

## **Community knowledge of law at the end of life: availability and accessibility of web-based resources**

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## **Abstract**

**Objective:** To identify online resources community members might access to inform themselves about their legal duties and rights in end-of-life decision-making.

**Methods:** Resource mapping identified online resources that members of the public in New South Wales, Victoria and Queensland are likely to identify, and assessed the ease or difficulty in locating them. Resources were then critically analysed for accessibility of language and format using the Patient Education Materials Assessment Tool (PEMAT).

**Results:** Identified resources differed considerably based on whether search terms identified by community members or experts were used. Most resources focused on advance directives, enduring powers of attorney and substitute decision-making. Relatively few provided information about legal duties (e.g., powers and responsibilities of substitute decision-makers) or resolving conflict with health practitioners. Accessibility (understandability and actionability) of resource content varied.

**Conclusions:** While numerous resources on end-of-life law are available online, community members may not be able to identify relevant resources or find resource content accessible.

## **Key Question Summary**

**1. What is known about the topic?** Research on participation by patients in decision-making about their treatment has focused primarily on medical rather than legal knowledge.

**2. What does this paper add?** We investigated which online resources community members might access to inform themselves about the law on end-of-life decision-making. Resources identified were analysed for ease of location and content accessibility.

**3. What are the implications for practitioners?** Authors of online resources on end-of-life decision-making should consider whether their resources can be: identified by search terms used by the public, understood by a general audience and readily used to promote reader action.

## Introduction

End-of-life (EOL) care is health care provided to those with a terminal disease or illness, or catastrophic injury, and aims to minimise symptoms, provide psychological, social, spiritual and practical support and optimise quality of life.<sup>1</sup> Integral to EOL care are legal considerations including the right of an adult patient to consent to receive, withhold or withdraw treatment, complete advance directives (ADs) about EOL care and appoint legally recognised substitute decision-makers (SDMs).<sup>2</sup> Australian law is complex and differs between states and territories.<sup>3</sup>

Community knowledge of the law enhances participation in treatment decisions through advance care planning (ACP),<sup>4</sup> helps avoid conflict between patients, families and health practitioners<sup>5</sup> and prevents known adverse EOL outcomes: receiving unwanted burdensome (and costly) treatments and/or distressing symptoms including dying in pain.<sup>6</sup> Government inquiries have identified the need for information resources which are widely available, have user-friendly content and meet the needs of different community groups.<sup>7-10</sup> Other research has identified that older Australians particularly should be more knowledgeable about EOL issues.<sup>11</sup> Research also indicates patients and their carers want more information on this area of law.<sup>12</sup>

Australian research while limited, has considered knowledge within particular populations including older people,<sup>12-15</sup> gay, lesbian, bisexual and transgender people,<sup>16-18</sup> or focussed on euthanasia.<sup>19</sup> Most Australian studies are state-specific.<sup>12, 14, 15, 20</sup> Research has examined specific aspects of EOL law e.g., knowledge of ACP,<sup>12, 13, 17, 18, 21-24</sup> ADs,<sup>15, 20, 25</sup> or substitute decision-making<sup>14, 16, 19</sup> and attitudes towards the patient and SDM rights to demand treatment that is not clinically indicated.<sup>23</sup>

There is however relatively little research on community knowledge of EOL law more broadly. Prior research indicates that community knowledge of the law on EOL medical decisions is often limited.<sup>26, 27</sup> Many community members including older people are unaware of the existence of ADs,

<sup>12, 15</sup> and have inadequate understanding of the aim, content and scope of ACP documents, including ADs and enduring powers of attorney (EPAs).<sup>13, 22, 23, 28</sup>

There is a need to identify current information sources about EOL law, and to understand if and how this information enhances knowledge. Since patients and families have the legal right to participate in EOL medical treatment decisions, legal knowledge enhances this participation, facilitating patient-centred care<sup>29</sup> and improving patient outcomes by ensuring they do not receive unwanted treatment and receive appropriate pain relief.<sup>6</sup>

This study aimed to identify and evaluate current web-based information available to the general community about legal duties, rights and powers pertaining to EOL medical treatment decisions in New South Wales (NSW), Victoria (Vic) and Queensland (Qld). These states were selected because of the complexity and differences between their laws. This research identifies information gaps and suggests improvements to resource content.

## **Methods**

The research reported here is part of a larger project examining community knowledge of and engagement with the law in EOL decision-making. The research project is funded by (*omitted for review*) and conducted with ethical approval from (*omitted for review*). Stage 1 (this paper's focus) involved: (1) mapping current information available to consumers about legal duties, rights and powers, including the ease with which information was identified online ('resource mapping'), and (2) a critical analysis of resource content for accessibility of format and language ('content analysis'). Each process included a pilot phase to refine methodology. For brevity, only the main study results are reported.

Resource mapping

*Eligibility criteria:* Eligible webpages ('resources') were: freely available, referenced EOL law, and were intended for the community. We excluded resources where reference to EOL law was so minimal as to not be construed as a legal resource, resources that did not aim to inform on EOL law even if it was mentioned (e.g., media, marketing materials) and primary sources of law (i.e. cases and legislation). However, information not designed to inform consumers about EOL law was also included (as an exception) where it would be usable for consumers and was easily identified (i.e. identified in over two web searches). For example, the Qld Ambulance Service palliative care resource outlined clinical practice guidelines for paramedics but had easily understandable content.

*Identifying search terms and conducting searches:* One author conducted internet searches for all three states using the Google search engine. Google was selected because of its significant market share and frequent use by Australians to source health information.<sup>30</sup> For searches the location was set to the relevant jurisdiction (NSW, Vic, Qld), reflecting the experience of consumers searching in that State.

Searches were conducted using several 'lay' and 'expert' search terms. Lay search terms were gathered from 15 adults with non-legal backgrounds (recruited via convenience sampling). Participants were emailed three scenarios involving EOL decision-making and asked what search terms (up to ten) they would use to locate further information about the law in each scenario (see Appendix 1). Search terms returning zero resources matching the inclusion criteria were excluded from the main exercise. 'Lay search terms' (pilot n = 43, main exercise n = 23) are listed in Appendix 2. The authors identified 'expert search terms'. Given legal differences across States, these included relevant jurisdictional terms (NSW/Vic/Qld). Expert search terms (pilot n = 12, main exercise n = 12) are listed in Appendix 3.

*Selection:* For feasibility, only the first two Google search results pages were screened for eligibility. Research consistently reports most internet users do not look beyond the first results page.<sup>31</sup> Where a website was identified by a search result, all relevant resources within the website were recorded as being identified by that search. Links to external pages were not followed as this would lead to an unmanageable proliferation of resources. One exception (Australian Government: Powers of Attorney) was where the resource's purpose was to link to external webpage(s) (i.e. it comprised a list of links); here external site(s) were recorded as being identified by the search.

*Inclusion assessment:* Search results were exported offline to PDF and screened for eligibility. PDF search results were annotated, indicating which resources met eligibility criteria.

*Data extraction:* Details of included resources (author, URL and other relevant resources within the website) were extracted and inserted into an Excel (Microsoft Corporation, Redmond, WA, USA) spreadsheet. This spreadsheet also recorded the number of times the resource was identified by Google search(es); search term(s) returning the resource; position on search results page(s) and external websites primarily aiming to link to that resource. These recorded details were the primary areas of focus for resource mapping. Hence format, nature of information and intended audience of included resources were not recorded in the Excel spreadsheet, and were analysed qualitatively rather than quantitatively.

#### Content analysis

*Measure:* Reviewers used the Patient Education Materials Assessment Tool (PEMAT)<sup>32</sup> to assess resource content accessibility. The PEMAT provides a systematic method to evaluate and compare understandability and actionability of patient education materials. It includes 26 criteria within seven categories: content, word choice and style, use of numbers, organisation, layout and design, use of visual aids and actionability (identifying an action readers can take and how action is

presented). Each resource was scored against the criteria using a 'disagree' (0) or 'agree' (1) answer. Ten items had a 'not applicable' response option. Final understandability and actionability scores were converted to two separate percentages where higher values reflect more (1) understandable and/or (2) actionable material. The PEMAT's focus on actionability was consistent with our research aims, namely to assess whether resources promote patient and SDM participation in EOL decision-making.

*Sampling:* Given the substantial volume of resources identified, PEMAT assessments were conducted on a purposive sample reflecting resource diversity across:

- States (NSW, Vic, Qld, nationally applicable); and
- Authorship categories: Government (including Federal and State government and statutory bodies); Diagnosis-specific organisations; Legal organisations (including law firms); and 'Other' (e.g., carer and palliative care groups, legal information resources not produced by legal organisations).

Within these categories, the most commonly identified resources were selected. Instances of duplicated content on a website were recorded, and in sampling resources, those aimed at the public (e.g., consumer brochures) were selected. The final sample comprised approximately one third (12/67, 31%) of retrieved resources.

*Procedure:* Accessibility of resource content was independently evaluated by nine reviewers for the pilot and three reviewers for the main exercise. Pilot scores initially varied considerably between assessors. However, after moderation by consensus and setting additional guidelines for the application of PEMAT criteria to web-resources (as recommended in the PEMAT user guide), consistent scoring was established.

## Results

### Resource mapping

*Websites identified:* Pilot phase searches indicated that almost half the lay search terms failed to identify any relevant search results. The number of times that websites were identified by lay and expert searches in the main exercise is listed in Appendix 4. The number of resources identified varied considerably depending on whether expert (n = 58) or lay searches were employed (n = 43).

*Authors:* Identified resources on EOL law (n = 67) were authored by state government departments (n = 27, 40%), diagnosis-specific organisations (n = 9, 13%), legal organisations (n = 11, 16%) or 'other' authors (n = 20, 30%).

*Format:* Resources included webpages, brochures, booklets, manuals, reports, fact/information sheets and forms e.g., for ADs, EPAS. Format of resources assessed using the PEMAT is provided in Appendix 5. These observations (based on assessment of one-third of the resources identified per jurisdiction) suggest that the majority (67%) of resources were webpages.

*Intended audience:* Many resources applied to the general community, while others targeted specific groups e.g., older people, people with particular medical diagnoses, those accessing palliative care, and lesbian, gay, bisexual, transgender and intersex people. Resources from diagnosis-specific organisations were primarily aimed at patients with dementia and their carers. Other resources were produced by organisations for individuals with motor neuron disease, mental health issues, chronic illnesses and brain disorders. Resources included by exception were primarily for health practitioners (and some for legal professionals).

*Nature of information:* Most resources addressed the overall decision-making hierarchy for EOL decisions (i.e., the list and order of people set out in legislation who can make these decisions) or

focused on ADs, default decision-makers, EPAs (medical/other), guardianship, consent and capacity issues, treatment refusal , and to a lesser extent SDM powers and responsibilities. Resources on ADs and EPAs predominantly focused on defining these documents, circumstances under which they come into effect, completion and revocation processes, and sources of further information. A few resources advised on selecting an appropriate SDM. Law firm resources primarily provided procedural information and promoted EOL documents (e.g., ADs, EPAs). Some resources informed on palliative care, although few mentioned that all patients are legally able to receive sufficient pain relief, even if providing that pain relief may hasten death.

More resources focused on legal rights and powers (e.g., to write an AD or appoint an enduring guardian/attorney) than duties (e.g., for SDMs to make treatment decisions the patient would have wanted). While one scenario related to disputes about EOL decisions, few resources (primarily those included by exception for health practitioners) discussed resolving conflict with health practitioners. In explaining legal rights, powers and duties, almost no resources referred to applicable law (case law or sections of legislation) or provided scenarios explaining how the law operates in practice.

*How hard resources were to identify:* Across all State and authorship categories, expert search terms identified more sites (n = 58) than lay terms (n = 43). Government-authored websites were identified by lay (n = 17 websites) and, more commonly, expert searches (n = 23 websites) across States. In NSW, lay searches identified as many Government-authored websites (n = 7) as did expert searches. In all states, websites from diagnosis-specific organisations (n = 9) were primarily or exclusively identified by expert searches, although lay and expert searches identified equal numbers of nationally applicable websites by diagnosis-specific organisations (n = 1). Slightly more websites authored by legal organisations were identified by expert searches in Qld and NSW (n = 2 per state compared to n = 1 per state for lay searches), while for both Victorian and nationally applicable websites one more website was identified by lay searches. Websites containing nationally

applicable information were more often identified by lay search terms (n = 12 compared to n = 11 for expert search terms) as few lay searches included jurisdiction name. Websites identified by numerous lay searches were Office of the Public Advocate (Victoria) (n = 14 searches), Qld Government: Power of attorney and making decisions for others (n = 14), the Office of the Public Guardian (Qld) (n = 11), Palliative Care Victoria (n = 7), Advance Care Planning Australia (n = 6) and the NSW Government: Planning Ahead site (n = 6). Resources identified by numerous expert searches were Advance Care Planning Australia (n = 30 searches), Advance Care Planning Australia (Victoria) (n = 20), Health Law Central (n = 20), Office of the Public Guardian (Queensland) (n = 18), Victoria Health (n = 15) and the Advance Care Planning Australia (NSW) site (n = 13).

#### Content analysis

These observations are based on assessment of 72% of the resources identified per jurisdiction. PEMAT scores varied considerably across resources and State and authorship categories (see Appendix 5). Understandability scores ranged from 33-94 (mean score = 78, median = 79, mode = 75) while actionability scores ranged from 0-100 (mean = 72, median = 80, mode = 100).

On average, resource language was highly accessible, with 79% of sampled resources using common everyday language, 94% defining medical terms and 98% using the active voice. Resources were well-organised, although very few (two per cent) included a summary. Layout and design was effective in highlighting key points for readers in 92% of sampled resources, however visual aids were under-utilised (64% of resources included these).

*Factors contributing to high scores:* In the understandability section, titles and headings using everyday language increased scores. For example, 'Who will the doctor ask to give consent for my medical treatment if I am not able to give my own consent?' was more accessible than 'Statutory

health attorney'. Most (n=45) resources assessed scored well on understandability for explaining medical terms. A clear statement of action to be taken by readers (e.g., instructions on downloading an AD form and discussing treatment preferences with family and health practitioners) improved actionability scores for most (n=45) resources.

Numerous resources did not use visual aids (tables, illustrations) and those that did often scored relatively higher on the PEMAT. Most higher scoring resources also stated a clear purpose.

*Factors contributing to low scores:* Titles and headings using language that may be unknown to lay consumers reduced understandability scores. Most representations of decision-making hierarchies across jurisdictions were confusing and did not clarify when, for example, an AD would operate as compared with a decision made by a SDM. Several sites included excessive technical detail, detracting from key messages. Relatively few resources (36%) included visual aids, e.g., flowcharts, to explain decision-making hierarchies or recommended ACP processes. Often resources scored relatively poorly in actionability, presenting information without indicating any action readers could take.

## **Conclusion**

Our research revealed that various online resources about legal duties, rights and powers in EOL decision-making are available. However, relatively few informed on legal duties (e.g., SDM powers and responsibilities) or resolving conflict with health practitioners. Fifty four percent of resources were authored by government departments or statutory bodies. Search results varied significantly depending on whether lay or expert search terms were used.

An important feature of EOL law is variation across States. It is therefore critical for searches to include a jurisdictional search term to obtain relevant results. Our research suggests that this rarely

happens. Thus when searching for information on EOL law, community members may not retrieve state-specific information. Further, one expert search term retrieved a resource from a different state, therefore readers should also check that retrieved resources are relevant to their state. Our results suggest that community members may have difficulty identifying relevant resources on EOL law, depending on the search terms used, the information sought and their State.

Accessibility of resource content varied greatly. This conclusion fits with prior research on patients accessing palliative care services, which found that written information may not be understandable for all and can be insufficient without accompanying discussions with health practitioners.<sup>20</sup>

Drawing on our review, we recommend:

1. High quality online resources are needed to address the current paucity of information on legal duties, resolving conflict with health practitioners and applicable law on consumers' legal rights, powers and duties at the EOL.
2. When developing resources the author needs to consider how consumers search for information online. Resources should be tagged using everyday language and search engine optimisation techniques. Including key questions as headings within resources may assist.
3. Existing resources should include links to other relevant information sources.
4. Resources should clarify that EOL decisions are governed by state-based law so community members are aware they should check that retrieved resources are relevant to their state. Resource authors should make clear the state/s to which their information applies.
5. Resources should use everyday language, explain medical terms, use informative titles and headings and include a clear action statement. Resources should articulate their purpose, use visual aids (e.g., flowcharts, illustrations) and provide a summary, particularly for resources other than webpages. Where resources suggest action by readers, they should include a tangible tool (e.g., checklist).

This research has limitations. First, for resource mapping, searches including a diagnosis-related term could retrieve additional resources. Second, for searches the Google location was set to the relevant jurisdiction. However it is acknowledged that in addition to location, Google search results are determined partly by search and web browsing history, and this may have influenced search results. Third, the PEMAT was designed for written patient resources about health information rather than web-based community resources about law. Some features were consistently absent from resources e.g., only two percent contained a summary, as this is not customary in web-based resources. Therefore, low scores on some items may not represent a failure of the resources. Similarly for actionability ratings, not all resources were intended to promote action. Fourth, resource format varied considerably and could have influenced scores e.g., brochures may be more accessible than detailed reports. Fifth, observations on resource content accessibility are based on a sample of resources. Sixth, we did not examine whether resources were available in other languages.

Consideration of barriers to accessing online resources, and the availability and quality of other resource types was outside the scope of this work. These areas are important avenues for future research. A later stage of this research project will explore what information sources are actually accessed by community members, adult patients, and SDMs.

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## Supplementary Material

### **Community knowledge of law at the end of life: availability and accessibility of web-based resources**

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## **Appendix S1 Scenarios in email to participants**

### **To prompt queries about ACP**

Scenario 1: You have been diagnosed with a terminal illness. You want to plan your future health care and treatment so that if you were later unable to make decisions for yourself, you could ensure your wishes were followed.

What internet search terms would you use to find out more about this topic?

### **To prompt queries about substitute decision-making**

Scenario 2: Your elderly mother is critically ill in hospital and does not have long to live. Decisions need to be made about her medical treatment, but you are worried about what will happen if she becomes too unwell to make those decisions for herself.

What internet search terms would you use to find out more about this topic?

### **To prompt queries about disputes and rights**

Scenario 3: Your partner is in a coma in the Intensive Care Unit and their doctors want to discontinue life support. You disagree because you know your partner would want every opportunity to live.

What internet search terms would you use to find out more about your options?

## Appendix S2 Lay search terms employed in the pilot phase and main exercise

- disagreeing with turning off life support Australia
- enduring power of attorney
- health decisions elderly
- health decisions relatives
- health directive
- how do I get power of attorney and how do I get to make medical decisions
- legality of life support medical options
- making decisions for someone who is terminally ill and unable to make decisions australia
- making end of life decisions
- making health plan for future incapacity australia
- next of kin terminally ill medical treatment plan
- power of attorney
- power of attorney for health decisions
- power of attorney information
- power of attorney life support
- power of attorney medical healthcare decisions, elderly
- power of attorney medical healthcare decisions terminal
- terminal illness legislation
- terminal illness legislation australia
- terminal illness medical treatment plan legal responsibility
- terminal illness policy NSW/Vic/Qld
- terminal illness power of attorney
- what to do if a person who is dying cannot make own health decisions

- coma decisions appeal healthcare life support duty of care
- decision making for family members whilst sick in coma
- discontinue life support options
- discontinue life support without consent
- do I need to use a lawyer
- health aging
- health decisions for mother
- how do i make a will
- intensive care decisions
- life support decisions
- life support legislation
- making decisions for loved ones
- medical treatment decision making for family members whilst terminally ill
- right to live coma life support
- rights of partner in coma on life support
- terminal illness health requests
- terminal illness options
- terminal illness plan
- wills and deceased estates
- wills terminally ill

Note: Underlined terms were retained in the main exercise; the others were discarded because the pilot indicated they failed to retrieve relevant results.

## Appendix S3 Expert search terms employed in the pilot phase and main exercise

- advance care planning NSW/Vic/Qld
- advance health directives NSW/Vic/Qld
- end of life consent NSW/Vic/Qld
- end of life law NSW/Vic/Qld
- guardianship law NSW/Vic/Qld
- legal rights end of life NSW/Vic/Qld
- medical decisions NSW/Vic/Qld
- patient rights medical decisions NSW/Vic/Qld
- substitute decision making law NSW/Vic/Qld
- terminal illness medical decision NSW/Vic/Qld
- palliative care law NSW/Vic/Qld \*
- withholding withdrawing treatment law NSW/Vic/Qld \*
- withdrawing treatment Qld
- withholding treatment Qld

Note: \* Included in main exercise only. Underlined terms were retained in the main exercise.

## Appendix S4 Websites identified containing resources on end-of-life law –

### Differences between expert and lay search terms

State and Author of Website	Number of searches that identified the website	
	Lay search terms	Expert search terms
<u>Queensland</u>		
Government and Statutory Bodies		
<ul style="list-style-type: none"> <li>Queensland Government: Power of Attorney and Making Decisions for Others</li> </ul>	14	9
<ul style="list-style-type: none"> <li>Office of the Public Guardian (Queensland)</li> </ul>	11	18
<ul style="list-style-type: none"> <li>The Public Trustee (Queensland)</li> </ul>	4	1
<ul style="list-style-type: none"> <li>Legal Aid Queensland</li> </ul>	3	2
<ul style="list-style-type: none"> <li>Queensland Ambulance Service*</li> </ul>	1	2
<ul style="list-style-type: none"> <li>Queensland Health: Advance Care Planning Online</li> </ul>	0	9
<ul style="list-style-type: none"> <li>Queensland Civil and Administrative Tribunal (QCAT)</li> </ul>	0	1
	33	42
Diagnosis-specific Organisations		
<ul style="list-style-type: none"> <li>Start2Talk Queensland (Alzheimer's Australia)</li> </ul>	0	2
<ul style="list-style-type: none"> <li>Synapse (Brain Disorders organisation)</li> </ul>	0	2
	0	4

State and Author of Website	Number of searches that identified the website	
	Lay search terms	Expert search terms
Legal Organisations		
• Health Practitioners (Slater and Gordon)*	2	1
• Queensland Public Interest Clearing House*	0	2
	2	3
Other		
• Advance Care Planning Australia (Queensland)	4	5
• <i>Find Law Australia</i>	1	0
	5	5
<b>Searches that identified Queensland websites</b>	<b>40</b>	<b>54</b>
<b><u>New South Wales</u></b>		
Government and Statutory Bodies		
• <i>NSW Government: Planning Ahead</i>	6	2
• NSW Trustee and Guardian	5	0
• NSW Health	2	3
• State Library NSW: Legal Answers	2	0
• Legal Aid NSW	2	0
• NSW Department of Finance and Services	2	0

State and Author of Website	Number of searches that identified the website	
	Lay search terms	Expert search terms
<ul style="list-style-type: none"> <li>• <i>NSW Health: End of Life Decisions, the Law and Clinical Practice*</i></li> </ul>	1	8
<ul style="list-style-type: none"> <li>• <i>Office of the Public Guardian (NSW)</i></li> </ul>	0	5
<ul style="list-style-type: none"> <li>• NSW Attorney-General's Department</li> </ul>	0	2
<ul style="list-style-type: none"> <li>• New South Wales Civil and Administrative Tribunal (NCAT)</li> </ul>	0	2
<ul style="list-style-type: none"> <li>• Central and Eastern Sydney Primary Health Care Network*</li> </ul>	0	1
	20	23
Diagnosis-specific Organisations		
<ul style="list-style-type: none"> <li>• <i>Mental Health Coordinating Council</i></li> </ul>	1	9
<ul style="list-style-type: none"> <li>• Motor Neuron Disease NSW</li> </ul>	0	3
<ul style="list-style-type: none"> <li>• Start2Talk New South Wales (Alzheimer's Australia)</li> </ul>	0	1
	1	13
Legal Organisations		
<ul style="list-style-type: none"> <li>• <i>Health Practitioners (Slater &amp; Gordon)*</i></li> </ul>	1	4
<ul style="list-style-type: none"> <li>• Foolkit (Minotaur Law)</li> </ul>	0	1
	1	5

State and Author of Website	Number of searches that identified the website	
	Lay search terms	Expert search terms
Other		
• Advance Care Planning Australia (NSW)	7	13
• Carers NSW	4	1
• Dying with Dignity NSW	2	6
• Emeritus Professor Colleen Cartwright	1	1
• Palliative Care NSW	0	2
• Family Law Express	0	1
• Life Circle	0	1
	14	25
<b>Searches that identified NSW websites</b>	<b>36</b>	<b>66</b>

State and Author of Website	Number of searches that identified the website	
	Lay search terms	Expert search terms
<b><u>Victoria</u></b>		
Government and Statutory Bodies		
• <i>Office of the Public Advocate (Victoria)</i>	14	6
• Legal Aid Victoria	2	3
• Victoria Health	1	15
• Better Health Channel Victoria	0	4
• Victorian Civil and Administrative Tribunal (VCAT)	0	3
• Northern Health Advance Care Planning Program	0	2
	17	33
Diagnosis-specific Organisations		
• <i>Chronic Illness Alliance</i>	4	1
• Oncology Clinics Victoria	0	1
• Start2Talk Victoria (Alzheimer's Australia)	0	1
	4	3

State and Author of Website	Number of searches that identified the website	
	Lay search terms	Expert search terms
Legal Organisations		
<ul style="list-style-type: none"> <li>Health Professionals (Slater and Gordon)*</li> </ul>	1	2
<ul style="list-style-type: none"> <li><i>Law Institute of Victoria</i></li> </ul>	1	1
<ul style="list-style-type: none"> <li>Mental Health Legal Centre</li> </ul>	1	1
<ul style="list-style-type: none"> <li>Everydaylaw</li> </ul>	1	0
	4	4
Other		
<ul style="list-style-type: none"> <li><i>Palliative Care Victoria</i></li> </ul>	7	12
<ul style="list-style-type: none"> <li><i>Advance Care Planning Australia (Victoria)</i></li> </ul>	5	20
<ul style="list-style-type: none"> <li><i>Carers Victoria</i></li> </ul>	0	2
<ul style="list-style-type: none"> <li>Mondaq</li> </ul>	0	1
	12	35
<b>Searches that identified Vic websites</b>	37	75
<b><u>National</u></b>		
Government and Statutory Bodies		
<ul style="list-style-type: none"> <li><i>Advance Care Planning Australia</i></li> </ul>	6	30
<ul style="list-style-type: none"> <li>Australian Human Rights Commission</li> </ul>	3	4
<ul style="list-style-type: none"> <li>Australian Government: My Aged Care</li> </ul>	0	1
	9	35

State and Author of Website	Number of searches that identified the website	
	Lay search terms	Expert search terms
Diagnosis-specific Organisations		
<ul style="list-style-type: none"> <li>• <i>Alzheimer's Australia</i></li> </ul>	5	1
	5	1
Legal Organisations		
<ul style="list-style-type: none"> <li>• Intellectual Disability Rights Service</li> </ul>	2	8
<ul style="list-style-type: none"> <li>• Health Practitioners (Slater and Gordon)*</li> </ul>	1	6
<ul style="list-style-type: none"> <li>• <i>Legal123</i></li> </ul>	1	0
	4	14
Other		
<ul style="list-style-type: none"> <li>• Australian Investors Association: Powers of attorney</li> </ul>	4	0
<ul style="list-style-type: none"> <li>• Sydney Morning Herald: The medical enduring power of attorney</li> </ul>	3	1
<ul style="list-style-type: none"> <li>• Health Law Central</li> </ul>	2	20
<ul style="list-style-type: none"> <li>• Australian Health Consumer</li> </ul>	1	1
<ul style="list-style-type: none"> <li>• Find Law Australia</li> </ul>	1	0
<ul style="list-style-type: none"> <li>• National Seniors</li> </ul>	1	0
<ul style="list-style-type: none"> <li>• <i>Palliative Care Australia</i></li> </ul>	0	3
	12	25

State and Author of Website	Number of searches that identified the website	
	Lay search terms	Expert search terms
Searches that identified national websites	30	75
Total number of searches that identified websites	143	270

Note: Some websites contained multiple resources. Websites italicised were included in the sample assessed for accessibility. \* This website fell into the 'Resources included by exception' category.

## Appendix S5 PEMAT scores from accessibility assessments by jurisdiction

<u>NSW</u>	Name and type of resource	PEMAT Score % U <sup>a</sup>	PEMAT Score % A <sup>b</sup>
Government and Statutory Bodies			
NSW Government: Planning Ahead	Advance Care Planning (webpage)	83	100
	Appoint an Enduring Guardian (webpage)	83	100
NSW Health: End-of-Life Decisions, the Law and Clinical Practice	ACP and the Law (webpage)	73	80
	Decision making at the end of life (webpage)	73	80
Diagnosis-specific Organisations			
Mental Health Coordinating Council	Advance Care Directives (manual section)	83	60
	Specific rights in relation to medical treatment (manual section)	75	80
	Substitute Decision Making (manual section)	73	80
	Guardianship (manual section)	58	60

<u>NSW</u>	Name and type of resource	PEMAT Score % U	PEMAT Score % A
Legal Organisations			
Health Practitioners (Slater & Gordon)*	Common Law Advance Directives (webpage)	80	0
Other			
Dying with Dignity NSW	What is Advance Care Planning (webpage)	93	100
	Guide to Advance Care Directive (booklet)	93	100
Carers NSW	Enduring powers of attorney (webpage)	83	100

<u>Victoria</u>	Name and type of resource	PEMAT Score %	
		U	A
Government and Statutory Bodies			
Office of the Public Advocate (Vic)	Enduring Power of Attorney (Medical Treatment) – Pink (fact/information sheet)	92	100
	Good Guardianship (booklet)	93	100
	Enduring Power of Attorney (Medical Treatment) – Purple (fact/information sheet)	92	100
	Refusal of Medical Treatment (fact/information sheet)	83	80
	Take Control booklet (booklet)	94	100
Diagnosis-specific Organisations			
Chronic Illness Alliance	Introduction (webpage)	75	60
	Enduring Power of Attorney (Medical Treatment) (webpage)	83	80
	Guardianship (webpage)	75	80
Legal Organisations			
Law Institute of Vic	Powers of Attorney (webpage)	75	40

<b><u>Victoria</u></b>	<b>Name and type of resource</b>	<b>PEMAT Score % U</b>	<b>PEMAT Score % A</b>
Other			
Advance Care Planning Australia	Advance Care Planning Information Sheet (fact/information sheet)	92	100
	Vic Advance Care Planning (webpage)	75	80
Palliative Care Vic	A Guide to Decision-Making in Healthcare (booklet)	83	60
	Appointing an Enduring Power of Attorney (brochure)	92	100
Carers Vic	Enduring Powers of Attorney (webpage)	75	100
<b><u>Queensland</u></b>	<b>Name and type of resource</b>	<b>PEMAT Score % U</b>	<b>PEMAT Score % A</b>
Government and Statutory Bodies			
Qld Government: Power of attorney and making decisions for others	Advance health directive (webpage)	83	83
	Making decisions for others (webpage)	58	17
	Power of attorney (webpage)	67	67

<u>Queensland</u>	Name and type of resource	PEMAT Score %	PEMAT Score %
		U	A
Office of the Public Guardian (Qld)	Advance health directive (fact/information sheet)	83	67
	Statutory health attorney (webpage)	75	17
	Health care decisions (webpage)	33	33
Diagnosis-specific organisations			
Start2Talk Qld (Alzheimer's Australia)	Who will the Dr ask to give consent ... (webpage)	83	17
	Will my advance directive and other ... (webpage)	92	83
	Apart from appointing a substitute decision-maker ... (webpage)	92	83
	How do I legally appoint someone of my choice ... (webpage)	75	67
Synapse (Brain Disorders organisation)	Substitute decision making (webpage)	58	0
	A guide to applying for guardianship and administrative orders (webpage)	75	100

<u>Queensland</u>	Name and type of resource	PEMAT Score % U	PEMAT Score % A
Legal Organisations			
Find Law Aust	Power of Attorney or Enduring Guardian (webpage)	50	0
<u>National</u>	Name and type of resource	PEMAT Score % U	PEMAT Score % A
Government and Statutory Bodies			
Advance Care Planning Australia	Advance care planning for a family or friend (webpage)	78	80
	Choosing someone to speak for you (webpage)	83	100
	Writing down your wishes (webpage)	75	100
	Law of ACP* (webpage)	73	0
Diagnosis-specific Organisations			
Alzheimer's Australia	Planning for the end of life for people with dementia (booklet)	83	60
Legal Organisations			
Legal 123	Enduring Power of Attorney (webpage)	75	80

<b><u>National</u></b>	<b>Name and type of resource</b>	<b>PEMAT Score %</b>	<b>PEMAT Score %</b>
		<b>U</b>	<b>A</b>
Other			
Palliative Care	Advance care planning (webpage)	83	60
Australia	Decision making for the end of life (webpage)	92	100

Note: a. U = understandability score. b. A = actionability score. \* This resource fell into the

‘Resources included by exception’ category.