NSW Medical Practitioners Knowledge of and Attitudes to Advance Care Planning

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LIST OF ACRONYMS

ACP – Advance Care Planning
AHCD – Advance Health Care Directive
AHS – Area Health Service
ASLaRC – Aged Services Learning and Research Centre
EG – Enduring Guardian
EPA – Enduring Power of Attorney
GP – General Practitioner
RACF – Residential Aged Care Facility
GLOSSARY OF TERMS

Advance Health Care Directive (AHCD) is a written document which allows a person to make their wishes for future health care known, in case the time should come when they do not have the capacity to do so. AHCDs may include specific instructions for treatment wanted or not wanted at such a time or may be a more general statement of values and wishes. They only become effective where the person has lost the capacity to make their own decisions.

Advance Care Planning (ACP) refers to the process of preparing for likely scenarios when decisional capacity is lost near the end of life and the care that the person would want at such a time. It usually includes assessment of and dialogue about a person’s understanding of their medical history and condition, values, preferences and personal and family resources. ACP may involve writing an AHCD and can also include appointing a proxy or substitute decision-maker (in NSW this is an Enduring Guardian) or identifying the appropriate Person Responsible, as specified in legislation (in NSW, the Guardianship Act 1987 [NSW]). Ideally ACP includes the person themselves, if they have capacity, plus their health-care providers and family or significant others.

Enduring Guardian: Under the Guardianship Act 1987 (NSW) an Enduring Guardian is someone appointed by the person themselves, who then has the authority to exercise all or some of the following functions; deciding the health care that the appointer is to receive, and giving consent to the carrying out of medical or dental treatment on the appointer. (Note: The Guardianship Tribunal may appoint a Guardian if deemed necessary; in such cases, where an Enduring Guardian exist, the Tribunal-appointed Guardian takes precedence over the Enduring Guardian).

Enduring Power of Attorney: Under the Powers of Attorney Act 2003 (NSW) a person can appoint an Enduring Power of Attorney to make financial or property decisions for them; the appointee can decide when the power is to commence (i.e. it may take effect while the person still has capacity) but the term “Enduring” means it continues if the appointee loses capacity. Under the Act, the Power of Attorney can be terminated or suspended by the Guardianship Tribunal if it considers that such action is in the best interests of the person who made the Enduring Power of Attorney.
EXECUTIVE SUMMARY

INTRODUCTION

In 2008, NSW Health appointed 8 project officers to promote Advance Care Planning (ACP) across the state. Researchers from the Aged Services Learning and Research Centre (ASLaRC) of Southern Cross University, NSW Department of Health and the School of Public Health and Community Medicine at the University of New South Wales collaborated to conduct a state-wide survey of medical practitioners’ knowledge of and attitudes to ACP. The study aimed to investigate the level of knowledge about, experience with and attitudes to ACP of NSW medical practitioners, in order to complement the work of the NSW Health ACP Project Officers.

BACKGROUND:

In the past few decades, an ageing population, increasing levels of dementia, rising health care costs and the shift to increased patient involvement in decisions about their care have focused attention on ACP, especially in relation to end-of-life decision-making, both in Australia and internationally.

ACP is a process which assists people with decision-making capacity, ideally in consultation with their health care providers, family members and other important people in their lives, to make decisions/choices about what medical treatments they would or would not want in the future based on their values, beliefs and goals in life. In NSW, the primary legislative options for ACP are: the appointment of a proxy or substitute decision-maker under Enduring Guardianship Legislation (Guardianship Act 1987 [NSW]) and the completion of a written document called an Advance Health Care Directive (AHCD). In NSW, AHCDs rely on common law provisions for their legal status.

In 2004, NSW Health produced a set of guidelines “Using Advance Care Directives (NSW)” aimed at encouraging health care providers to discuss with patients and families, planning medical care at the end of life and using an AHCD. However, there still appears to be poor understanding of ACP and the legal basis for substitute decision-making across the state. To address this issue, NSW Health funded 8 x 0.6 full time equivalent ACP Project Officer
positions (one in each Area Health Service) for the financial year 2008/09, to promote ACP in partnership with Residential Aged Care Facilities (RACFs) and primary health care providers such as GPs. To complement the work of the Project Officers, the authors conducted a survey of NSW medical practitioners to assess their levels of knowledge of and understanding about ACP and the legal requirements for promoting this with their patients, or responding to family members or others who claim to speak for patients who are deemed to have lost decision-making capacity.

**METHODOLOGY:**

Ethics Approval was provided by Southern Cross University Human Research Ethics Committee. A 5-page anonymous questionnaire which aimed to test participants’ knowledge of ACP legal mechanisms in NSW was mailed to 640 GPs and 339 medical specialists (N=979) across NSW, randomly sampled from a commercially available database.

**RESULTS**

The overall response rate was 27% (N = 260; GPs 24%, n = 150; and specialists 34%, n = 110). Prior to receiving the questionnaire a majority of respondents had heard of AHCDs, Enduring Power of Attorney, Enduring Guardian and Person Responsible and from 49-64% of respondents had had experience with at least one of these instruments.

Only 30% of the total cohort said that they had ever received educational material about AHCDs, with most of that material being provided through the Divisions of General Practice (25%), NSW Health (19%) and their workplace (8%) or combinations of the above (31%).

Although only 23% of respondents had been asked by a patient to assist in the writing of an AHCD, 77% said that they would be willing to do so if asked; 90% of respondents said that if a patient had made an AHCD, that would assist them in making health care-related decisions should the patient lose capacity, while 73% said that they supported the use of AHCDs. When asked if they had completed their own AHCD, only 7% of respondents said that they had, although 58% stated that they intend to do so in the future.
Respondents were next asked what they perceived might prevent their patients from making an AHCD; overall, 86% agreed or strongly agreed that patients have limited knowledge about AHCDs; 64% perceive that patients do not want to think about end-of-life issues; and 72% felt that patients would rather leave it until the situation where such a directive could become relevant arises. Respondents were equivocal when it came to whether patients would prefer to leave decision making to their doctors, with 38% strongly agreeing or agreeing that patients would prefer to do this, 27% disagreeing or strongly disagreeing and 35% neither agreeing nor disagreeing. There was also less consensus about whether or not patients would prefer to leave decision-making to their family, with 40% of respondents strongly agreeing or agreeing that patients would prefer to do so, 34% neither agreeing nor disagreeing, while 26% disagreed or strongly disagreed.

The following sections of the survey aimed to ascertain the level of knowledge and understanding of the medical practitioners regarding various legally-available instruments for substitute decision-making in NSW. In response to the question: “How often do you ask your patients whether they have given anyone Enduring Power of Attorney for Financial Matters?” 11% of respondents said that they always or usually ask this; 24% said that they sometimes ask but 65% said that they rarely or never do so.

The next question asked: “If one of your patients has given someone Enduring Power of Attorney, do you think that the person appointed has authority to make health care decisions?” 47% of respondents understood that an EPA appointment does not allow the appointee to make health care decisions but 30% were unsure and 23% incorrectly thought that it did.

A brief explanation of the role and functions of an Enduring Guardian (EG) was next provided, along with an outline of the hierarchy of “Person Responsible”, i.e. the person under the Guardianship Act 1987 (NSW) who has decision-making authority for someone who has lost the capacity to make their own health-care decisions. Respondents were asked whether any patient of theirs had told them that they had appointed an EG and/or whether they had recommended to any of their patients that they appoint an EG: 44% of respondents said that patients had told them that they had done so and 38% had recommended to patients that they do so. However, 94% agreed that it would be helpful to know who has legal authority to make such decisions.
Scenarios: In order to ground the theoretical questions, respondents were presented with 2 brief scenarios and asked a series of questions to assess their applied knowledge of AHCDs. In the first scenario they were asked what they would do if they were called to treat a frail, older, non-competent patient and did not agree with the patient’s wishes as expressed in an AHCD. Responses indicated that almost all participants would respect patient autonomy even if they did not agree with the patient’s previously-expressed decision (which also accords with the law in NSW).

The second scenario involved an 87 year-old non-competent woman in a residential aged care facility. She has two children, Theo, the eldest and a daughter, Maria, who has been caring for her at home and who holds Enduring Power of Attorney for her mother. The patient never completed an AHCD and her children disagree about her treatment. Respondents were told:

“Theo says that he should have the right to make decisions about what treatment Georgina does or does not receive because he is the eldest and therefore her next-of-kin. Maria says that she has been managing all her mother’s affairs, paying bills and doing her banking and that because her mother gave her Enduring Power of Attorney to do that, she should have the right to make the decisions.”

Respondents were then asked: “Who do you think has the legal right to make health care decisions for Georgina?” and “Why?”

While 54% of respondents correctly nominated Maria as the person with authority to make Georgina’s decisions, when asked why this was so, 65% of these respondents demonstrated that they were not familiar with the law; only 35% correctly recognised that Maria would be Person Responsible under the Guardianship Act 1987 (NSW), because she had been Georgina’s carer (and Georgina no longer had a spouse); 50% of those who nominated Maria said it was because she held Georgina’s Enduring Power of Attorney. Very few respondents (n=8) thought that Theo would have the authority (which legally he would not), and of those only four thought that this was because he was next-of-kin.
DISCUSSION
The results indicate that many medical practitioners in NSW support ACP and the use of AHCDs, and believe that ACP would greatly assist them in making treatment decisions for patients who lack capacity to consent to their own treatment. However, it is apparent that there is a significant gap in relation to medical practitioners’ understanding of the law.

As noted above, one of the major areas of misunderstanding or uncertainty is in relation to the powers conferred on someone by being appointed Enduring Power of Attorney (23% of respondents thought this gave the person authority to make health care decisions and another 30% were not sure whether it did or not). This confusion was also reflected in Scenario 2, where it was obvious that almost all respondents were ignorant of the requirements of Part 5 of the *Guardianship Act 1987* (NSW), which states that responsibility for determining correct Person Responsible lies with the treating medical practitioner. This is concerning as it places medical practitioners at legal risk if they allow someone who does not have authority to make decisions for a non-competent patient.

The confusion and uncertainty amongst medical practitioners regarding the law and ACP is further evidenced in responses to Scenario 1 which relates to the legal status of AHCDs. Only 76% of respondents said that they would follow the AHCD even if they did not agree with it. Legally, under the common law in NSW, medical practitioners are obliged to do so unless they believe that the document is unsound or uncertain, in which case they should seek a ruling from the court or the NSW Guardianship Tribunal.

It appears from this study that there is little impetus to date from patients to pursue the making of AHCDs with their medical practitioners, with only 23% of respondents indicating that a patient had ever requested their assistance in writing an AHCD. Previous studies found that many community members/patients did not know anything about ACP options and the impetus, therefore, needs to come from their healthcare providers (GPs, specialist and nurses). Although some people may find discussions of end-of-life issues, including ACP, distressing, the majority of people in the general community do not.

So why does this confusion exist? Is the law too complex? Is education and training not provided in a useful/accessible way? Perhaps there are other reasons. The *Guardianship Act 1987* (NSW) sets out quite clearly the order of authority for substitute decision-making for
patients who lack capacity (i.e. Person Responsible hierarchy) but this information does not appear to have been successfully conveyed to medical practitioners (or to have impacted to any great extent on hospital or RACF Admission processes). This clearly is an area for further research to determine the barriers in order to develop appropriate strategies to promote medical practitioners’ knowledge of the ACP process and community engagement in the process.

Recommendations
Based on the study results, the following recommendations are made:-

- Further education is required for medical practitioners regarding common law and ACP is indicated to protect them from legal risks and promote patient autonomy.
- Those charged with implementing ACP should consider a strategy to increase the empowerment of individuals through community education programs regarding the benefits of ACP and the role and function of substitute decision makers.

Study Limitations/Barriers
The limited resources available to undertake this study impacted on some areas of the study methodology, including the option of stratifying the sample by speciality or by Area Health Service and limited questionnaire follow-up. As a result, the random sample of specialists yielded a much higher number of anaesthetists than respondents from other specialties and the overall response rate was poor despite follow up (arguably the case with many medical practitioner surveys).

Due to the above issues it is not possible to confidently generalise the results to all medical practitioners in NSW. It could be expected that medical practitioners who had some interest in these topics would be more likely to respond than those who were not interested; it is therefore possible that the general population of medical practitioners in NSW would have even less understanding and knowledge of the law in NSW in relation to the issues covered (understanding that EPA does not give authority for health care decision-making; knowing who the correct Person Responsible is) than those who responded to this study.
CONCLUSIONS
The study was undertaken, in part, because of an increase in activity in NSW on ACP. This study measured the knowledge of medical practitioners about ACP and the legal requirements for promoting this with their patients.

Despite a high level of support for ACP and the use of AHCDs in NSW and some related educational activity, the study revealed confusion and a broad lack of understanding among medical practitioners of the function of the various substitute decision-making legal instruments in NSW. In particular, there was misunderstanding about the scope of EPAs and the legal status of AHCDs. Responses in the study reflect that some medical practitioners could be putting themselves at legal risk by not following an ACHD made when the patient still had decision-making capacity.

The results also support earlier studies reflecting patients’ and community members’ lack of knowledge in relation to ACP; very few medical practitioners indicated that patients instigated discussions with them on ACP.

More positively, what is changing are health professionals’ attitudes towards the barriers of ACP. Earlier studies found that practitioners believed that patients would prefer to wait until such situations arose and make decisions at that point or that they would prefer to leave such decisions to their doctor of family members (a view not shared by community members in the previous studies). The views of practitioners in this study align far more closely with the community views in those studies.

Extensive education on ACP and the law for medical practitioners is strongly recommended, to protect them from legal risk and to support patient choice, as well as community education and awareness-raising about ACP and AHCDs to ensure patient autonomy and choice.

Future research is required to understand the barriers to education of medical practitioners in relation to both the common law and statute law governing substitute decision-making in NSW.
SECTION ONE – INTRODUCTION

In 2008, NSW Health appointed 8 project officers to promote Advance Care Planning (ACP) across the state. Researchers from the Aged Services Learning and Research Centre (ASLaRC) of Southern Cross University, NSW Department of Health and the School of Public Health and Community Medicine at the University of New South Wales collaborated to conduct a state-wide survey of medical practitioners’ knowledge of and attitudes to ACP.

The Aged Services Learning and Research Centre (ASLaRC), Southern Cross University, undertakes scholarship, research, education and training to maximise the delivery of services to the expanding ageing population in the North Coast region of NSW.

The NSW Health Department is a complex and dynamic organisation that undertakes various core and support roles to set the directions for the NSW health system, ensure implementation of Government policy and support the Minister for Health.

The School of Public Health and Community Medicine at the Faculty of Medicine, University of New South Wales is committed to excellence in research, learning and teaching and action to enhance health and health services. Major research strengths within the School are infectious diseases, global health, health and human rights, primary health care and indigenous health.

STUDY AIM: The study aimed to investigate the level of knowledge about, experience with and attitudes to Advance Care Planning (ACP) of NSW medical practitioners, in order to complement the work of NSW Health ACP Project Officers.
SECTION TWO – BACKGROUND

In the past few decades, an ageing population, increasing levels of dementia, rising health care costs and the shift to increased patient involvement in decisions about their care have focussed attention on Advance Care Planning (ACP), especially in relation to end-of-life decision-making, both in Australia and internationally.

ACP is a process which assists people with decision-making capacity to make decisions/choices about future health care, ideally in consultation with their health care providers, family members and other important people in their lives. ACP involves conversations between the patient, their health care providers and, where appropriate, their family/loved ones about their values, beliefs and goals in life, and, in light of their current health status, what medical treatments they would or would not want in the future. ACP can be done by any adult at any time, but is particularly relevant to older people, people with late stage chronic disease or people likely to progress to a point in their disease where they are unable to communicate their wishes. Based on the ethical principle of patient autonomy and the legal doctrine of patient consent, ACP is designed to ensure that patient choice is respected if the patient becomes incapable of participating in treatment decisions.

In NSW, the primary legislative option for ACP is the appointment of a proxy or substitute decision-maker under Enduring Guardianship Legislation (Guardianship Act 1987 [NSW]). In addition, people may complete a written document called an Advance Health Care Directive (AHCD) or Advance Care Directive (ACD) (and previously sometimes called a Living Will) (hereafter AHCD, as this was the term used in the survey for this study). However, unlike other Australian jurisdictions, there is no specific legislation in NSW covering the AHCD, with the common law provisions being relied upon to protect patient autonomy and right to self-determination (see Addendum, p28). If a patient chooses not to complete these documents it is still possible to use ACP by recording their wishes, as expressed in discussions with their health care providers, in their medical records.

Australian data on ACP is limited (Parker, Stewart, Willmott & Cartwright, 2007; Cartwright, Williams, Parker & Steinberg, 2006; Cartwright & Parker, 2004; Taylor & Cameron, 2002; Nair et al, 2000; Taylor & Tan, 2000). However, studies in Queensland (Steinberg et al, 1996) and the Northern Territory (Cartwright et al, 1998) on awareness of, and attitudes to ACP demonstrated strong support from doctors, nurses and the general community for such actions.
Despite this wide-spread support, Taylor & Cameron observe that “ACP appears poorly developed in Australia” (2002:475) and suggest that many patients will not have their wishes for their end-of-life care understood and respected. Nair et al (2000) conducted a cross-sectional study of aged care facilities in the Hunter region of NSW, collecting data on 2,764 residents, which showed that only 0.2% had a written living will (AHCD) and 1.2% had a ‘do not resuscitate order’ in place; the study also found that where decisions needed to be made, they were usually done informally through staff consensus.

In addition, a number of studies indicate that there is a lack of understanding about, and use of, ACP in the Australian context, on the part of both health service providers and the wider community (Tan & Taylor, 2000; Stewart, 2005), nor is there good understanding of who has authority to give consent for medical treatment for a patient who lacks capacity (Clarnette, 2000; Parker et al, 2007). Studies in Queensland (Hawkins & Cartwright, 2000) and South Australia (Brown, 2002) also found very low levels of formal planning in GP surgeries. There has been some progress in implementing ACP in the residential and primary care setting via the Commonwealth’s Palliative Care in Residential Care program and the “Respecting Patient Choices Program”, a comprehensive, resource-intensive ACP program which began in 2002, based mainly in Victoria. There has also been work on implementing ACP in the Residential Aged Care setting in metropolitan NSW (Caplan et al, 2006). However, Bezzina (2009) and Shanley et al (2009) found that such implementation was not consistent, even in facilities in the same area, and depended on the particular inclination of staff members.

In 2004, NSW Health produced a set of guidelines “Using Advance Care Directives (NSW)” aimed at encouraging health care providers to discuss with patients and families, planning medical care at the end of life and using an AHCD. The Guardianship Act 1987 (NSW) was amended in 1994 to include the hierarchy of person responsible scheme and again in 1997 to allow the legal appointment of Enduring Guardians to provide for formal substitute health care decision making processes. Despite this, many hospitals and aged care facilities in NSW still have admission forms and policies that do not recognise the impact of the legislation (e.g. many admission forms still ask ‘Who is your next-of-kin?’ whereas ‘next-of-kin’ has no legal status in NSW in relation to substitute decision-making).

There is increasing impetus from a national perspective to improve the uptake of ACP. In 2007 the Australian Medical Association, Palliative Care Australia and The House of
Representatives Standing Committee on Legal and Constitutional Affairs, in the Older People and the Law report, recommended the development of nationally consistent legislation governing ACP/AHCDs in all Australian jurisdictions. Following these recommendations, in March 2008 the Australian Health Ministers’ Advisory Council (AHMAC) recommended the development of nationally consistent guidelines for ACP. To this end a national working party has been formed, with cross-jurisdictional representation, to progress this body of work. Lastly, the recently-released report of the National Health and Hospitals Reform Commission (2009) clearly advocates for increased education and training of staff and the community to facilitate greater uptake of ACP activity, to enable better congruence with patients’ expressed wishes for health care at end of life or loss of capacity.

In 2008, NSW Health funded 8 x 0.6 full time equivalent ACP Project Officer positions (one in each Area Health Service) for the financial year 2008/09, to promote ACP in partnership with Residential Aged Care Facilities (RACFs) and primary health care providers such as GPs. Concurrent ACP knowledge and awareness-raising activity at important interface points between primary and secondary health care settings such as Emergency Departments and other community outreach programs under AHS auspice (e.g. Hospital in the Nursing Home; and Hospital in the Home) will also be required to facilitate transfer and action of patient wishes expressed in advance through ACP activity. Some Commonwealth Department of Health and Ageing initiatives have provided resources to rural and remote networks of GPs to provide increased access to community-based palliative care through appointment of community-based palliative care Clinical Nurse Consultants. Education and training regarding ACP, AHCDs and related matters may form part of the remit of these positions. In addition, the Royal Australian College of General Practitioners and a number of Divisions of General Practice (now called GP Networks) have provided education and resources relating to ACP to general practitioners over a number of years.

Given the increased activity relating to ACP in NSW, it seemed appropriate to conduct a survey of medical practitioners in this state to assess their levels of knowledge of and understanding about ACP and the legal requirements for promoting this with their patients, or responding to family members or others who claim to speak for patients who are deemed to have lost decision-making capacity.
SECTION THREE - METHODOLOGY

Ethics Approval: Ethics Approval was provided by Southern Cross University Human Research Ethics Committee.

Questionnaire Development: The majority of the questions were taken from questionnaires used in well-reviewed studies with medical practitioners in Queensland (Steinberg et al, 1996; Cartwright et al 2002) and the Northern Territory (Cartwright et al, 1998), modified where necessary to reflect NSW legislative provisions and NSW Government policies. The survey included a case study designed to test participants’ awareness and level of applied knowledge of ACP and instruments for substitute decision-making in NSW.

Sample Selection: The study used a random sample of 1,000 medical practitioners in NSW, i.e. 650 general practitioners (GPs) and 350 medical specialists* from specialties most likely to be involved in ACP, taken from a commercially available data base of NSW medical practitioners. (*Note: The population sample of specialists [N=1,555] from which the random sample of 350 was drawn included a disproportionate number of anaesthetists [i.e. n = 845], which resulted in a predominance of anaesthetists in the final group of participants).

Survey: Participants completed a 5-page mailed questionnaire which aimed to test their applied knowledge of instruments for health care-related substitute decision-making (ACP) in NSW. The questionnaires had no identifying codes and were therefore completely anonymous. A Reply-Paid envelope was provided for return of the questionnaire and a Reply-Paid card was included for separate return to indicate completion of the questionnaire and request feedback from the study, if that was wanted. A follow-up reminder was sent three weeks after the original posting.

Data analysis: As questionnaires were returned they were coded and entered into an SPSS 17 database. Descriptive statistics were generated and chi-square analysis of relationships by: Area Health Service; main professional affiliation (GP or specialist); gender; age group; years as a medical practitioner; and religious affiliation was undertaken.
SECTION FOUR – RESULTS

RESPONSE RATES:
After removing duplications and a small number of non-NSW medical practitioners from the sample, questionnaires were sent to 640 general practitioners (GPs) and 339 medical specialists (N=979). Twenty-two questionnaires (11 in each cohort) were returned where the GP or specialist was deceased, retired or not in clinical practice, leaving a sample size of 957 (629 GPs and 328 specialists). The overall response rate was 27% (N = 260; GPs 24%, n = 150; and specialists 34%, n = 110).

Demographic Characteristics:

- **Gender**: Of the 254 respondents who answered the question, 37% (n=95) were female and 63% (n=159) were male. Among GPs the percentages were 48% female and 52% male, while among specialists there was a much higher percentage of males (78%) compared to females (22%).

- **Age**: Overall, 16% of respondents were aged less than 40; 32% were aged 40-49; 34% were 50-59 and 18% were aged 60 or over; age distribution was similar for both groups, with just a small difference in that only 16% of specialists were aged over 60.

- **Country of Birth**: Just over 70% of respondents were born in Australia or the UK, while 15% were born in Asia.

- **Religious Affiliation**: When asked for their religious affiliation (which has a demonstrated link to attitudes to end-of-life issues), 35% (n=88) of the 254 respondents who answered the question said that they had no religious affiliation; 50% (n=133) nominated Christian religions (23%: n=58 Catholic; 17%: n=43 Anglican; 9%: n=23 “other Christian”; and 4%: n=9 Uniting Church); 4% (n=10) were Hindu; 2% each (n = 6,6,and 5 respectively) were Jewish, Muslim and Buddhist, while the remaining respondents were Atheist (1%, n=3), Sikh (1%, n=2) and Zoroastrian (<1%, n=1).

- **Main Area of Practice**: as expected from the questionnaire distribution, the majority of respondents (56%, n=146) said that their main area of practice was general practice. (Although 150 participants responded from those identified in the original sample as GPs, four nominated a different area of practice, i.e. one each said Paediatrics, Psychotherapy, Rehabilitation and Medical Administration [Defence Force]). Among the 110 specialists who responded, 46% (n=51) were anaesthetists, 15% (n=16) were oncologists (radiation
and medical), 14% (n=15) worked in emergency medicine, 10% (n=11) were geriatricians, 9% (n=10) were palliative care specialists, 6% (n=6) were intensive care specialists and 1% (n=1) was a rehabilitation specialist.

- **Years as Medical Practitioner:** Overall 62% (n=160) of respondents (and 67%: n=74 of specialists) had more than 20 years experience as a medical practitioner; 25% (n=65) had between 11 and 20 years and the remaining 13% (n=33) had 10 years or less.

- **Respondents by Area Health Service:** Table 1 presents the number of GPs and specialists from each of the 8 Area Health Services who were randomly selected for the study and the number who actually responded to the survey.

### TABLE 1 – Number Sampled and Responded from each Area Health Service

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* Response rates by AHS for GPs ranged from 15-35%; for Specialists from 18-50%; and overall from 19-36%.

** The highest response rate for GPs was from North Coast; for Specialists and overall it was from North Sydney/ Central Coast.
Knowledge of and Experience with Advance Care Planning Options, by main professional affiliation (GP or Specialist): (see Tables 2 and 3)

Prior to receiving the questionnaire:

- 80% of respondents (79% of GPs and 81% of specialists) had heard of AHCDs and 50% (47% of GPs and 53% of specialists) had had experience with them;
- 93% of both groups had heard of Enduring Power of Attorney, with 60% of GPs and 64% of specialists saying that they had had experience with this instrument.
- 79% (82% of GPs and 75% of specialists) had heard of Enduring Guardian with 52% (51% of GPs and 53% of specialists) having had experience with this;
- 72% of respondents overall (68% of GPs and 77% of specialists) said that they had heard of Person Responsible* but only 49% (39% of GPs and 62% of specialists) said that they had had experience with Person Responsible.

There were no significant differences between GPs and specialists in relation to their knowledge of or experience with Advance Care Planning options, except for Experience with Person Responsible, where specialists were significantly more likely than GPs to say that they had had experience with this option. (*Note: It is unclear whether respondents understood the term Person Responsible in its legal sense or only in the general sense of someone with responsibility for the patient).

Table 2: Heard of ACP Options

<table>
<thead>
<tr>
<th>Main Area of Practice</th>
<th>AHCD</th>
<th>Enduring Power of Attorney</th>
<th>Enduring Guardian</th>
<th>Person Responsible</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Yes</td>
<td>No</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td></td>
<td>%</td>
<td>% (n)</td>
<td>% (n)</td>
<td>% (n)</td>
</tr>
<tr>
<td>GP</td>
<td>79 (116)</td>
<td>21 (31)</td>
<td>93 (138)</td>
<td>7 (10)</td>
</tr>
<tr>
<td>Specialist</td>
<td>81 (88)</td>
<td>19 (21)</td>
<td>93 (100)</td>
<td>7 (8)</td>
</tr>
<tr>
<td>TOTAL</td>
<td>80 (204)</td>
<td>20 (52)</td>
<td>93 (238)</td>
<td>7 (18)</td>
</tr>
</tbody>
</table>

χ²; p val

<table>
<thead>
<tr>
<th></th>
<th>n.s</th>
<th>n.s</th>
<th>n.s. but 2.217;0.092</th>
<th>n.s. but 2.494;0.075</th>
</tr>
</thead>
</table>

Maximum N for all options: GPs 148; Specialists 109; Total 256
Table 3: Had Experience with ACP Options

<table>
<thead>
<tr>
<th>Main Area of Practice</th>
<th>AHCD</th>
<th>Enduring Power of Attorney</th>
<th>Enduring Guardian</th>
<th>Person Responsible</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Yes</td>
<td>No</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>GP</td>
<td>47 (62)</td>
<td>53 (69)</td>
<td>60 (80)</td>
<td>40 (53)</td>
</tr>
<tr>
<td>Specialist</td>
<td>53 (55)</td>
<td>47 (48)</td>
<td>64 (66)</td>
<td>36 (38)</td>
</tr>
<tr>
<td>TOTAL</td>
<td>50 (117)</td>
<td>50 (117)</td>
<td>62 (146)</td>
<td>38 (91)</td>
</tr>
</tbody>
</table>

χ²; P val: n.s.  n.s.  n.s.  12.253; <0.001

Maximum N for all options: GPs 133; Specialists 104; Total 237

Advance Care Planning Options: Response Ranges and Relationships by Demographic Characteristics

Note 1: Unequal numbers in each AHS means that an AHS with very few participants can show the highest percentage of respondents with an affirmative answer.

Note 2: For the analysis below:

- age group categories <30 and 30-39 were collapsed to <40, because of small number <30;
- years as a medical practitioner was collapsed to 1-10; 11-20; >20;
- religion was collapsed into “All Christian”, “Other Religions” and “No affiliation”.

Heard of Advance Health Care Directives, by:

- **Area Health Service**: Range 95% AHS 3 (North Coast) to 64% AHS 8 (Greater Southern) (differences were non-significant);
- **Gender**: Females (87%) were significantly more likely than males (76%) to have heard of AHCDs (χ²<sub>1</sub>, 4.56; p=0.033)
- There were no significant differences by Age Group, Years as a medical practitioner or Religion.
Experience with Advance Health Care Directives, by:
- **Area Health Service**: Range 84% AHS 3 (North Coast) to 30% AHS 4 (Sydney West) ($\chi^2 = 17.028$; $P= 0.030$);
- There were no significant differences by Age group, Gender, Years as a medical practitioner or Religion.

Heard of Enduring Power of Attorney, by:
- **Area Health Service** – Range 100% AHS 3 (North Coast) to 80% AHS 1 (Greater Western) (non-significant);
- **Gender**: Females (99%) were significantly more likely than males (89%) to have heard of EPA ($\chi^2_{1}, 8.31; p=0.004$);
- There were no significant differences by Age Group, Years as a medical practitioner or Religion.

Experience with Enduring Power of Attorney, by:
- **Area Health Service** – Range 90% AHS 8 (Greater Southern) to 48% AHS 4 (Sydney West) (non-significant);
- **Age group** – Respondents aged 50-59 were most likely (71%) and those aged <40 were least likely (43%) to have experience with EPA ($\chi^2_{3}, 8.454; p=0.038$);
- **Years as a medical practitioner**: While differences reached significance, this was a not a linear relationship (i.e., >20 = 69%; 11-20 = 48%; 1-10 = 55%), ($\chi^2_{2}, 7.911; p=0.019$);
- There were no significant differences by Gender or Religion.

Heard of Enduring Guardian, by:
- **Area Health Service**: Range 96% AHS 2 (Hunter/New England) to 69% AHS 7 (South East/Illawarra) (non-significant);
- There were no significant differences by Age group, Gender, Years as a medical practitioner or Religion.
Experience with Enduring Guardian, by:

- **Area Health Service:** Range 80% AHS 8 (Greater Southern) to 33% AHS 4 (Sydney West) (non-significant);
- **Years as a medical practitioner:** While differences reached significance, again it was a not a linear relationship (i.e., >20 = 57%; 11-20 = 38%; 1-10 = 53%), ($\chi^2_{2}, 6.186$; $p=0.045$);
- There were no significant differences by Age group, Gender or Religion.

Heard of Person Responsible, by:

- **Area Health Service:** Range 85% AHS 4 (Sydney West) to 46% AHS 8 (Greater Southern) (non-significant but $\chi^2_{8} = 13.641$; $P=0.092$);
- There were no significant differences by Age group, Gender, Years as a medical practitioner or Religion.

Experience with Person Responsible, by:

- **Area Health Service:** Range 59% AHS 2 (Hunter/New England) to 36% AHS 8 (Greater Southern) (non-significant);
- **Gender:** Males (58%) were significantly more likely than females (36%) to say that they had experience with Person Responsible ($\chi^2_{1}, 10.19$; $p=0.0014$);
- **Years as a medical practitioner:** Once again, respondents with >20 years experiences were most likely to say that they had experience with Person Responsible (55%) and those with 11-20 years were least likely to do so (37%); (1-10 = 50%); the differences approached but did not reach significance ($\chi^2_{2}, 5.462$; $p=0.065$);
- There were no significant differences by Age group or Religion.
AHCD Education: Only 30% of the total cohort said that they had ever received educational material about AHCDs (32% GPs and 28% specialists; n.s.). Most material was provided through the Divisions of General Practice (25%), NSW Health (19%) and the workplace (8%) or combinations of the above (31%). A small number of respondents nominated other sources of education about ACP which included: the internet, a patient, a palliative care seminar or University study. Specialists particularly identified receiving information via NSW Health and/or their workplace (55%) whilst 40% of GPs received most of their information through their Division.

Assisting patients to complete AHCDS: Respondents were asked if they had ever been asked by a patient to assist in the writing of an AHCD and 77% reported that they had not; GPs (34%) were significantly more likely to have received this request than specialists (8%) ($\chi^2 = 24.120; p < .001$). There was no significant difference by age group, years as a medical practitioner or religion but differences by gender approached significance, with females (30%) being more likely than males (20%) to have been asked ($\chi^2 = 2.788; p = 0.095$).

Although only 23% of respondents had, to date, been asked by a patient to assist in the writing of an AHCD, 77% of respondents (89% GPs and 61% specialists) indicated they would be willing to do so if asked. The difference between the two groups was significant ($\chi^2 = 27.179; p < .001$). There was no significant difference by age group, years as a medical practitioner or religion but differences by gender approached significance, with females (83%) being more likely than males (74%) to be willing to assist ($\chi^2 = 2.764; p = 0.096$).

Would AHCDs assist medical practitioners with decision-making?: Respondents were asked to what extent they agreed that an AHCD would assist them in making health care-related decisions should their patient lose capacity (on a 5-point scale from *strongly agree* to *strongly disagree*); 90% of respondents (87% GPs and 93% specialists) agreed or strongly agreed that an AHCD would be helpful. When asked if they support the use of AHCDs, 73% (70% GPs and 76% specialists) said that they did. There was no significant difference by GP/Specialist, age group, gender, years as a medical practitioner or religion in relation to agreeing that AHCDs would be helpful. There was no significant difference by GP/specialist or gender in relation to support for use of AHCDs but there were significant differences by age group, with the two younger groups being significantly more likely than the oldest group to support the use of AHCDs (<40 = 76%; 40-59 = 77%; 60+ = 53%; $\chi^2 = 17.325; p = 0.002$).
Only 7% of respondents (5% GPs and 8% specialists) indicated that they had completed their own AHCD, although 58% (58% GPs and 57% specialists) stated that they intend to do so in the future. There was no significant difference by GP/specialist, age group, years as a medical practitioner or religion but females (68%) were significantly more likely than males (50%) to say that they intended to make their own AHCD ($\chi^2 = 8.50; p = 0.037$).

**Barriers to patients writing AHCDs:** Respondents were next asked what they perceived might prevent their patients from making an AHCD; a list of possible barriers was provided and respondents were asked the extent to which they agreed that each option might be such a barrier (*responses were on a 5-point scale, from 1 = Strongly Agree to 5 = Strongly Disagree*). Overall, 86% (88% GPs and 83% specialists) agreed or strongly agreed that patients have limited knowledge about AHCDs; 64% (62% GPs and 67% specialists) perceive that patients do not want to think about end-of-life issues; and 72% (68% GPs and 77% specialists) felt that patients would rather leave it until the situation where such a directive could become relevant arises. There were no significant differences between GPs and specialists in relation to these questions, nor by gender, years as a medical practitioner or religion. There was also no significant difference by age group, although differences approached significance in relation to patients preferring to leave the decision until the situation arises, with the youngest (<40 = 85%) and the oldest (60+ = 78%) groups more likely than those aged 40-59 (67%) to strongly agree or agree that this is what patients would prefer ($\chi^2 = 8.618; p =0.071$).

Respondents were equivocal when it came to whether patients would prefer to leave decision making to their doctors, with 38% overall strongly agreeing or agreeing (37% GPs and 41% specialists) that patients would prefer to do this, 27% (28% GPs and 25% specialists) disagreeing or strongly disagreeing and 35% (35% GPs and 34% specialists) neither agreeing nor disagreeing. There was also less consensus about whether or not the patient would prefer to leave decision-making to the family, with 40% overall strongly agreeing or agreeing that patients would prefer to do so, 34% neither agreeing nor disagreeing, while 26% disagreed or strongly disagreed. There were no significant differences between GPs and specialists in relation to these questions, nor by age group, gender, years as a medical practitioner or religion.
**Knowledge of legal instruments for substitute decision-making:** The following sections of the survey aimed to ascertain the level of knowledge and understanding of the medical practitioners regarding various legally-available instruments for substitute decision-making in NSW. First they were asked “How often do you ask your patients whether they have given anyone Enduring Power of Attorney for Financial Matters?” (*Responses were on a 5-point-scale, 1 = Always; 2 = Usually; 3 = Sometimes; 4 = Rarely; 5 = Never*): Only 11% of respondents (10% GPs and 12% Specialists) indicated that they always or usually ask patients whether they have given anyone EPA while 24% (39% GPs: 12% specialists) said that they sometimes ask and 65% (57% GPs: 76% specialists) said that they rarely or never do so. Differences between GPs and specialists were significant ($\chi^2 = 15.235; p <.0001$). There was no significant difference by age group, gender, years as a medical practitioner or religion.

The next question asked: “If one of your patients has given someone Enduring Power of Attorney, do you think that the person appointed has authority to make health care decisions?” 47% of respondents (45% GPs and 48% specialists) understood that an EPA appointment does not allow the appointee to make health care-related decisions but 30% (27% GPs and 34% specialists) were unsure and 23% incorrectly thought that it did. There was no significant difference between GPs and specialists in relation to this question, nor by age group, gender, years as a medical practitioner or religion.

A brief explanation of the role and functions of an Enduring Guardian (EG), as per the *Guardianship Act 1987* (NSW), was next provided, along with an outline of the hierarchy of “Person Responsible”, i.e. the person under the Act who has decision-making authority for someone who has lost the capacity to make their own health-care decisions. Respondents were asked whether any patient of theirs had told them that they had appointed an EG and/or whether they had recommended to any of their patients that they appoint an EG: 44% of respondents (49% GPs and 37% specialists; $\chi^2 = 3.866; p=0.049$) said that patients had told them that they had done so; 38% of respondents (50% GPs and 23% specialists; $\chi^2 = 19.018; p <.0001$) had recommended to patients that they do so. There was no significant difference by age group, gender, years as a medical practitioner or religion.
Finally in this section, respondents were asked: “How helpful do you think it would be for you to know who has legal authority to make health care decisions/give consent for treatment, if one of your patients loses decision-making capacity?” Again, responses were on a 5-point scale, this time from 1 = Very Helpful to 5 = Very Unhelpful. Almost all respondents (93% GPs and 96% specialists) agreed that it would be very or somewhat helpful to know who has legal authority to make such health care decisions, with 4% unsure and only 2% (n=6) saying that it would be unhelpful or very unhelpful. There were no significant differences between GPs and specialists, nor by gender, years as a medical practitioner or religion in relation to this question but differences did reach significance by age group; while a very large majority in each age group said that it would be very or somewhat helpful to know, those aged <40 and those 40-59 (95% and 96% respectively) were significantly more likely than respondents aged 60+ (87%) to say that it would be very or somewhat helpful to know who has such legal authority ($\chi^2 = 10.968; p = 0.027$).

**SCENARIOS:**

In order to ground the theoretical questions, respondents were presented with 2 brief scenarios and asked a series of questions to assess their applied knowledge of AHCDs.

**Scenario 1**

You are called to treat a frail, older, non-competent patient who has severe pneumonia. When the patient was competent, s/he made an Advance Health Care Directive, stating that, if the current situation should ever arise, s/he did not want life-sustaining treatment, including antibiotics. The Advance Health Care Directive has been correctly signed by a doctor and witnessed by an independent witness (solicitor).

Respondents were then asked: If you do not agree with the decision the patient made (i.e. to refuse life-sustaining treatment), to what extent do you agree that you would take the following actions: *(Response options were from 1 = Strongly Agree to 5 = Strongly Disagree)*

- Treat the patient as you think best, regardless of the Advance Health Care Directive?
- Ask the patient’s Person Responsible for consent to treat the patient as you think best?
- Ask the NSW Public Guardian for consent to treat the patient as you think best?
- Follow the Directive.
Table 4 presents the responses to each statement (collapsed to 1 = Strongly Agree/Agree; 2 = Neither Agree nor Disagree; 3 = Disagree/Strongly Disagree; a Mean of the 5 responses is also provided to allow comparison).

<table>
<thead>
<tr>
<th>Possible Options</th>
<th>Strongly Agree/Agree</th>
<th>Neither Agree nor Disagree</th>
<th>Disagree/Strongly Disagree</th>
<th>Mean/5:</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Total (% (n))</td>
<td>GP (% (n))</td>
<td>Spec (% (n))</td>
<td></td>
</tr>
<tr>
<td>Treat regardless of AHCD</td>
<td>13 (31)</td>
<td>16 (22)</td>
<td>9 (9)</td>
<td>8 (8)</td>
</tr>
<tr>
<td>Ask Person Responsible for Consent</td>
<td>38 (94)</td>
<td>47 (66)</td>
<td>27 (28)</td>
<td>14 (35)</td>
</tr>
<tr>
<td>Ask Public Guardian for Consent</td>
<td>17 (41)</td>
<td>21 (29)</td>
<td>12 (12)</td>
<td>20 (49)</td>
</tr>
<tr>
<td>Follow the Directive</td>
<td>76 (193)</td>
<td>76 (109)</td>
<td>77 (84)</td>
<td>18 (44)</td>
</tr>
</tbody>
</table>

Responses to this question indicated that the majority of respondents would follow the patient’s wishes, even if they did not agree with the decision the patient had made (which also accords with the law in NSW), with 75% of respondents (68% GPs and 84% specialists; $\chi^2 = 7.664$, $p=0.022$) disagreeing or strongly disagreeing that they would treat the patient as they thought best regardless of the AHCD and only 13% saying that they strongly agreed or agreed with taking this position. There was somewhat higher agreement (38% overall: 47% GPs: 27% specialists; $\chi^2 = 10.067$, $p=0.007$) that respondents would ask the patient’s Person Responsible for consent to treat the patient as they (the respondent) thought best, while only 17% (21% GPs: 12% specialists; $\chi^2 = 6.493$, $p=0.039$) said that they would seek substitute consent from the NSW Public Guardian to treat the patient as they (the respondent) thought best. The majority of respondents (76% GPs: 77% specialists) said that they would follow the Directive, even if they did not agree (no significant difference).
Differences by age group reached significance in relation to two of the four options: (1) the oldest group of medical practitioners was significantly more likely than the two younger groups to strongly agree or agree that they would treat the patient regardless of the AHCD (60+ = 28%; 40 – 59 = 9%; <40 = 10%) and significantly less likely to disagree or strongly disagree that they would do so (60+ = 57%; 40 – 59 = 79%; <40 = 80%) ($\chi^2_4 = 13.914; p =0.008$); (2) again, the oldest group of medical practitioners was significantly more likely than the two younger groups to strongly agree or agree that they would ask the patient’s Person Responsible for consent to treat the patient as they (the respondent) thought best (60+ = 57%; 40 – 59 = 37%; <40 = 22%) ($\chi^2_4 = 17.138; p =0.002$). However, the youngest group were more likely to be undecided about this (30% cf 12% for 40-59 and 9% for 60+) than to disagree or strongly disagree (48% cf 51% for 40-59 and 35% for 60+). There was no significant difference by gender in relation to any of the options, nor by years as a medical practitioner in relation to treating the patient regardless of the AHCD or following the Directive but differences by years as a medical practitioner reached significance in relation to asking the Person Responsible for consent, with those longest in practice most likely to strongly agree or agree that they would do so (>20 years 43%; 11-20 years 29%; 1-10 years 34%; $\chi^2_4 = 9.742; p=0.045$), and also for asking the Public Guardian for consent, but in this case the differences related to “neither agree nor disagree” (>20 years 21%; 11-20 years 10%; 1-10 years 38%) and to “disagree or strongly disagree” (>20 years 61%; 11-20 years 75%; 1-10 years 47%; $\chi^2_4 = 10.413; p =0.034$). There were no significant differences by religion in relation to treating the patient regardless of the AHCD but differences by religion reached or approached significance in relation to the other three options, as presented in Table 5.

Table 5: Disagree with AHCD, Differences by Religion, Options 2-4. (Percent)

<table>
<thead>
<tr>
<th>Religious Affiliation</th>
<th>Ask Person Responsible for Consent</th>
<th>Ask Public Guardian for consent</th>
<th>Follow the Directive</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>SA/A</td>
<td>N</td>
<td>D/SD</td>
</tr>
<tr>
<td>All Christian</td>
<td>37</td>
<td>12</td>
<td>51</td>
</tr>
<tr>
<td>Other Religions</td>
<td>52</td>
<td>26</td>
<td>22</td>
</tr>
<tr>
<td>No Affiliation</td>
<td>37</td>
<td>15</td>
<td>48</td>
</tr>
<tr>
<td>Total</td>
<td>39</td>
<td>15</td>
<td>47</td>
</tr>
</tbody>
</table>

$\chi^2_4$: p value 8.520; .074 8.585; .072 12.390; .015
Scenario 2: Respondents were presented with the following scenario, designed to test their understanding of the role of an appointed Enduring Power of Attorney and of the hierarchy of Person Responsible:

Georgina is an 87 year-old woman who has recently moved into a residential aged care facility (RACF). She has come to the facility from a rural town 30 kms away and does not have a local GP. A GP who regularly visits the facility, Dr Adams, has agreed to take over her care. The senior nurse has suggested to Dr Adams that they meet with Georgina and her family in order to develop an Advance Care Plan. Georgina has two children, Theo, the eldest and a daughter, Maria, who has been caring for Georgina at home.

On examination, Dr Adams realises that Georgina does not have capacity and that she has end stage COPD. He asks Theo and Maria if their mother had ever completed an Advance Health Care Directive or told them what treatment she would/ would not want if she were to become terminally ill. They say no and it is clear that there is some disagreement between them about how Georgina should be cared for.

Theo says that he should have the right to make decisions about what treatment Georgina does or does not receive because he is the eldest and therefore her next-of-kin. Maria says that she has been managing all her mother’s affairs, paying bills and doing her banking and that because her mother gave her Enduring Power of Attorney to do that, she should have the right to make the decisions.

Respondents were then asked: “Who do you think has the legal right to make health care decisions for Georgina?” and “Why?”

While 54% (n= 137) of respondents overall (GPs 51%, n=74: specialists 58%, n=64) correctly nominated Maria as the person with authority to make Georgina’s decisions, when asked why this was so, the majority (65%) of these respondents demonstrated that they were not familiar with the law; only 35% correctly recognised that Maria would be Person Responsible under the Guardianship Act 1987 (NSW) because she had been Georgina’s carer (and Georgina no longer had a spouse); 50% of those who nominated Maria said it was because she held Georgina’s Enduring Power of Attorney. Very few respondents (n=8) thought that Theo would have the authority (which legally he would not), and of those only four thought that this was because he was next-of-kin. (Note: Person Responsible hierarchy [i.e. EG; spouse; carer; close relative or friend], not next-of-kin, is the criterion for determining who has the legal authority for health care decision-making for someone who has lost capacity).
SECTION FIVE – SUMMARY

Discussion:

As noted above, there was a high level of support for Advance Care Planning and the use of AHCDs among responding medical practitioners in NSW, with many indicating that AHCDs would greatly assist them in making treatment decisions for patients who lack capacity to consent to their own treatment. However, it is apparent that there is a broad lack of understanding of the function of the various substitute decision-making legal instruments in NSW, such as Enduring Power of Attorney and Enduring Guardian, and that the hierarchy of “Person Responsible” as provisioned in the Guardianship Act 1987 (NSW) is a concept that is poorly understood. It is also apparent that educational material regarding AHCDs has not been well accessed by either GPs or medical specialists.

Responses to the question about what might prevent patients from making an AHCD were consistent with previously-reported viewpoints of medical practitioners in relation to patients not knowing enough about the process, patients not wanting to think about end-of-life issues and patients preferring to leave such matters until the situation arises (Steinberg et al, 1996; Cartwright et al, 1998). In those studies, the views of community members were very much more in favour of ACP than medical professionals thought they would be, with community members considering the barriers mentioned above to be much smaller obstacles than health professionals thought they would be. However, responses in this study in relation to patients preferring to leave the decision to their doctor or family (i.e. 38% and 40% respectively) were quite different to those by health professionals in the studies by Steinberg et al (1996) and Cartwright et al (1998) and were, in fact, much closer to the responses given in those studies by community members. It is possible that health professional education and experience in the last 10 years, as well as the greatly increased number of publications on ACP in the medical literature, has had a positive impact on both knowledge and attitudes of medical practitioners, bringing their views closer to those of the general community.

However, despite apparent improvement in knowledge and attitudes of some medical practitioners, this study indicates that significant gaps in relation to their understanding of the law still exist. As noted above, one of the major areas of misunderstanding or uncertainty is in relation to the powers conferred on someone by being appointed Enduring Power of Attorney (23% of respondents thought this gave the person authority to make health care decisions and another 30% were not sure whether it did or not). This confusion was also reflected in
Scenario 2, where it was obvious that almost all respondents were ignorant of the requirements of Part 5 of the *Guardianship Act 1987* (NSW), which states that responsibility for determining correct Person Responsible lies with the treating medical practitioner. This is concerning as it puts medical practitioners at legal risk if they allow someone who does not have authority to make decisions for their non-competent patient.

The other main area of apparent confusion relates to the legal status of AHCDs; responses to Scenario 1 indicated that medical practitioners in NSW could be putting themselves at legal risk; only 76% of respondents said that they would follow the AHCD even if they did not agree with it. Legally, under the common law, they are obliged to do so unless they can show that the document is unsound or uncertain - which does not just mean that the treating medical practitioner does not agree with the patient’s decision; it would require evidence that there is a problem with the document. However, even if such were the case, the next step according to the law is not for them to treat the patient as they think best (which 13% of respondents said they would do) but to seek a ruling from the court or the NSW Guardianship Tribunal.

So why does this confusion exist? Is the law too complex? Is education and training not provided in a useful/accessible way? The *Guardianship Act 1987* (NSW) sets out quite clearly the order of authority for substitute decision-making for patients who lack capacity (i.e. Person Responsible hierarchy) but this information does not appear to have been successfully conveyed to medical practitioners (or to have impacted to any great extent on hospital or RACF Admission processes).

The situation is made even more difficult in relation to the legally-binding status of AHCDs in NSW because, unlike most other Australian states/territories, their authority arises from the common law. The development of the law/knowledge of the law relating to patient care and consent has previously been progressed by legal cases and while, at the time the study was conducted, there had been no common law cases in Australia in relation to the binding nature of AHCDs, there were common law cases in the UK to provide a precedent and there has recently been a case in the NSW Supreme Court (*Hunter and New England Area Health Service v A* [2009] NSWSC 761) which has put the matter beyond doubt (see Addendum, p28).
It also appears from this study that there is little impetus to date from patients to pursue the making of AHCDs with their medical practitioners, with only 23% of respondents indicating that a patient had ever requested their assistance in the writing of an AHCD. Previous studies found that many community members/patients did not know anything about ACP options and the impetus, therefore, needs to come from their healthcare providers (GPs, specialist and nurses). The studies by Steinberg et al (1996) and Cartwright et al (1998) demonstrated that the majority of people in the general community do not find discussions of end-of-life issues, including ACP, distressing. These findings were supported by Kass et al., (2003; 12), who reported that, in particular studies, 33% of patients would participate in ACP if the physician initiated the discussion and only 5% indicated that they found these discussions too difficult.

More recently, Wright et al (2008) demonstrated the benefits to patients and their families of discussions relevant to ACP and end of life care. These researchers found that there was no evidence of increased psychological distress for patients through end-of-life/ ACP discussions; in fact, worse psychological outcomes were seen for patients who did not have the conversations. Subject to the limitations of the study, the researchers found that when end-of-life/ACP- related conversations were not conducted, patients were more likely to receive more aggressive medical treatment and less referrals to hospice care, there was an increased level of caregiver bereavement, as well as subsequent loss of quality of life. While it is still not clear whether ACP can always deliver its traditional benefits in terms of increasing patient’s autonomy, there is evidence that ACP can deliver other benefits such as improved trust and deeper relationships with family members, as well as helping prepare patients and their families for end-of-life situations (Kolarik et al., 2002; Seymour et al., 2004). These findings should reassure medical practitioners that patients and their carers do indeed benefit from such conversations and that better outcomes are clearly achievable as a result.

There is much more that needs to be done, underlining the need for community education as well as health professional education.
Recommendations

As ACP and AHCDs gain increasing prominence in Australia, it is important that genuine effort is made to enable medical practitioners to acquire the appropriate knowledge and skills to support patients in the articulation of their goals and aspirations and treatment choices. The role of Enduring Guardian and the hierarchy of “Person Responsible” go hand-in-hand with the process of enabling patients’ autonomy and self-determination in the face of loss of capacity to consent to medical treatment. It would appear that current mechanisms for dissemination of educational material and methods of increasing knowledge and awareness of ACP and AHCDs are not meeting the need.

While this study did not ask respondents what strategies they felt could assist them, we strongly recommend that further education be provided for medical practitioners regarding the common law and statute law provisions for ACP, both to protect them from legal risks and to promote patient autonomy. The findings confirm that greater effort in this area needs to be made, both in medical student training and for experienced clinicians.

It is also of importance to consider that informed consumers have the power to drive clinical practice change. Those charged with implementing ACP should consider a strategy to increase the empowerment of individuals through community education programs regarding the benefits of ACP and the role and function of substitute decision-makers.

Study Limitations/Barriers:

The very limited resources available to undertake this study precluded the option of stratifying the sample by speciality or by Area Health Service; had this been possible it would have greatly strengthened the study. While standard methodology was used in this study in relation to questionnaire distribution and follow-up, the response rate was disappointing. Initial mail out in October 2008 and a follow up mail out in November to those who had not responded in the first round yielded an overall response rate of 27%. Again, a higher level of resourcing for this study would have allowed for more intense follow-up of survey recipients by telephone and may have produced a greater response rate. However, it is not uncommon for surveys of medical practitioners (particularly GPs) to only achieve low response rates. While it is thus not possible to confidently generalise from this sample to all medical practitioners in NSW, it could be expected that medical practitioners who had some interest in these topics would be somewhat more likely to respond than those who were not interested. Therefore, it may be
arguable that the general population of medical practitioners in NSW would have even less understanding and knowledge of the law in NSW in relation to a number of issues (e.g., thinking that EPA gives authority for health care decision-making; knowing who the correct Person Responsible is).

In addition, the study used a random sample of medical practitioners in NSW most likely to be involved in ACP, rather than randomly sampling from all medical practitioners in NSW. While respondents appear to be reasonably representative of medical practitioners in NSW in relation to age, gender, country of birth, religion and years in practice, there were more GPs than specialists in the sample and more anaesthetists than other specialists in the specialist sample, as explained earlier. Therefore, in addition to the problem of a low response rate, it is not possible to generalise reliably based on demographic characteristics.

**Future research**

The study results indicate that medical practitioners need to be better informed in relation to their understanding of the common law and the function of the various substitute decision-making legal instruments in NSW. Future research that maps current educational strategies is required.

Other findings from the paper related to the limited number of patients approaching their medical practitioners regarding an ACHD. This is a recurrent theme in studies and would benefit further research to determine the underlying issues regarding awareness raising and public education in relation to ACP. Further research is also required to identify potential barriers to patients raising these issues with their health care providers or for health care providers raising the issue with their patients.

**CONCLUSIONS**

The study was undertaken, in part, because of an increase in educational activities about ACP by NSW Health which sought to promote ACP in Residential Aged Care Facilities and by primary health care providers e.g. GPs. This study measured the knowledge of medical practitioners’ knowledge about ACP and the legal requirements for promoting this with their patients.

Despite evidence of a high level of support among NSW medical practitioners for ACP, including the use of AHCDs, the study found a broad lack of understanding and confusion of
the function of the various substitute decision-making legal instruments in NSW. Whilst there are educational materials regarding ACP available, from the responses in the study it is apparent that they have not been well accessed by medical practitioners.

Major areas of misunderstanding or uncertainty related to the powers conferred on someone by being given Enduring Power of Attorney, which became evident in Scenario 2, and almost all respondents were ignorant of the requirements of Part 5 of the *Guardianship Act 1987* (NSW) relating to Person Responsible.

There was also poor understanding of the legal status of AHCDs; responses to Scenario 1 indicated that some medical practitioners in NSW could be putting themselves at legal risk by not following an ACHD made when the patient was cognitively stable. Questions need to be asked about why this is so when the educational materials are available; are the educational materials not made available in a readily accessible format? Is their importance not stressed sufficiently? Or is knowledge only changed when impacted on by events such as legal cases?

At the time this study was done there had been no common law cases in Australia in relation to the binding nature of AHCDs but a recent case in the NSW Supreme Court (*Hunter and New England Area Health Service v A* [2009] NSWSC 761) has clearly demonstrated that they are legally binding (see Addendum, p28).

The confusion and lack of awareness in relation to AHCDs also extends to patients and community members; very few medical practitioners had been asked by their patients to discuss ACP or AHCDs.

On a more positive note, the study found evidence that health professionals’ attitudes towards potential barriers to patients completing AHCDs have changed. In earlier studies (Steinberg et al, 1996; Cartwright et al, 1998) medical practitioners thought that the community members would not want to complete AHCDs but would prefer to wait until such situation arose or to leave such decisions to their treating medical practitioner or family. This did not correlate with the general community’s opinion at that time and the views of medical practitioners in this study were far more aligned with the views of the community expressed in the previous work.
Further education to promote patient self-determination through medical practitioners’ familiarity with the common and statute law relating to ACP will also ensure that medical practitioners are not placing themselves or other health professionals at legal risk.

It is also of importance to consider a strategy to increase the empowerment of individuals through community education programs regarding the benefits of ACP and the role and function of substitute decision makers.
REFERENCES


Cartwright CM, Williams GM, Steinberg MA, Najman JM. *Community and Health/Allied Health Professionals’ Attitudes to Euthanasia: What are the Driving Forces?* Report to the National Health and Medical Research Council, August 2002.


ADDENDUM


In simple terms, Mr A was a patient in a hospital within the Hunter and New England Area Health Service. He had been admitted to the emergency department of the hospital suffering from septic shock and respiratory failure and showing a decreased level of consciousness. He was transferred to the Intensive Care Unit the following day. Although all appropriate treatment had been given to Mr A, his condition deteriorated and he developed renal failure and subsequently was being kept alive by mechanical ventilation and dialysis.

The Service became aware of a document, apparently prepared by Mr A a year earlier, which indicated that he would refuse dialysis. The Service then sought a declaration from the NSW Supreme Court to the effect that the document was a valid “Advance Care Directive” given by Mr A, and that it would be justified in complying with his wishes as expressed in that directive.

The presiding judge gave the declaration and the medical treatment was to be withdrawn. In his reasons the judge concluded that:

On the basis of the medical evidence, I accept that the result of withdrawal of dialysis will be to hasten Mr A’s death. That is a consequence of the decision that he made (in an Advance Directive). What my orders did was recognise his right to make that decision.

This is a significant event in Australian common law and reinforces the legally binding nature of AHCDs for all health professionals. As stated in the paper, cases at law do change practice and additional research into medical practitioner’s knowledge following the case would be appropriate to explore if this is the case.
[date]

Dr

Dear Dr

Recently NSW Health provided funding for the appointment of a Project Officer to promote Advance Care Planning (ACP) in each Area Health Service. This is partly a response to the fact that, with an ageing population, it is likely that there will be increasing use of ACP mechanisms e.g. Advance Health Care Directives and substitute decision-makers. There are significant legal implications relating to ACP (e.g. who has the legal authority to consent to treatment for patients who lack capacity) and it is important that medical practitioners understand these, not only for their own protection but also so that they are better able to inform their patients and families.

The AMA has acknowledged the likely benefits of ACP. In addition to providing more certainty for patients and reducing their fears about future incapacity, ACP can also assist medical practitioners to understand what treatment their patients would want or not want at such a time. This may also have the effect of reducing family discord in times of stress and trauma.

We would like to invite you to participate in a research project about ACP which is being conducted by ASLaRC, Southern Cross University, in collaboration with the School of Public Health and Community Medicine, UNSW and NSW Health. This research aims to investigate what medical practitioners already know about ACP, in order to assist the Project Officers to target their education initiatives to provide better support to you and, in turn, make your practicing life easier. A random sample of NSW medical practitioners has been drawn from the Medical Directory of Australian doctors (a database published by AMPCo Direct, a subsidiary of the Australian Medical Association).

Your role in the study will involve completing the attached brief questionnaire, which should take you approximately 15 minutes. On completion, please return the questionnaire using the Reply-Paid envelope supplied. As the questionnaire is totally anonymous and has no code number or other identifying information on it, you have also been sent a Reply-Paid card with your name and address on it, by which you can (a) indicate that you have completed and returned the questionnaire and (b) request feedback on the results of the research. If you choose to participate, you may elect not to answer any question asked.

The results of this research may be submitted to a peer-reviewed journal for publication at a later date and may be presented at conferences, but only group data will be reported.

ASLaRC Southern Cross University
Hogbin Drive
Coffs Harbour NSW 2450
Email: aslarc@scu.edu.au
Website: http://aslarc.scu.edu.au
Should you wish to discuss further any of the issues raised by the study please do not hesitate to contact any of the researchers: contact details are listed below.

This research has been approved by the Southern Cross University Human Research Ethics Committee. The approval number is EeN-08-116. If you have any concerns about the conduct of the research, please contact:

Ethics Complaints Officer HREC Southern Cross University PO Box 157 Lismore NSW 2480
 Tel: (02) 6626 9139 Email: sue.kelly@scu.edu.au

All information is confidential and will be handled as soon as possible

Yours sincerely

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Advance Care Directives
Principal Project Officer
NSW Health
Ph: 02 9391 9908
Email: jmont@doh.health.nsw.gov.au
NSW Medical Practitioners
Knowledge of and Attitudes to
Advance Care Planning

Questionnaire
NSW Medical Practitioners Knowledge of and Attitudes to Advance Care Planning

Section 1: Advance Care Planning

Because of an accident or an illness a patient may lose capacity and not be able to tell the doctor what medical treatment s/he wants or does not want. Some people choose to appoint a substitute decision maker and/or to write down their wishes beforehand. In NSW this written document is called an *Advance Health Care Directive* or an *Advanced Care Directive*. *(Note: in some places they are called Living Wills.)* Advance Health Care Directives are legally binding on health care practitioners, (whilst most Australian States/ Territories have specific legislation on Advance Directives, in NSW this is covered by the common law). They come into effect only when the patient is no longer competent to make her/his own decisions. That is, the patient can change her/his mind, provided s/he is competent to do so.

**Competence**

*Competence* to make health care decisions means that the person understands the *nature* and the *effect* of the decisions they are making and can communicate that in some way.

Please work through each section of the questionnaire before moving on to the next one.

Q1. Before completing this questionnaire have you heard of, or had any experience with, the following terms? *(Please circle all that apply)*

<table>
<thead>
<tr>
<th></th>
<th>Heard of</th>
<th>Had experience with</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Advance Directive</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Enduring Power of attorney</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Enduring Guardian</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Person Responsible</td>
<td>1</td>
<td>2</td>
</tr>
</tbody>
</table>

Q2. Have you received any education material about Advance Health Care Directives?

Yes  1

No  2  →  go to question 4

Q3. Where did you receive the material from? *(Please circle all that apply)*

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>i)</td>
<td>NSW Health</td>
</tr>
<tr>
<td>ii)</td>
<td>Division of GPs</td>
</tr>
<tr>
<td>iii)</td>
<td>Workplace presentations</td>
</tr>
<tr>
<td>v)</td>
<td>Other <em>(please specify)</em></td>
</tr>
<tr>
<td></td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>4</td>
</tr>
</tbody>
</table>
Q4. Have you ever been asked by a patient to assist her/him to write an Advance Health Care Directive?

<table>
<thead>
<tr>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>2</td>
</tr>
</tbody>
</table>

Q5. If asked by a patient, would you be willing to assist her/him to make an Advance Health Care Directive?

<table>
<thead>
<tr>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>2</td>
</tr>
</tbody>
</table>

Q6. To what extent do you agree that if a patient has written an Advance Health Care Directive, this would assist you to make decisions about the patient's medical care if s/he loses competence? *(Please circle one number only)*

<table>
<thead>
<tr>
<th>Strongly Agree</th>
<th>Agree</th>
<th>Neither Agree Nor Disagree</th>
<th>Disagree</th>
<th>Strongly Disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>

Q7 Have you completed your own Advance Health Care Directive? *(Please circle one number only)*

<table>
<thead>
<tr>
<th>Yes</th>
<th>No, but I intend to</th>
<th>No, and I don't want to</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
</tbody>
</table>

Q8 To what extent do you support the use of Advance Health Care Directives? *(Please circle one number only)*

<table>
<thead>
<tr>
<th>Strongly Support</th>
<th>Don't Support</th>
<th>Not Sure</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
</tbody>
</table>

Q9. To what extent do you agree that the following would prevent your patients from making an Advance Health Care Directive?

*Please circle one number for each statement: SA = strongly agree; A = agree; N = neither agree nor disagree; D = disagree; SD = strongly disagree*

<table>
<thead>
<tr>
<th></th>
<th>SA</th>
<th>A</th>
<th>N</th>
<th>D</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>a) They have limited knowledge about Advance Health Care Directives</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>b) They would prefer not to think about end-of-life issues</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>c) They would prefer to leave it until the situation arises</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>d) They would prefer to leave the decision to the doctor</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>d) They would prefer to leave the decision to the family</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>d) Other (please specify)</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>
Section 2: Enduring Power of Attorney

Q10. How often do you ask your patients whether they have given anyone Enduring Power of Attorney for Financial Matters?

<table>
<thead>
<tr>
<th>Always</th>
<th>Usually</th>
<th>Sometimes</th>
<th>Rarely</th>
<th>Never</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>

Q11. If one of your patients has given someone Enduring Power of Attorney, do you think that the person appointed has authority to make health care decisions?

<table>
<thead>
<tr>
<th>Yes</th>
<th>No</th>
<th>Not sure</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
</tbody>
</table>

Section 3: Enduring Guardian/Person Responsible

Under the NSW Guardianship Act (1987) a competent adult 18 years or over may appoint an Enduring Guardian to make personal and/or health care decisions for them in case they lose the capacity to make such decisions for themselves. In most cases this would be a close relative or friend. Under the legislation, an Enduring Guardian is the first in a “Person Responsible” hierarchy.

If there is no “Enduring Guardian”, authority for decision making moves to “spouse” (if any); then to “non–professional carer”; if there is no carer, authority moves to “close relative or friend”.

Q12. Has any patient of yours ever told you that s/he has appointed an Enduring Guardian?

<table>
<thead>
<tr>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>2</td>
</tr>
</tbody>
</table>

Q13. Have you ever recommended to a patient that s/he should appoint an Enduring Guardian?

<table>
<thead>
<tr>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>2</td>
</tr>
</tbody>
</table>

Q14. How helpful do you think it would be for you to know who has legal authority to make health care decisions/give consent for treatment, if one of your patient’s loses decision-making capacity? (Please circle one number only)

<table>
<thead>
<tr>
<th>Very Helpful</th>
<th>Somewhat Helpful</th>
<th>Neither Helpful or Unhelpful</th>
<th>Unhelpful</th>
<th>Very Unhelpful</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>
Section 4: Scenarios

Please consider the following scenarios

Q15. You are called to treat a frail, older, non-competent patient who has severe pneumonia. When the patient was competent, s/he made an Advance Health Care Directive, stating that, if the current situation should ever arise, s/he did not want life-sustaining treatment, including antibiotics. The Advance Health Care Directive has been correctly signed by a doctor and witnessed by an independent witness (Solicitor).

If you do not agree with the decision the patient made (i.e., to refuse life-sustaining treatment), to what extent do you agree that you would take the following actions?

*Please circle one number for each statement: SA = strongly agree; A = agree; N = neither agree nor disagree; D = disagree; SD = strongly disagree*

<table>
<thead>
<tr>
<th></th>
<th>SA</th>
<th>A</th>
<th>N</th>
<th>D</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>a) Treat the patient as you think best, regardless of the Advance Health Care Directive</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>b) Ask the patient's Person Responsible for consent to treat the patient as you think best</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>c) Ask the NSW Public Guardian for consent to treat the patient as you think best</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>d) Follow the Directive</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>

Q.16 Georgina is an 87 year old woman who has recently moved into a residential aged care facility (RACF). She has come to the facility from a rural town 30 kms away and does not have a local GP. A GP who regularly visits the facility, Dr Adams, has agreed to take over her care. The senior nurse has suggested to Dr Adams that they meet with Georgina and her family in order to develop an Advance Care Plan. Georgina has two children, Theo, the eldest and a daughter, Maria, who has been caring for Georgina at home.

On examination, Dr Adams realises that Georgina does not have capacity and that she has end stage COPD. He asks Theo and Maria if their mother had ever completed an Advance Health Care Directive or told them what treatment she would/ would not if she were to become terminally ill. They say no and it is clear that there is some disagreement between them about how Georgina should be cared for.

Theo says that he should have the right to make decisions about what treatment Georgina does or does not receive because he is the eldest and therefore her next-of-kin. Maria says that she has been managing all her mother’s affairs, paying bills and doing her banking and that her mother gave her Enduring Power of Attorney to do that so she should have the right to make the decisions.

(a) Who do you think has the legal right to make health care decisions for Georgina?

(b) Why?
# Section 5: About You

Now we would like to ask a few questions about you to help us understand the ideas and opinions of specific groups of medical practitioners.

For all the questions in this section, please circle one number only.

<table>
<thead>
<tr>
<th>a) What is your age group?</th>
<th>b) Are you female or male?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Less than 30</td>
<td>Female</td>
</tr>
<tr>
<td>30 – 39</td>
<td>Male</td>
</tr>
<tr>
<td>40 – 49</td>
<td></td>
</tr>
<tr>
<td>50 – 59</td>
<td></td>
</tr>
<tr>
<td>60 or over</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>c) What is your main area of practice?</th>
<th>d) How many years have you worked as a medical practitioner?</th>
</tr>
</thead>
<tbody>
<tr>
<td>General Practice</td>
<td>Less than 6</td>
</tr>
<tr>
<td>Geriatrics</td>
<td>6 to 10</td>
</tr>
<tr>
<td>Palliative Care</td>
<td>11 – 15</td>
</tr>
<tr>
<td>Oncology (medical or Radiation)</td>
<td>16 – 20</td>
</tr>
<tr>
<td>Intensive Care</td>
<td>More than 20</td>
</tr>
<tr>
<td>Emergency Medicine</td>
<td></td>
</tr>
<tr>
<td>Anaesthesia</td>
<td></td>
</tr>
<tr>
<td>Other <em>(please specify)</em></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>e) What is the postcode of your main practice location?</th>
<th>g) What religious affiliation do you have, if any?</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Anglican</td>
</tr>
<tr>
<td></td>
<td>Buddhist</td>
</tr>
<tr>
<td></td>
<td>Catholic</td>
</tr>
<tr>
<td></td>
<td>Jewish</td>
</tr>
<tr>
<td></td>
<td>Muslim</td>
</tr>
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<td></td>
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| f) What is your country of birth (or culture with which you identify)? | |
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