commission comprised of 16 members: 8 doctors, 4 lawyers and 4 others. Publishes two-year reports.	Establishes Regional Review Committees who determine if physician has acted in accordance with the requirements of due care. Committees issue annual report. Made up of a physician, a lawyer and an ethicist.

Appendix 6: References to decision-making capacity in Western Australian legislation

Legal presumption about a person's capacity:

- s4(3) Every person shall be presumed to be capable of –
- a. looking after his own health and safety;
 - b. making reasonable judgements in respect of matters relating to his person;
 - c. managing his own affairs; and
 - d. making reasonable judgements in respect of matters relating to his estate,

until the contrary is proved to the satisfaction of the State Administrative Tribunal.

(extract from the *Guardianship and Administration Act 1990*)

- s13(1) For the purposes of this Act, an adult is presumed to have the capacity to make a decision about a matter relating to himself or herself unless the adult is shown to not have that capacity.

(extract from the *Mental Health Act 2014*)

The *Mental Health Act 2014* also provides what is required to be demonstrated when assessing capacity:

- s15 For the purposes of this Act, a person has the capacity to make a decision about a matter relating to himself or herself if another person who is performing a function under this Act that requires that other person to determine that capacity is satisfied that the person has the capacity to —
- a. understand any information or advice about the decision that is required under this Act to be provided to the person; and
 - b. understand the matters involved in the decision; and
 - c. understand the effect of the decision; and
 - d. weigh up the factors referred to in paragraphs (a), (b) and (c) for the purpose of making the decision; and
 - e. communicate the decision in some way.

(extract from the *Mental Health Act 2014*)

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