

Supplementary Material

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

Ben White^{1,6} DPhil, LLB (Hons), Professor

*Lindy Willmott*¹ PhD, LLM, LLB (Hons), BCom, Professor

*Cheryl Tilse*² PhD, GCEd, BSocWk, BA, Associate Professor

*Jill Wilson*² PhD, GCEd, MSW, BSocSt, Professor

*Deborah Lawson*³ PhD, LLB, BA, Legal Policy Advisor

*Angela Pearce*⁴ BSocSc (Hons), Quality and Evaluation Manager,

*Jeffrey Dunn*⁵ PhD, MSPD, BSc, Associate Diploma in Community Studies, Professor

*Joanne F. Aitken*⁵ PhD, MSc, BSc(Hons), Professor

*Rachel Feeney*¹ PhD, CPSP, BSpPath, CertTESOL, Senior Research Assistant

*Stephanie Jowett*¹ LLB (Hons), Senior Research Assistant

¹Australian Centre for Health Law Research, Queensland University of Technology, GPO Box 2434, Brisbane, Qld 4001, Australia. Email: l.willmott@qut.edu.au; rachel.feeney@qut.edu.au; s.jowett@qut.edu.au

²School of Nursing, Midwifery and Social Work, The University of Queensland, Brisbane, Qld 4072, Australia. Email: c.tilse@uq.edu.au; wilsonj@uq.edu.au

³Cancer Council of Victoria, 100 Drummond Street, Carlton, Vic. 3053, Australia. Email: deborah.lawson@cancervic.org.au

⁴Cancer Council New South Wales, PO Box 572, Kings Cross, NSW 1340, Australia. Email: angelap@nswcc.org.au

⁵Cancer Council Queensland, PO Box 201, Spring Hill, Qld 4004, Australia. Email: jeffdunn@cancerqld.org.au; JoanneAitken@cancerqld.org.au

⁶Corresponding author. Email: bp.white@qut.edu.au

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"> Queensland Government: Power of Attorney and Making Decisions for Others 	14	9
<ul style="list-style-type: none"> Office of the Public Guardian (Queensland) 	11	18
<ul style="list-style-type: none"> The Public Trustee (Queensland) 	4	1
<ul style="list-style-type: none"> Legal Aid Queensland 	3	2
<ul style="list-style-type: none"> Queensland Ambulance Service* 	1	2
<ul style="list-style-type: none"> Queensland Health: Advance Care Planning Online 	0	9
<ul style="list-style-type: none"> Queensland Civil and Administrative Tribunal (QCAT) 	0	1
	33	42
Diagnosis-specific Organisations		
<ul style="list-style-type: none"> Start2Talk Queensland (Alzheimer's Australia) 	0	2
<ul style="list-style-type: none"> Synapse (Brain Disorders organisation) 	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
Searches that identified Queensland websites	40	54
<u>New South Wales</u>		
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"> • <i>NSW Health: End of Life Decisions, the Law and Clinical Practice*</i> 	1	8
<ul style="list-style-type: none"> • <i>Office of the Public Guardian (NSW)</i> 	0	5
<ul style="list-style-type: none"> • NSW Attorney-General's Department 	0	2
<ul style="list-style-type: none"> • New South Wales Civil and Administrative Tribunal (NCAT) 	0	2
<ul style="list-style-type: none"> • Central and Eastern Sydney Primary Health Care Network* 	0	1
	20	23
Diagnosis-specific Organisations		
<ul style="list-style-type: none"> • <i>Mental Health Coordinating Council</i> 	1	9
<ul style="list-style-type: none"> • Motor Neuron Disease NSW 	0	3
<ul style="list-style-type: none"> • Start2Talk New South Wales (Alzheimer's Australia) 	0	1
	1	13
Legal Organisations		
<ul style="list-style-type: none"> • <i>Health Practitioners (Slater & Gordon)*</i> 	1	4
<ul style="list-style-type: none"> • Foolkit (Minotaur Law) 	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
• <i>Carers NSW</i>	4	1
• <i>Dying with Dignity NSW</i>	2	6
• Emeritus Professor Colleen Cartwright	1	1
• Palliative Care NSW	0	2
• Family Law Express	0	1
• Life Circle	0	1
	14	25
Searches that identified NSW websites	36	66

State and Author of Website	Number of searches that identified the website	
	Lay search terms	Expert search terms
<u>Victoria</u>		
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		
• Health Professionals (Slater and Gordon)*	1	2
• <i>Law Institute of Victoria</i>	1	1
• Mental Health Legal Centre	1	1
• Everydaylaw	1	0
	4	4
Other		
• <i>Palliative Care Victoria</i>	7	12
• <i>Advance Care Planning Australia (Victoria)</i>	5	20
• <i>Carers Victoria</i>	0	2
• Mondaq	0	1
	12	35
Searches that identified Vic websites	37	75
<u>National</u>		
Government and Statutory Bodies		
• <i>Advance Care Planning Australia</i>	6	30
• Australian Human Rights Commission	3	4
• Australian Government: My Aged Care	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"> • <i>Alzheimer's Australia</i> 	5	1
	5	1
Legal Organisations		
<ul style="list-style-type: none"> • Intellectual Disability Rights Service 	2	8
<ul style="list-style-type: none"> • Health Practitioners (Slater and Gordon)* 	1	6
<ul style="list-style-type: none"> • <i>Legal123</i> 	1	0
	4	14
Other		
<ul style="list-style-type: none"> • Australian Investors Association: Powers of attorney 	4	0
<ul style="list-style-type: none"> • Sydney Morning Herald: The medical enduring power of attorney 	3	1
<ul style="list-style-type: none"> • Health Law Central 	2	20
<ul style="list-style-type: none"> • Australian Health Consumer 	1	1
<ul style="list-style-type: none"> • Find Law Australia 	1	0
<ul style="list-style-type: none"> • National Seniors 	1	0
<ul style="list-style-type: none"> • <i>Palliative Care Australia</i> 	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 ^a	PEMAT Score % A ^b
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 %	PEMAT Score %
		U	A
Legal Organisations			
Health Practitioners (Slater & Gordon)*	Common Law Advance Directives (webpage)	80	0
Other			
Dying with Dignity	What is Advance Care Planning (webpage)	93	100
NSW	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

<u>Victoria</u>	Name and type of resource	PEMAT Score % U	PEMAT Score % A
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
<u>Queensland</u>	Name and type of resource	PEMAT Score % U	PEMAT Score % A
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 %	
		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

<u>National</u>	Name and type of resource	PEMAT Score %	PEMAT Score %
		U	A
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.