

Review of advance care planning laws across Australia

Short report 2018

Advance Care Planning Australia

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Advance Care Planning Australia provides expertise in advance care planning practice, health professional education, translational research, information resources and advisory services. Our purpose is to build the foundation for a national collaborative approach to advance care planning.

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1 Introduction

This short report summarises the review of Australian advance care planning related legislation. It identifies all relevant legislation, explores consistencies and variation in terminology, scope and obligations. This report provides information to inform leading organisations such as Advance Care Planning Australia and Palliative Care Australia, policy makers, programs, and advisory services. This report is most relevant to Australian health and residential aged care services.

2 Background

Advance care planning is a process of planning for future health and personal care whereby the person's values, beliefs and preferences are made known so they can guide decision-making at a future time when that person cannot make or communicate his or her decisions.

Australian Governments have committed to addressing the palliative care and advance care planning needs of Australians through the *National Palliative Care Strategy 2010: Supporting Australians to live well at the end of life*. Many states and territories have advance care planning strategies and programs. A key priority is to increase the uptake of advance care planning and the relevant legislation is an important enabler for this.

Legislation to promote advance care planning exists in Australia in all states and territories. However the extent of legislation and type of statutory directive varies. Statutory advance care directive documents are a legislated state-based advance care directive used to outline a person's preferences for care and/or appoint a substitute decision-maker. These documents are completed and signed by a competent person. All jurisdictions have legislative provisions allowing a person to appoint a substitute decision-maker in the event that he or she loses capacity. However, not all jurisdictions have a legislative regime for advance care directive documents for preferences of care and the common law (i.e. case law of decisions made by the courts) applies.

A National Framework for Advance Care Directives 2011 provided aspirational goals relating to advance care planning and its implementation. The legislation and advance care directive documentation across the jurisdictions lacks consistency. This lack of consistency may create a barrier to wider adoption of advance care planning, influence compliance with documentation and impact the low prevalence of advance care directive documentation in Australian health and residential services.

The purpose of this review was to:

1. undertake a comprehensive review of the laws that are relevant to advance care planning across all jurisdictions, with a focus on the differences between jurisdictions, to identify barriers that affect understanding and implementation of advance care planning
2. to outline enablers that may promote consistency in relevant laws across Australia and increase the uptake of advance care planning.

3 Review methodology

This review involved examining 31 legislative instruments (see Section 7) and at least 18 policy directives and guidelines.

The review methodology involved:

1. identifying and analysing as of March 2018:
    - the legislation relating to advance care directive documents - preferences for care and/or appoint a substitute decision-maker, legislation regarding the appointment of guardians and attorneys, and mental health legislation
    - relevant policy guidance and directives in relation to advance care planning across Australia
    - relevant case law relating to advance care planning in all jurisdictions across Australia
2. preparing a report on each jurisdiction in relation to a variety of topics relevant to advance care planning
3. analysing and comparing the legislation across all jurisdictions to identify similarities and differences between the jurisdictions and identify issues associated with the law across Australia
4. formulating a list of enablers to promote consistency in relevant laws across Australia and increase the uptake of advance care planning.

4 Findings

Advance care planning legislation exists in all Australia states and territories. All jurisdictions have legislative provisions allowing a person to appoint a substitute decision-maker in the event that he or she loses capacity. However, New South Wales and Tasmania do not have a legislative regime for advance care directive documents for preferences of care, therefore the common law (i.e. case law of decisions made by the courts) applies. However, there are inconsistencies across the jurisdictions in terms of the terminology, the scope and formalities for advance care directive documents.

4.1 Advance care directive documents

4.1.1 Types and scope of statutory advance care directive documents

The legislation uses different terminology to describe the documents that a person can make to set out instructions and preferences for future health care. The seven different legislative regimes (excluding mental health legislation) describe documents: 'health direction', 'advance personal plan', 'advance health directive', 'advance care directive' and 'refusal of treatment certificate', see Table 1. This situation may create confusion for the community and health practitioners.

Table 1. Terminology used, by jurisdiction

Jurisdiction	Name of advance care directive document prescribed by legislation	Legislation
Australian Capital Territory	Health direction	Medical Treatment (Health Directions) Act 2006 (ACT)
Northern Territory	Advance personal plan	Advance Personal Planning Act 2013 (NT)
Queensland **Western Australia**	Advance health directive	Powers of Attorney Act 1998 (Qld) Guardianship and Administration Act 1990 (WA)
South Australia **Victoria (from March 2018)***	Advance care directive	Advanced Care Directives Act 2013 (SA) Medical Treatment Planning and Decisions Act 2016 (Vic) (effective March 2018)
Victoria (past legislation)	Refusal of treatment certificate (still valid as an instructional directive if relevant to the specified health condition)	Medical Treatment Act 1988 (Vic)

Where legislation exists for advance care directives preferences for care, it applies to adults. The exception is in Victoria under the new Medical Treatment Planning and Decisions Act 2016, a child can also complete advance care directive documentation.

In jurisdictions with legislation for advance care directives documentation outlining preference for care, the provisions are broadly consistent in relation to when a person can make documentation (i.e. if he or she has decision-making capacity). However, the terminology differs between the jurisdictions such as 'decision-making capacity', 'full legal capacity' or no term but instead sets out the criteria a person must satisfy. The person can only make an advance care directive documentation if he or she understands the nature and effect of the directions and can communicate his or her directions. See Table 2.

Table 2. Who can make an advance care directive document, by jurisdiction

Jurisdiction	Name of advance care directive document	Who can make advance care directive document
Australian Capital Territory	Health direction	Any adult, unless he or she has a guardian appointed under the *Guardian and Management of Property Act 1991* (ACT) or has 'impaired decision-making capacity'.[1] A person has 'impaired decision-making capacity' if he or she cannot make decisions in relation to his or her affairs or does not understand the nature or effect of the decisions he or she makes in relation to his or her affairs.
Northern Territory	Advance personal plan	Any adult who has 'planning capacity'.[2] A person has 'planning capacity' if he or she has 'decision-making capacity' for making an advance personal plan and does not have an adult guardian. A person has 'decision-making capacity' if he or she has the capacity to understand and retain information about the matter, weigh the information in order to make a decision about it and communicate that decision in some way.[3]
Queensland	Advance health directive	In relation to an advance health directive that does not give power to an attorney, any adult (referred to as a 'principal') if he or she understands the nature and the likely effects of each direction in the advance health directive. In relation to an advance health directive that gives power to an attorney, any adult who (in addition to the above) also understands the matters necessary

[1] This term is defined in s. 9 of the *Powers of Attorney Act 2006* (ACT).

[2] *Advance Personal Planning Act 2013* (NT), s. 4.

[3] ibid., s. 6(1).

Jurisdiction	Name of advance care directive document	Who can make advance care directive document
		to make an enduring power of attorney giving the same power.[4]
South Australia	Advance care directive	Any competent adult if he or she understands what an advance care directive is and understands the consequences of giving an advance care directive.[5] The term 'competent' is not defined.
Victoria (from March 2018)	Advance care directive	Any person (including a child) who has 'decision-making capacity' and understands the nature and effect of each statement in the directive.[6] A person has 'decision-making capacity' if he or she is able to (a) understand the information relevant to the decision and the effect of the decision, (b) retain that information to the extent necessary to make the decision, (c) use or weigh that information as part of the process of making the decision, and (d) communicate the decision and his or her views and needs as to the decision in some way.[7]
Western Australia	Advance health directive	Any person who has reached 18 years of age and has full legal capacity.[8] The term 'full legal capacity' is not defined. However, if the person does not understand the nature of the treatment decision or the consequences of making the treatment decision, the advance health directive will be invalid.[9]

[4] As set out in s. 41 of the *Powers of Attorney Act 1998* (Qld).

[5] *Advance Care Directives Act 2013* (SA), s. 11(1).

[6] *Medical Treatment Planning and Decisions Act 2016* (Vic), s. 13(a).

[7] ibid., s. 4.

[8] *Guardianship and Administration Act 1990* (WA), s. 110P.

[9] ibid., s. 110R(2).

The scope of legislated advance care directive documents differs, see Table 3. There is variation in relation to the refusal or withdrawal of treatment, or whether he or she can also give directions about the administration of treatment. In some jurisdictions (Australian Capital Territory and, until March 2018, Victoria), directions can only be given about the refusal or withdrawal of treatment. In other jurisdictions (the Northern Territory, Queensland, South Australia, Victoria from March 2018, and Western Australia), directions can be given about the administration of treatment as well as the refusal or withdrawal of treatment.

Table 3. The scope of advance care directive documents, by jurisdiction

Jurisdiction	Name of advance care directive document	Can document contain directions about administration of treatment as well as refusal / withdrawal of treatment?	Scope of advance care directive document	What about palliative care?
Australian Capital Territory	Health direction	No: refusal/withdrawal only	Contains directions to refuse or require the withdrawal of medical treatment.[10]	Legislation does not apply to palliative care.[11] Therefore a health practitioner may administer palliative care despite any instructions to the contrary in a health direction.[12]
Northern Territory	Advance personal plan	Yes	Contains 'advance consent decisions' about 'future health care action'[13], which includes commencing, continuing, withholding or withdrawing 'health care'.[14] 'Health care' means '*health care of any kind*'.	The legislation is silent in relation to palliative care. However, decisions in advance personal plans relate to 'health care', which means '*health care of any kind*' and, therefore, can include decisions about palliative care.

[10] *Medical Treatment (Health Directions) Act 2006* (ACT), s. 7(1).
[11] ibid., s. 6(2).
[12] The legislation does not affect any right, power or duty that a health professional or anyone else has in relation to palliative care: *Medical Treatment (Health Directions) Act 2006* (ACT), s. 6(2).
[13] *Advance Personal Planning Act 2003* (NT), s. 8(a).
[14] ibid., s. 3.

Jurisdiction	Name of advance care directive document	Can document contain directions about administration of treatment as well as refusal / withdrawal of treatment?	Scope of advance care directive document	What about palliative care?
Queensland	Advance health directive	Yes	Contains directions about a person's future 'health care',[15] which includes care or treatment of, or a service or a procedure for the person, to diagnose, maintain, or treat his or her physical or mental condition. Can only contain directions that a life-sustaining measure be withheld if certain criteria are satisfied.[16]	The legislation is silent as to palliative care. However, if the care or treatment does not involve diagnosing, maintaining or treating the person's physical or mental condition, it does not fall within the definition of 'health care'.
South Australia	Advance care directive	Yes, but commencement directions are 'non-binding'	Contains provisions relating to future health care, which includes the withdrawal of health care.[17] Provisions about the refusal of health care are binding. Other provisions (e.g. for administration of health care) are non-binding.	An advance care directive cannot authorise a substitute decision-maker to, in effect, refuse palliative care on behalf of the person.[18]

[15] *Power of Attorney Act 1998* (Qld), s. 35.
[16] ibid., s. 36(2)(c).
[17] *Advance Care Directives Act 2013* (SA), s. 4.
[18] The legislation states that despite any provision in an advance care directive to the contrary, an advance care directive does not authorise a substitute decision-maker to refuse the administration of drugs to relieve pain or distress, or the natural provision of food and liquids by mouth.

Jurisdiction	Name of advance care directive document	Can document contain directions about administration of treatment as well as refusal / withdrawal of treatment?	Scope of advance care directive document	What about palliative care?
Victoria	Advance care directive (from March 2018)	Yes	Contains binding 'instructional directives'[19] and/or 'values directives'[20] in relation to 'medical treatment' (which includes treatment with physical or surgical therapy, treatment for mental illness, treatment with prescription pharmaceuticals, dental treatment and palliative care, but not a 'medical research procedure').[21]	Advance care directive can contain directives about palliative care. A health practitioner may administer palliative care to a person despite any decision of his or her medical treatment decision-maker, but must have regard to the person's preferences and values and consult with the medical treatment decision-maker (if any).[22]
Western Australia	Advance health directive	Yes	Contains 'treatment decisions' (which includes consent or refusal to consent to commencement or continuation of treatment) in relation to future treatment.[23]	The definition of 'treatment' includes 'palliative care'.[24] An advance health directive can contain treatment decisions about palliative care.[25]

[19] An 'instructional directive' is an express statement of a person's medical treatment decision and takes effect as if the person who gave it has consented to, or refused the commencement or continuation of, medical treatment: *Medical Treatment Planning and Decisions Act 2016* (Vic), s. 6.
[20] A 'values directive' is a statement of a person's preferences and values as the basis on which the person would like any medical treatment decisions to be made on behalf of the person, including a statement of medical treatment outcomes that the person regards as acceptable.
[21] *Medical Treatment Planning and Decisions Act 2016* (Vic), s. 12.
[22] ibid., s. 54.
[23] See *Guardianship and Administration Act 1990* (WA), s. 110P.
[24] ibid., s. 3. 'Palliative care' is defined as '*a medical, surgical or nursing procedure directed at relieving a person's pain, discomfort or distress, but does not include a life sustaining measure*'.
[25] ibid., sections 110ZL.

The legislation in some jurisdictions allows advance care directive documents to contain directions about palliative care, whereas in others, the legislation states that it does not apply to palliative care.

4.1.2 Obligations on health practitioners to comply with advance care directives

In general, health practitioners are obliged to comply with directions in an advance care directive document. There are some anomalies. For example:

- In the Australian Capital Territory, a health practitioner must reasonably believe that the direction complies with the legislation and that the person who made it has not revoked it or changed his or her mind since making it. This puts an obligation on the health practitioner to consider the validity of the document and to make enquiries about whether the person who made the direction may have changed his or her mind since making it.
- In Queensland, there is confusion about whether a health practitioners has an obligation to follow an advance health directive if he or she has reasonable grounds to believe that a direction in it is uncertain or inconsistent with good medical practice, or that circumstances have changed to the extent that the terms of the direction are inappropriate. The legislation states that a health practitioner will not incur any liability in those circumstances.
- South Australian and Victorian legislation (i.e. the new MTPD Act 2016) recognises that health practitioners should not always be obliged to comply with directions about the administration of treatment. South Australia has adopted the concept of 'binding provisions' (i.e. a provision to refuse particular health care) and 'non-binding provisions' (i.e. all other provisions, such as a provision for the administration of health care). A health practitioner must comply with a binding provision. In relation to a non-binding provision, the health practitioner should, as far as reasonably practicable, comply with it. The new Victorian legislation, states a health practitioner must give effect to any instructional directive in an advance care directive. However, in relation to an instructional directive consenting to administration of treatment, the health practitioner is only obliged to give effect to it if he or she is of the opinion that it is clinically appropriate.

4.1.3 Advance care planning in the context of mental health

A Mental Health Act exists in all jurisdictions except for Northern Territory. The Australian Capital Territory and Victoria Mental Health Acts include advance directive documents known as an advance agreement or advance consent direction and an advance statement, respectively. In all other jurisdictions including Northern Territory, advance care directive documentation can include advance consent and directions inclusive of mental health.

Since March 2018 when Victoria introduced an advance care directive, there are now two different statutory advance care directive documents that can be made in relation to mental health: an advance statement and an advance care directive. This has the potential to cause confusion. It also has the potential to cause difficulties if a person has an advance care directive and an advance statement that contain different directions and preferences in relation to treatment for a mental illness.

In Queensland, the government has published a document described as 'Advance health directive for mental health'. This document is made under the *Power of Attorney Act 1998* (Qld) as referenced in the Queensland Mental Health Act 2016. Therefore there are two documents, one called an 'advance health directive for mental health' and the other an 'advance health directive'. Both documents allow for advance consent and directions inclusive of mental health. This has the potential to cause confusion. It also has the potential to cause difficulties if a person has an advance health directive for mental health and a standard advance health directive that contain different directions and preferences in relation to treatment for a mental illness.

4.1.4 Formalities of advance care directive documents

Across jurisdictions, there are inconsistent requirements in relation to the use of prescribed advance care directive forms, see Table 4.

Table 4. Forms to be used for advance care planning, by jurisdiction

Jurisdiction	Is there a prescribed form?	Does the prescribed form need to be used?
Australian Capital Territory	Yes	Yes: a health direction must be in the prescribed form, unless it is made orally.
New South Wales	No	N/A: there is no legislation and therefore no prescribed form. However, the Ministry of Health has published an advance care directive form that it recommends be used.[26]
Northern Territory	Yes	No: there is a prescribed form for an advance personal plan, but it does not need to be used.[27] If the prescribed form is not used, the advance personal plan must be in writing and comply with requirements prescribed in the regulations (discussed below).[28]
Queensland	Yes	No: there is a prescribed form for an advance health directive, but it does not need to be used.[29]
South Australia	Yes	Yes: an advance care directive must be in the prescribed

[26] This form is included within a document package called 'Making an advance care directive'.

[27] *Advance Personal Planning Act 2013* (NT), s. 9.

[28] ibid., s. 9(2).

[29] *Powers of Attorney Act 1998* (Qld), s. 44(2).

Jurisdiction	Is there a prescribed form?	Does the prescribed form need to be used?
		form.[30]
Tasmania	No	N/A: there is no prescribed form. However, the Department of Health and Human Services has published an advance care directive form that it recommends be used.
Victoria (from March 2018)	No	The MTPD Act 2016 does not prescribe form(s), however the Victorian Department of Health and Human Services has produced a range of recommended forms.

In addition, the formal requirements as to signing are inconsistent.

- In South Australia, an advance care directive document must be signed by the person making it. There is no provision for another person to sign it at the direction of the person making it.
- In the Australian Capital Territory, the Northern Territory, Queensland, Victoria (from March 2018) and Western Australia, advance care directive documents can be signed by a person acting at the direction of the person making it, subject to certain requirements. This recognises that it is not always possible for the person who is making the advance care directive document to sign it.

The legislation across the jurisdictions also varies in relation to who can witness an advance care directive document and the requirements for witnessing documents. All jurisdictions refer to advance care directive documents being signed and witnessed, but no jurisdictions have legislation that specifies whether an electronic signature is sufficient. Currently, there appears to be no suitable technological application that enables advance care directive documents to be signed, witnessed and stored electronically. However, in the future, people will increasingly expect to be able to complete advance care directive documents online (e.g. through an application on a smartphone or other device) and to be able to use an electronic signature and have a witness use an electronic signature. Although the legislation does not state that electronic signatures are not sufficient, it would be preferable if the legislation specifically addressed the availability of electronic signatures.

There is a lack of consistency across the jurisdictions in relation to the validity of advance care directive documents if the formal legislative requirements are not satisfied, see Table 5. This variation can cause confusion for health practitioners and the community.

[30] *Advance Care Directives Act 2013* (SA), s. 11(3).

Table 5. The validity of statutory advance care directive documents if the formal legislative requirements are not satisfied, by jurisdiction

Jurisdiction	Is advance care directive document valid if formalities not satisfied?	Additional comments
Australian Capital Territory	No: a health direction will be invalid if formal requirements not satisfied.[31] In relation to advance agreements and advance consent directions, the legislation is silent.	
Northern Territory	No: an advance personal plan will not be valid if formal requirements not satisfied.[32]	Even if an advance personal plan is not valid, it may constitute a statement of the person's views and wishes that may be taken into account by a person acting for him or her.[33] The Northern Territory Civil and Administrative Tribunal may declare an advance personal plan to be a valid advance personal plan despite non-compliance with formal requirements.[34]
Queensland	Unclear, as the legislation is silent.	The legislation does not affect the recognition at common law of instructions given by an adult about his or her health care.[35] Therefore, if the advance care directive complies with common law requirements, it should be valid, even if the formal requirements have not been satisfied. The Supreme Court of Queensland may decide that an advance health directive (or power of attorney or enduring power of attorney) is valid even if the document does not satisfy the formal requirements.[36] However further advice is available at End of Life Law in Australia.
South Australia	It can be, depending on the nature of the formalities that	A minor irregularity will not affect the validity of the advance care directive, but

[31] *Medical Treatment (Health Directions) Act 2006* (ACT), s. 8.

[32] *Advance Personal Planning Act 2013* (NT), s. 13.

[33] ibid., s. 13.

[34] ibid., s. 13(3).

[35] *Powers of Attorney Act 1998* (Qld), s. 39.

[36] ibid., s. 113.

Jurisdiction	Is advance care directive document valid if formalities not satisfied?	Additional comments
	have not been satisfied.	a more substantive irregularity will affect the validity.[37] For any other irregularity, the advance care directive is likely to be invalid (e.g. if the person making the directive fails to complete a section of the form that is specified as being a section that must be completed).
Victoria (past legislation)	Unclear, as the previous relevant legislation is silent. Now considered a values directive under the new legislation.	The legislation does not limit the operation of any other law. Therefore, if the formal requirements for a refusal of treatment certificate have not been satisfied, it may still be valid under common law if the common law requirements are met.
Victoria (from March 2018)	No: an advance care directive will not be valid if formal requirements not satisfied. However, it may nevertheless constitute a statement of the person's preferences and values that may be taken into account by a medical treatment decision-maker, a health practitioner or the Public Advocate.[38]	
Western Australia	It can be, depending on the nature of the formalities that have not been satisfied.	One of the formal requirements is that the person making the advance health directive needs to be encouraged to seek legal or medical advice. If that requirement is not satisfied, the advance health directive will nevertheless be valid. However, for any other irregularity, the advance health directive will be invalid.[39]

[37] Refer to *Advance Care Directives Act 2013* (SA), s. 11(5). An advance care directive will not be invalid merely because: (a) the person giving it did not complete a particular section of the form (except for a section specified as being a section that must be completed); or (b) the person giving the advance care directive did not appoint a substitute decision-maker; or (c) the person giving the advance care directive was not fully informed in relation to each medical condition, or any other circumstance, to which the advance care directive relates; or (d) the person giving the advance care directive did not seek legal or other professional advice in relation to the advance care directive; or (e) the advance care directive contains a minor error (i.e. an error that does not affect the ability to understand the wishes and instructions of the person, such as a misspelling); or (f) instructions in the advance care directive are expressed in informal language rather than medical or technical terminology; or (g) the person expressed his or her wishes in general terms rather than specific instructions, or that his or her wishes in relation to a particular matter need to be inferred from the advance care directive; or (h) instructions in the advance care directive are based solely on religious, moral or social grounds.

[38] *Medical Treatment Decisions and Planning Act 2016* (Vic), s. 21.

[39] *Guardianship and Administration Act 1990* (WA), s. 110Q.

4.1.5 Amending and revoking advance care directive documents

The legislation across the jurisdictions varies in relation to amending advance care directive documents.

- In South Australia, an advance care directive cannot be amended. Therefore, if a person wishes to vary the terms of an advance care directive he or she has made, he or she must make a new one.
- In the Northern Territory, an advance personal plan can be amended by making a new one, although this does not have the effect of automatically revoking the earlier advance personal plan, as in South Australia.
- In the Australian Capital Territory, Queensland, and Western Australia, the legislation is silent about whether the relevant advance care directive document can be amended; therefore, it is unclear whether an advance care directive document can be amended in those jurisdictions.
- In Victoria, under the new legislation, it allows an advance care directive document to be amended by making the amendment on the face of the original document. The directive may also be revoked via an expiry date within it, in accordance with the Act.

The legislation across the jurisdictions varies regarding the requirements to revoke an advance care directive.

- In some jurisdictions (e.g. South Australia), making an advance care directive document where one already exists has the effect of automatically revoking the earlier instrument, whereas in others (e.g. the Northern Territory), more than one advance care directive document can co-exist.
- In some jurisdictions (i.e. the Northern Territory, Queensland, South Australia), an advance care directive document must be revoked in writing.
- In the Australian Capital Territory, a health direction can be revoked in writing, orally or in any other way. In Victoria, a person can cancel an existing refusal of treatment certificate through a clear expression of a decision to cancel it.
- In Western Australia, a treatment decision in an advance health directive is taken to have been revoked if the person has changed his or her mind about the treatment decision since making the directive and the legislation does not otherwise set out any formal requirements for revoking an advance health directive in its entirety.

Inconsistent approaches to variation and revocation of advance care directive documents can cause confusion for health practitioners and the community.

4.1.6 Storage of advance care directive documents

The legislation relating to advance care directive documents does not contain provisions about storage of these documents. Therefore, there is no consistent practice as to where advance care directive documents are stored. It can be difficult for a health practitioner to know whether the advance care directive document he or she is looking at is the correct document, or whether there exists a later advance care directive document, which has the automatic effect of revoking the earlier one.

If legislation requires or encourages a person to keep a copy of any advance care directive document he or she has made in a specified place (eg. My Health Record), it will be much easier for health practitioners to comply with their obligations to ascertain whether a person has an advance care directive document or has appointed a substitute decision-maker. My Health Record could be used for this purpose and designed so that when a new advance care directive document is submitted or uploaded, the system automatically watermarks any earlier advance care directive document as being revoked (assuming that is the effect of the relevant legislation). This would minimise the risk of a health practitioner relying upon the wrong advance care directive document.

4.1.7 Substitute decision-makers: appointment and scope of powers

Substitute decision-makers appointed by a principal

Across the eight jurisdictions, there are six different descriptions of substitute decision-makers who can be appointed by a person for what is essentially the same role: 'attorney', 'decision-maker', 'enduring guardian', 'attorney for a health directive', 'substitute decision-maker' and 'appointed medical treatment decision-maker'.

The powers given to substitute decision-makers appointed by a principal also differ between jurisdictions. There is some commonality across the jurisdictions about the procedures for which a substitute decision-maker cannot consent (e.g. they cannot consent to the sterilisation of a person or termination of pregnancy). However, not all jurisdictions have provisions about procedures in respect of which an appointed substitute decision-maker may not consent. For example, in New South Wales, a substitute decision-maker's powers are only limited to the extent specified in the instrument of appointment.

There are inconsistencies across the jurisdictions about who can and cannot be appointed by a person as his or her substitute decision-maker. In particular, some jurisdictions prohibit a person's paid carer or health practitioner from being appointed as a substitute decision-maker, but some allow it.

This variation can cause confusion for health practitioners and the community.

Substitute decision-makers appointed by a tribunal

The legislation in all jurisdictions refers to substitute decision-makers appointed by a tribunal as 'guardians'. However, legislation in some jurisdictions refers to a full (or plenary) guardian and a limited guardian, whereas legislation in other jurisdictions does not.

'Default' substitute decision-makers

The legislation across all jurisdictions excluding Northern Territory provides for a default substitute decision-maker, see Table 6. Default substitute decision-makers come into effect if there is no guardian and the person has not appointed a substitute decision-maker. Legislation varies regarding the order of persons who will be designated as a substitute decision-maker. In Northern Territory, there is no hierarchy specified.

Health practitioners who need to identify the appropriate person to act as substitute decision-maker must navigate the relevant order of priority. If all legislation specified a consistent hierarchy of default decision-makers, this would reduce confusion.

Table 6. The order in which a person may be deemed to be the default decision-maker, by jurisdiction

Jurisdiction	Description of default substitute decision-maker	Order of priority in becoming a substitute decision-maker (if there is no substitute decision-maker appointed by the person and no guardian)
Australian Capital Territory	Health attorney[40]	1. Domestic partner 2. Carer for the person 3. Close relative or close friend
New South Wales	Person responsible[41]	1. Spouse 2. Carer for the person 3. Close friend or relative
Northern Territory	Available consenter (a decision-maker appointed by principal or adult guardian appointed by tribunal who is willing and able to make an informed consent decision about the relevant healthcare action)[42]	No hierarchy specified
Queensland	Statutory health attorney[43]	1. Spouse or domestic partner 2. A person who is at least 18 years old and provides (unpaid) care to the patient 3. Adult who is a close friend or relation of the patient
South Australia	Person responsible[44]	1. Relative (spouse, partner, relative) with close and continuing relationship 2. Adult friend with close and continuing relationship 3. Overseer of supervision, care and well-being 4. Person appointed by Tribunal
Tasmania	Person responsible[45]	For a person under 18 years: 1. Spouse (if he or she has a spouse) 2. Parent (if he or she does not have a

[40] *Guardianship and Management of Property Act 1991* (ACT), s. 32B.

[41] *Guardianship Act 1987* (NSW), s. 33A.

[42] *Advance Personal Planning Act 2016* (NT), s. 42(1)(b).

[43] *Guardianship and Administration Act 2000* (Qld), s. 66; *Powers of Attorney Act 1998* (Qld), s. 63.

[44] *Consent to Medical Treatment and Palliative Care Act 1995* (SA), s. 14 ('person responsible').

[45] *Guardianship and Administration Act 1995* (Tas), s. 4.

Jurisdiction	Description of default substitute decision-maker	Order of priority in becoming a substitute decision-maker (if there is no substitute decision-maker appointed by the person and no guardian)
		spouse) For a person 18 years or older: 1. Spouse 2. Carer 3. Close friend or relative
Victoria (past legislation)	Person responsible[46] [this will be repealed from March 2018]	[To be repealed from March 2018] 1. Spouse or domestic partner 2. Primary carer 3. Nearest relative (as defined)
Victoria (from March 2018)	Medical treatment decision maker [47]	First of the following who is in a close and continuing relationship: 1. The spouse or domestic partner of the person 2. The primary carer of the person 3. The first of the following: a) an adult child of the person (if there are more than one, the oldest) b) a parent of the person (if there are more than one, the oldest) c) an adult sibling of the person (if there are more than one, the oldest)
Western Australia	Person responsible[48]	1. Spouse or de facto partner 2. Nearest relative (child) 3. Nearest relative (parent) 4. Nearest relative (sibling) 5. Primary provider of (unpaid) care and support 6. Any other adult who maintains close personal relationship with the patient

[46] *Guardianship and Administration Act 1986* (Vic), s. 37.

[47] *Medical Treatment Planning and Decisions Act 2016* (Vic), s. 55(3).

[48] *Guardianship and Administration Act 1990* (WA), s. 110ZD.

Applicable standards to be applied by substitute decision-makers

The applicable standard to be applied by a substitute decision-maker when making a decision about a health matter on behalf of a person is similar across the jurisdictions. This is regardless of whether the substitute decision-maker was appointed by the represented person, appointed by a tribunal or is deemed to be the default decision-maker because of the operation of legislation. In general, substitute decision-makers are required to act in the best interests of the represented person or work out what the represented person's views and wishes would have been (if it is reasonably practicable to do so) and take those views and preferences into account. However, there are slight differences between the provisions across the jurisdictions.

4.1.8 Guidance for health practitioners

Seeking consent from substitute decision-makers

The legislation across the jurisdictions has differing provisions in relation to obtaining consent from substitute decision-makers (e.g. whether written consent is required and the effect of consent provided by a substitute decision-maker).

Legal protections

In most jurisdictions, there are legislative legal protections for health practitioners in relation to complying with directions in advance care directive documents and consent given by substitute decision-makers. However, the extent of these protections and the circumstances in which they apply differs across the jurisdictions.

4.1.9 Recognition of interstate documents

There are inconsistencies in the legislation across the jurisdictions regarding recognition of advance care directive documents and documents appointing substitute decision-makers. The effect of this is that an advance care directive document made by a person in his or her home jurisdiction will be valid in that jurisdiction and in some other jurisdictions, but may not be valid in all other jurisdictions. In the Australian Capital Territory, the legislation does not recognise advance care directive documents made in other jurisdictions. Similarly, as New South Wales and Tasmania do not have any legislative regime relating to advance care directive documents, there are no legislative provisions regarding the recognition of interstate instruments. Other jurisdictions (the Northern Territory, Queensland, South Australia, Victoria and Western Australia) have legislative provisions recognising interstate instruments, but there is no uniformity across those provisions in terms of the requirements that must be met and the extent to which those documents are recognised as valid advance care directive documents.

There is a single common law in Australia that may be interpreted differently depending upon the statutory context in each jurisdiction. In some states the common law sits alongside the legislation and people can make a directive under either. In general, it is believed that advance care directives documents will be recognised under legislation or common law.

5 Limitations

The limitations of this review were as follows.

- This review was conducted at a point in time and legislation changes were underway in one jurisdiction and a review of legislation had commenced in at least two jurisdictions. The main focus of this report is statutory advance care directive documents (i.e. those made under the relevant legislation) rather than common law advance care planning documents.
- This report considers legislative provisions regarding substitute decision-makers. Under the mental health legislation in most jurisdictions, a person can appoint a 'nominated person' (sometimes called a 'support person' or 'designated carer'). The role of a nominated person is to provide support to the represented person in relation to his or her treatment and care for a mental illness and help represent his or her interests. The nominated person is also entitled to receive information about the represented person and be consulted about decisions in relation to his or her treatment and care. Nominated persons do not, however, have power to make medical consent decisions on behalf of the represented person. Therefore this report does not consider nominated persons.
- This report does not define the relevant health practitioners for each legislation relating to advance care directives for preferences of care.
- This report does not address the issue of advance care directive documents being developed for persons who do not have legal capacity or competence to make such a document.
- This report does not address the understanding of the community (including health practitioners and the general population) in relation to the purpose, scope and legislative requirements of advance care directive documents. However, the authors note the findings identify challenges for increasing the community's understanding of advance care directive documents, especially among diverse communities and those with low health literacy.

6 Legislative implications

The review of advance care planning related legislation in all Australian states and territories has identified consistencies and variation in terminology, scope, formalities, obligations and recognition. It is acknowledged that variation can create confusion at all levels of the health system and particularly for service providers, health practitioners and the community. This variation may impact on the uptake of advance care planning throughout Australia. There are opportunities for governments reviewing existing legislation to improve consistency in terminology, scope and obligations.

There is opportunity to improve the alignment of advance care planning terminology and definitions across the variety of legislation considered in this review. Improvements include document names (eg. advance care directive), role name such as the individual making decisions on behalf of the person (eg. substitute decision-makers), role name of those appointed by a tribunal, definition of a person who has decision-making capacity to make an advance care directive, definition of health practitioners and more.

Variation in the scope of legislation could be improved. In jurisdictions with legislation, legislation could contain directions about the administration of treatment, as well as the refusal or withdrawal of treatment. This would promote legislation to support directions in relation to both physical and mental health, reducing the need for duplication under Mental Health Acts and duplication of forms within two jurisdictions. In addition, all jurisdictions could specify a hierarchy of persons who, by default, will be a person's substitute decision-maker. Consideration could be given to updating the scope of legislation in relation to provisions to seeking consent from substitute decision-makers and standards to be applied by substitute decision-makers when making a treatment decision on behalf of a person (eg. substituted judgement approach). Other considerations include the inclusion of children, processes for amending or revoking documentation, electronic signatures and/or storage. The scope relating to amendment or revocation of documents could be addressed by legislation containing two provisions: (1) that advance care directive documents cannot be amended; and (2) that making an advance care directive document has the automatic effect of revoking any previously made documents.

Consistent formalities relating to advance care directive documentation and forms could be promoted. Forms could be prescribed within the legislation and it could allow for documentation that is 'substantially' the same to be valid. There could be consistency in forms across jurisdictions. Legislation in jurisdictions could have a provision that allows the person making the advance care directive document to direct another person to sign the document on his or her behalf. Legislation across the jurisdictions could have consistent provisions in relation to the witnessing requirements for advance care directive documents. Legislation across jurisdictions could recognise that electronic signatures are acceptable for the person signing the

document and the witness(es) signing the document. This is likely to encourage people to make better use of any available technological applications for signing and storage of advance care directive documents. In addition, legislation across all jurisdictions could contain a provision recognising the validity of advance care directive documents even if all formal requirements are not satisfied.

The obligation on health practitioners to comply with advance care directive documents could be made more clear and consistent in legislation. For example, a health practitioner is only obliged to comply with a direction for the administration of treatment if he or she is of the opinion that it is clinically appropriate. For example, consent given by a person responsible for the patient to the administration of a proposed medical treatment will be taken to be a consent given by the patient and to have the same effect as if it were given by the patient. Protections available to health practitioners across all jurisdictions could be more consistent and sufficiently broad to provide adequate protection to health practitioners who, acting reasonably and in good faith, rely upon directions in an advance care directive document.

Jurisdictional advance care planning legislation could contain a provision recognising the validity of advance care directive preferences for care or appointment of a substitute decision-maker documents made in other jurisdictions.

7 Legislation included in this review

Specifically, this project involved reviewing the following legislation.

Commonwealth

- Aged Care Act 1997 (Cth)

Australian Capital Territory

- Medical Treatment (Health Directions) Act 2006 (ACT)
- Guardianship and Management of Property Act 1991 (ACT)
- Powers of Attorney Act 2006 (ACT)
- Mental Health Act 2015 (ACT)

New South Wales

- Guardianship Act 1987 (NSW)
- Guardianship Regulations 2016 (NSW)
- Mental Health Act 2007 (NSW)

Northern Territory

- Advance Personal Planning Act 2013 (NT)
- Guardianship of Adults Act 2016 (NT)
- Mental Health and Related Services Act 1998 (NT)

Queensland

- Guardianship and Administration Act 2000 (Qld)
- Powers of Attorney Act 1998 (Qld)
- Mental Health Act 2016 (Qld)

South Australia

- Advance Care Directives Act 2013 (SA)
- Consent to Medical Treatment and Palliative Care Act 1995 (SA)
- Powers of Attorney and Agency Act 1984 (SA)

- Guardianship and Administration Act 1993 (SA)
- Health Care Act 2008 (SA)
- Mental Health Act 2009 (SA)

Tasmania

- Guardianship and Administration Act 1995 (Tas)
- Powers of Attorney Act 2000 (Tas)
- Mental Health Act 2013 (Tas)

Victoria

- Medical Treatment Act 1988 (Vic)
- Medical Treatment Planning and Decisions Act 2016 (Vic) (effective March 2018)
- Guardianship and Administration Act 1986 (Vic)
- Powers of Attorney Amendment Act 2016 (Vic)
- Powers of Attorney Act 2014 (Vic)
- Mental Health Act 2014 (Vic)

Western Australia

- Guardianship and Administration Act 1990 (WA)
- Mental Health Act 2014 (WA)

8 Resources and links

Australian Capital Territory

Palliative Care ACT

- Health direction form: http://www.pallcareact.org.au/images/pdfs/Health_form_interactive_100209r.pdf
- Enduring power of attorney form: https://www.ptg.act.gov.au/images/pdf/ptg-end-poa-form.pdf

Department of Health

- Advanced care plan statement of choice (competent person) form: http://www.bemyvoice.com.au/Documents/Advance-Care-Plan-Competent-Mar-2015.aspx
- Advance consent directions form: https://www.health.act.gov.au/sites/default/files//15303%20Advance%20Consent%20DirectionSAMPLE.pdf
- Paths of healing, 'Your advance agreement': http://health.act.gov.au/sites/default/files/paths%20of%20healing%20Your%20Advance%20Agreement.pdf

New South Wales

NSW Government

- Making an advance care directive (including advance care directive form): http://www.health.nsw.gov.au/patients/acp/Publications/acd-form-info-book.pdf
- Advance planning for quality care at end of life: Action plan 2013–2018: http://www.health.nsw.gov.au/patients/acp/Publications/acp-plan-2013-2018.pdf
- Consent to medical treatment - patient information (2005): http://www1.health.nsw.gov.au/pds/ActivePDSDocuments/PD2005_406.pdf
- Advance care directives - using: http://www1.health.nsw.gov.au/pds/ActivePDSDocuments/GL2005_056.pdf
- End-of-life care and decision-making – guidelines (2005): End-of-Life Care and Decision-Making - Guidelines

Department of the Attorney General

- Capacity toolkit: http://www.justice.nsw.gov.au/diversityservices/Documents/capacity_toolkit0609.pdf

Northern Territory

Northern Territory Government

- Advance personal plan form: https://nt.gov.au/__data/assets/pdf_file/0006/169071/advance-personal-plan-form.pdf
- Application to register an advance personal plan: https://nt.gov.au/__data/assets/pdf_file/0017/170432/application-to-register-advance-personal-plan.pdf

Queensland

Queensland Government

- Advance health directive form: https://publications.qld.gov.au/dataset/0e798d96-9ba6-4aa0-95cd-5a017a0589a9/resource/6a3af073-cdba-4b82-8de7-eabe65950c24/download/advancehealthdirectiveformform4.pdf
- Enduring power of attorney (short form): https://publications.qld.gov.au/dataset/0e798d96-9ba6-4aa0-95cd-5a017a0589a9/resource/94c27605-28ad-4e71-846b-04b0d66ef3b8/download/enduringpowerofattorneyshortformform2.pdf
- Enduring power of attorney (long form): https://publications.qld.gov.au/dataset/0e798d96-9ba6-4aa0-95cd-5a017a0589a9/resource/d33b1e89-0b07-4a14-a4d8-05ff4f610b25/download/enduringpowerofattorneylongformform3.pdf
- Revocation of enduring power of attorney: https://publications.qld.gov.au/dataset/0e798d96-9ba6-4aa0-95cd-5a017a0589a9/resource/f94f016c-5fff-4b27-9f77-a957bd120865/download/revocationofenduringpowerofattorneyform6.pdf

South Australia

South Australian Government

- Advance care directive form: https://advancecaredirectives.sa.gov.au/forms-and-guides/advance-care-directive-fillable-pdf

Department of Health

- Advance care directives policy directive (2014): http://www.sahealth.sa.gov.au/wps/wcm/connect/ef45c780405ec39183feb7a05d853418/Directive_Advance+Care+Directives_policy_July2014.pdf?MOD=AJPERES&CACHEID=ef45c780405ec39183feb7a05d853418
- Consent to medical treatment and health care policy guideline (2015): http://www.sahealth.sa.gov.au/wps/wcm/connect/f0ee918046d8588f8b8ffb22d29d99f6/Guideline_Consent+to+Medical+Treatment+and+Health+Care_June2015.pdf?MOD=AJPERES&CACHEID=f0ee918046d8588f8b8ffb22d29d99f6

Tasmania

Department of Health

- Advance care directive form: http://www.dhhs.tas.gov.au/__data/assets/pdf_file/0008/129455/2482_ACD_Form_Online_Version_4_page.pdf

Victoria

Palliative Care Victoria

- Advance care planning: have the conversation. A strategy for Victorian health services 2014–2018: http://www.pallcarevic.asn.au/library-media/advance-care-planning-strategy/

Office of the Public Advocate

- Refusal of medical treatment fact sheet: http://www.publicadvocate.vic.gov.au/our-services/publications-forms/medical-consent/refusal-of-treatment/108-refusal-of-treatment-fact-sheet
- Refusal of treatment certificate (competent person): http://www.publicadvocate.vic.gov.au/our-services/publications-forms/medical-consent/refusal-of-treatment/81-refusal-of-treatment-certificate-competent-person
- Refusal of treatment certificate (agent or guardian of incompetent person): http://www.publicadvocate.vic.gov.au/our-services/publications-forms/medical-consent/refusal-of-treatment/82-refusal-of-treatment-certificate-agent-or-guardian-of-incompetent-person

Department of Health

- Advance statements: https://www2.health.vic.gov.au/mental-health/practice-and-service-quality/mental-health-act-2014-handbook/recovery-and-supported-decision-making/advance-statements

Western Australia

Department of the Attorney General

- Your choice to … make an advance health directive, appoint an enduring guardian: http://www.publicadvocate.wa.gov.au/_files/EPG_and_AHD.pdf
- A guide to enduring power of guardianship in Western Australia (including enduring power of guardianship form): http://www.publicadvocate.wa.gov.au/_files/epg_guide.pdf
- Enduring power of guardianship in Western Australia information kit (including enduring power of guardianship form): http://www.publicadvocate.wa.gov.au/_files/epg_kit.pdf
- Information sheet 9: Enduring powers of guardianship: http://www.publicadvocate.wa.gov.au/_files/is9_enduring_powers_guardianship.pdf
- Information sheet 10: Planning for the future: http://www.publicadvocate.wa.gov.au/_files/is10_planning_for_the_future.pdf
- A guide to enduring power of attorney in Western Australia (including enduring power of attorney forms): http://www.publicadvocate.wa.gov.au/_files/EPA_Guide.pdf
- Enduring power of attorney information kit (including enduring power of attorney forms): http://www.publicadvocate.wa.gov.au/_files/epa_kit.pdf

Please note all state and territory forms are available in a centralised location via the Advance Care Planning Australia website http://www.advancecareplanning.org.au/resources/advance-care-planning-in-my-state

Advance Care Planning Australia

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