Withholding and withdrawing life-sustaining medical treatment from adults who lack capacity:

the role of law in medical practice

FINAL REPORT

Ben White

Lindy Willmott

Colleen Cartwright

Malcolm Parker

Gail Williams

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Research Team

- Professor Ben White, Australian Centre for Health Law Research, Queensland University of Technology
- Professor Lindy Willmott, Australian Centre for Health Law Research, Queensland University of Technology
- Professor Colleen Cartwright, ASLaRC Aged Services Unit, Southern Cross University
- Professor Malcolm Parker, School of Medicine, University of Queensland
- Professor Gail Williams, School of Population Health, University of Queensland

Research Assistants

- Dr Betty Collerson, Queensland University of Technology
- Amanda Donnet, Queensland University of Technology
- Dr Carly Lassig, Queensland University of Technology
- Penny Neller, Queensland University of Technology
- Stephanie Jowett, Queensland University of Technology
- Karen Nixon, Southern Cross University

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TABLE OF CONTENTS

ACKNOWLEDGMENTS i
LIST OF TABLES iii
INTRODUCTION 1
METHODS 2
RESULTS 3
Response Rates 3
Attitude to the Law 5
Experience of the Law 10
Perceptions of Knowledge of the Law 11
Knowledge of State-Specific Law 12
Education and Training on the Law 15
Practice and the Law 16
DISCUSSION 22
Response Rates 22
Attitudes and Perspectives on the Role of Law in Medical Practice 22
Attitudes and Perspectives on Knowing and Following the Law 23
Actual Knowledge of the Law 23
Compliance with the Law 24
Potential Influence of Ethics Education 25
Implications of the Research Findings 26
CONCLUSIONS AND RECOMMENDATIONS 27
Need for Law Reform 28
Recommendation 1 28
Need for Improved Training and Resources 28
Recommendation 2 29
Need for Greater Understanding of the Importance of the Law in Medical Practice 30
Recommendation 3 30
FUTURE RESEARCH 31
STUDY LIMITATIONS 32
REFERENCES 33
PUBLICATIONS FROM STUDY 35

LIST OF TABLES

Table 1 Demographic Characteristics by State 4

Table 2 Extent of Agreement with Q1 Statements re Perspectives on the Law 5

Table 3 Extent of Agreement with Q2 Statements re Perspectives on the Law 7

Table 4 Q1 Statements Attitude Score by Specialty by State: % Score 8

Table 5 Q2 Statements Attitude Score by Specialty by State: % Score 9

Table 6 Motivations for Decision where the Specialist Doubted that the Decision Followed the Law 11

Table 7 Participants' Responses to the Scenario 13

Table 8 Percentage and Number of Respondents Scoring <4 and 4-7 Correct Responses, plus Mean Score, by State 14

Table 9 Percentage and Number of Respondents Scoring <4 and 4-7 Correct Responses, plus Mean Score, by Specialty 15

Table 10 Would you Commence Antibiotics? Responses by State 17

Table 11 Why Respondents Would Commence Antibiotics: Responses by State 18

Table 12 Why Respondents Would Not Commence Antibiotics: Responses by State 18

INTRODUCTION

Decisions to withhold or withdraw life-sustaining treatment (WWLST) are a necessary and legitimate part of mainstream medical practice in Australia and precede almost 40,000 adult deaths each year[1]. Such decisions can only be lawful if made under certain conditions. Yet, despite the significance and frequency of these decisions, there is little evidence about whether or not doctors know and comply with the law when deciding to stop providing, or not to provide, life-sustaining treatment. An unlawful decision in this context has grave consequences for both the medical practitioners themselves and for their patients: ending life, and exposing doctors and their employers to criminal and civil sanctions. Despite this, it is likely that doctors sometimes do not comply with the law, partly because the law is complex and ambiguous[1-5] but also from lack of awareness of their legal duties.

The role of doctors in WWLST decisions is legally significant: guardianship legislation may grant them power to be a decision-maker (e.g., in an emergency) or to supervise decisions made by others; they make choices to limit treatment options; and they give information about the lawful decision-making process to be followed.

This study sought to understand the role of law in medical decision-making and to determine doctors' legal awareness, identify training needs, and find ways to improve the law. Lawful decision-making is already a key issue and will become even more important with Australia's ageing population and medical advances prolonging the lives of very ill patients. The study was motivated by concerns that doctors' lack of knowledge and the inadequacy of the law could lead to unlawful decisions to WWLST. There was evidence of non-compliance in legally reported cases[6] and a gap in the evidence base because the nature and extent of the problem had not been rigorously investigated. In this context, not only are patients' lives and liberties at stake, but doctors and their employers (including governments) have a vital interest in ensuring best practice that is both lawful and medically sound. These legal, medical and moral interests made the need for this research compelling.

The study explored knowledge of medical practitioners in Queensland, New South Wales and Victoria about the law with respect to WWLST from adult patients who have lost capacity. It was carried out by a multi-disciplinary team of researchers from the Queensland University of Technology, Southern Cross University and the University of Queensland.

More information about the project is available from the following website:
https://research.qut.edu.au/achlr/projects/withholding-and-withdrawing-life-sustaining-medical-treatment-from-adults-who-lack-capacity-the-role-of-law-in-medical-practice/

METHODS

Following ethics approval from all three universities, an extensive two-year process was undertaken to develop a survey instrument, which included legal research and analysis resulting in three publications[1, 4, 5], focus groups, questionnaire development and pre-testing and piloting of the instrument.

The sample cohort for the pilot study was determined through focus group and pre-pilot participant feedback and a review of the literature. It involved doctors specialising in Intensive Care, Emergency Medicine, Palliative Medicine, Medical Oncology (hereafter Oncology), Respiratory (Thoracic) Medicine, Renal Medicine, Geriatric Medicine and General Medicine, as these specialties are most often involved in end-of-life decisions.

Following a lower-than-anticipated response rate to the pilot survey (26%) and projected consequent low response rate for the main study, the survey instrument was reduced from 13 to six pages, wording and formatting were changed to improve readability and considerable effort was made to engage the various specialty groups. In addition, given an extremely low response rate from General Physicians (6%) and feedback received in the survey development phase that they are less often involved in end-of-life decisions than other specialists, they were not included in the main study, leaving seven main specialty groups in the main study.

Participants for both the pilot and main study were recruited from the Queensland, New South Wales and Victoria databases of AMPCo Direct (AMPCo), a subsidiary of the Australian Medical Association. These jurisdictions were selected because they have the highest number of doctors in Australia (77% of all Australian doctors[7]), and they have key similarities and differences in the law relating to end-of-life decision-making. Engaging AMPCo to administer the survey established a 'firewall' between the researchers and potential participants, thereby strengthening the protection of their identity.

A postal survey was conducted of all specialists in the seven selected specialties who were in one of the three State AMPCo databases, less those who had been involved in the pilot phase of the study. The survey was initially posted to participants on 18 July 2012 and was closed on 31 January 2013, after two reminders.

RESULTS

This section provides an overview of the major findings of the project. More detailed analyses are not reported here but are included in the project's publications which are listed on p35. Where relevant, we have drawn on all analyses undertaken to reach conclusions and develop recommendations in this report.

Response Rates

The final eligible sample was 2,702. A total of 867 completed questionnaires were received, an overall response rate of 32 percent; 218/598 completed questionnaires were received from Queensland (37%), 335/1,147 from New South Wales (29%) and 314/957 from Victoria (33%). The highest response rate by Main Medical Specialty overall was from Palliative Care (52%) followed by Geriatric Medicine (43%), and the lowest was from Emergency Medicine (25%). The highest response rate from any Specialty by State was Palliative Care in Victoria (75%) and the lowest was from Respiratory Medicine in New South Wales and Emergency Medicine and Oncology in Victoria (all 24%).

A comparison of the demographic characteristics of those who returned questionnaires with the original sample from the AMPCo database allowed comparison by Age, Gender, Specialty and State. The study respondents were similar to the AMPCo sample except that there were fewer younger doctors among respondents, particularly in relation to Intensive Care, Renal and Emergency Medicine.

Other demographic characteristics included:

- **Years in Practice:** 92 percent of respondents had 10 years or more in practice, with 35 percent having 30 or more years in medical practice;
- **Religion:** 40 percent of respondents had no religious affiliation; 47 percent belonged to one of the mainstream Christian religions in Australia; and there were a range of other religious affiliations;
- **Country of Birth:** 60 percent of respondents were born in Australia, 18 percent in other English-speaking countries, 14 percent in Asia, three percent in Europe and five percent in a range of other countries.

Table 1 provides a breakdown of demographic characteristics by State.

Table 1: Demographic Characteristics by State

	QLD (N=218*)	NSW (N=335*)	VIC (N=314*)	TOTAL (N=867*)
	% (n)	**% (n)**	**% (n)**	**% (n)**
Gender				
Male	70 (148)	66 (221)	63 (198)	66 (567)
Female	30 (69)	34 (114)	37 (115)	34 (298)
Main Specialty				
Emergency Medicine	34 (73)	31 (106)	29 (91)	31 (270)
Geriatric Medicine	10 (21)	15 (51)	11 (35)	13 (107)
Intensive Care	16 (35)	14 (47)	14 (43)	15 (125)
Oncology	7 (16)	9 (30)	11 (34)	9 (80)
Palliative Care	6 (14)	5 (17)	7 (21)	6 (52)
Renal Medicine	7 (15)	10 (33)	10 (32)	9 (80)
Respiratory Medicine	11 (25)	11 (36)	12 (37)	11 (98)
Other/Unspecified	9 (19)	5 (15)	6 (21)	6 (55)
Religion				
No Religion	38 (79)	40 (129)	45 (133)	42 (341)
Catholic	18 (38)	23 (74)	19 (55)	20 (167)
Anglican	16 (32)	14 (44)	11 (34)	13 (110)
Other	28 (57)	23 (76)	25 (74)	25 (207)
Country of Birth				
Australia	52 (112)	58 (195)	67 (210)	60 (517)
Other English-speaking	27 (58)	22 (73)	16 (51)	21 (182)
Asia	15 (32)	14 (48)	13 (40)	14 (120)
Other	6 (13)	6 (19)	4 (11)	5 (43)
Country of Medical Training				
Australia	65 (138)	73 (243)	84 (260)	75 (641)
Other English-speaking	23 (48)	16 (54)	10 (32)	16 (134)
Asia	9 (20)	7 (22)	4 (11)	6 (53)
Other	3 (7)	4 (12)	2 (8)	3 (27)
Age				
Mean	47	49	48	48
Range	31-75	32-83	29-81	29-83
Years in Practice				
Mean	22	23	22	22
Range	2-50	6-57	3-56	2-57

* Maximum N for any variable

In addition to the demographic section, the questionnaire contained five other sections which asked respondents a range of questions on their perspectives, knowledge and training on the law relating to WWLST from adults who lack capacity in their specific State, as well as their medical practice and experience with the law relating to WWLST from adults who lack capacity.

Attitude to the Law

Respondents were asked two questions, each with 11 statements, about the WWLST law for adults who lack capacity. Q1 asked the extent to which they agreed or disagreed with a series of statements in relation to the WWLST law and its role in medical practice. Response options were on a 5-point scale: 1. Strongly Disagree = SD; 2. Disagree = D; 3. Not Sure = NS; 4. Agree = A; 5. Strongly Agree = SA. **Table 2** provides responses (for all three States combined) and all response options.

Table 2: Extent of Agreement with Q1 Statements re Perspectives on the Law

Q1	Statement	N	1. SD % (n)	2. D % (n)	3. NS % (n)	4. A % (n)	5. SA % (n)	MEAN/5
a	The law is not relevant to making these decisions	857	25 (213)	52 (446)	8 (72)	12 (100)	3 (26)	2.16
b	The law provides a useful framework for decision-making	858	5 (39)	21 (181)	27 (242)	42 (357)	5 (39)	3.21
c	The law is out of touch with medical practice	857	1 (11)	24 (202)	39 (332)	28 (242)	8 (70)	3.18
d	The law is helpful when making these decisions	854	4 (38)	28 (234)	28 (238)	38 (327)	2 (17)	3.06
e	Resolving disputes through legal processes takes too long	858	<1 (5)	3 (25)	14 (130)	41 (349)	41 (349)	4.18
f	The law promotes good relationships between doctors and their patients and families	858	10 (87)	35 (300)	39 (336)	15 (125)	1 (10)	2.62
g	Following the law can lead to inappropriate treatment decisions	859	2 (17)	21 (177)	27 (231)	41 (353)	9 (81)	3.35
h	The law has a place in the practice of medicine	857	1 (9)	3 (28)	8 (65)	68 (584)	20 (171)	4.03
i	The law impinges on doctors' professional autonomy	857	4 (36)	42 (359)	24 (206)	25 (216)	5 (40)	2.84
j	The law supports good medical practice	858	3 (27)	16 (135)	39 (333)	38 (328)	4 (35)	3.24
k	Medical and family consensus matters more than the law	860	2 (15)	21 (183)	17 (144)	42 (362)	18 (156)	3.54

Overall, there was strong agreement that "the law has a place in the practice of medicine" and the majority of respondents disagreed that "the law is not relevant to making these decisions".

However, other responses were less positive about the law. For example, 60 percent agreed or strongly agreed that "medical and family consensus matters more than the law" and many did not agree that "the law promotes good relationships between doctors and their patients and families". While there was more agreement than disagreement with the other positive attitude statements about the law, there was not majority agreement (e.g., 47% agreed that the law provides a useful framework for decision-making, 26% disagreed with this and 27% were not sure; 42% agreed that the law supports good medical practice, 19% disagreed that it did and 39% were not sure). In addition, 82 percent of respondents said that "resolving disputes through legal processes takes too long" and 50 percent thought that "following the law can lead to inappropriate treatment decisions".

Q2 asked the extent to which respondents agreed or disagreed with a series of statements in relation to knowing and following the WWLST law (response options as for Q1). There was much stronger agreement than disagreement from respondents that it is important for them to know and follow the law and that knowing the law would both help them to follow it and to manage legal risk. A slight majority agreed that "acting in accordance with good medical practice will be lawful". A strong majority wanted to know more about the law (**Table 3**).

Table 3: Extent of Agreement with Q2 Statements re Perspectives on the Law

Q2	Statement	N	1. SD % (n)	2. D % (n)	3. NS % (n)	4. A % (n)	5. SA % (n)	MEAN/ 5
a	It is important for me to know the law	860	0 (0)	1 (12)	3 (22)	65 (555)	32 (271)	4.26
b	It is important for me to follow the law	856	<1 (2)	4 (34)	12 (102)	61 (524)	23 (194)	4.02
c	I worry about legal risk	859	2 (19)	26 (225)	9 (75)	52 (444)	11 (96)	3.43
d	Following the law is the right thing to do	857	1 (5)	8 (71)	32 (277)	49 (422)	10 (82)	3.59
e	The law is too complex	860	1 (7)	12 (103)	33 (286)	40 (346)	14 (118)	3.54
f	Knowing the law would help me manage legal risk	859	<1 (3)	5 (41)	8 (65)	73 (623)	15 (127)	3.97
g	Knowing the law better would help me follow it	859	1 (7)	8 (66)	18 (153)	59 (510)	14 (123)	3.79
h	I am too busy to find time to know the law	859	5 (40)	38 (330)	15 (125)	34 (299)	8 (65)	3.02
i	I would like to know more about the law	858	1 (8)	6 (47)	11 (94)	64 (554)	18 (155)	3.93
j	The law is unclear	858	1 (11)	15 (127)	48 (410)	28 (240)	8 (70)	3.27
k	Acting in accordance with good medical practice will be lawful	858	1 (11)	13 (113)	32 (277)	44 (378)	9 (79)	3.47

An “attitude to the law” score was calculated for both sets of statements, with a maximum possible score of 55 for Q1 statements (reverse scoring negative statements), and a maximum possible score of 50 for Q2 statements (as above but not scoring the one neutral statement). For Q1 the highest score was 52, and 77 percent of respondents achieved a score that was more positive than negative: 48 percent scored 34-52/55 (with 11% scoring 41-52/55) and an additional 29 percent scored 29-33/55. For Q2, 86 percent of respondents scored 31 or more/50: 59 percent scored 34-47/50 (with 12% scoring 39-47/50) and an additional 27 percent scored 31-33/50.

Tables 4 and 5 present the Attitude Scores by Specialty for each State. (For total respondents by Specialty and State, see **Table 1**.)

Table 4: Q1 Statements: Attitude to the Law and its Role in Medical Practice: Score (%) by Specialty by State (N=810*)

	QLD			NSW			VIC			TOTAL		
SPECIALTY	**<29**	**29-34**	**35-52**	**<29**	**29-34**	**35-52**	**<29**	**29-34**	**35-52**	**<29**	**29-34**	**35-52**
Emergency Medicine	27	45	28	25	44	31	19	47	34	23	46	31
Geriatric Medicine	29	14	57	16	31	53	6	34	60	15	29	56
Intensive Care	57	25	17	39	37	24	14	37	49	35	34	31
Oncology	6	50	44	20	33	47	27	23	50	20	32	48
Palliative Care	0	43	57	0	53	47	14	24	62	6	38	56
Renal Medicine	27	53	20	21	49	30	28	38	34	25	45	30
Respiratory Medicine	16	44	40	20	47	33	24	30	46	20	40	40
TOTAL	**28**	**39**	**33**	**23**	**41**	**36**	**19**	**36**	**45**	**22**	**39**	**39**

* Overall, 862 respondents received an attitude score for Q1: 196 scored <29 (57 in Qld, 74 in NSW and 65 in Vic); 328 scored 29-34 (85 in Qld, 135 in NSW and 108 in Vic); and 338 scored 35-52 (75 in Qld, 125 in NSW and 138 in Vic). As not all respondents indicated their main specialty, or indicated a specialty outside the a bove groups, N for this Table = 810.

Overall, Geriatricians and Palliative Care specialists recorded the most positive attitudes (highest percentage of scores of 35-52) in relation to the WWLST law and its role in medical practice. They also recorded the highest percentages by State, along with Oncologists in New South Wales.

Intensive Care specialists recorded the highest percentage of scores in the least positive (<29) category, overall and in Queensland and New South Wales, but not in Victoria, where Renal specialists and Oncologists recorded the highest percentage of scores in the <29 category. The difference between Intensive Care specialists across the three States is particularly notable: in Queensland, 57 percent scored <29 and 39 percent did so in New South Wales, but, in Victoria, only 14 percent scored <29 (with corresponding differences in scores of 35-52).

Table 5: Q2 Statements: Attitude to Knowing and Following the Law: Score (%) by Specialty by State (N=809**)

	QLD			NSW			VIC			TOTAL		
SPECIALTY	**<32**	**32-35**	**36-50**	**<32**	**32-35**	**36-50**	**<32**	**32-35**	**36-50**	**<32**	**32-35**	**36-50**
Emergency Medicine	26	49	25	18	51	31	22	50	28	22	50	28
Geriatric Medicine	19	52	29	20	28	53	11	23	66	17	31	52
Intensive Care	23	60	17	28	35	37	9	42	49	20	44	36
Oncology	25	31	44	27	57	16	24	38	38	25	44	31
Palliative Care	14	22	64	6	47	47	10	19	71	9	29	62
Renal Medicine	13	40	47	21	49	30	19	50	31	19	47	34
Respiratory Medicine	28	36	36	22	53	25	22	46	32	23	46	31
TOTAL	**23**	**46**	**31**	**21**	**45**	**34**	**18**	**41**	**41**	**20**	**44**	**36**

** Overall, 861 respondents received an attitude score for Q2: 182 scored <32 (51 in Qld, 70 in NSW and 61 in Vic); 370 scored 32-35 (97 in Qld, 147 in NSW and 126 in Vic); and 309 scored 36-50 (69 in Qld, 96 in NSW and 124 in Vic). As not all respondents indicated their main specialty, or indicated a specialty outside the above groups, N for this Table = 809.

Palliative Care specialists recorded the most positive attitudes (scores of 36-50) overall and for Queensland and Victoria, and the second highest for New South Wales, in relation to knowing and following the WWLST law; Geriatricians recorded the next highest overall positive score of 36-50, the highest for New South Wales and the second highest for Victoria.

Oncologists, followed by Respiratory specialists, recorded the highest percentage of scores in the least positive (<32) category overall; in Queensland, Respiratory specialists followed by Emergency Medicine specialists scored highest in this category; in New South Wales, Intensive Care specialists and Oncologists recorded the highest percentage of scores in the <32 category and, in Victoria, Oncologists scored highest in this category. An anomaly in this table is the score of only 29 percent of Geriatricians in Queensland scoring 36-50, compared with 53 percent in New South Wales, 66 percent in Victoria and 52 percent overall.

Experience of the Law

Respondents were asked how many decisions about whether to WWLST from adults who lacked capacity they had been involved in over the previous 12 months (including decisions where WWLST was considered, even if treatment was ultimately provided or continued). Approximately a quarter of the respondents had been involved in more than 30 decisions in the previous year; 29 percent had been involved in 11-30 decisions; 40 percent in 1-10. Overall, 801 respondents had been involved in at least one decision. Differences between respondents reached significance in relation to Age, Years in Practice and Specialty.

Respondents aged 60+ had been involved in significantly fewer decisions over the previous 12 months than the other age groups, while those aged 40-49 recorded the highest Mean for this question.

Respondents with >40 years in practice reported being involved in significantly fewer decisions over the previous year than any of the other groups, while those with 10-19 years in practice recorded the highest Mean.

Intensive Care specialists recorded the highest Mean for this question, with 10 percent saying that they had been involved in more than 100 decisions in the previous 12 months and more than a quarter of this specialty having been involved in >50 decisions. The next highest Mean, and also with more than a quarter of this specialty having been involved in >50 decisions in the previous 12 months, was recorded by Palliative Care specialists.

Respondents who said that they had been involved in at least some decisions in the previous 12 months were then asked whether they had ever doubted that these decisions followed the law. More than half of the respondents said that they Never or Seldom had such doubts; less than five percent said that they Often or Very often had such doubts; 36 percent Sometimes doubted that the decisions they were involved in followed the law. Differences between groups reached significance only in relation to State.

Queensland respondents were significantly more likely than respondents from New South Wales or Victoria to say that they Sometimes doubted that the decisions that they had been part of followed the law and less likely to say that they Never had such doubts.

Respondents who had expressed doubt were asked what had motivated them to go ahead and make the decision, despite their doubts. (A list of possible reasons was provided, including Other – which they could specify.) Multiple responses were possible and there was a total of 1,283 responses (**Table 6**).

Table 6: Motivations for Decision where the Specialist Doubted that the Decision Followed the Law (More than one response possible)

Q	Statement	Yes n	As % of 1,283
a	Managing resourcing constraints was more important than following the law	63	5
b	Managing demands on clinical time was more important than following the law	37	3
c	Professional guidelines were more important than following the law	117	9
d	Personal ethical principles were more important than following the law	201	16
e	Religious beliefs were more important than following the law	8	1
f	Acting as clinically indicated was more important than following the law	490	38
g	Family views were more important than following the law	271	21
h	Other	96	7
	TOTAL RESPONSES	**1,283**	**100**

The most frequently selected motivation was statement f: "Acting as clinically indicated was more important than following the law" (490/1283 responses = 38%).

Perceptions of Knowledge of the Law

Respondents were asked how much knowledge they thought they had of the law, to provide a baseline against which previous education/training, or the need for future education/training, could be assessed. Response options were Very Little Knowledge; Some Knowledge; Moderate Knowledge; and Considerable Knowledge (Mean/4). Only five percent of respondents (n=42) said that they had Considerable Knowledge; 34 percent (n=258) said that they had Moderate Knowledge; 43 percent (n=330) had Some Knowledge and 18 percent (n=136) said that they had Very Little Knowledge.

Response differences to this question reached significance by State, Age, Specialty, Country of Birth and Country of Degree.

- **State:** Respondents in New South Wales were significantly more likely than their counterparts in Victoria to say that they only had Some Knowledge of the law and significantly less likely than respondents in the other two States to say that they had Moderate or Considerable Knowledge.
- **Age:** Respondents aged 60+ were the most likely to say that they had Moderate Knowledge of the law while those aged <40 were the most likely to say that they had Some Knowledge.
- **Specialty:** Palliative Care specialists (Mean 2.73/4), followed by Geriatricians (Mean 2.63/4) and Intensive Care specialists (Mean 2.55/4) were significantly more likely than the other specialist groups to say that they had Moderate or Considerable Knowledge of the law. Oncologists were significantly less likely than the other groups to say that they had Moderate or Considerable Knowledge of the law (Mean 1.88/4).
- **Country of Birth:** Respondents who were born in Asia and Other countries (Table 1) were significantly less likely than the other two groups to say that they had Moderate Knowledge and significantly more likely to say they had Some Knowledge of the law.
- **Country of Degree:** Respondents who completed their medical degree in Asia and Other countries (Table 1) were significantly less likely than the other two groups to say that they had Moderate Knowledge or Considerable Knowledge of the law and significantly more likely than the other two groups to say they had Very Little Knowledge of the law.

Knowledge of State-Specific Law

Respondents were presented with six statements about the WWLST law in their State in relation to Advance Directives and substitute decision-making, with respect to providing treatment to an adult who has lost capacity. (The wording of the questions in this section varied slightly to ensure that it was State-relevant.) They were asked to rate each statement as True, False or I Don't Know.

Each respondent was given a score of 1 for each correct answer, resulting in a score of 0-6, with an overall Mean score of 2.97. Calculating Mean scores by State found that respondents in New South Wales were correct in their responses more often than respondents in Victoria or Queensland (Means of 3.44/6, 2.81/6 and 2.49/6 respectively). (Note: "I Don't Know" was an option that respondents could choose and this was scored as incorrect. However, very few respondents chose this option for any question, indicating that, overall, respondents "did not know what they did not know.")

To test their knowledge further, respondents were then presented with a scenario which involved a middle-aged woman with a life-limiting disease who is taken to hospital unconscious, with a consequent need for health decisions to be made by others. Respondents were told that the following potential decision-makers were present at the hospital: the patient's husband (from whom she has been separated for many years); her son (who is also her attorney for financial matters); her daughter (who is currently her full-time carer); and her same-sex partner of five years. Respondents were asked who would be legally entitled to make decisions about her medical treatment (in their respective jurisdictions). **Table 7** presents results by State.

Table 7: Participants' Responses to the Scenario

Question		N	Husband % (n)	Son % (n)	Daughter % (n)	Same-Sex Partner % (n)	Don't Know % (n)	Correct Answer
Who would be legally entitled to consent to medical treatment?	**QLD**	214	18 (39)	15 (31)	12 (26)	31 (67)	24 (51)	Partner
	NSW	331	8 (28)	52 (172)	8 (27)	22 (71)	10 (33)	Partner
	VIC	306	21 (65)	7 (20)	13 (39)	36 (111)	23 (71)	Partner
Overall		**851**	**16 (132)**	**26 (223)**	**11 (92)**	**29 (249)**	**18 (155)**	
			$\chi^2_8 = 194.473; p < 0.001$					

Differences between respondents by State for all responses were highly significant. A higher percentage of respondents in Victoria (36%) and Queensland (31%) than in New South Wales (22%) correctly identified the same-sex partner as the person legally entitled to consent to medical treatment for this patient. While in Victoria and Queensland this was more than those who selected any other option, it was still only about one-third of respondents in each State. In New South Wales, slightly more than half of the respondents (52%) incorrectly named the patient's son as the legally-entitled consent giver, possibly because he had Enduring Power of Attorney. However, in New South Wales, an Enduring Power of Attorney only allows the person appointed to make decisions about property and money, not to make healthcare decisions. Authority for healthcare decisions in New South Wales is conferred by the appointment of an Enduring Guardian.

Overall responses were collapsed into two categories: Partner and Other. Chi-square analysis of the results was undertaken by State, Age, Gender, Years in Practice, Specialty and Religion. Differences were only significant by State and Specialty.

- **State:** As for the overall results, respondents from New South Wales were significantly more likely than those from Queensland and Victoria to provide an incorrect response.
- **Specialty:** Intensive Care specialists, Palliative Care specialists and Geriatricians were significantly more likely than other specialists to correctly answer "same-sex partner" (although still less than half of each group did so). Renal and Respiratory specialists were significantly less likely than other specialists to give the correct answer.

Chi-square analysis of scores/6 for the True/False/I Don't Know statements were undertaken by responses for the scenario. There was no significant difference between respondents on the basis of their scores/6; while respondents who scored 5 or 6 on the statements were *more likely* than those with lower scores to know who the correct substitute decision-maker was (37%/38% respectively, compared with scores ranging from 24%-30% for the other five groups) the differences were not significant.

Adding a score of 1 for correct responses to this scenario (and a score of 0 for incorrect responses) provided a total knowledge score out of 7. The percentage of respondents who scored <4 or 4-7 correct was calculated for the whole sample. **Table 8** presents those results, and the Mean score/7, by State.

Table 8: Percentage and Number of Respondents Scoring <4 and 4-7 Correct Responses, plus Mean score, by State

State	N	Score <4/7 % (n)	Score 4-7/7 % (n)	Mean/7
QLD	218	74 (162)	26 (56)	2.79
NSW	335	45 (150)	55 (185)	3.65
VIC	314	61 (190)	39 (124)	3.17
TOTAL	**867**	**58 (502)**	**42 (365)**	**3.26**
		$\chi^2_2 = 48.637$; $p < 0.001$		

Despite being significantly more likely to give an incorrect response to the scenario, respondents in New South Wales (Mean 3.65/7) were still correct in their overall responses to the statements plus scenario more often than respondents in Victoria (Mean 3.17/7), with those in Queensland having the least correct responses (Mean 2.79/7).

Additional chi-square analysis was undertaken by Age, Gender, Years in Practice, Specialty and Religion. Differences reached significance only for Specialty (**Table 9**).

Table 9: Percentage and Number of Respondents Scoring <4 and 4-7 Correct Responses, plus Mean Score, by Specialty

Specialty	N	Score <4/7 % (n)	Score 4-7/7 % (n)	Mean/7
Emergency Medicine	270	62 (167)	38 (103)	3.09
Geriatric Medicine	107	43 (46)	57 (61)	3.89
Intensive Care	125	50 (62)	50 (63)	3.48
Oncology	80	64 (51)	36 (29)	3.07
Palliative Care	52	48 (25)	52 (27)	3.71
Renal Medicine	80	54 (43)	46 (37)	3.37
Respiratory Medicine	98	75 (73)	25 (25)	2.72
TOTAL	**812**	**58 (467)**	**42 (345)**	**3.28**
		$\chi^2_6 = 29.709; p < 0.001$		

Respiratory Medicine specialists were significantly more likely than any of the other specialties to score less than 4/7 correct responses; Geriatricians and Palliative Care specialists were significantly more likely than the other specialists to score 4 or more correct answers out of 7.

Overall, respondents' estimation of their own knowledge did relate to their scores. The results demonstrated a highly significant and linear association between doctors' perception of and actual knowledge of the law. However, 33 percent of those who only scored 1/7 and 31 percent of those who only scored 2/7 thought that they had Moderate Knowledge of the WWLST law.

Education and Training on the Law

Respondents were asked if they had received/undertaken any education or training on the law in their basic medical degree, immediate postgraduate medical training or through continuing professional development (CPD). Sixty percent of respondents overall had received such education/training through CPD (62% in Qld, 59% in NSW and 60% in Vic) and 50 percent overall had done so in their immediate postgraduate training (55% in Qld, 46% in NSW and 49% in Vic). Although less than 50 percent of respondents in any State had received such training as part of their basic medical degree, respondents from Victoria were significantly more likely to have done so than their counterparts in Queensland or New South Wales (41% cf 28% and 27% respectively).

Respondents were asked how helpful the education/training was that they had received (if any). While a majority of those who had received such education at any time said that they found such training Helpful or Very Helpful, those who received CPD training were most likely to say so. Palliative Care specialists were significantly more likely than the other groups to say that their CPD education/training was Helpful/Very Helpful (Mean 1.98/4; 1 = Very Helpful). In all three States, 14% of respondents who received CPD training and approximately 20% of those who received immediate postgraduate training found it Very Unhelpful or Unhelpful. However, 35 percent of respondents who had received such education as part of their basic medical degree found it Unhelpful or Very Unhelpful.

The "attitude to the law" score was used to assess attitude by education/training received at any time in respondents' medical career. Those who had received CPD education were significantly more likely to have a very positive attitude to the law than those who had only received such education/training as undergraduates or immediately post-graduation.

Respondents were asked, considering only CPD, which methods (from a list of eight provided) they thought would be most helpful for providing them with education or training on the WWLST law. Workshops based on case studies was the preferred method for the majority of respondents.

Practice and the Law

A second scenario involved a patient who had completed an Advance Health Directive (AHD Qld)/ Advance Care Directive (ACD NSW)/ Refusal of Treatment Certificate (RoTC Vic) five years previously, soon after being diagnosed with AIDS. In his AHD/ACD/RoTC he refused antibiotics for any future life-threatening infection and wished only to be kept comfortable. He becomes ill with a life-threatening infection and requires antibiotics to survive. Both his family and doctors wish him to receive antibiotics as he would be likely to recover from the infection and continue to live as before. If he is not given the antibiotics it is likely he will die.

Respondents were asked "Would you commence antibiotics?". They were told to assume that they had already had extensive discussions with family and others, and that their only choices were Yes or No. **Table 10** presents the result of this question by State.

Table 10: Would you Commence Antibiotics? Responses by State

State	N	Yes % (n)	No % (n)
QLD	215	72 (155)	28 (60)
NSW	329	72 (236)	28 (93)
VIC	309	63 (195)	37 (114)
TOTAL	**853**	**69 (586)**	**31 (267)**
		χ^2_2=7.05; p=0.03	

Note: The law relating to this scenario is different in each State and would give the following results:

- **Queensland:** Give antibiotics, as the conditions required for the AHD to apply are not met and the substitute decision-maker(s) says "treat";
- **New South Wales:** Do not give antibiotics, as the conditions fulfil the requirements for a valid common law ACD;
- **Victoria:** Although not as clear cut as in the other jurisdictions, the antibiotics should not be given because the RoTC applies (the pneumonia would count as part of his "current condition" of AIDS, as required by Victorian law for an RoTC to be followed).

Chi-square analysis of the overall results was undertaken by State, Age, Gender, Years in Practice, Specialty and Religion. Differences reached significance in relation to commencing antibiotics or not commencing antibiotics only by State (p=0.029) and Specialty (p=0.002).

Respondents in Queensland and New South Wales were significantly more likely than those in Victoria to say that they would start antibiotics. A majority in every Specialty said that they would commence antibiotics; Intensive Care specialists (76%) and Respiratory Medicine specialists (77%) were significantly more likely than the other specialists to say this. Palliative Care specialists (46%) and Geriatricians (42%) were significantly more likely than the other specialists to say that they would not do so.

They were also asked why they would choose that action, from a list of reasons provided and an "Other" option where they could provide other reasons. **Table 11** presents the reasons given by those who would commence antibiotics and **Table 12** by those who would not.

Table 11: Why Respondents Would Commence Antibiotics: Responses by State

Q	Reasons provided for a "Yes" response	QLD % (n)	NSW % (n)	VIC % (n)
a	I do not have to follow the AHD* because it is inconsistent with what is clinically indicated	14 (21)	13 (31)	11 (21)
b	The AHD is relevant to my decision-making process but other factors are more relevant	70 (108)	70 (164)	73 (142)
c	The AHD is not relevant to my decision-making because I don't believe AHDs are appropriate to determining treatment	1 (1)	2 (4)	1 (1)
d	The AHD does not have legal effect	3 (5)	3 (8)	6 (12)
e	Other	10 (17)	10 (24)	8 (16)
	TOTAL	**100 (152)**	**100 (231)**	**100 (192)**

*AHD in Qld Questionnaire; ACD in NSW; RoTC in Vic

Approximately 70 percent of the respondents in each State who said that they would commence antibiotics selected the reason that "The AHD is relevant to my decision-making but other factors are more relevant."

Table 12: Why Respondents Would Not Commence Antibiotics: Responses by State

Q	Reasons provided for a "No" response	QLD % (n)	NSW % (n)	VIC % (n)
a	The most important consideration is following the patient's wishes	33 (20)	43 (40)	30 (34)
b	The most important consideration is that the law requires me to follow AHD	10 (6)	8 (7)	4 (5)
c	Both of the above considerations are equally important	57 (34)	48 (45)	64 (73)
d	Other	0 (0)	0 (0)	2 (2)
	TOTAL	**100 (60)**	**100 (92)**	**100 (114)**

For those who would commence antibiotics, most said that the AHD is relevant but other factors were more relevant. For those who would not commence antibiotics, the majority said that both following the patient's wishes and the fact that the law requires them to follow the AHD were equally important. Analyses of each set of reasons by State, Age, Gender, Years in Practice, Specialty and Religion showed that differences did not reach significance by any variable for "Yes" reasons and only by Gender for "No" reasons ($p=0.026$), with Males significantly more likely than Females to say that the patient's wishes were the most important reason why they would not commence antibiotics; Females were significantly more likely than Males to say that the patient's wishes and the requirements of the law were equal in their decision-making.

Respondents were asked to indicate the relevance, on a 4-point scale: 1 = Not Relevant; 2 = Somewhat Relevant; 3 = Relevant; and 4 = Very Relevant, of each factor on a list provided, in their decision-making process for Scenario 2, assuming that the incident occurred in the principal place where they practised medicine.

Using Mean scores, the order of relevance of decision-making factors (1-6) was:

1. Patient's expected quality of life after the proposed treatment (3.43);
2. Whether the treatment was clinically indicated (3.18);
3. Personal ethical principles (2.95);
4. Following the patient's AHD (or equivalent) (2.90);
5. Following the law (2.77); and
6. Family views (2.70).

The other factors (hospital policies, professional guidelines, views of colleagues, and concern about being sued) all scored less than 2.70 (range 2.16 – 2.69). Of least relevance was "Your religious beliefs" (Mean 1.25). (We note that this is consistent with the data as a whole: personal ethical values appear to have much more influence on the attitudes of the respondents than their religious beliefs.) Chi-square analysis of the results for this question found significant differences by State, Age, Gender, Years in Practice, Specialty and Religion.

State

- Respondents from Queensland were significantly more likely than those from New South Wales or Victoria to say that the views of their colleagues were Relevant in their decision-making for Scenario 2 and they also recorded the highest Mean.
- Respondents from Victoria were significantly more likely than the other two groups to report that following the law was Very Relevant (and they had the highest Mean), those from Queensland that it was Relevant, and those from New South Wales that it was Somewhat Relevant, in their decision-making for Scenario 2.
- Respondents from Victoria were significantly more likely than the other two groups to report that following the patient's AHD/ACD/RoTC was Very Relevant, those from Queensland that it was Relevant, and those from New South Wales that it was Somewhat Relevant in their decision-making for Scenario 2. Victoria recorded the highest Mean.
- Significantly more Queensland respondents said that family views were Very Relevant to their decision-making, compared to respondents from the other two States. Queensland recorded the highest Mean for the question.

Age

- Respondents aged <40 were significantly less likely than the other age groups to say that professional guidelines were Not Relevant in their decision-making process for Scenario 2. This group recorded the highest Mean for the question.
- While only a small percentage of respondents said that their colleagues' views were Not Relevant, those aged 60+ were significantly more likely than the other groups to do so. Those aged <40 recorded the highest Mean for the question.
- Respondents aged <40 were significantly more likely than the other age groups to report fear of being sued as being Somewhat Relevant or Relevant in their decision-making process for Scenario 2. Those aged 60+ were significantly more likely to say that fear of being sued was Not Relevant in their decision-making process.

Gender

- Males were more likely than Females to say that the views of their colleagues were Not Relevant to their decision-making process for Scenario 2.

Years in Practice

- Respondents who had >40 years medical practice were significantly more likely than the other groups to say that professional guidelines were Very Relevant in their decision-making. Respondents with <10 years in practice were significantly more likely to say that they were Relevant. Those with <10 years in practice recorded the highest Mean for the question, closely followed by those with >40 years' experience.
- Respondents with <10 and 10-19 years of medical practice were significantly more likely than the other three groups to say that their colleagues' views were Relevant or Very Relevant in their decision-making, and significantly less likely to say that they were Not Relevant. Respondents with >40 years in practice were significantly more likely than the other four groups to say that such views were Not Relevant in their decision-making. Those with 10-19 years in practice recorded the highest Mean.
- Respondents with <10 years in practice were significantly more likely than the other groups to say that concerns about being sued were Somewhat Relevant in their decision-making process for Scenario 2 and they recorded the highest Mean score. Respondents with >40 years in practice were significantly more likely to report it as being Not Relevant in their decision-making, with a Mean score of 1.78; there was a direct linear relationship between years in practice and the percentage of respondents who said that this factor was Not Relevant, with concern decreasing with experience.

- Respondents with <10 years and those with >40 years in practice were significantly more likely than the other three groups to say that whether or not treatment was clinically indicated was a Very Relevant factor in their decision-making. Those with <10 years in practice recorded the highest Mean for the question.
- Overall, 87 percent of respondents said that the patient's quality of life was Very Relevant or Relevant to their decision-making. Respondents with <10 years in practice were significantly more likely than the other four groups to say that it was Very Relevant and they also recorded the highest Mean for the question.
- Respondents with <10 years in practice were significantly more likely than the other four groups to say that family views were Somewhat Relevant in their decision-making. Those with 10-19 years in practice recorded the highest Mean; 68 percent said that family views were Relevant or Very Relevant in their decision-making.

Specialty

- Oncologists and Geriatricians were significantly more likely than the other specialist groups to say that following the law was Relevant/Very Relevant in their decision-making. They also recorded the highest Means for the question.

Religion

- Overall, 75 percent of respondents said that their personal ethical views were Relevant or Very Relevant in their decision-making. Hindus were significantly more likely, and those who were Buddhist, Jewish and Other Christian were significantly less likely, than the other groups to say this; Jewish and Buddhist respondents were significantly more likely than the other groups to say that their personal ethical views were Not Relevant to decisions. Hindus, followed by Anglicans, recorded the highest Mean for the question.
- In contrast to responses about personal ethical views, only 6 percent of respondents overall said that their religious beliefs were Relevant or Very Relevant to making decisions. Respondents who said that they had No Religion were significantly more likely than the other groups to say that their religious beliefs were Not Relevant when making decisions (96%) (which is logical). However, 83 percent of all respondents – and more than half of every group – said that their religious beliefs were Not Relevant when making decisions; this included Jewish (91%), Hindu (88%), Buddhist (82%) and Anglican (81%) respondents. Those who belonged to an Other Christian group were significantly more likely than all other groups to say that their religious beliefs were Somewhat Relevant or Relevant. Other Christians, followed by Catholics, recorded the highest Mean for the question.

DISCUSSION

An overall discussion of the main findings of the research is presented here. More in-depth discussion relating to specific components of the study can be found in the journal articles that have been and will be published from the study (see the list of current publications, p 35).

Response Rates

While the overall response rate of 32 percent was less than ideal, response rates by State for some specialties exceeded 50 percent and reached as high as 75 percent. A comparison of the Age, Gender, State and Specialty demographic characteristics of those who completed the survey with the whole AMPCo database population from which they came found that respondents were similar on all characteristics, except that there were fewer younger doctors in the respondent sample. This suggests that those who responded were generally representative of the sample from which they were drawn. However, it is reasonable to assume that, in most cases, those who chose to complete the survey had more interest in the topic, and, therefore, were possibly more positively inclined to the role of law in medicine than those who did not complete the survey. To the extent that this is the case, then the actual knowledge, attitudes and practices of medical practitioners working in end-of-life care may be even more concerning than these results indicate.

Attitudes and Perspectives on the Role of Law in Medical Practice

Overall, there was strong agreement that the law has a place in the practice of medicine and is relevant to making these decisions. However, for most of the other attitude statements, including that “medical and family consensus matters more than the law” and that “the law promotes good relationships between doctors and their patients and families”, responses were more equivocal. It was somewhat surprising, given the emphasis on caring for both patient and family in the philosophy and practice of palliative care, that Palliative Care specialists were the least likely to agree that medical and family consensus matters more than the law (although note that Palliative Care specialists generally had very positive attitudes to law).

While overall responses to the two sets of “attitude to the law” statements found that respondents had more positive than negative attitudes, most respondents thought that resolving disputes through legal processes takes too long and half of them also said that following the law can lead to inappropriate treatment decisions. However, only 30 percent of respondents said that the law impinges on doctors’ professional autonomy.

Attitudes and Perspectives on Knowing and Following the Law

There was much stronger agreement with the second set of statements relating to respondents' actual practice, with very strong majority agreement that it is important for them to know and follow the law and that knowing the law would help them both to follow it and to manage legal risk (63% acknowledged that they worry about legal risk). A slight majority also agreed that following the law is the right thing to do. However, while 53 percent said that acting in accordance with good medical practice would be lawful, 32 percent were Not Sure about this, indicating some ambivalence. This was also indicated by the fact that while 54 percent of respondents thought that the law is too complex, only 36 percent thought that the law is unclear (although 48% were Not Sure about this). There was almost equal agreement and disagreement from respondents that they considered themselves too busy to find time to know the law.

It was encouraging that almost all of the respondents wanted to know more about the law. Only 55/867 respondents said that they would not want to know more about the law and it is possible that these respondents felt that they were already sufficiently well versed in the law. This was supported by the findings about perceived knowledge levels where respondents were asked to estimate their current level of knowledge of the law; 48 of the 55 respondents who did not want to know more about the law answered this question and 32 of the 48 thought that they already had Moderate or Considerable knowledge of the WWLST law.

Actual Knowledge of the Law

This study demonstrated critical gaps in the legal knowledge of many of the study participants. When respondents rated a series of statements about the law in their respective States as True, False or I Don't Know, many not only gave incorrect responses but, as they did not select I Don't Know, it seems that "they don't know what they don't know".

In relation to a question that asked participants to identify the correct substitute decision-maker in a particular scenario, respondents from New South Wales were least likely to select the correct substitute decision-maker (only 22% did so), while only 31 percent from Queensland and 36 percent from Victoria were correct.

In addition to State, another strong predictor of knowledge was Specialty. When scores/7 for the True/False/I Don't Know statements plus Scenario 1 were analysed by Specialty, Geriatricians and Palliative Care specialists were significantly more likely than the other specialists to score 4-7/7 correct.

Gender and Country of Birth, when adjusted for State and Specialty and for each other, were found to be significant but weaker predictors of knowledge. Females and Australian-born doctors scored somewhat higher than other groups (p=0.05 and 0.017 respectively).

The results demonstrated a highly significant and linear association between the number of decisions doctors made and their knowledge of the law (p<0.001), an effect which remained after adjustment for State, Specialty, Gender and Country of Birth (p=0.008). In addition, doctors who had received CPD training had greater knowledge than those who had not, and the association between knowledge and recency of training was significant and linear (p=0.007 for linear trend in Mean scores, after adjusting for State, Specialty, Gender and Country of Birth). The results also demonstrated a highly significant and linear association between doctors' perception of and actual knowledge of the law (p<0.001). This effect remained after adjusting for State, Specialty, Gender and Country of Birth (p<0.001).

Compliance with the Law

Responses to the scenario about whether participants would follow an Advance Directive (however named in each State) demonstrate either the confusion that exists about when an Advance Directive is valid (i.e., has been completed and witnessed according to the law in the relevant jurisdiction) and should be followed under the prevailing conditions, or the fact that medical practitioners are likely to follow what they consider to be good medical practice even if it does not comply with the law. In the scenario provided, the Advance Directive should have been followed in New South Wales (so the antibiotics should not be given), not followed in Queensland (so the antibiotics should be given, as requested by the substitute decision-maker), and almost certainly followed in Victoria (so the antibiotics should not be given). Despite this, a majority in each State said that they would give the antibiotics, with 70 percent or more of the respondents in each State saying that the Advance Directive "is relevant to my decision-making process but other factors are more relevant".

In Queensland, where providing the antibiotics was consistent with the law, 34 of the 60 respondents who said that they would not give the antibiotics gave as their reason that both the patient's wishes and the law are equally important, with another six saying that "The most important consideration is that the law requires me to follow (the Advance Directive)". This means that at least 40 of these 60 respondents are confused about the law, while the other 20 indicated that respecting patients' wishes is more important than the law.

In New South Wales and Victoria, where non-compliance with the law was highest in the Advance Directive scenario, specialists' prioritised patient-related clinical factors over following the law where following the law was inconsistent with what is clinically indicated. Although there was an association between knowledge of the law and legal compliance among the specialists in those States, further analysis of the reasons for decision-making and the matters specialists considered relevant revealed that knowledge of the law did not affect decision-making in the scenario. Legally knowledgeable specialists and those who were not knowledgeable complied with the law (by not treating the patient) for the same reasons and relying on the same factors. Likewise, level of legal knowledge did not affect how specialists who did not comply with the law (by treating the patient) made their decisions. This is particularly interesting in the case of those who are giving more weight to the law but don't know what it requires. Accordingly, what the law requires (and here we distinguish this from doctors' generalised concerns about law or perceptions about what the law might be) appears not to be an influential factor in decision-making about life-sustaining treatment for adults who lack capacity.

We suggest that there is some other variable operating which is associated with enhanced knowledge of the law and that it is responsible for the association between specialists' compliance and legal knowledge. A logical candidate is ethical reasoning.

Potential Influence of Ethics Education

The interconnectedness of law and ethics means that, although they are distinct institutions, they help shape each other[16]. It is possible that many of the respondents who said that they would provide the antibiotics (even when to do so would be contrary to the law) were motivated by ethical considerations. Medical ethics and law are often taught together in an integrated way[13], which could explain how a doctor acting on the basis of ethical considerations could comply with the law (given they often overlap) without knowing it.

There is some support for this hypothesis in the data. Again focusing on results from New South Wales and Victoria, when specialists were given the chance to articulate reasons for not providing treatment in the scenario, the "respect for autonomy" option (patient wishes) featured significantly more highly than "following the law" (respondents could also choose "both were equally important"). Further, when looking at the variables specialists identified as relevant or not to their decision-making in the Advance Directive scenario, "personal ethical principles" was the third most selected option behind "expected quality of life" and "whether the treatment was clinically indicated". After that came "following the patient's AHD (or equivalent)", and only then came "following the law". This hierarchy of "ethics then law" is also supported by an exploratory study of Emergency Medicine specialists' use of Advance Directives in decision-making.[14]

Better knowledge of the law should increase respect for patient autonomy in practice such as through complying with Advance Directives and seeking consent from authorised substitute decision-makers. Ignorance of the law can also push doctors towards more defensive and unnecessary practices[22-24]. We recognise that the law may be challenged on ethical grounds, and that doctors may not always agree with the law that governs their practice. However, doctors should know the relevant law and its rationale, including the legal consequences of acting contrary to the law in such situations.

Implications of the Research Findings

As participants were all from specialties which deal most often with end-of-life decisions, the lack of knowledge and/or confusion about and/or choice to not follow the law presents a high degree of risk to both the doctors and their patients. As noted in White, Willmott, et al.,[8] if life-sustaining treatment is unlawfully withheld or withdrawn, for example, where the purported decision-maker lacks legal authority, patients' lives may be ended wrongly. Conversely, if life-sustaining treatment is unlawfully provided, despite a lawful refusal of treatment through an Advance Directive or by a substitute decision-maker, patients' legal rights may be infringed, and patients may survive with poor quality of life, which they had sought to avoid. For medical professionals, where treatment is withheld or withdrawn unlawfully, they could risk prosecution for unlawful killing; where treatment is provided without appropriate consent or authorisation, they could risk a charge of assault. A lack of legal knowledge will not excuse a medical professional from liability. In addition, conflict may arise where medical professionals and patients' family or friends have different understandings of what the law requires, leading to adverse consequences for everyone involved.[9]

CONCLUSIONS AND RECOMMENDATIONS

This study identified major gaps in knowledge of the WWLST law among medical specialists most often involved in end-of-life decision-making in Queensland, New South Wales and Victoria. It has also raised concerns about compliance with the law and the impact that legal considerations have on medical decision-making.

Law is ultimately a reflection of community values and has an important role to play in medicine. A societal decision through the institution of Parliament (and sometimes the courts) has been made to establish decision-making processes that safeguard the rights and interests of a vulnerable group in our community, adults who lack capacity, and to allow people to express treatment preferences in advance and appoint substitute decision-makers.

Law is also an integral component of clinical practice concerning WWLST from incompetent adults, but this can be generalised to other aspects of end-of-life care, and beyond that to almost every aspect of clinical practice. In the context of continuing inadequacies and variations in undergraduate and postgraduate instruction in medical law, our results point to the need for increased efforts to strengthen and formalise teaching and learning formats that provide comprehensive coverage of existing law and changes over time. Accurate knowledge of the law is one of the requirements to ensure good medical practice and the protection of patient rights at the end of life.

However, this research demonstrates that to improve compliance with law, increasing medical practitioners' legal knowledge is *necessary,*[8] but not *sufficient*. This points to the need for education that addresses not only what the law is but the law's rationale and arguments for complying with it. Our conclusions about the possible role of ethics in compliance also suggest a need to be clear when teaching law and ethics that they are separate, albeit interacting, social institutions. Both law and ethics impose obligations to be followed, but what is required by law may differ from what is deemed ethically appropriate, either broadly or within particular groups in society. There may also be merit in conceptualising legal knowledge and compliance as an ethical and professional responsibility, given ethics has a more entrenched role and greater legitimacy within the profession. More education and training is needed to demonstrate the role, relevance and utility of law in end-of-life care.

Our research demonstrates that the current level of knowledge of medical specialists working in the end-of-life area, as well as the complexity of the law and medical practitioners' attitudes to it, put both medical practitioners and patients at risk. To address this situation, three things must occur: law reform; improved training and resources; and a shift in the level of importance that medical practitioners place on knowing the law.

Need for Law Reform

We have argued elsewhere that there are problems with the law in New South Wales[1], Victoria[5] and Queensland[4] and have identified aspects that could be simplified. The complexity of the law and the inconsistency across the three jurisdictions, highlighted by responses to the knowledge questions, confirms this. Some level of legal complexity in this area is unavoidable but, where it is unnecessary, the law should be reformed. There is also an urgent need for a national approach to the law in this area.[10] For medical professionals, a single Australian legislative framework, or a harmonised national approach, should be easier to know and understand, although achieving this is not likely to be easy.

1

Recommendation 1

That States and Territories (with the Commonwealth) work towards:

- simplifying the law that governs end-of-life decision-making for adults who lack decision-making capacity, including the law regulating Advance Directives; and
- harmonising that legislation nationally.

Need for Improved Training and Resources

Training in medical law remains uneven and unsystematic at all stages of medical education[11]. This is reflected in the general knowledge deficits and variations by Specialty demonstrated by our research, only partly offset by knowledge gained by practical involvement (the number of decisions). We argue that knowledge of the law as a primary social institution, and in its specific role in areas of clinical practice such as the end of life, should be a routine, comprehensive aspect of all stages of medical education.[15] If legal knowledge is integral to good clinical practice, its continuing teaching should be mandatory. At all stages, the current state of the law should be confirmed and taught. Each stage of instruction would support the next, and subsequent stages would reinforce the conceptual and practical attainments of earlier ones.

Even if simplified State and harmonised national legislation were to be achieved, the need for a substantial increase in educational effort would remain to ensure that all doctors involved in end-of-life care know and understand the applicable law. We believe the best way of achieving both better recognition of patient rights and a mature but critical respect for the law is through teaching

that integrates ethical, professional and legal perspectives at all stages. Because medical ethics and law are still relatively new educational fields for medical students, we know – at least anecdotally – that students and junior doctors know more about the law than their consultants. This should revert to the norm in time, but also should motivate those providing medical practitioners with CPD education to focus their attention on specific areas such as this one.

The correlation between knowledge level and recent CPD training is promising. The study found a strong positive link between knowledge level and recent CPD training and CPD training was also selected by respondents as being the most helpful. In addition, CPD training fits well with respondents' preferred mode of education and training delivery, i.e., workshops based on case studies.

2

Recommendation 2

That a broad approach to improving doctors' knowledge of the State-specific law is undertaken by those with responsibility for change, across the three main stages of medical education:

- undergraduate training in basic ethical principles and the related law at the end of life, within a wider framework of dedicated coursework in ethics, law and professional practice (universities and medical schools, Australian Medical Council);
- continuing training for interns and junior doctors in the hospital setting, in relevant rotations, as components of educational packages under accreditation requirements (hospital executives, directors of clinical training, medical education officers, specialist consultant leaders, intern training accreditation bodies, Medical Board of Australia); and
- specialist college-sponsored, non-elective, systematised CPD training programs in all specialties concerned with end-of-life decision-making (specialist colleges, Australian Medical Council).

Need for Greater Understanding of the Importance of the Law in Medical Practice

Medical practitioners are under ever-increasing time pressures and learning about and understanding the law that applies at the end of life will require significant intellectual engagement and commitment of time. The challenge is to convince medical practitioners that undertaking additional education in the law is worth the effort. A good start is to ensure that they recognise that lack of legal knowledge not only places their patients' interests and rights at risk but also places medical practitioners themselves at legal risk. It is also important that law's role in representing community values in this challenging area be understood as well as its facilitative function in providing, for example, a dispute resolution process for intractable conflict.

3

Recommendation 3

That Specialist Colleges and Medical Defence organisations alert their members to the potential risks that they and their patients face, and offer education, information and advice to members about the law in this area. This education should explain law's role in society (and in medicine) including its facilitative function. Medical Schools in Universities also need to address these issues when teaching medical law to ensure that emerging clinicians understand these perspectives.

FUTURE RESEARCH

Further research is needed to better understand the respective roles of law and ethics (and their intersections) in specialists' decision-making in end-of-life care. We believe there is also a need to undertake this study with general practitioners as they are increasingly being asked to provide end-of-life care for patients in the community and in residential aged care facilities.

STUDY LIMITATIONS

The major limitation in this study was the response rate of 32 percent. This is a feature common to survey research involving doctors, particularly to surveys about end-of-life decisions, as response rates from this cohort are low and declining[17-18]. While non-response bias cannot be ruled out, participant characteristics were similar to the overall sample from which they were drawn, except that there were fewer young respondents. It is therefore reasonable to assume that the responses are either fairly representative of the doctors who practise end-of-life medicine, or possibly better, given that it is more likely that those with an interest in the law would have been more likely to respond.

The fact that there were fewer young respondents than in the overall sample means that it is possible that the impact of any changes in medical education relating to the law on end-of-life decision-making is under-represented. The sample, which included all doctors from the seven specialties most likely to be involved in end-of-life decision-making in the largest Australian States, is also more representative than previous related studies which have generally been drawn from those participating in specified training courses or cohorts[19-21], specific health facilities[22-25], or a single specialty/society[14, 26-28].

Another limitation is that our measurement of compliance is based on a particular scenario. Different results could occur where following the law is not clinically challenging, but a scenario where law and medicine are in conflict was used so that the impact of law on clinical decision-making could be better evaluated. A single scenario is also not able to test the full range of legal issues that can arise at the end of life.[21]

REFERENCES

1. White B, Willmott L, Trowse P, Parker M & Cartwright C. (2011). The legal role of medical professionals in decisions to withhold or withdraw life-sustaining treatment: Part 1 (New South Wales). *Journal of Law and Medicine,* 18(3): 498-522.
2. White B & Willmott L. (2005). *Rethinking life-sustaining measures: Questions for Queensland*. Brisbane, Australia: QUT. With url link: http://eprints.qut.edu.au/7093/.
3. Willmott L & White B. (2005). Charting a course through difficult legislative waters: Tribunal decisions on life-sustaining measures. *Journal of Law and Medicine*, 12(4): 441-454.
4. Willmott L, White B, Parker M & Cartwright C. (2011). The legal role of medical professionals in decisions to withhold or withdraw life-sustaining treatment: Part 2 (Queensland). *Journal of Law and Medicine,* 18(3): 523-544.
5. Willmott L, White B, Parker M & Cartwright C. (2011). The legal role of medical professionals in decisions to withhold or withdraw life-sustaining treatment: Part 3 (Victoria). *Journal of Law and Medicine*, 18(4): 773-797.
6. *Northridge v Central Sydney Area Health Service* 2000 NSWSC 1241 (29 December 2000).
7. Australian Institute of Health and Welfare. (2013). *Medical workforce 2011. National health workforce series no. 3. Cat. No. HWL 49.* Canberra, Australia: AIHW.
8. White B, Willmott L, Cartwright C, Parker M & Williams G. (2014). Doctors' knowledge of the law on withholding and withdrawing life-sustaining medical treatment. *Medical Journal of Australia*, 201(4): 229-232.
9. CRELS Project Working Group. (2010). *Conflict resolution in end of life settings (CRELS).* Sydney, Australia: NSW Department of Health.
10. House of Representatives Standing Committee on Legal and Constitutional Affairs. (2007). *Older people and the law.* Canberra, Australia: Parliament of Australia.
11. Preston-Shoot M & McKimm J. (2011). Towards effective outcomes in teaching, learning and assessment of law in medical education. *Medical Education*, 45(4): 339-346.
12. Shah ND. (2008). The teaching of law in medical education. *The Virtue Mentor*, 10(5): 332-337.
13. Preston-Shoot M & McKimm J. (2010). Prepared for practice? Law teaching and assessment in UK medical schools. *Journal of Medical Ethics*; 36(11): 694-699.
14. Wong RE, Weiland TJ & Jelinek GA. (2012). Emergency clinicians' attitudes and decisions in patient scenarios involving advance directives. *Emergency Medicine Journal,* 29(9): 720-724.
15. Campbell AV. (2011). The teaching of medical ethics. *Medical Teacher*, 33(5): 349-350.
16. Van der Burg W. (2013). Law and bioethics. In H. Kuhse & P. Singer (Eds.), *A companion to bioethics,* 2nd Edition (pp. 56-64). Oxford, UK: Wiley-Blackwell.
17. Van Geest JB, Johnson TP & Welch VL. (2007). Methodologies for improving response rates in surveys of physicians: A systemic review. *Evaluation & the Health Professions,* 30(4): 303-321.

18. Cook JV, Dickinson HO & Eccles MP. (2009). Response rates in postal surveys of healthcare professionals between 1996 and 2005: An observational study. *BMC Health Services Research,* 9(160). doi:10.1186/1472-6963-9-160.
19. Schildmann J, Doyal L, Cushing A & Vollmann J. (2006). Decisions at the end of life: An empirical study on the involvement, legal understanding and ethical views of preregistration house officers. *Journal of Medical Ethics,* 32(10): 567-570.
20. Stark Toller CA & Budge MM. (2006). Compliance with and understanding of advance directives among trainee doctors in the United Kingdom. *Journal of Palliative Care,* 22(3): 141-146.
21. Burkle CM, Mueller PS, Swetz KM, Hook CC & Keegan MT. (2012). Physician perspectives and compliance with patient advance directives: The role external factors play on physician decision making. *BMC Medical Ethics*, 13(31). doi:10.1186/1472-6939-13-31.
22. McCrary SV, Swanson JW, Perkins HS & Winslade WJ. (1992). Treatment decisions for terminally ill patients: Physicians' legal defensiveness and knowledge of medical law. *The Journal of Law, Medicine & Health Care*, 20(4): 364-376.
23. McCrary SV, Swanson JW, Coulehan J, Faber-Langendoen K, Olick RS & Belling C. (2006). Physicians' legal defensiveness in end-of-life treatment decisions: Comparing attitudes and knowledge in states with different laws. *Journal of Clinical Ethics*, 17(1): 15-26.
24. McCrary SV & Swanson JW. (1999). Physicians' legal defensiveness and knowledge of medical law: Comparing Denmark and the USA. *Scandinavian Journal of Public Health*, 27(1): 18-21.
25. Hardin SB & Yusufaly A. (2004). Difficult end-of-life treatment decisions: Do other factors trump advance directives? *Archives of Internal Medicine,* 164(14): 1531-1533.
26. Carver AC, Vickrey BG, Bernat JL, Keran C, Ringel SP & Foley KM. (1999). End-of-life care: A survey of US neurologists' attitudes, behaviour, and knowledge. *Neurology,* 53(2): 284-293.
27. Perkins HS, Bauer RL, Hazuda HP & Schoolfield JD. (1990). Impact of legal liability, family wishes, and other "external factors" on physicians' life-support decisions. *The American Journal of Medicine*, 89(2): 185-194.
28. Foss C, Milnes S, Orford N, Corke C, Porter D & Henry MJ. (2009). The influence of medical enduring power of attorney and advance directives on decision-making by Australian intensive care doctors. *Critical Care Resuscitation,* 11(2): 122-128.

PUBLICATIONS FROM STUDY

1. Cartwright C, White B, Willmott L, Parker M & Williams G. (2018). Australian doctors' knowledge of and compliance with the law relating to end-of-life decisions: Implications for LGBTI patients. *Culture, Health & Sexuality,* DOI: 10.1080/13691058.2017.1385854.
2. Parker M, Willmott L, White B, Williams G & Cartwright C. (2018). Law as clinical evidence: A new constitutive model of medical education and decision-making. *Journal of Bioethical Inquiry,* DOI: 10.1007/s11673-017-9836-3.
3. White B, Willmott L, Cartwright C, Parker M, Williams G & Davis J. (2017). Comparing doctors' legal compliance across three Australian states for decisions whether to withhold or withdraw life-sustaining medical treatment: Does different law lead to different decisions? *BMC Palliative Care*, 16(1): 63-70.
4. White B, Willmott L, Williams G, Cartwright C, & Parker M. (2017). The role of law in decisions to withhold and withdraw life-sustaining treatment from adults who lack capacity: A cross-sectional study. *Journal of Medical Ethics*, 43(5): 327-333.
5. Cartwright C, White B, Willmott L, Williams G & Parker M. (2016). Palliative care and other physicians' knowledge, attitudes and practice relating to the law on withholding/withdrawing life-sustaining treatment: Survey results. *Palliative Medicine*, 30(2): 171-179.
6. White B, Willmott L, Cartwright C, Parker M, & Williams G. (2016). Knowledge of the law about withholding or withdrawing life-sustaining treatment by intensivists and other specialists. *Critical Care and Resuscitation*, 18(2): 109-115.
7. White B, Willmott L, Cartwright C, Parker M, & Williams G. (2016). The knowledge and practice of doctors in relation to the law that governs withholding and withdrawing life-sustaining treatment from adults who lack capacity. *Journal of Law & Medicine*, 24: 356-370.
8. Willmott L, White B, Cartwright C, Parker M, Williams G & Neller P. (2016). Doctors' perspectives on law and life-sustaining treatment: Survey design and recruitment strategies for a challenging cohort. *Progress in Palliative Care: Science and the Art of Caring*, 24(4): 213-220.
9. Willmott L, White B, Parker M, Cartwright C & Williams G. (2016). Is there a role for law in medical practice when withholding and withdrawing life-sustaining medical treatment? Empirical findings on attitudes of doctors. *Journal of Law & Medicine*, 24: 342-355.
10. Parker M, Willmott L, White B, Williams G & Cartwright C. (2015). Medical Education and Law: Withholding/withdrawing treatment from adults without capacity. *Internal Medicine Journal*, 45(6): 634-640.
11. White B, Willmott L, Cartwright C, Parker M & Williams G. (2014). Doctors' knowledge of the law on withholding and withdrawing life-sustaining medical treatment. *Medical Journal of Australia*, 201(4): 229-232.
12. White B, Willmott L, Parker M, Cartwright C & Williams G. (2012). What do emergency physicians think of law? *Emergency Medicine Australasia*, 24(4): 355-356.
13. White B, Willmott L, Parker M, Cartwright C & Williams G. (2012). Should law have a role in end-of-life care? *Internal Medicine Journal*, 42(9): 966-968.

14. White B, Willmott L, Trowse P, Parker M & Cartwright C. (2011). The legal role of medical professionals in decisions to withhold or withdraw life-sustaining treatment: Part 1 (New South Wales). *Journal of Law & Medicine, 18*(3): 498-522.

15. Willmott L, White B, Parker M & Cartwright C. (2011). The legal role of medical professionals in decisions to withhold or withdraw life-sustaining treatment: Part 2 (Queensland). *Journal of Law & Medicine*, 18(3): 523-544.

16. Willmott L, White B, Parker M & Cartwright C. (2011). The legal role of medical professionals in decisions to withhold or withdraw life-sustaining treatment: Part 3 (Victoria). J*ournal of Law & Medicine*, 18(4): 773-797.