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**Submission to the Government of Western
Australia Ministerial Panel on Voluntary
Assisted Dying**

May 2019

About the Royal Australasian College of Physicians (RACP)

The RACP trains, educates and advocates on behalf of over 17,000 physicians and 8,000 trainee physicians across Australia and New Zealand.

The College represents a broad range of medical specialties including general medicine, paediatrics and child health, cardiology, respiratory medicine, neurology, oncology, public health medicine, occupational and environmental medicine, palliative medicine, sexual health medicine, rehabilitation medicine, geriatric medicine and addiction medicine. Beyond the drive for medical excellence, the RACP is committed to developing health and social policies which bring vital improvements to the wellbeing of patients.

The RACP welcomes the opportunity to provide a submission to the Western Australian Parliament's Ministerial Expert Panel on Voluntary Assisted Dying in relation to its discussion paper. The College has chosen to comment on several issues most relevant to its remit and expertise.

RACP Position on Voluntary Assisted Dying

In recent years, several proposals to legalise voluntary assisted dying have been considered by Parliaments in Australia and New Zealand. As evidenced by recent public inquiries and sustained reform attempts, including the work of this Ministerial Expert Panel, there is significant community interest in having voluntary assisted dying as an option at the end of life.

In November 2018, following an extensive consultation and drafting process involving a wide range of its members, the RACP issued a Statement on Voluntary Assisted Dying. The following response is based on the statement, which we encourage the Panel to consult in full on the [RACP website](#).

The RACP Statement

The RACP respects and supports all its members and does not believe it is appropriate or possible to enforce a single view on a matter where individual conscience is important. The RACP recognises that legalisation of voluntary assisted dying is for governments to decide and that it must be informed by the will of the community, research, and the views of medical and health practitioners.

Legislative change related to voluntary assisted dying will affect individual medical practitioners in different ways. Different clinical settings require ethical and clinical considerations to be made carefully, deliberately and systematically. Our members are not unanimous in their support for or opposition to legislative change. The existence of divergent views constrains the RACP from developing a single position on the legalisation of voluntary assisted dying.

The RACP takes the following positions if and where voluntary assisted dying is legalised:

- Every patient should have access to timely, equitable, good quality end-of-life care, with access to specialist palliative care where appropriate. These services must not be devalued.
- On the specific issue of a competent adult in the last stages of incurable illness requesting voluntary assistance to die, the RACP supports a clinical approach of critical neutrality to encourage reflective dialogue.
- 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.
- Patients seeking voluntary assisted dying should be made aware of the benefits of palliative care. Referral to specialist palliative care should be strongly recommended but cannot be made mandatory. Voluntary assisted dying must not be seen as part of palliative care.

- Legitimate concerns exist around protection of vulnerable individuals or groups. Government, society and physicians must ensure that specific groups have equitable access to palliative and end-of-life care and that relationships of trust are not jeopardised. Specific regard must be given to cultural and Indigenous experience.
- All physicians must affirm the value of all patients' lives, exploring reasons for requests for voluntary assisted dying while remaining alert to any signs of coercion and reduced capacity.
- Assessments must not follow a 'tick box' approach. They must be underpinned by adequate physician-patient relationships, including appropriate training, skill and experience.
- Support, counselling and conflict mediation services must be available for individuals, families and health professionals involved.
- There must be rigorous documentation and data collection to enable review of any scheme and to assess changes in practice and the impacts on health professionals, patients and families.

This statement should not be taken as support for legislative change. The RACP will continue to highlight concerns about legislative proposals, drawing on both clinical experience and the ethical perspectives of our members. The RACP will continue to advocate for patient and physician well-being in order to support our members and contribute our expertise as medical specialists who care for dying patients.

General recommendations for policymakers

The RACP has concerns about the potential for legalised voluntary assisted dying to jeopardise vulnerable populations, be abused, expose health practitioners to professional risk, harm patients and families and erode trust in the medical profession. If Parliaments in Australia decide that laws should be changed, the development of laws, regulations and guidelines must be undertaken in consultation with medical and health experts, the RACP and other medical and health organisations.

Some key recommendations for policymakers are set out below. These have been developed in consultation with our members as the RACP has responded to previous legislative proposals. The issues relate to the accessibility of good end-of-life care.

The recommendations stated in the RACP's position statement *Improving Care at the End of Life: Our Roles and Responsibilities* (May 2016) should also be referred to in this context, including:

- ensuring that all clinicians are adequately trained to recognise the need for palliative and/or end-of-life care and to refer to or deliver appropriate palliative and end-of-life care;
- supporting system changes enabling health professionals to take the time they need to discuss end-of-life care with patients, and to conduct and document family/whānau conferences including goals-of-care discussions, appropriate social work support and bereavement care;
- providing adequate resources in the community to support patients wishing to die at home, in a hospice or in a residential aged care facility;
- ensuring patients can access specialist palliative care support as needed, at any time of day or night;
- streamlining patient information to ensure health professionals have access to key patient information and documents; and
- funding systems to measure and benchmark outcomes of end-of-life care.

Inequitable access to good quality end-of-life care persists for many Australian citizens. This includes Aboriginal and Torres Strait Islander people and people from culturally and linguistically diverse backgrounds. Other groups that experience inequitable access to care include people with acquired or congenital intellectual disability, patients dying from diseases other than cancers, and people living in residential aged care facilities, some of whom are under 65 years of age, living with one or more chronic diseases. Inconsistent care is more prevalent in rural and remote communities in Australia.

Governments must remain vigilant in the areas of palliative care and aged care and commit adequate resourcing to ensure that good end-of-life care is being delivered to all citizens. Every

patient should receive timely, equitable, good quality end-of-life care, including access to specialist palliative care where appropriate.

If voluntary assisted dying is legalised in Western Australia, the government should consider the following recommendations regarding end-of-life care and palliative care:

- The need for palliative care services must not be devalued; indeed, palliative care must be given even greater priority and resourcing than it is now.
- Governments must ensure that all patients have access to good end-of-life care and palliative care as needed. This includes equitable access for populations that currently experience poor access, such as people from rural, regional and remote areas, Culturally and Linguistically Diverse backgrounds, Indigenous backgrounds, people with intellectual disability, patients dying from diseases other than cancers, and people living in residential aged care facilities.
- Governments and oversight bodies must dedicate resources to closely examine voluntary assisted dying requests that arise where the patient has poor options for good end-of-life care, for example in circumstances where symptom relief and a peaceful death cannot be provided to the patient because of limited access to palliative and supportive care.
- Patients seeking voluntary assisted dying must be made aware of the benefits that palliative care can offer at the end of life and referral to specialist palliative care should be strongly recommended.
- However, palliative care referral or consultation following a request for voluntary assisted dying cannot be mandatory given that:
 - consultation or referral to palliative care services, like any medical referral, is not mandated and is a care option that a patient may or may not choose to accept;
 - legalisation of voluntary assisted dying in any form will create significant challenges for palliative medicine specialists, palliative care organisations and health care institutions;
 - voluntary assisted dying must not be seen as part of palliative care - these are distinct practices; and
 - the risk that involvement of palliative care referral and/or consultation is simply seen as, and becomes, a procedural step or “tick-the-box” exercise.

In addition to these recommendations, the RACP would like to provide comments in response to several issues raised in the discussion paper that fall within the College’s remit:

Decision making, consent and safeguards against coercion

Coercion of patients will be difficult to safeguard against completely. A significant proportion of the terminally ill and elderly are estimated to experience some form of self-perceived burden. Coercion may also arise where individuals with poor access to good end-of-life care may choose voluntary assisted dying even though symptom relief and a peaceful death could have been provided if they had had appropriate access to end-of-life care.

Recommendations regarding consent and coercion:

- Consideration must be given to enabling the exchange of information in formats accessible to the patient such as in the patient’s preferred language, via sign language, interpreters, or orally.
- Legislative and regulatory measures must reflect the legitimate concerns that exist around protection of vulnerable individuals or groups, especially where discussions may not be perceived to have been fully transparent.
- Data must be collected, monitored and reported in a manner that can pinpoint abuse at an individual and population level.
- Avenues to report and investigate suspected coercion must be built into any scheme including via coronial review.

Conflict and bereavement support

Adequate family support, counselling and conflict mediation services will be required in the event of legalisation. Frameworks for voluntary assisted dying are based on the culture-specific concept

of individual autonomy and do not necessarily acknowledge that end-of-life decisions are not made in a vacuum.

The role of and the effect on family, carers and other loved ones are important considerations. What support systems will be provided for individuals, families and health professionals who may be involved and who may suffer personal trauma or other harm because of this involvement, regardless of whether the patient ultimately proceeds with a medically assisted death?

This must be dealt with in any proposed framework. The impact of conflict and bereavement can be considerable, as can the stress on individual doctors receiving requests on a regular basis and at varying levels of involvement. Doctors may, for example, face pressure from patients who are deemed not to meet the criteria for access. Patients may also face pressure or coercion from family members or carers.

Voluntary assisted dying may also lead to enduring conflict and complex grief for remaining family members, carers and health professionals. Physicians may be placed in very difficult situations when an individual wishes to access voluntary assisted dying but family members or other health professionals disagree with their decision: the family may blame the physician if the request goes ahead. Evidence shows that many doctors who have participated in voluntary assisted dying experience emotional distress.¹ If a proposal is legalised, there is a clear need for education, support and guidance for bereaved family members and health professionals.

Recommendations regarding conflict and bereavement support:

- Time for family/carer conferencing must be available to patients and health professionals to acknowledge the impact on families and to enable family/carer participation and response.
- Support systems must be provided for individuals, families and health professionals who may be involved and who may suffer emotional distress, personal trauma or other harm because of this involvement, regardless of whether the patient ultimately proceeds with a medically assisted death.
- Adequate funding will be required for such family support, counselling and conflict mediation services.

Referral and conscientious objection

In general, where objections of conscience have arisen in medical practice in Australia and New Zealand, clinicians have accepted they should refer patients to another practitioner. However, for some physicians the moral impact of referring a request for voluntary assisted dying to a willing practitioner may be felt deeply. The RACP holds that physicians should not be forced to refer, but neither should they hinder patients from accessing such services.

Conscientious objection affects not only the medical practitioner but the interdisciplinary team treating the patient. Conscientious objection may also occur for other non-medical individuals within multidisciplinary teams or at an institutional level.

Conscientious objection may present issues in certain settings, for example amongst inpatients of an objecting hospital or hospice, those who are unable to go to another clinic, practitioners who would perform voluntary assisted dying but are not accredited at a given site, and patients living in rural areas serviced only by an objecting practitioner(s).

Protections should be available for participating or objecting practitioners who do not wish to be identified. If a public register of practitioners were to be mandated, some practitioners might encounter stigma, victimisation, harassment and other issues relating to the perception by patients, families, colleagues and the broader community. A practitioner may not want to be identified because they are concerned that patients will not come to see them if they are known

¹ Stevens, K, 'Emotional and Psychological Effects of Physician-Assisted Suicide and Euthanasia on Participating Physicians', *Linacre Quarterly*, 2006

to be participating in voluntary assisted dying. Conversely, a patient may refuse to see a doctor if they choose not to participate. This could compromise timely assessment and care in a geographical area where there are limited doctors to see.

It should also be recognised that some practitioners may be willing to participate in voluntary assisted dying for eligible patients in restricted ways, e.g. in a limited range of cases, or in only providing a second opinion.

Recommendations regarding conscientious objection:

- Physicians should not be forced to refer, but neither should they hinder patients from accessing such services.
- A central information source on the scheme should be available to assist patient access.
- Should a register of practitioners be developed, protections should be available for both participating and objecting practitioners who do not wish to be identified for reasons of harassment and stigma.
- Provision could be made for practitioners who are willing to participate in restricted ways, e.g. in a limited range of cases, or in only providing a second opinion.

Expertise and training required of participating practitioners

Participating practitioners would have to be properly skilled in a number of domains and would have to be qualified in the diagnosis and prognosis of the specific medical condition(s) presenting in each person requesting assistance in dying. Proposals could consider setting out the domains of expertise required to provide voluntary assisted dying, rather than restricting it to a particular profession or qualification level, which could create barriers to access or lead to an inexperienced medical practitioner confirming a request.

For example, a neurologist who specialises in stroke care, and holds qualifications in neurology may still not have sufficient experience of motor neurone disease management to be able to discuss prognosis in detail or answer questions about artificial ventilation. This would need to be balanced against the access issues that arise in regional and remote areas when patients are too sick to travel. These situations would require detailed consideration around how assessment could be done by someone suitably skilled.

Genuine engagement with the person must be a feature of any proposal to reduce the risk of “doctor-shopping” and multiple cursory assessments being undertaken by a small number of practitioners. There is a need for assessment to be underpinned by a genuine and enduring relationship with the person. This is an important safeguard to avoid reliance on potentially simplistic assessments/reviews of paper documentation. Whilst the RACP has been made aware of recommendations for a specifically trained occupational group/practitioners as an alternative approach, this concept has not been further developed during preparation of this Statement.

Recommendations regarding expertise and training in the event of change to current law:

- Upholding the trust society places in the medical profession is of key importance.
- Participants must practise with the appropriate level of training, skill and experience, within systems of collegial accountability.
- Assessment of the requesting person must be underpinned by:
 - a genuine and enduring relationship with the participating practitioner;
 - a sufficient understanding of the patient’s preferences and values; and
 - an informed understanding of the diagnosis and prognosis of the person’s medical condition.
- Policymakers must safeguard against simplistic assessments/reviews of paper documentation, “doctor shopping”, inexperienced practitioners confirming requests and cursory assessments being undertaken by a small number of practitioners.

- Training, including clinical supervision where appropriate, must be adequately funded and available for those practitioners interested and/or willing to participate, particularly in relation to:
 - the law and its implementation;
 - communicating options at the end of life;
 - the psychodynamic issues that may be involved in making and receiving requests;
 - defining whether a “disease or illness is advanced and progressive”;
 - exploring the reasons for a request;
 - assessment of mental state and capacity in the context of end-of-life care;
 - defining “grievous and irremediable suffering due to the disease or illness that cannot be alleviated in a manner acceptable to the person”; and
 - potential impact on already complex care.

This training must be available to all physicians, including trainees who may be asked to explore patient requests.

- To ensure legal clarity, clear and consistent guidance will need to be developed by relevant authorities in consultation with the medical profession and other relevant health professions on a range of practical issues, for example, around attendance by a treating practitioner and their obligations in the event the lethal dose is not effective.
- Prudent prescribing and storage principles apply as much as ever; participating practitioners must understand and communicate the possible outcomes and harms for medications. In the case of intentionally lethal doses of medicines, this would include the possibility that they are used otherwise than as intended, do not work and may cause unwanted symptoms.

Reporting and evidence-based practice

A major practical role for involved physicians will be the capture of information around the quality, performance and outcome of activities that result from legalisation. It is imperative that robust and accurate records are kept both at the micro and macro levels and as part of the medical record. Reporting must be undertaken directly to a monitoring body to track trends, patient motivations etc. For example, there could be a specific reportable form filled out and sent to a monitoring body for review.

Instances of voluntary assisted dying must be reported to enable audit of the scheme. It is acknowledged there may be stigma felt by individuals in knowing that voluntary assisted dying may be listed as the cause of death on the death certificate. Even so, there is overriding public interest in having this information available in a de-identified manner. Enabling both the immediate and underlying causes of death to be listed and reported should be considered. Cause of death data must remain completely accurate for future planning of medical care. The cause of death must not only include the terminal illness that made the patient eligible, but also that a substance was taken to provide active assistance to the patient in dying.

All records in connection with a voluntary assisted death should be provided to a central body for transparent monitoring and to enable important research on areas such as uptake, the reasons for requests and requests amongst vulnerable groups. There should be a two-stage process, which includes recording all requests, requests which are declined and patients who change their mind following a request.

At a minimum, a central database of all who have requested and been approved to access voluntary assisted dying and a research programme that reports the outcomes of the new legislation over time will be necessary to track uptake and outcomes. Accurate and explainable records of all deaths that occur due to voluntary assisted dying should be maintained. Patient-level reporting processes for pharmacovigilance must also be built into any proposed scheme. Monitoring should cover a range of areas including reasons for requests, conscientious objection, disposal of unused lethal medication and impact on suicide rates more generally.

As a minimum a parliamentary committee should scrutinise the data collected and the operation of the legislation. This might lead to amendment or further public consultation. If the introduction of voluntary assisted dying is found to have negative or unintended effects, there must be a mechanism to review or even withdraw legislation and to examine and manage problems arising in practice, unforeseen or otherwise.

Recommendations regarding reporting and evidence-based practice:

- A central database of all who have requested and been declined or approved to access voluntary assisted dying and a research programme that transparently reports the uptake and outcomes of the new legislation over time will be necessary. Areas of key interest include the reasons for requests, patient demographics, requests amongst vulnerable groups, impact on suicide rates, the disposal of unused lethal medication and patient-level reporting processes for pharmacovigilance purposes.
- Review of each individual case by a competent judicial officer (e.g. coroner) may be required to ensure that the legislation has been complied with (parallel to the current system of checks regarding deaths in medical care).
- A parliamentary committee must scrutinise the data collected and the operation of the legislation with the potential for its review, amendment, further public consultation or withdrawal.
- For future planning of medical care, cause of death data must remain completely accurate by specifying the terminal illness that made the patient eligible and that a substance was taken to provide voluntary assisted dying.