

ADVANCE HEALTH DIRECTIVES: COMPETING PERCEPTIONS, INTENTIONS AND USE BY PATIENTS AND DOCTORS IN QUEENSLAND

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This paper reports on mixed method empirical research undertaken with individuals who have completed advance health directives ('principals') and doctors who have either attested to the principal's capacity when the document was completed or been called upon to use these documents in clinical settings. Principals and doctors appear to have different understandings of the purpose of these documents and their role in decision-making about medical treatment. We recommend changes to the advance health directive form in Queensland to promote informed decision-making which will help to better align perceptions of principals and doctors about the role of these documents.

I INTRODUCTION

In recent years there has been renewed interest from Australia's Commonwealth, State and Territory governments and policy makers in advance care planning, advance directives and palliative care. This shifting policy focus has been driven by a combination of factors including Australia's rapidly ageing population, medical and technological advances which prolong life, increased emphasis on patient-centred, consumer-driven health care and patient demand for quality care at the end of life. The importance of advance care planning, advance directives and palliative care has been recognised through the Australian Government's 2010 *National Palliative Care Strategy* and the Australian Health Ministers' Advisory Council's 2011 *A National Framework for Advance Care Directives*.¹

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¹ The Clinical, Technical and Ethical Principal Committee of the Australian Health Ministers' Advisory Council, *A National Framework for Advance Care Directives* (September 2011) 1

The Australian Government's 2012 *Living Longer, Living Better* aged care reforms also provide for advance care planning through the establishment of palliative care advisory services to provide access to specialist palliative care and advance care planning expertise in the aged care setting.² And at the legislative level, most Australian states and territories have enacted statutes that enable individuals to complete advance directives.³ Yet despite these legislative and policy developments, serious concerns have been raised about the uptake, understanding and appropriate use of advance directives by legal and health professionals and service providers.

A multidisciplinary team with expertise in both law and social work was formed to undertake empirical research to explore one aspect of those concerns: the impact of the advance health directive form on the use and uptake of this document by the public.⁴ The primary goal of the research was to gather data on the content and useability of the advance directive form, particularly from the perspective of individuals who are being encouraged to record their wishes about treatment to guide decision-making at a later time. This knowledge is necessary to improve the useability and accessibility of the form and thus increase the likelihood of uptake. In addition, and as a secondary goal, the researchers were interested to explore the perspectives of health professionals who rely on this document when making treatment decisions. It was hoped that a better understanding of both perspectives would improve the value of the document in the clinical context.

In the course of the research, some broader issues were identified which have an impact on the effectiveness of the advance directive in achieving its goal of allowing a person to make decisions about health care in advance of losing capacity. It became apparent that individuals who complete advance directives may have different perceptions about the role of the document than the doctors who use it. Given the potentially adverse impact these different perceptions may have on their relevance in the clinical context, they are worthy of closer examination. To this end, we commence with a brief consideration of the context in which advance directives operate: some of the perceived concerns expressed about advance directives; and the relatively recent reviews of relevant legislation

http://www.ahmac.gov.au/cms_documents/AdvanceCareDirectives2011.pdf;

Commonwealth of Australia, *National Palliative Care Strategy - Supporting Australians to live well at the end of life* (2010) 1-2

<http://www.health.gov.au/internet/main/publishing.nsf/Content/palliativecare-strategy.htm>.

² Commonwealth of Australia, *Living Longer, Living Better* (April 2012) 19
[http://www.health.gov.au/internet/publications/publishing.nsf/Content/CA2578620005D57ACA2579E2007B9DFC/\\$File/D0769%20Living%20Longer%20Living%20Better%20SCREEN%20070512.pdf](http://www.health.gov.au/internet/publications/publishing.nsf/Content/CA2578620005D57ACA2579E2007B9DFC/$File/D0769%20Living%20Longer%20Living%20Better%20SCREEN%20070512.pdf).

³ Lindy Willmott, Ben White, Shih-Ning Then, 'Adults who lack capacity: Substitute Decision-Making' in Ben White, Fiona McDonald and Lindy Willmott (eds), *Health Law in Australia* (Thomson, 2010) [6.210]-[6.240].

⁴ The research project, entitled 'Enduring Documents: Improving the forms, improving the outcomes' was broader in its scope in that it reviewed both the 'enduring power of attorney' and 'advance health directive' forms. This article focuses only on the research that was undertaken into the latter form. This research project was funded by the Legal Practitioners Interest on Trust Account Fund (Queensland). For the full report, see: Cheryl Tilse, Jill Wilson, Anne-Louise McCawley, Lindy Willmott and Ben White, *Enduring Documents Improving the forms, improving the outcomes* (2011) <http://eprints.qut.edu.au/46893/>.

that have occurred in Australia. We then outline the research design adopted by the researchers before describing what the data reveals about the different perceptions of those completing and those relying on (and trying to interpret) these documents, and the implications of this for clinical practice. We then report on the analysis of this data, and conclude by making some recommendations for reform which we hope will address some of the tensions identified by the research.

Finally, a note on scope and terminology. This article does not consider the wider process of advance care planning. Its focus is on ‘advance directives’ (usually written documents) that are commonly used as part of this process. An advance directive has been defined as ‘a means by which a competent adult can determine the medical treatment that he or she wants to accept or refuse in the future if decision-making competence is lost’.⁵ This terminology will be used when referring to advance directives generally. However, in Queensland, this document is called an ‘advance health directive’ (AHD) and its form and scope of operation is governed by both the *Powers of Attorney Act 1998* (Qld) and *Guardianship and Administration Act 2000* (Qld). The *Powers of Attorney Act 1998* (Qld) also refers to an individual who completes an AHD as a ‘principal’. The term is also adopted in this article but, depending on the context, this person is also referred to as the ‘patient’.

II ADVANCE HEALTH DIRECTIVES: A CONTEXTUAL OVERVIEW

For many years individuals have been encouraged to turn their minds to their future health care and how they would like it to be managed if they are no longer able to make decisions for themselves. Yet, as a planning tool, AHDs have not proven popular.⁶ It has been suggested that these documents are ‘under-rated by health professionals’⁷ and ‘undersold by legal practitioners’.⁸ There is ongoing debate about the appropriateness, utility and uptake of advance directives. Concerns have been expressed that the person making the AHD lacks the

⁵ Lindy Willmott, Ben White, Ben Mathews, ‘Law, autonomy and advance directives’ (2010) 18 *Journal of Law and Medicine* 366, 366.

⁶ The empirical research into the uptake of advance directives by principals is limited, but the research that exists indicates that uptake is low: D M Taylor et al, ‘Advance directives and emergency department patients: ownership rates and perceptions of use’ (2003) 33(12) *Internal Medicine Journal* 586; Colleen Cartwright et al, *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) as cited in Alzheimer’s Australia, Submission to the House of Representatives Legal and Constitutional Affairs Committee Inquiry into Older People and the Law (30 November 2006) 10 <http://www.aph.gov.au/parliamentary_business/committees/house_of_representatives_committees?url=laca/olderpeople/subs.htm>; Julie Mador, ‘Advance care planning: Should we be discussing it with our patients?’ (2001) 20(2) *Australasian Journal on Ageing* 89; B Nair et al, ‘Advance care planning in residential care’ (2000) 30(3) *Australian and New Zealand Journal of Medicine*.

⁷ The New South Wales Department of Health acknowledges that medical professionals may not appreciate the legal effect of advance directives: New South Wales Department of Health, *Using Advance Care Directives* (2004) 4 <http://www0.health.nsw.gov.au/policies/gl/2005/GL2005_056.html>.

⁸ Brian Herd, ‘The Advance Health Directive – Is It Worth It?’ (Paper presented at the *Queensland Law Society Elder Law Conference*, Brisbane, 14 June 2007) 14.

information required to make an informed choice.⁹ This is particularly so where the AHD is made prior to the onset of the condition or illness for which a treatment decision must be made.¹⁰ The fact that an individual's treatment preferences can change over time is another factor which causes concern that an AHD made at a particular point in time may not accurately reflect the person's wishes later on. A person's view about treatment may evolve through personal experience and maturity, proximity to death,¹¹ changes in physical or psychological condition,¹² and the setting in which treatment is received.¹³ Others have expressed the view that an AHD may not be a true reflection of a person's wishes as the way in which they are recorded can be influenced by the way questions are posed to the person.¹⁴ Also, a person may wish family and friends to retain discretion despite their wishes being clearly recorded.¹⁵ The person's true wishes may also be unable to be ascertained where inconsistent statements are recorded.¹⁶ Other potential problems relate to the drafting of the document. It may be of little use where the wishes of patients are not recorded with sufficient clarity so as to assist doctors in a meaningful way.¹⁷ This is particularly so where forms are too general and superficial or too narrow.¹⁸ Finally, AHDs do not take into account changes in circumstances. AHDs are based on medical practice and outcomes as they stand when the directive is made and fail to take into account advances in medicine,¹⁹ or changes in personal circumstances.

As part of the research project, the significant body of literature on AHDs was considered, including recent government reviews. In September 2011, the Clinical, Technical and Ethical Principal Committee of the Australian Health Ministers' Advisory Council²⁰ recommended a national approach to AHDs.²¹ To

⁹ Christopher James Ryan, 'Betting your life: an argument against certain advance directives' (1996) 22 *Journal of Medical Ethics* 95; Rebecca Dresser, 'Precommitment: a misguided strategy for securing death with dignity' (2003) 81(7) *Texas Law Review* 1823.

¹⁰ Willmott, White and Mathews, above n 5, 385.

¹¹ Ryan, above n 9; Rebecca Dresser, 'Dworkin on Dementia: Elegant Theory, Questionable Policy' (1995) 25(6) *Hastings Center Report* 32; Dresser, above n 9.

¹² TR Fried et al, 'Prospective Study of Health Status Preferences and Changes in Preferences Over Time in Older Adults' (2006) 166(8) *Archives of Internal Medicine* 890.

¹³ Peter H Ditto et al, 'Context Changes Choices: a Prospective Study of the Effects of Hospitalization on Life-Sustaining Treatment Preferences' (2006) 166 *Archives of Internal Medicine* 890; Marion Danis et al, 'Stability of Choices about Life-Sustaining Treatments' (1994) 120 *Annals of Internal Medicine* 567.

¹⁴ A Fagerlin and CE Schneider, 'Enough: The Failure of the Living Will' (2004) 34(2) *The Hastings Center Report* 30.

¹⁵ Dresser, above n 9.

¹⁶ Dresser, above n 11.

¹⁷ Susan E Hickman, Bernard J Hammes, Alvin H Moss and Susan W Tolle 'Hope for the future: achieving the original intent of advance directives' (2005) 11 *The Hastings Center Report* S26; Andrew W Holt and Alnis E Vedig, 'Do advance care directives improve acute care services for older people?' (2006) 185(7) *Medical Journal of Australia* 406.

¹⁸ Dresser, above n 11; Dresser, above n 9.

¹⁹ Marion Danis et al, 'A prospective study of advance care directives for life sustaining care' (1991) 324 *New England Journal of Medicine* 882; Stephen Bonner, Michael Tremlett and Dominic Bell, 'Are advance directives legally binding or simply the starting point for discussion on patients' best interests?' (2009) 339 *British Medical Journal* 1230.

²⁰ The Australian Health Ministers' Advisory Council advises Australian Health Ministers Conference.

this end, the Council released a document entitled ‘*A National Framework for Advance Care Directives*’ (‘the framework’).²² In this document, the importance of individuals being able to plan for their future through completing AHDs was acknowledged, while at the same time recognising the reasons for reluctance of doctors to follow the directions contained in advance directives. The framework acknowledged that people are concerned that if they are unable to make their preferences known, they may be kept alive in a state which is unacceptable to them.²³ This is reflected in the renewed focus on advance care planning and how it can support patient autonomy and self-determination.²⁴ Nevertheless, there are potential dangers when healthy Australians prepare AHDs for a time when they might be unable to make their own decisions. How do you know how you will feel until you actually experience a particular circumstance?²⁵ Further, the framework queries how decision-makers later interpret decisions that are uninformed, out-dated, or have not anticipated the development of new technologies.²⁶

The Queensland Law Reform Commission (QLRC) also considered the regulation of AHDs as part of its comprehensive review of guardianship law. In its final Report, the QLRC acknowledged that AHDs arose out of respect for patient autonomy and the right to self-determination.²⁷ Further, it noted that it is important to balance the need for clarity and certainty that doctors require, with the flexibility necessary to make AHDs a useful tool for patients.²⁸ In an attempt to balance the need to recognise an individual’s right to self-determination, yet address the potential problems of following directions drafted in advance, the QLRC recommended that a direction in an AHD not apply if it is uncertain, or if circumstances (including medical advances) have changed to the extent that the individual would not have made the directive had he or she known of the change in circumstances.²⁹

The need to recognise the differing perceptions was also an element in the 2009 South Australian review³⁰ of AHD forms and guidelines. The review committee ultimately recommended that forms and guidelines be sufficiently flexible to accommodate those who wish to appoint an attorney without writing specific

²¹ The Clinical, Technical and Ethical Principal Committee of the Australian Health Ministers’ Advisory Council, above n 1, 1.

²² *Ibid* 2.

²³ *Ibid* 4.

²⁴ *Ibid*.

²⁵ *Ibid* 5.

²⁶ *Ibid* 6.

²⁷ Queensland Law Reform Commission, *A Review of Queensland’s Guardianship Laws*, Report No 67, Volume 2 (2010) 4.

²⁸ *Ibid* 7.

²⁹ *Ibid* 83, 87.

³⁰ South Australian Advance Directives Review Committee, *Advance Directives Review – Planning Ahead: Your Health, Your Money, Your Life. First Report of the Review of South Australia’s Advance Directives – Proposed Changes to Law and Policy* (2009) <<http://www.agd.sa.gov.au/sites/agd.sa.gov.au/files/documents/Promotional%20material%20by%20AGD%20for%20external%20audiences/ag-review-advance-directives.pdf>> and South Australian Advance Directives Review Committee, *Advance Directives Review – Planning Ahead: Your Health, Your Money, Your Life. Second Report of the Review of the South Australia’s Advance Directives – Proposals for Implementation and Communication Strategies* (2009) <http://www.agd.sa.gov.au/news/pdfs/2009/Stage_2_report_final.pdf>

instructions and those who want to write a range of instructions for different attorneys. There was explicit recognition of the differing perceptions about AHDs held by patients who focus on the right to direct what quality of life means to them, whilst acknowledging that the document must be useful to doctors who are integrally involved in the later decision-making.³¹ The review noted that comprehensive guidelines for principals, attorneys and witnesses are the basis for effective use. In reaching this conclusion, the South Australian review acknowledged the effect that new treatments can have on AHDs and highlighted the importance of reviewing the documents to ensure that they are current, which is one way in which to attempt to address these tensions.³²

In undertaking the empirical research, the researchers were cognisant of the perceived shortcomings of AHDs as a clinical tool and the challenges identified in the above reviews. These factors influenced the issues that were explored. The research project therefore was not limited to practical details concerning the length, complexity, format and language of the forms, and the extent to which these factors were barriers to their completion. The research went further and explored issues regarding the principal's perceptions of the AHD itself. Such issues included: the reasons why principals chose to complete the form; whether the AHD was intended to reassure family or friends or rather to be an instruction to the treating doctor; whether the principal preferred to give general instructions about an acceptable quality of life or rather more specific instructions about particular treatment; and whether the principal intended directions to be binding on the doctor, or a guide only. Such information, in isolation, would be useful, but greater insight into the effectiveness of the AHD as a decision-making tool could only be achieved if the perspectives of treating doctors were known. The researchers therefore also explored the perceptions of doctors about the role played by the AHD in clinical practice: whether they found the form helpful (and whether some kinds of instructions were more helpful than others); whether they regarded themselves as being bound by the directions; and whether they had concerns more generally about relying on instructions in the AHD. The following section of the article describes how this data was collected.

III RESEARCH DESIGN

The primary goal of the research was to determine whether the AHD form itself presented a barrier to its uptake. It was therefore necessary for the research to be targeted in terms of recruitment of participants, and to recruit individuals who had experience with this document. As explained earlier, the researchers also sought to gain insight into its effectiveness in guiding decision-making in practice, so participants also needed to include doctors who used the form in their clinical practice.

Data was collected using a three stage mixed methods approach: the first stage involved engaging with a critical reference group; the second stage involved semi-structured interviews and focus groups; and the third stage was an on-line

³¹ South Australian Advance Directives Review Committee, *First Report*, above n 30, Letter of Transmittal, 44, 63, 69-71.

³² South Australian Advance Directives Review Committee, *Second Report*, above n 30, 41.

survey.³³ A purposive sampling strategy was adopted for the second and third stages which identified the following groups:

1. Individuals who have used or might use the forms; and
2. Doctors who have been involved in completing the form by attesting to the individual's capacity and/or who rely on the form when treating a patient.³⁴

The three stage mixed methods approach is outlined in more detail below.³⁵

Stage 1: a *critical reference group* was formed which provided expert input and assisted in summarising existing knowledge. The group included representatives from legal and advocacy organisations (Office of the Adult Guardian and Public Advocate, Queensland Civil and Administrative Tribunal, Queensland Aged and Disability Advocacy, the Department of Justice and Attorney-General (Justices of the Peace Branch)), medical practitioners (an intensive care specialist, a palliative care specialist, a geriatrician and a general practitioner) and a social worker (with the Aged Care Assessment Team). The issues raised by the critical reference group provided the foundation for designing the Stage 2 interviews and focus groups, as well as informing the data analysis.

Stage 2: *semi-structured interviews and focus groups* were conducted with a purposive sample of key stakeholders. A copy of the relevant form (the AHD) was provided to each participant. This stage of the data collection facilitated a detailed examination of the form and feedback on its content and useability which informed the development of the short, targeted on-line survey in Stage 3. Individual interviews were held with 18 people³⁶ about their experiences with AHDs, focusing on how the form was used and understood. Two focus groups commented on AHDs: one group of health professionals who worked in the health or mental health setting (four participants) and one group of people from culturally and linguistically diverse (CALD) backgrounds (15 participants).³⁷ Interviews were also conducted with 11 Aboriginal (n = 5) and Torres Strait Islander (n = 6) people about AHDs.

Stage 3: an *on-line survey* of a purposive sample of consumer and user groups for AHDs was conducted using *Survey Monkey*, a web-based survey tool. Two of the

³³ Before the data collection phase, ethics approval was obtained from the University of Queensland Human Research Ethics Committee.

³⁴ The research also obtained data from other individuals who, in addition to doctors, are required and authorised under the relevant legislation to attest to the capacity of the individual who completes the form.

³⁵ The description of the second and third stages is limited to data collection that was undertaken which is relevant to the issues considered in this article. For a more detailed account of the data collected in the research, see the full report of Tilse, Wilson, McCawley, Willmott and White, above n 4.

³⁶ These people were: treating doctors (2), doctors involved in the completion of the AHD by attesting to capacity (2), other professionals who assisted in the completion of the forms (3), a witness (1), and principals (10).

³⁷ Results from the CALD focus group and interviews with Aboriginal and Torres Strait Islanders are not included in this study as these groups were primarily identified as currently non-users of AHDs. Key issues for these groups were about knowledge, cultural appropriateness of concepts and accessibility of the forms.

surveys that were developed are relevant to this article. One was completed by principals, and the other by doctors. Doctors completed this survey in two different capacities: as a doctor who is treating a patient lacking capacity and for whom an AHD exists ('treating doctor'); and as a doctor who attests to the principal's capacity at the time the AHD is completed ('nominated doctor'). The on-line survey provided the opportunity to obtain data from a greater number of respondents and to explore satisfaction with the current form, identify areas of agreement/disagreement with the issues raised, and note any innovative ideas for change. In total, 37 surveys were completed by 26 principals who were generally well educated (with an over representation of tertiary education), and 11 doctors as treating or nominated doctor. Descriptive and thematic analysis of the data was undertaken. Preliminary data analysis occurred simultaneously with the data collection, the intent being to identify any gaps in the data gathered.

Before considering the research findings, the limitations of the research design should be acknowledged. Firstly, in this exploratory study, the purposive sampling strategy sought to include a wide range of user groups who could comment on knowledge, understanding and use of AHDS. The intention was to include a range of perspectives rather than seek a representative sample. The range of issues raised by these participants is therefore not generalizable to the Queensland population. Secondly, although the aim of the research was to learn why individuals did not complete the AHDs, there were difficulties in recruiting those who did not know about the forms. The researchers were able to include such individuals through specific outreach to CALD and Indigenous groups but were not successful in recruiting those with limited knowledge or resistance to the idea of AHDs to complete the survey. The recruitment strategies comprised using professional networks of the team and the critical reference group to invite people to participate in interviews and distributing the on-line surveys through e-newsletters and contacts in a broad range of consumer and professional organisations across Queensland.³⁸ Thirdly, web-based surveys need to be short. The advantage is the opportunity for a broad and low cost distribution. The disadvantage is that only a limited range of questions can be asked. Finally, given that the survey was web-based, the cohort surveyed over-represented those who are computer literate.

Attempts were made to guard against potential researcher bias by accurately representing the participants' viewpoint. The overall findings are representative of the data collected, and the social and legal contexts in which the research occurred.

IV PERCEPTIONS ABOUT ADVANCE HEALTH DIRECTIVES

Perceptions about what an AHD is, or should be, and the role that it does, or should, play are critical to the effectiveness of the AHD as a tool in clinical practice. A principal may complete an AHD for a particular purpose and may want the document to play a specific role in his or her treatment. The principal's doctor, on the other hand, may be of the view that the AHD serves a different function and may even be of limited relevance when making medical decisions

³⁸ Further details about the sampling are available in Tilse, Wilson, McCawley, Willmott and White, above n 4.

about the patient's treatment. This kind of disconnect, if it exists, would have significant implications for the effectiveness of an AHD as a clinical tool.

Yet little is known about the perceptions of principals and treating doctors in relation to this document. What motivates an individual to complete an AHD? Are the directions it contains aimed at family and friends to reassure them about a particular course of treatment (or non-treatment), or at the doctor to make sure the principal receives only the treatment that they want? Does an individual just want to give broad directions about receiving treatment only if he or she has a certain quality of life so that enjoyment is still possible, or does the individual want to provide specific instruction about the medical treatment he or she wants or does not want to receive? The perspective of the treating doctor is also important. In providing a high quality of care to a patient, does the doctor find it more useful to have a broad understanding that if a certain quality of life is no longer possible, the patient does not wish to receive aggressive treatment, or does the doctor want more specific information about the treatment that the patient wants or does not want? Also critical is the doctor's view on whether he or she considers an AHD to be useful. If the doctor has serious concerns about the efficacy of the AHD as a tool in clinical practice, or believes AHDs impede the provision of good care, he or she will be reluctant to implement the wishes expressed within. Further, while a principal may believe an AHD to be a binding statement of wishes about future health care in the event that he or she lacks legal capacity, the treating doctor may hold a different perspective on whether an AHD is binding or merely a 'guide'.

These potentially competing perspectives were explored in the research, in a more general way in the interviews, and by more targeted questions in the survey. In the surveys completed by principals of an AHD, questions were asked to extract information about the following:

1. Motivation for the principal completing an AHD. Participants were given a number of prompts and asked to select those that were relevant to them:

- a. *I wanted to ease any feelings of guilt for my family/attorney if they refuse life sustaining treatment on my behalf.*
- b. *I was concerned about doctors prolonging my life unnecessarily.*
- c. *I was concerned about family members wanting to prolong my life unnecessarily.*
- d. *I was concerned about doctors letting me go, before I am ready for my life to end.*
- e. *I have a specific medical condition and a clear idea of how I wanted to be treated.*
- f. *I have religious beliefs I want to ensure are respected.*
- g. *The negative experience of a family member or friend with the*

health care system.

- h. *My lawyer, doctor, family member or friend recommended it to me.*
 - i. *Other (please specify).*
2. When completing the AHD, who the principal primarily intended to communicate health care decisions to: the principal's treating doctors, family or friends, or both groups equally.
 3. Whether the principal preferred to write 'quality of life' outcomes (with those outcomes determining whether treatment should be provided or not), or instead list specific treatment that the principal would like to receive or not receive.
 4. Whether the principal expected doctors to follow the AHD exactly, or that doctors treat the directions as a guide only.

Doctors were also surveyed, and two of the above issues (issue three and four) were also explored with them. Doctors were also asked more generally about their views of AHDs as a tool to use in clinical practice. Questions were asked to extract information about the following:

1. Whether the doctor thought it would be more useful for the principal to write 'quality of life' outcomes that he or she considered acceptable, or instead for the principal to list specific treatment that he or she would like to receive or not receive.
2. Whether the doctor follows the AHD exactly, or uses the AHD only as a guide to how the patient wishes to be treated.
3. Ways in which the doctor finds the AHD both useful, and unhelpful.

The sections that follow provide detail of the responses to these questions.

A Principals' Perceptions of AHDs

Four specific aspects of principals' perceptions relating to AHDs were explored in the interviews and surveys. The first involved the principals' motivations for completing the AHD document. The primary motivation of the principals who responded to this survey question was a desire to prevent a principal's life from being prolonged against his or her wishes, including the situation where the ensuing quality of life was unacceptable to the principal. Principals therefore want an opportunity to express in the AHD outcomes that are unacceptable to them and also to expressly reject some treatments in particular circumstances. Twelve of the 18 respondents who answered this question (67%) noted the unnecessary prolongation of life by doctors as a primary motivation for completing an AHD document; while seven (39%) cited the fear of unnecessary

prolongation of life by family members. The desire to ease the guilt of those left behind because they knew what the principal wanted was also noteworthy (and was the case for 10 survey respondents (56%)). As one principal commented:

For as long as I can remember [I] have known that I never wanted to end up in a nursing home, never wanted to be looked after. If anything happens to me I'd rather go, and so I filled one out.

Most were motivated by a concern to have their wishes known and/or to relieve pressure on families. Other motivations include witnessing unsatisfactory experiences of friends and family (five respondents (28%)) or prompting by others (four respondents (22%) prompted by professional, family member or friend). Two of the survey respondents (11%) had a specific medical condition and were clear about how they wanted to be treated, and two (11%) had specific religious beliefs they wished to be respected. Only one person in the study was concerned about doctors *not* treating when that person *wanted* treatment.

Similar motivations were revealed by principals who were interviewed. In addition, interviewees spoke of the desire to ensure particular people had authority to act; one person wanting to ensure that their same-sex partner had more legal rights to speak for the person in future health care situations. Others were concerned about lack of family and prepared an AHD to ensure that friends have the appropriate authority to act.

Informing these identified motivations were the principals' desire for control, avoiding bad outcomes, and ensuring security for the future. Principals were generally of the view that if they lost the capacity to communicate their wishes, their care options might not be what they would have chosen, and completing an AHD was a strategy to ensure this did not occur.

The second aspect of the participant perceptions of AHDs centres on how the participants preferred to phrase their directions in an AHD. There was stronger support in the data for describing general quality of life outcomes that were unacceptable than for providing specific directions. One interviewee commented:

And I think when you try and outline all of the different situations you can never outline all [of them] ... so sometimes it is better to have a general statement about the kind of thing you would like to see happen ... I think the important thing is that you have talked to your attorney about your wishes and that they know what your wishes would be in certain situations.

However, it was also clear that a large cohort of survey respondents valued being able to make specific statements about particular treatments, in addition to broad statements about quality of life outcomes. Two of the interviewees liked completing the specific directions because it is easy to 'just tick the boxes'; and they considered it made their intentions clearer, therefore ensuring that the treating doctor would better understand their intentions and thus be more likely to follow them.

A third aspect explored was the target audience for AHD documents. Data collected from the interviews conducted with the principals suggested that the directions contained in the AHDs were intended for the principal's family, friends

and attorneys more so than for treating health professionals. The survey data revealed a slightly different perspective. Respondents were asked who they were *primarily* intending to communicate their future health care decisions to by competing AHDs. Ten of the 17 respondents to this question (59%) intended to communicate equally with family and friends and treating practitioners; four (23%) primarily intended it for their treating doctor; and three (18%) primarily for their family and friends.

Overall, almost all of the survey respondents reported that they considered that the directions in their AHD were communicated effectively to family or friends. Only one of the 17 respondents to this question was unsure whether the AHD effectively did so.

The fourth, and arguably critical issue, was whether principals intended the directions in an AHD to be binding on a treating doctor, or merely used as a guide in determining clinical treatment. Of the participants in this research, a strong majority indicated that they intended the AHDs to be binding, but a small number did consider them to be a guide only. The survey data revealed that 16 of the 18 respondents (89%) believed that the completed AHD clearly reflected their goals for future health care, and 14 respondents (77.8%) expected doctors to follow their AHD exactly. A minority thought that their AHD would be used as a guide only. Of the respondents, 16 (89%) considered that the written directions were communicated effectively to their respective doctors.

B *Doctors' Perceptions of AHDs*

Some clear themes also emerged from the data collected from both the interviews with and surveys of treating doctors. The first is that, generally speaking, doctors expressed the view that AHDs could serve a useful function in the treatment of an individual who had lost decision-making capacity. Doctors are primarily motivated by a desire to provide patients with good quality of care, and consider that AHDs could assist with the provision of such care. In this regard, comments were made about the relative helpfulness of AHDs in which principals made comments about quality of life outcomes as opposed to specific directions about particular medical treatment. While there was some variance in opinion, there was general consensus that broad approaches that specify quality of life outcomes that are not acceptable were preferred because they allow for flexibility in decision-making. It was noted by one doctor that quality of life preferences also enabled good medical practice considerations to operate.

The two treating doctors who were interviewed expressed a strong preference for an outcomes approach because treatments can change over time and it is difficult to anticipate all contingencies when stating specific directions. One doctor provided the following illustration as support for this view:

So I am elderly, I am living in my own home, if it is unlikely I am going to get back to my own home and I am going to end up in a nursing home or whatever, then I don't want to be ventilated. ... some people say look if I end up in a nursing home, that's fine as long as I can think and read my book, whereas for somebody else it's physical ability. But I think that sort of general statement is much more useful and then the decisions about antibiotics and fluids are less

[difficult]. ... Having a clear philosophy of what sort of outcomes they want and that is probably the key thing.

The survey data was more mixed. When asked what AHDs were *most helpful* for, six out of seven doctors selected understanding the principal's attitudes, goals and values with only one doctor suggesting that AHDs were most helpful when giving direction about specific medical treatments. But when asked to rate the helpfulness of AHDs that gave general statements about quality of life outcomes as opposed to decisions made about specific medical treatments, six of the eight treating doctors who responded to this question (75%) reported that both sorts of directions were equally useful. And eight out of nine doctors (89%) agreed that the form should give an opportunity to describe the quality of life considered unacceptable such that life-sustaining treatment should stop.

The other way in which AHDs were considered useful for doctors is that they can provide the opportunity for doctors to have conversations with patients' families and friends about withdrawing or withholding treatment. This can be a useful tool, particularly when the patients' loved ones are wishing treatment to be provided that is not medically indicated. Despite this potential benefit, doctors also reported that even where an AHD directs that treatment should not be provided, relatives of a principal with a poor diagnosis sometimes request the doctor not to follow the AHD and to provide an active intervention.

The second theme from the data concerns the potential problems of AHDs. Although doctors generally thought that AHDs could be helpful, they also expressed reservations about their use and were concerned that such documents could potentially present a barrier to the provision of good patient care. This will be the case if the directions in an AHD do not coincide with the best treatment pathway. Several reasons were given to justify this position.

1 AHDs can be uncertain and difficult to interpret

Observations were made that it can be difficult to ascertain what a principal wants with respect to the future health care planning. Directions in AHDs can be uncertain and there can be internal inconsistencies within the document. One doctor provided the following example:

It is very difficult to cover in detail what principals wanted in areas such as 'artificial nutrition' or 'terminal phase of an incurable illness'.

Given this uncertainty, some doctors need to seek clarification from the family:

What we actually want is guidance ... my experience is that families who are making most of the decisions ... even when I have an AHD [for the patient], which I totally respect, I usually cannot apply it in the situation in which the patient is in ... I still have to ask the health attorney for agreement of the decision.

Three doctors surveyed (of the six who answered this question) had been in a situation where the directions were unclear and two from six doctors also reported that family or friends helped interpret the written directions.

2 *AHDs may request provision of treatment that is not in the patient's best interests*

Doctors also reported AHDs to be unhelpful where principals requested treatments that doctors did not want to offer on the basis that the treatment was not clinically indicated.

3 *Concern that AHDs may not represent the true wishes of the patient*

An important reservation revealed in the research was that a direction in an AHD may not represent the real wishes of the patient. This may be for a variety of reasons. There is no requirement for a principal to discuss the content of the AHD with a doctor (other than as may be required to assess capacity), and concerns were expressed that there may not always be a complete understanding by the principal of the directions that they are giving.

Another reason that the AHD may not represent a principal's true wishes is that decisions contained in an AHD are not necessarily based on full (or any) information about the relevant medical condition or treatment options. Given this lack of information, principals cannot make informed decisions about treatment. One issue that arose from the research was a concern that a principal could refuse medical treatment in an AHD which may have the unintended consequence of preventing that person from receiving appropriate and necessary palliative treatment.

Concern was also expressed about the ability of a principal to predict the medical treatment that he or she would want when they have never experienced a particular medical condition. Without knowledge about the condition, possible treatment options and consequences, it was suggested that a person would be unable to make an informed decision about treatment.

An associated issue is that circumstances can change between completing the document and a later time when a treatment decision must be made, and an updated AHD may not be completed. How is a treating practitioner to know that a document, especially one which was not recently executed, contains the current wishes of the principal? Further, what if the medical condition was not specifically anticipated by the AHD or there have been advancements in medical knowledge which call the AHD in question? Is this still what the principal wants?

The third theme is whether the doctors regard AHDs as binding, or not. As mentioned above, doctors acknowledged that an AHD can be valuable, especially where directions are in the form of general outcomes that are acceptable and the document is discussed with the treating doctor. Nevertheless not all doctors regarded the directions in the AHD as binding on them. Of the seven doctors who responded to the question about whether they regarded the AHD to be binding on them, three reported that they followed the AHD exactly and four that they used it as a guide only as to how the principal wished to be treated. One doctor stated that if the principal is non-verbal, he consulted with the family about which part of the AHD they considered to be the most important to the principal.

V TENSIONS BETWEEN PRINCIPALS AND DOCTORS

The data collected from this research suggests that individuals who complete AHDs have different perceptions than their doctors about the role that the document should play in their end of life care. These differences are likely to have significant practical consequences. It may mean that the AHD is not used by doctors in the manner contemplated by the principal. Further, at the time the principal's doctor looks to the AHD to direct or guide treatment, the principal will have lost decision-making capacity, and any questions that the doctor may have about what the principal actually wanted and how they wished their AHD to be interpreted or used can no longer be asked of the principal. The doctor can only look to family and close friends for guidance, and an outcome that may not have been desired by the principal. In this section, we highlight the more significant differences in perceptions held by principals and their doctors, as revealed by the data described in the previous section.

A Motivations

When a person who is approaching the end of their life is treated by a doctor, one thing that both the patient and doctor will share is a desire for the patient to receive optimal medical care, whether that is more invasive or aggressive treatment, or palliative treatment. In some cases though, the patient and doctor might disagree about what constitutes the optimal care. An AHD provides the principal with the opportunity to describe, either in general terms or by using specific directions, the treatment that he or she wishes to receive or refuse. If the AHD is written with sufficient precision, everyone who is interested in the principal's medical care will know the views and wishes of the patient, at least in relation to the matters that are within the scope of the AHD.

The research results indicate that the motivation for the majority of participants to complete an AHD is to ensure that their lives are not prolonged unnecessarily by the desire of their doctor, family members or close friends to continue treatment and maintain their life. These participants wanted to retain control over the medical decision-making at the end of their lives, and they completed an AHD to ensure that their desire not to have their lives prolonged unnecessarily was achieved.

These research findings, however, do not sit comfortably with the findings about doctors' perceptions of the role of AHDs. Ethical principles and professional guidelines demonstrate the importance of beneficence and the (linked) importance of patient welfare in medical practice.³⁹ The findings suggest that these values are

³⁹ The principle of beneficence is one of the four key principles in the so-called 'four-principles approach' to medical ethics, as developed by TL Beauchamp and JF Childress in *Principles of Biomedical Ethics* (Oxford University Press, 6th ed, 2009). The principal of beneficence requires a doctor to promote the best interests of the patient. And pursuant to paragraph 2.1 of Medical Board of Australia, 'Good Medical Practice: A Code of Conduct for Doctors in Australia' <<http://www.amc.org.au/index.php/about/good-medical-practice>>, 'the care of your patient is your primary responsibility'. In the AMA Position Statement, 'The Role of the Medical Practitioner in Advance Care Planning – 2006', the AMA recognises the importance of advance care planning in ensuring the patient's right of self-determination (paragraph 1.1). However, the Position Statement also stipulates that 'doctors should be under no absolute legal obligation to follow an AD which is not consistent with Good Medical Practice' (paragraph

significant, and perhaps more important to these doctors than following the patient's directions as expressed in an AHD. While doctors considered that directions in AHDs could be useful, as explained in the previous section, there were concerns that following an AHD may constrain good medical practice. An additional concern to doctors was that the expressed directions may not represent the actual wishes of the patient. As such, doctors may be understandably reluctant to withhold or withdraw treatment that will result in the patient's death. This reluctance to follow a direction to refuse treatment can be further heightened if the family (with whom the doctor will liaise, given the lack of the patient's capacity) opposes the direction in the AHD, and supports the doctors' desire to provide treatment.

This analysis reveals an interesting dynamic about control. Who *is* the decision-maker? Who *should* the decision-maker be? This research indicates that principals complete AHDs to retain control over the decisions being made about their treatment at the end of life. On the other hand, the research also reveals frustrations of treating doctors who are concerned that AHDs may constrain 'good' medical decision-making. They are concerned that AHDs may prevent or impede decisions being made about medical treatment that promotes the patient's best interests. This finding may suggest that doctors see treatment decisions as falling within their expertise.

Principals wish to have control over their treatment while doctors are primarily motivated by patient welfare which may mean providing (possibly unwanted) treatment. If this tension means that the directions are not followed, the principal may not achieve the outcome he or she is seeking by completing the document. The patient's right to autonomy has been denied. On the other hand, doctors may be concerned about not fulfilling their duty of beneficence to the patient if they act on a direction to stop treatment without being confident that it represents the true wishes of the patient. It is desirable for the form to help resolve this tension between motivations of principals and doctors.

B *Intended use*

The principle of autonomy underpins legal regimes that govern AHDs. The law is designed to enable an individual to determine medical treatment before decision-making capacity is lost, thereby retaining control over their future health care. As explored in the section above, the desire for control has also been identified by this research. Given this desire for control, the extent to which the directions in an AHD are followed, that is whether the directions are followed precisely or are used as a guide only, is important to the principal. However, as explained above, the research indicates that principals and treating doctors have different approaches to how AHDs are used. While the majority of principals indicated that they want their AHDs followed exactly, doctors were divided on this point. Some doctors believed that they should be followed precisely while others, driven by their concern that the AHD may contain directions that did not necessarily reflect the wishes of the principal, regarded it only as a guide to decision-making.

4.2) <<https://ama.com.au/position-statement/role-medical-practitioner-advance-care-planning-2006>>.

Again, tensions arise from the different perceptions about the role of the AHD, and this tension can lead to unintended consequences for the principal. A principal who completes the AHD with the intention that it be followed precisely will not have his or her desire for self-determination fulfilled if the doctor treats the AHD only as a guide to treatment. Given the concerns felt by some doctors about the AHD not necessarily representing the wishes of the patient, requiring the doctor to follow it will also present an ethical dilemma for the doctor. He or she will be concerned that following an AHD may lead to an unnecessary and unintended death.

C *Nature of directions*

The different kinds of directions that can be used in an AHD were outlined earlier: either general statements about quality of life outcomes that would not be acceptable for a principal; or specific statements about treatment that is desired or refused. Again, there were different perceptions about which kinds of directions should be contained in an AHD. Principals thought that both had a role to play and may be useful to include in their AHD. While some doctors agreed that both could be useful, some doctors expressed concern about an AHD containing directions refusing specific treatment. Again, it is likely that these reservations stem from a concern that the directions in an AHD may not represent the true wishes of the patient or not be based on relevant information. As such, the tensions of the kind outlined above arise again. A principal who prefers to give specific directions about treatment he or she does not wish to receive may not have their wishes followed if treated by a doctor who favours general guidance from an AHD in the form of outcomes that are or are not suitable to the patient.

D *Concluding comment*

This research has revealed tensions between principals who complete AHDs and doctors who treat patients who have completed one. These tensions have the potential to limit the usefulness of the directions that may have been carefully considered and crafted by a competent individual. The researchers believe that the fundamental explanation of these different perceptions is that principals and doctors view the AHD as achieving a different purpose. The principal generally completes the document to have control about the treatment received and not received, while the treating doctor sees the AHD as a guide to decision-making, and uses it as a tool, in conjunction with guidance received from the principal's family and close friends. Doctors are cautious because they are concerned that the directions in an AHD may not represent the principal's actual wishes. They are concerned that: the AHD may not have been based on reliable (or any) information; the principal's position may have changed and the AHD may no longer represent current wishes; the directions themselves may be unclear; and the direction given may not be consistent with good medical practice.

In the following section, we make recommendations that, if implemented, may reduce some of the tensions described above so that principals and doctors may have a closer understanding of the AHD and what it is able to achieve.

VI RECOMMENDATIONS FOR AHD FORMS

The tensions that exist between the perceptions of principals and doctors have the potential to undermine the effectiveness of the AHD as a mechanism for a principal to make treatment decisions in advance of losing capacity. Not all of these tensions can be resolved. Some doctors are philosophically opposed to following AHDs as they believe that patient welfare can be compromised by doing so.⁴⁰ Amending enabling legislation and redrafting the AHD form and supporting documents will not address this fundamental objection. At a practical level, given the current low uptake of AHDs, these documents are not a common feature of clinical practice. Medical practice in this regard therefore is still evolving. It is therefore timely to consider ways in which some of the tensions identified by this research can be addressed. The authors believe that this is possible, and have made recommendations that could be effective to do so. These recommendations are informed by the literature, the empirical data, and the subsequent analysis. The reasoning underpinning the recommendations, as well as the recommendations themselves, are set out below.

At this point, the scope of the research, and the implications for the recommendations that flow from the scope, should be reiterated. The brief of the researchers was to review the AHD form and supporting documentation to improve its readability and useability with a view to increasing uptake of the AHD. Accordingly, the below recommendations are limited to recommendations about the AHD form only, and do not extend to legislative mechanisms that may also assist to resolve some of these tensions.

The guiding principle of the researchers was recognition that competent individuals have a right to make decisions about their treatment, in advance of losing capacity, should they wish to do so. The relevant forms should support an individual to give informed, considered and articulate directions in his or her AHD, whether their preference is for the document to provide general guidance about a quality of life that is not acceptable to them, or to provide more specific directions about particular medical treatment. The recommendations below are designed to improve the quality of the directions given by providing more guidance in the AHD form, as well as including in the form additional prompts that would require the principal to turn his or her mind to various issues that might not otherwise be considered. If these alterations result in individuals giving clear and considered directions, it may also alleviate some of the concerns that doctors expressed about the directions not truly representing the wishes of the principal. Wishes are more likely to be respected and followed when the doctor has confidence that they have been carefully considered and reflect the views of the patient.

⁴⁰ See, for example, Rebecca E Wong, Tracey J Weiland and George A Jelinek, 'Emergency clinicians' attitudes and decisions in patient scenarios involving advance directives' (2012) 29 *Emergency Medicine Journal* 720; Cees MPM Hertogh, 'The misleading simplicity of advance directives' (2011) 23(4) *International Psychogeriatrics* 511; Ciaran T Bradley, Karen J Brasel and Margaret L Schwarze, 'Physician attitudes regarding advance directives for high-risk surgical patients: A qualitative analysis' (2010) 148(2) *Surgical Journal* 209; Ryan E Lawrence and Daniel J Brauner, 'Deciding for Others: Limitations of Advance Directives, Substituted Judgment, and Best Interest' (2009) 11(8) *Virtual Mentor* 571.

A *The nature of the directions: quality of life outcomes or specific directions*

Individuals need to be able to make an AHD that allows specific directions to be given about treatment. This is important as a matter of principle and, as indicated by the research, is also desired by principals. It is also important to enable individuals to make more general statements about quality of life outcomes which can guide a treatment path. This approach may be preferable for individuals who do not wish to turn their minds to the detail of specific treatment that they may want to receive or refuse in the future. The research also indicates that this choice should be open to individuals.

The researchers therefore recommended that the AHD should continue to facilitate individuals making directions about quality of life outcomes and/or directions about specific treatment.

The AHD should retain both the opportunity for the principal to provide guidance as to desired outcomes, as well as an opportunity to provide specific directions about treatment that a principal wishes to accept or refuse.⁴¹

Some principals indicated a preference for making directions concerning quality of life outcomes that were or were not acceptable to them. However, only limited guidance is currently provided by the AHD form in terms of how to frame such directions. To provide more assistance to principals and, at the same time, provide greater clarity and specificity to doctors and others seeking to rely on the form, the researchers made a specific recommendation to improve the form in this regard.

Clearer guidance, perhaps through more examples, regarding what might be useful 'quality of life outcomes' statements. An option for a 'quality of life outcome' may also include a statement that if the principal reached a particular stage (for example, they were unable to recognise family members, or unable to return to independent living) then they would not wish to receive particular, or any, kind of treatment.⁴²

Finally, the researchers wanted to address the problem that can arise where a general direction made about quality of life outcome is inconsistent with a specific direction about treatment. Uncertainty arises where there is such inconsistency, as it may be impossible to determine the course of action that the principal wanted. In such a case, the AHD could not be followed, and the doctor would need to turn to a substitute decision-maker to make a decision about treatment.

The researchers recommended that the form prompts the principal to elect which of these directions (the quality of life outcome or specific direction about treatment) should prevail in the event of inconsistency. Two additional benefits

⁴¹ Tilse, Wilson, McCawley, Willmott and White, above n 4, recommendation C1.

⁴² Ibid, recommendation C5.

(besides resolving this deadlock) should flow from this initiative. Firstly, this will at least alert the principal to the potential inconsistency of their directives, and allow them to turn their minds to which of those directives is more important to them – the general, or more specific. In this way, the AHD should be a more accurate reflection of their wishes. Secondly, by being alerted to a potential inconsistency, the principal may take time to reflect on the directives given which may decrease the likelihood of inconsistent directives being given.

The AHD should contain an option for the principal to specify whether he or she would prefer the quality of life outcome statement (if any) or specific direction regarding medical treatment (if any) to prevail if there is an inconsistency.⁴³

B *Requirement to consider treatment for palliative purposes*

A problem that was identified by the research related to the potential need to give a principal medical treatment for palliative purposes. As a person is dying, some treatment (such as antibiotics, pain relief or, in limited circumstances, surgery) may be required to improve the quality of the person's death rather than to extend that person's life. The concern is that a person may refuse such treatment in an AHD on the assumption that the treatment would inappropriately extend their life. This directive would have the unintended consequence of preventing appropriate palliative care that would provide comfort to the person as he or she died.

To address this potential problem, the researchers recommended that the AHD form contain a clause which asks the principal to consider whether treatment should be given for palliative purposes despite another direction in their AHD.

The AHD should provide the principal with the option to specify that the directive refusing treatment does not apply if the treatment is needed for palliative purposes, rather than for the purpose of prolonging life.⁴⁴

C *Recording of pre-existing illness*

As explained in this article, one of the major concerns of doctors is that directives in an AHD are not (or may not be) based on sufficient (or any) information. On some occasions, this may be the case. However, in some cases a person may choose to complete an AHD after having been diagnosed with an illness and made decisions about a treatment pathway after fully investigating available options. Doctors may be more comfortable in following an AHD, particularly if it is contrary to the doctor's view about the best treatment pathway, if aware that the AHD was made following the diagnosis.

In a similar vein, the medical treatment that a person has received in the past may shed light on treatment decisions included in the AHD. Specifying the medical

⁴³ Ibid, recommendation C3.

⁴⁴ Ibid, recommendation C7.

treatment received by the principal may therefore provide the doctor with confidence that the views expressed in the AHD reflect the principal's true wishes.

The AHD should provide a space for a principal to record a pre-existing illness and his or her medical history. This will give confidence that the wishes expressed in the AHD are informed by that situation.⁴⁵

D *Opportunity to allow direction in AHD to be overridden*

Although the research revealed that most principals expect their AHDs to be followed precisely, some did not. Moreover, some doctors preferred to use AHDs as a guide to making treatment decisions only. The implication of these different perspectives was rehearsed above. Undesirable outcomes may result in particular for the principal who wants their directive to be followed precisely but is being treated by a doctor who does not share this view, but also for a principal who intends the AHD to be used as a general guide only, and is treated by a doctor who follows it precisely.

The current tension is fuelled by a lack of understanding of the legal significance of an AHD and the obligation on a doctor to follow it.⁴⁶ Because of the different views about whether or not the AHD should be followed precisely, the researchers recommended altering the form so that the principal is directly asked whether they want a substitute decision-maker or doctor to be able to disregard a directive if it is not in his or her best interests. The benefit of this recommendation is that the principal is required to turn his or her attention to this issue. If the principal does not want their wishes overridden, the form will provide an opportunity to make this clear. If a person indicates that this is not their choice, this should also provide further reassurance to the doctor that the AHD represented the true wishes of the patient.

The AHD should provide the principal with the option, if they so wish, to allow his or her substitute decision-maker or doctor to override a directive in the AHD if either considers the directive not to be in the principal's best interests.⁴⁷

VII CONCLUSION

An AHD has a potentially important role in determining future medical treatment of a competent adult in the event of a loss of capacity. Given the ageing demographic of the Australian population, the ability to plan medical treatment in advance of losing capacity becomes critical. However, the research described in this article has identified some serious limitations on how AHDs are working in

⁴⁵ Ibid, recommendation C37.

⁴⁶ This obligation is not absolute and, in certain circumstances, a doctor will be excused for non-compliance: *Powers of Attorney Act 1998* (Qld) s 103.

⁴⁷ Tilse, Wilson, McCawley, Willmott and White, above n 4, recommendation C8.

practice. These limitations largely stem from the different perceptions that principals who complete an AHD and doctors who later rely on the AHD have in relation to the role of the document. While principals see the AHD as a mechanism by which they can control their later medical treatment to ensure they are not given unwanted treatment, doctors feel that AHDs can constrain or hinder the provision of high quality care to their patients. For principals, the risk is that their AHD will not be followed, and their right to self-determination will be undermined. In contrast, doctors who fail to provide treatment in reliance on an AHD fear that they risk breaching ethical and professional guidelines if the directive in the AHD is not only inconsistent with good medical practice, but also does not reflect the principal's wishes.

While the authors recognise the limitations of their study due to the nature and size of the sample, the concerns that were identified are consistent with those revealed in the broader literature. It is therefore critical to take action to reduce these tensions. The recommendations made by the researchers as described in this article are relatively easy to implement as they relate only to the AHD form and do not require legislative amendment. Of course, improving the forms (and even amending legislation) alone is insufficient to ensure appropriate practice. Medical decision making at the end of life is a collaborative process which requires good communication between doctors and patients and, when patients' lack capacity, with their families. Nevertheless, the recommendations will go some way towards improving the current situation. If implemented, principals will be better placed to give directives that are meaningful and will better assist a doctor at a later stage when decision-making capacity is lost. At the same time, doctors should be more comfortable in relying on the AHD as they would have greater assurance that the document represents the true wishes of the principal.

The recommendations described in this article are presently with the Queensland Government and, it is understood, are being considered as part of a wider guardianship review.