Submission: Inquiry into the adequacy of existing financial protections for Queensland's seniors

FPQS Inquiry
Sub.010

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1. Introduction

The Assets, Ageing and Intergenerational Transfers Research Program at the University of Queensland has examined asset management and older people, financial abuse, financial capacity, substitute and supported decision making and intergenerational transfers. We wish to make comment on the adequacy of existing financial protections for Queensland's Seniors on the basis of this fifteen year program of research.

In this submission we will outline key findings and conclusions, identify areas for future research and propose some recommendations. Copies of selected papers have been attached to the email.

2. Key findings: Asset management and financial abuse:

Extensive interest and involvement in older people's assets

- One in four Australians (most commonly adult children) had helped an older person with their assets in the past year (2002)
- Providing assistance with managing assets is often the first form of assistance offered by family members providing care for an older person
- Assistance is provided not only as a result of cognitive incapacity but also linked to physical and sensory impairments that limit use of current financials systems and/or lack of confidence in managing complex financial tasks.

Asset management practices varied and contained some risk

- Asset management included informal mechanisms (e.g. using ATMs), semi formal arrangements with banks (e.g. joint accounts) and formal appointments as EPA or as an administrator.
- Family asset managers and older people reported both sound and risky practices
- Risk was identified in relation to poor accountability/record keeping processes, attitudes of entitlement to assets by family members, ageist attitudes, poor understanding or skills in prudent asset management by carers, limited knowledge of EPAs and impairment in capacity of older person
- Good management practices can take considerable time and effort on the part of the asset manager

- In residential aged care there is a strong tendency to prioritise managing risk over ensuring autonomy in Aged Care Facilities

Older people report a range of preferences and experiences of asset management practices

- Older person as decision maker with others implementing decisions
- Older person consulted and informed of decisions
- Older person voluntarily cedes management to other
- Older person has management taken over by others

What was important in understanding their satisfaction with asset management was the ***fit*** between the older person's expectations and the degree of their involvement.

Financial abuse is related to opportunity, attitudes and lack of monitoring

Abusive practices were related to

- Access to financial assets either through informal, semi formal or formal mechanisms
- Having adult children who use such access improperly or who do not understand their role as a formal decision maker for an older person with impaired capacity.
- Attitudes held - cultural, social and familial- that underpin practices
- Absence/presence of a capable guardian of the assets - someone who monitors what is happening. Financial abuse can be largely invisible

3. Key findings: Capacity substituted and supported decision making:

Limited understanding/interest

- Limited understanding by families and service providers of the principles of substituted decision making
- It is common to default to the attorney to make decisions where there is capacity for the older person to make the decisions
- Assisting an older person to remain part of the decision making process can be time consuming and resource intensive for families and residential care workers
- Aboriginal and Torres Strait Islanders hold a range of views on the appropriateness and utility of EPAs

EPAs and the role of attorneys

- EPAs do not protect from abuse and in some cases can facilitate abuse
- Substituted decision making can be a highly skilled task and there are few resources to support people to do it well

- Current forms and processes do not work well (See Enduring Documents Report) in ensuring that attorneys understand their role as financial administrators, are supported to enact it in line with the principles of the substituted decision making legislation and monitored appropriately to ensure accountability

4. Conclusions and recommendations

What we know to date in relation to financial abuse

Financial decision making is likely to become complex and more contested within families with the changes to financial contributions to residential and community care, changes to asset tests, more complex family structures and increasing pressure to use assets to support care needs. Such contexts can foster financial abuse if protecting and conserving assets are prioritised over decision making with and for older people that puts their interests first.

Financial management and decision making with and for older people are

- Embedded in a social, policy and cultural context that incorporate social attitudes and cultural values relating to older people **and** to their assets. Our research suggests there is no clear understanding of who is entitled to older people's assets while they are alive.
- Embedded in the everyday activities of managing money in families, expectations about intergenerational transfers and inheritances, knowledge and use of substitute/assisted decision making
- Protected by having a capable guardian and appropriate reporting arrangements by attorneys

Our research suggests that responses seeking to enhance the protection of Queensland Seniors will need to be multilevel and multisectorial. They must also recognise the importance of striking a balance between empowerment and protection of older people.

To address the risks of financial abuse and to support good practice in relation to financial decisions making, innovative responses are required in relation to:

(i) Awareness raising and challenges to community and family attitudes of entitlement to older people's assets.
(ii) Enhancing existing service responses at the level of prevention, reporting, advocacy and intervention (e.g. EAPU, SLASS) to older people who are abused
(iii) Providing advice and support for substitute and supported decision makers
(iv) Providing appropriate information at the time of drawing up EPAs (e.g. the appointment of attorneys, the ways in which they are to work together, the time at which the EPA comes into effect, and broad statements of what should guide attorney decision making) is likely to forestall some financial abuse. The registration of the document once it is activated will provide an

opportunity to ensure attorneys are aware of their responsibilities and are given appropriate support. They could be required to report regularly on their management of the older person's affairs, rather than asked for a report once abuse has occurred.

What we don't know to date

While there is data on people reporting abuse to services, there are few services and little data on the outcomes of various forms of intervention to prevent or mitigate financial abuse.

Various community education programs have generally brought an increase in the number of referrals to organisations such as the EAPU. This suggests that there are many cases of unrecognised as well as unreported cases of financial abuse. A prevalence study of the incidence of financial abuse of older people would give an indication of the size of the issue and provide baseline data against which the impact of various prevention strategies could be measured.

There is a clear need to support people supporting older people in the management of their assets. The most effective format for that support needs to be trialled and evaluated.

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Selected Publications

Tilse, C. Wilson, J, White, B Willmott, L. and. McCawley, A, 2014 Enduring Powers of Attorney: Promoting Attorneys Accountability as Substitute Decision Makers *Australasian Journal on Ageing, Vol 33 No 3 September 2014, 193–197*

Tilse, C. Wilson, J, McCawley, A, Willmott, L. and White, B. 2011 Enduring documents: improving the forms, improving the outcomes. Report to Qld Gov. Dept. of Justice and Attorney General. http://eprints.qut.edu.au/46893/

Tilse, Cheryl, Wilson, Jill, Rosenman, Linda, Morrison, David and McCawley, Anne-Louise (2011) Managing older people's money: Assisted and substitute decision making in residential aged-care. *Ageing and Society*, *31* 1: 93-109.

Wilson, Jill, Tilse, Cheryl, Setterlund, Deborah and Rosenman, Linda (2009) Older people and their assets: A range of roles and issues for social workers. *Australian Social Work*, *62* 2: 155-167.

Setterlund, Deborah, Tilse, Cheryl, Wilson, Jill, McCawley, Anne-Louise and Rosenman, Linda (2007) Understanding financial elder abuse in families: the potential of routine activities theory. *Ageing and Society*, *27* 4: 599-614.

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Research

Enduring Powers of Attorney: Promoting attorneys' accountability as substitute decision makers

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Aim: *The misuse and abuse of Enduring Powers of Attorney (EPAs) by attorneys, particularly in relation to financial decision-making, is a growing concern. This paper explores the opportunities to enhance accountability of attorneys at the time of the execution of the document in Queensland.*
Method: *A four-stage multi-method design comprised a critical reference group; semi-structured interviews with 32 principals or potential principals, attorneys and witnesses; two focus groups with service providers and a state-wide survey of 76 principals, attorneys and witnesses.*
Results: *Across all methods and user groups, understanding the role and obligations of the attorney in an EPA was consistently identified as problematic.*
Conclusions: *Promoting accountability and understanding can be addressed by greater attention to the role of the attorney in the forms/ guidelines and in the structure and witnessing of the forms, increased direction about record keeping and access to appropriate advice and support.*

Key words: *enduring powers of attorney, substitute decision making.*

Introduction

Policy interest in planning for later life decision-making has been driven by the need to provide for an extended period of older age and the potential for impairment in decision-making capacity in late old age. In response, many countries introduced legislation to provide for substitute decision makers in the event of incapacity. Such legal documents allow for a person with capacity (a principal or a donor) to nominate a substitute decision maker(s) (an attorney, agent or donee) to make personal/health and financial decisions if they are unable to make such decisions themselves. These documents vary in terminology (enduring or durable powers of attorney, advance directives, lasting powers of attorney or enduring guardianship) and whether if one document covers one or all domains.

Enduring powers of attorney (EPAs) are widely promoted as an accessible and affordable mechanism for substitute decision-making that can be completed, in many jurisdictions, in the absence of legal advice. The initial emphasis was commonly on simplicity, flexibility, convenience, ease of execution and accessibility. Over the past decade, striking a balance between ease of use and protection has been a growing concern. Concerns arise from the level of understanding of the documents and the powers they confer; the amount of protection provided for principals, particularly in relation to financial decision-making; limited understanding of the nature of decision-specific capacity assessment and inappropriate use of substituted decision makers when an individual has capacity to make a specific decision [1–4].

The most common critique of current practice relates to the misuse and abuse of EPAs by attorneys resulting from the breadth of financial powers conferred by the instruments combined with limited accountability and independent monitoring of attorneys [5–8]. Dessin [5] also highlights the lack of clarity of the role of attorney/agent, calling it 'unscripted'. Australian research demonstrates that financial abuse is contingent upon access to assets. EPAs provide such access [9].

Concerns about the failure to protect principals or safeguard vulnerable people have driven recent legislative changes in the United Kingdom [10] and the United States [8]. Such reforms have sought to enhance protection through changes in three main areas: (i) changing the requirements for executing an EPA by increasing notarisation requirements, the number of witnesses or introducing a registration system [11]; (ii) clarifying limitations on an attorney's authority or putting in new limitations around gift giving and self-dealing; and (iii) enhancing education, support and the ability of third parties to monitor EPA relationships [7,8,11]. Such changes have been applauded as providing greater safeguards for principals [8] and criticised for reducing accessibility by increasing cost and complexity [7].

Queensland context

Australian substitute decision-making legislation is state and territory based. Although there are differences in terminology, processes for execution of documents and adult protection systems, all have a form of financial EPA. In Queensland, under the *Powers of Attorney Act* 1998, an EPA can be

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executed for financial and personal/health decisions. In addition, an advance health directive (AHD) can also be completed. Under an EPA, one or multiple attorneys and different attorneys for different domains (financial, personal/health) can be appointed. The document can be executed without a lawyer. Forms are available on line and kits can be purchased from newsagents. The EPA, however, does have to be witnessed by a lawyer, a Justice of the Peace (JP) or a Commissioner for Declarations. The attorney's signature is not required at the time of execution and is not witnessed. There is no general registry for EPAs and there is no ongoing monitoring of an attorney, but registration is mandatory to deal with land. It is thus impossible to know how many EPAs are activated in the state. An EPA can include special conditions to limit the power (e.g. conditions about gifts, sale of property). Where a person has impaired capacity, concerns about the actions of an attorney can be brought to a tribunal.

Recent reviews and research [12,13] in relation to EPAs explored the best way to access, execute and use the information and forms appropriately. Our research arose from concerns of government, service providers, researchers and legal and health practitioners about the level of understanding, knowledge and use of EPAs and AHDs in Queensland. The interdisciplinary project examined barriers to uptake for both EPAs and AHDs, the content and usability of these forms and the processes and practices surrounding the execution and use of the documents. This paper focuses on the role of attorneys, particularly as financial decision makers, and opportunities to enhance accountability at the time of the execution of an EPA in Queensland. Although the research canvassed views on the role of attorneys as personal/health and financial decision makers, this paper focuses on financial decision-making as the domain consistently highlighted as the most problematic in relation to accountability.

Methods

The four-stage mixed-method design included a wide range of user and potential user groups. The purposive sampling strategy included (i) consumer groups – people who have used or might use the form as principals or attorneys and (ii) professionals (social workers, legal practitioners), service providers and witnesses. Outreach to Aboriginal and Torres Strait Islander people and people from culturally and linguistically diverse backgrounds (CALD) ensured a range of perspectives were considered. The research design comprised:

1. A Critical Reference Group (medical, social work, legal practitioners and advocacy and guardianship representatives) which provided expert input and reviewed research tools.
2. Semi-structured interviews with 21 principals, attorneys, potential principals, witnesses and guardianship staff. In addition, 11 Indigenous Australians (from Murri and Torres Strait Islander Groups) were interviewed by an indigenous researcher. The questions covered motivations and intentions in having an EPA, experiences with EPAs, capacity assessment, understanding by principals and attorneys of the powers and obligations being conferred, use and usability of the forms and the information provided and record keeping. All respondents had access to the relevant forms during the interview to facilitate specific feedback. Principals and attorneys who had completed an EPA were recruited through advertising in newsletters, websites, local community newspapers and University data bases. Professionals and witnesses with specialised knowledge about the use of the forms were recruited through professional networks and the Critical Reference Group members.
3. Online surveys distributed to principals, attorneys and witnesses across Queensland using a web-based survey tool. Copies of the EPA forms were attached so that respondents had the opportunity to consult the forms as they completed the survey. The surveys were distributed through e-newsletters, a broad range of organisations, professional networks, a consumer health forum and a regional forum on later life decision-making hosted by the Public Trustee of Queensland. The survey questions and Likert scales were developed from issues raised in the Stage 2 interviews. A total of 76 surveys relating to EPA forms were returned, 30 from principals, 23 from attorneys and 23 from witnesses with experience of EPAs. The sample is generally of well-educated users of the documents with an overrepresentation of tertiary education for principals and attorneys. Although there is a broad age range, there is also an overrepresentation of women, people born in Australia and with English as the first language. No Aboriginal or Torres Strait Islander person completed the survey as a principal; one attorney identified as Aboriginal or Torres Strait Islander. Thirty-five percent of principals and 44.5% of attorneys were from regional areas.
4. Two focus groups were held with practitioners in relation to their experiences, knowledge and use of EPAs: workers with CALD groups (15 participants) and social workers in health settings (eight participants).

The semi-structured interviews and focus group discussions were audio recorded, transcribed and analysed thematically. Descriptive statistics reported on patterns and trends in the survey data. The research had human ethics approval from The University of Queensland (No. 2009001660).

The purposive sample is not representative, probably attracting people with strong opinions about their experience of EPAs. The multi-method approach did, however, include a diversity of user groups. Although the survey sample of principals and attorneys primarily comprises people who are least likely to have difficulties in reading the form, problems they identify in understanding the forms, processes and practices are likely to be much greater for those in the population with more limited education and English language skills.

Results

Overall, the EPA was generally evaluated as working well for people as principals, witnesses and attorneys who are well

Australasian Journal on Ageing, Vol 33 No 3 September 2014, 193–197

informed about the purpose and operation of EPAs. However, some principals and attorneys are less informed about the powers and duties conferred. Additionally, some groups in the community, notably CALD and indigenous peoples, are less likely to be well informed about the EPA.

The most striking finding of the study is that across user groups and across all methods of data collection, the role of the attorney in an EPA was consistently identified as problematic. Principals, attorneys, witnesses and professionals/service providers all noted that aspects of the form, the information provided and processes in place at the time of executing the document do not necessarily assist attorneys and principals to fully understand the role and responsibilities of attorneys. Key issues identified included understanding the powers and obligations conferred by an EPA, clarity of record keeping obligations of an attorney and the use of terms or conditions to provide further direction to attorneys or restrict their powers.

Understanding powers and obligations

The principals' understanding of the powers being conferred varied considerably. Some had a very detailed understanding; others simply relied on the attorney to 'do the right thing'. Although some witnesses (e.g. lawyers and JPs) had a very careful process to ensure the principal understood the power being conferred, others took a more routine approach to witnessing the document.

Overall, respondents reported that the principal was responsible for ensuring the attorney understood the nature and scope of the powers and their role and obligations. Attorneys, however, generally reported that they did not have their responsibilities outlined to them by the principal or any intermediary who helped the principal draw up the form.

> [The form] is very useful; but it didn't stress, once again, perhaps the limits of being an attorney, and the duties and the responsibilities. [EPA Interview 18]

Attorneys reported they needed more information on how to make decisions, keep records, activate and terminate their role and where to go for advice. Some were concerned about their understanding of the commitment they were undertaking.

> For the attorney, I'm not sure that they fully understand that they are held accountable and that they could be involved in acting legally for the person. I think they understand the concept of paying the bills, but I'm not sure that they really understand that they are the legal representative and would be involved in any difficult or conflictual arrangements. [EPA Interview 7]

Overall, witnesses were concerned that principals did not completely understand a number of important issues relating to activation and termination, capacity and the use of special terms or conditions. Witnesses also considered that attorneys did not always understand what the powers and associated responsibilities were.

> [T]he main issues are that the attorney doesn't understand their responsibility and they think it's just a piece of paper that Mum or Dad wrote to give them the ability to manage their affairs or manage their health if they want to but they don't have to do it if they don't want to. . . . There's a small proportion that manipulate their form but the majority of people I think it is a lack of understanding of their obligation. [EPA Interview 16]
>
> I get a sense a bit that (principals are told) 'oh your attorney has to do these things, don't worry about that. Just appoint someone without getting into too much details'. [EPA Interview 4]

One respondent put an alternative view:

> I think if they [attorneys] read it there would be less misconduct. So that's no excuse. The form does what it needs to do to tell attorneys what their responsibilities are as opposed to other states' forms that don't, within the form. [EPA Interview 3]

This suggests that some of the issues for attorneys could be resolved if parties carefully read the form and are engaged in the processes surrounding the execution of the document. However, most groups reported problems with the information provided, the language and structure of the form itself and the practices surrounding the execution of the document.

The survey also demonstrates there are problems in ensuring that attorneys understood their role. In response to Likert scales seeking comment on the adequacy of the explanation of the role and obligations of an attorney in the form and the guidelines, 52% of principals agreed that it was adequate. Attorneys were much less sure, only 25% of attorneys agreed that the explanations were adequate. In addition, only 24% of attorneys agreed they were adequately alerted to the serious nature of their appointment as an attorney.

What was missing was reported to be descriptions and explanation about activation of the EPA, timelines and expenses; worst case scenarios – 'at present the forms assumes everything will go smoothly in families'; 'how to do the role' – make decisions and keep records; explanations about when it commences, how to make decisions about capacity for a matter, an explanation of the advocacy role of an attorney, or what happens if the attorney abuses power.

Record keeping

The obligation to keep records is core to accountability for financial decision-making. Although the form clearly indicates a responsibility to keep records, limited understanding of how to enact this responsibility and the implications of

inadequate recording keeping were consistently reported across principals, attorneys, service providers and witnesses.

An attorney with a background in the finance industry reported that when he started to act as an attorney, he reread the document and said, 'one of the things it really highlighted for me was you must keep records'. However, he was unable to find guidelines on what records to keep. Another attorney, with much less background in managing other people's money, agreed:

> There should be more guidance given to attorneys on what records to keep and how to keep them. [EPA Interview 14]

In addition, she added that there should be much more warning given to attorneys on what might happen if abuse occurs, or they do not meet their obligations.

From the survey, most principals (85%) and attorneys (94%) agreed that more information was needed on the responsibility to keep records. Attorneys also wanted more information on gifts and conflicts of interest (100%) and when the Office of the Adult Guardian will investigate (94%).

Use of conditions to limit attorneys' authority

Putting conditions or limitations on an attorney's authority to act can provide direction for attorneys and thus enhance accountability. The interviews revealed that most people did not use special conditions. This was attributed to a lack of understanding of what could be included, the design of the current form which actively discourages the use of conditions and the information provided. It also reflects a view of most principals outlined by one respondent:

> I did not set any conditions or read any information about setting conditions or potential abuse because I trust my attorneys. [EPA interview 12]

In the survey, most principals (66%) reported that they did not use special conditions, but the vast majority of principals (92%) wanted more information on how to include special conditions to add specific additional powers; while 80% wanted more information on how to restrict powers in relation to gifts, conflicts of interest, consulting with others, annual accounting and preventing some decisions about property. Findings suggest that the value of principals and attorneys having greater knowledge of how, when and whether to include conditions should be recognised, although this may restrict the ease of use of EPAs.

Discussion

Under ideal conditions, EPAs enhance autonomy by allowing principals to select agents to act on their behalf if decision-making capacity becomes impaired [7]. In many cases these documents work well. A major critique of EPAs, however, relates to the accountability of attorneys. Accountability depends upon them being informed of their roles and responsibilities, aware of the principal's intentions, having the motivation and skills for the tasks and the capacity to undertake the complex roles of substitute and supported decision maker and prudent asset manager and record keeper.

In Queensland, in Dessin's [5] term, there is a 'script'. There is considerable information in forms and guidelines about the role and responsibilities of attorneys. However, this does not mean that, at the time of execution, the attorney understands them. To improve accountability, education and support targeting the role of attorneys is a priority. This could include an extensive targeted information booklet, DVDs and case scenarios for attorneys, the provision of examples of record keeping and access to advice and assistance at the time of execution and when acting an ongoing decision maker.

Current practice allows for documents to be executed in the absence of the attorney. Executing an EPA as part of routine estate and financial planning runs the risk of paying insufficient attention to the serious nature of the appointment and role of the attorney. For some there was insufficient definition of the role and discussion of the seriousness of the appointment. In the research, there was little evidence of a collaborative process that involved the principal and attorney in discussion of powers, intentions, role and responsibilities. Kohn [11] has noted that establishing a collaborative relationship should enable the agent to make better decisions on behalf of the principal in the event that the principal becomes incapacitated. It also encourages communication between the principal and the attorney, which is at the heart of any substitute decision-making. Greater inclusion of attorneys in the processes at the time of execution of the document is vital to setting this up.

The obligations of attorneys need to be further highlighted in the structure and witnessing of the forms. Attorneys and principals should be required to read all parts of the document and indicate their understanding of the scope, nature and obligations of the power being conferred. Witnessing of their signatures would also highlight the importance of the role.

Conclusion

Carney [14] has noted that that an enduring power is only as good as the agent is trustworthy and willing to accept responsibility. The authors would add to this, the importance of the attorney understanding their responsibility and being capable of carrying out the tasks. In promoting changes to information, documents and processes, the tensions between accessibility/flexibility and appropriate use and protection need to be considered. As many jurisdictions contemplate enhancing protection through registration and/or increased monitoring of attorneys, it is timely to also consider what actions can be taken at the point of execution to improve protections for attorneys and principals, particularly in the area of financial decision-making.

Australasian Journal on Ageing, Vol 33 No 3 September 2014, 193–197

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Key Points

- EPAs have been widely promoted for substitute decision-making.
- Misuse and abuse of decision-making powers by attorneys are increasingly recognised.
- Attorneys often accept appointment without understanding their role and obligations.
- Access to information, advice and support at the time of execution of the EPA and when the document is activated is vital to promote accountability of and understanding by attorneys.

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Managing older people's money: assisted and substitute decision making in residential aged-care

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ABSTRACT
Current approaches to the assessment of cognitive capacity in many jurisdictions seek to balance older people's empowerment with their protection. These approaches incorporate a presumption of capacity, a decision-specific rather than global assessment of that capacity, and an obligation to provide the support needed for adults to make or communicate their own decisions. The implication is that older people are assisted to make decisions where possible, rather than using substitute decision makers. For older people, decision making about financial matters is a contentious domain because of competing interests in their assets and concerns about risk, misuse and abuse. In residential-care settings, older people risk being characterised as dependent and vulnerable, especially in relation to decisions about financial assets. This paper reports an Australian study of the factors that facilitate and constrain residents' involvement in financial decision making in residential settings. Case studies of four aged-care facilities explored how staff interpreted the legislative and policy requirements for assisted and substitute decision making, and the factors that facilitated and constrained residents' inclusion in decisions about their finances. The observed practices reveal considerable variation in the ways that current legislation is understood and implemented, that there are limited resources for this area of practice, and that policies and practices prioritise managing risk and protecting assets rather than promoting assisted decision making.

KEY WORDS – capacity, substitute decision making, financial management, residential care.

Background

Policy and practice interest in older people's decision-making capacity for financial matters has arisen from broad concerns around preserving and

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protecting assets for later life. Financial resources are central to older people exercising choice in living and care arrangements. Access to and control over decision making about money and property in older age also have psychological, cultural and social meaning, provide security, and symbolise continuing independence. Decision making about how assets are preserved or spent generates complex issues for older people, family members, formal carers, professionals and service providers (Langan and Means 1996; Tilse *et al.* 2007*a*). The complexities around the assessment of capacity for decision making in relation to financial matters and concerns about prevention and intervention in relation to financial abuse of older people have stimulated research and policy and practice interest (Letts 2009; McCawley *et al.* 2006).

Making decisions about assets requires a broad range of cognitive and procedural skills (Moye and Marson 2007). Diverse tasks, such as basic cash transactions when shopping, banking, paying bills and securing personal valuables, differ from long-term decision making about the conservation of financial resources. Impairment in cognitive capacity, communication difficulties and/or health, mental health or mobility problems can all affect an older person's capacity and willingness both to participate in some of the decisions and to implement decisions once made. The natures of the impairment and of the available support interact and affect an older person's capacity to engage with particular financial tasks.

Legislative changes in several countries have reflected changes in thinking about capacity assessment and the context in which decisions are made. A recent legal development is the shift from a global determination of capacity, based on the presence of a diagnosis alone, to a consideration of key functional abilities relevant for specific domains, including decision making about financial matters, entry into residential care, and consent for health-care treatment (Dwyer 2005; Grisso 2003). Legislative changes in Australia (Queensland Government 2000: *Guardianship and Administration Act 2000*, Chapter 2, Section 5), England and Wales (United Kingdom (UK) Department of Constitutional Affairs 2007: *Mental Capacity Act 2005*, Section 2, Principles 1 and 2), Scotland (Mackay 2009), Canada (Ontario Ministry of the Attorney General 2005), and the United States of America (Moye 2003) reflect this shift in principle. The new policy approaches incorporate a decision-specific approach which recognises that capacity to make decisions differs according to the nature and extent of the impairment, the type of decision to be made and the available support. The legislation seeks to achieve a balance between protection and empowerment based on a presumption of capacity and an obligation to provide the support needed to help adults make or communicate their own decisions (Johns 2007). The legislative intent appears to be that capacity to make a particular decision

in a particular context is assessed in relation to each matter. Where possible, the older person is assisted (or supported) in making their decision rather than having that decision referred to a substitute decision maker.

Some research has challenged whether this changed approach to decision-making capacity is appropriately understood and enacted in professional practice with older people. In an American study of health-care professionals, Ganzini *et al.* (2003: 241) noted that one pitfall in assessing decision-making capacity was little understanding that capacity or incapacity is not 'all or nothing' but rather specific to the particular decision. These authors made the point that if a clinician conceptualises a patient as globally lacking capacity, it is likely the patient will not be given the opportunity to make various decisions that he or she in fact has the capacity to make. In the Australian context, Bennett and Hallen (2006) called for greater understanding by medical practitioners of guardianship and financial management legislation. Wilson *et al.* (2009) argued that social workers need to open up opportunities for older people to be involved in making decisions about their financial assets. In the UK, the *Mental Capacity Act 2005 Code of Practice* (UK Department of Constitutional Affairs 2007: Chapter 3, 3.5) proposes that providing 'appropriate help with decision-making forms [is] part of care planning processes for people receiving health or social care services'. This includes providing relevant information, communicating in an appropriate way, making the person feel at ease and exploring who might support the person to make choices or express a view. The extent to which everyday practices in community and residential aged-care reflect these legislative principles is currently poorly understood across a range of disciplines.

Practice that is in keeping with these legislative and policy principles requires not only an assessment of capacity to make a particular decision but also an understanding of the nature of substitute and assisted (or supported) decision making together with a willingness and ability to retain the older person's involvement. Substitute decision making in relation to financial matters may be a formal or informal process (Tilse *et al.* 2005). In all cases there is a moral and, under some legislation such as the UK *Mental Capacity Act*, a legal imperative for decision makers to act in the best interest of the older person and, as far as possible, to take their wishes into account. Formal substitute decision-making instruments (commonly called enduring, durable or lasting power of attorney, financial guardianship, or administration orders) address impairments in decision-making capacity by providing legal authority for others to make financial (and other) decisions for older people. Jurisdictions vary, first in the type of decisions covered by the power (*e.g.* financial property, health and/or personal

care), second in their ability to specify what decisions are and are not to be made, and third in determining whether the power comes into effect immediately, at a specified time, or when incapacity to make the decision is established. What is common is that an enduring or lasting power of attorney is made when the donor (or principal) is capable of making his or her own decisions and is able to understand the consequences of preparing the document and its contents; and for the power to endure if the donor loses capacity. Criticisms of these instruments are based on concerns about whether their use achieves a balance between empowerment and protection (Wilbur 2001). Under the United Kingdom *Code of Practice for the Mental Capacity Act*, attorneys acting as a 'lasting power of attorney' have a legal duty to have regard to this *Code of Practice*, which describes their responsibilities when acting or making decisions on behalf of individuals who lack the capacity to act or make these decisions for themselves.

Many decisions about an older person's involvement in financial management are also made informally (Ganzini *et al.* 2003), by family carers (Tilse *et al.* 2005), and by managers and staff in community and residential care. Family members and formal carers may not understand or act in response to the duties that run alongside the power they have either been formally given, as by an enduring or lasting power of attorney, or have informally assumed. Research that explores the experiences of community care staff in relation to 'money handling' for clients has identified the need to improve training, support and good practice guidelines (Means and Langan 1996). Although the importance of assisted (or supported) as well as substitute decision making is a key implication of current policy, how this operates in various care settings is not well understood. Effective assisted decision making means determining and taking into account the wishes of older people and offering them the resources that make the difference between what they can do for themselves and what needs doing by others to reach or execute a decision (Wilson *et al.* 2009). Assisted and substitute decision making should take account of the context in which the asset management takes place and negotiate the fit between the tasks or decision to be made, the older person's wishes, the formal or informal carer's willingness and ability to respect the views of the older person, and the available support. Providing this form of support is not always easy, in part because professionals usually become involved in older people's lives at important decision points such as entry into residential care when the situation 'is not conducive to facilitating and respecting decision making by older people' (Dwyer 2005: 1089).

Older people are diverse and their interest in financial decision making varies. Research exploring the perspectives of older people receiving assistance with managing assets has highlighted the variation in older

people's wishes in relation to decision making (Tilse *et al.* 2007*b*). These range from a preference for either assisted decision making with help to implement and monitoring the decisions (including being consulted and having access to accounts), to ceding decisions to substitute or proxy decision makers on a basis of trust that their assets will be well managed. Research with informal carers in relation to asset management has identified a range of practices, attitudes and environments that include or exclude older people in decision making about their assets (Tilse *et al.* 2005*a*). Inclusive practices can be described in terms of the level of the involvement of the older person in decision making and the degree of fit with their preferences (Tilse *et al.* 2005, 2007*b*). A strong issue for carers is the dilemma of balancing the independence and self-determination of the older person with the need to protect their assets, and reconciling this aim with the carer's need to have effective and time-saving practices in place. In response to these pressures, some carers continued with assisted decision-making approaches, and others found acting as a substitute decision maker more convenient. How care staff in residential settings manage these tensions is little understood.

Residential-care facilities are important environments for understanding care practice in relation to current legislation. Older people in residential care are likely to be defined in terms of 'complex needs' and 'dependency' at the expense of being seen as adults capable of making a range of decisions (Scourfield 2007: 1136). The tasks and responsibilities of residential-care staff in relation to managing money and property differ from those of informal carers. The Australian Government Department of Health and Ageing *Aged Care Act 1997* and *User Rights Principles 1997* recognise, through a *Charter of Residents' Rights and Responsibilities*, the resident's right 'to maintain control over, and to continue making decisions about, the personal aspects of his or her daily life, financial affairs and possessions' and 'to have access to services and activities which are available generally in the community' (Australian Government Department of Health and Ageing 1997: Section 10.13). Unlike family, residential-care staff members do not have a decision-making role in managing residents' finances. Their responsibilities are first, to support residents who are able and wish to self-manage their assets or participate in tasks such as banking, shopping and consulting with financial advisers, and second, to help residents keep their money and valuables safe.

Assisting older people to remain involved in decision making about money and property poses particular challenges in residential aged-care environments. These include: the high level of impairment of many of the residents and the high prevalence of dementia (Australian Institute of Health and Welfare 2007; Knapp and Prince 2007); that the communal

setting means that cash, valuables and documents are at particular risk of loss, misuse and abuse; and the constraints on the roles of formal care providers in the financial affairs of residents. Little is known about how residential-care staff members manage these tensions or about the extent to which the spirit of the current legislation is reflected in day-to-day practices. The paper draws on findings from an in-depth study in Australian aged-care facilities of the residents' participation in decision making about their assets. It specifically explores assisted and substitute decision making in this context.

Research overview

The Assets and Ageing Research programme at the University of Queensland comprises eight interlinked projects on the management of older people's assets in Australia (Tilse *et al.* 2007*a*). The programme defines asset management as having some control over access to, organising, making decisions about or using an older person's financial or capital assets or valuables. Older people are defined as those aged 65 and over, but in the majority of studies most participants have been aged 80 or more years. All studies have taken place across urban and rural locations in South East Queensland, Australia. The data reported in this paper were collected through case studies of four residential facilities. This in-depth study explored policies and practices relating to residents' participation in accessing, managing and decision making about their finances and property. All facilities had a mix of residents requiring high and low levels of care, and all were subject to Australian government regulations and the *Charter of Residents' Rights and Responsibilities*. The sample of aged-care facilities (ACFs) in South East Queensland was selected to ensure inclusion of urban and rural locations, large (more than 150 residents) facilities that were part of a chain and small (less than 60 residents) facilities that were not and so had fewer levels of management. One facility specifically provided for people from culturally and linguistically diverse backgrounds.

The data were collected using semi-structured interviews with 102 participants. These consisted of 10 care managers and business managers, 48 care staff including registered nurses, personal care assistants and support staff, 12 residents and 32 residents' family members. In addition, there was an analysis of written policies and handbooks relating to residents' assets. This paper utilises data from interviews with care and business managers and direct care staff. Understanding the policies and practices from the perspective of staff is a vital first step in charting how changes in legislative principles and codes of practice are understood and implemented. While

the case studies of four facilities do not allow generalisations, they provide an in-depth exploration of this complex arena of care provision in specific contexts. The case study analysis provided the basis of a survey of a representative sample of aged-care facilities in the next stage of the project. The thematic analysis of the interviews sought to answer the following questions:

1. How do ACF staff interpret the legislative and policy requirements for assisted and substitute decision making?
2. What factors facilitate and constrain ACF residents' inclusion in decision making about their finances and property?

Findings

The case studies showed that although asset management was most commonly undertaken on behalf of residents by family members or public and private trust organisations, all facilities reported having a small number of residents who self-managed all or some of their banking, shopping, bill paying and investment transactions. Most of them were described as having no cognitive impairment or having family support to remain actively involved in managing their financial affairs. Across the four facilities, a range of opportunities for and constraints on assisting residents to remain involved in some of the tasks of managing assets were identified. These arose from how the legislative requirements that relate to substitute decision making were understood and used, in particular 'enduring powers of attorneys' (EPA); how the responsibility to assist residents to continue to make some decisions was viewed and resourced; and the concern to minimise risk of loss or and allegations of misuse of assets.

Interpreting legislative requirements

Various interpretations of existing legislation were evident in the interview data. In Queensland, a donor of an EPA can specify a time when it comes into effect. If no time is specified, then the attorney is able to exercise their financial decision-making power immediately but is nonetheless required to consult with the donor if the donor has capacity for the decision (Queensland Government, Department of Justice and Attorney General 2010). All facilities requested copies of EPAs upon the admission of the older person, but how these were understood and then used in respect of financial matters varied. Apart from the time of admission, only one facility had a system in place for checking the conditions of the EPA when

an attorney sought to use it. In one facility, the business manager reported that the holder of the EPA (the attorney) was the preferred point of contact and viewed as the primary decision maker regardless of whether or not the resident had capacity to make that decision. An example of this was consulting the attorney about a resident's decision to buy clothes when the resident clearly had the capacity to make that decision. A business manager commented:

> We become accustomed to dealing with the [person who has] the power of attorney. Our first instinct is to [contact] the power of attorney but they usually ... say, 'oh well, mum and dad still look after their own affairs'.[1]

This approach does not reflect a decision-specific assessment of capacity or an understanding of substitute decision making. Some staff also reported that some family members assumed a substitute decision-making role when the resident was willing and able to retain involvement. As one explained:

> [the resident] has been placed into care, has established his enduring power of attorney and the family seem to have taken over. They are making the major decisions for him and he's angry. He's a very angry person because he feels that everything has been taken away from him, like the whole dignity of his life has been taken away.

An alternative view from a manager in another facility reflected a clearer understanding of the principles underpinning substitute decision making: 'if the person [the resident] has cognitive capacity we would take whatever their wish is over the EPA [the attorney]'. The manager, reflecting on the practices in some facilities of referring to the holder of the EPA for all decisions commented, 'I can see why that happens but it is not right all the same. Because it is a cop out. It is easy to do that'.

Responsibility and resource constraints

A second barrier to assisting residents who were able and wished to have some involvement in managing their financial affairs arose from how the facility role was viewed and resourced. Some facilities took the view that assisting residents to retain an interest in managing some tasks of asset management was not part of their role and very much in the domain of families. These facility managers were much more likely to refer automatically to substitute decision makers for any decisions involving money. As one manager noted, 'we have care responsibilities, not financial responsibilities'. From this perspective, all financial matters and tasks – not only managing fees and charges and the more complex tasks of asset management – were seen to be the concern of families or trust organisations rather than of the resident or the facility's staff.

An alternative approach that acknowledged that the facility had responsibilities in this domain was also evident. In these facilities, managers and most personal care staff reported that it was important to support independence in asset management, especially in the situation where a resident had no family member to assist them. Diversional therapists or others who organised outings reported taking residents shopping or to the bank. One diversional therapist described her involvement:

> Well he is in a wheelchair, okay, so we go over and I just stand beside him at the ATM [automatic teller machine] in case he has a problem. ... If he has a problem, he will ask me and I will help him sort it out like maybe he hasn't pressed the numbers properly. ... Then we go into the stores. I push him. He says what he wants ... then we will go to the checkout. He has the money in his wallet. He takes it out and pays ... and gets the receipt and the change and puts it back in his wallet. So he has control of that. I don't touch it at all.

Care managers who supported this approach reported that it was resource intensive and could be difficult to facilitate. For example, assisting a resident to visit a bank required a staff member to escort the resident to the bank, arrange transport, and organise back-up staff to replace the absent staff member. As one care manager reported, 'It's all very well for us to say that the resident should have total independence but I've got to release a staff member for an hour at least. They have got to have transport and who pays for that?' In one case where an escort could not be arranged through the diversional therapy programme, the resident herself provided the funding for staff costs and transport to enable her to manage her own banking. Not all residents could afford this. In another facility, residents could access a bank only if they were able to do so without facility support. The rural facility reported a range of practices that included a front-line staff member taking a resident to a local bank. The manager said:

> It's not our role. ... I've taken her down to the bank to sort out getting monthly bank statements now that ... her one eye is done [has been operated on] so that she can see. ... We were going to do phone banking with her but we decided that she could get monthly statements and she was happy with that. So I just walked down to the bank with her one afternoon. But most of the time, we hand it over to families or a person holding the EPA.

Managing 'risk'

Managing risk also presented a barrier to supporting residents to remain involved in decision making about money and property. Risk in relation to a resident's involvement in banking and other asset management tasks was primarily handled by referring financial decisions to family members or appointed attorneys rather than supporting the resident to remain

involved. The day-to-day management of money and valuables in the facility was, however, a core concern of the care managers, all of whom sought to minimise the risk of money and valuables being mishandled, lost or stolen and to reduce allegations against staff of theft or undue financial influence. All senior staff saw the management of such allegations as extremely difficult and time consuming. They reported that the best option they have found is to ask residents to keep no or very small amounts of cash in their rooms. All the facilities actively discouraged bringing valuables, especially jewellery and money into the home, and all had transparent and well-developed practices around handling residents' money and to protect the residents' cash and valuables. Policies and practices that promoted resident involvement in decision making, however, were much more limited because the facilities managed risk by reducing residents' access to money and valuables. A business manager summed up his approach:

> The families are always advised when their family member comes in to keep their personal property down to a very minimum. ... I think it should be a regulation that they leave those sorts of personal belongings at home. Even though it should be their right to bring them in.

Cash was most commonly held at the office rather than in residents' rooms, and/or any incidental expenses for outings or shopping were often debited to the resident's account so that cash was not directly handled. For example, one care manager indicated that money is debited to the account 'when the resident has their hair done etc., newspaper and any other ongoing things so that makes life a lot easier for the resident'. A personal care worker explained the procedures associated with outings:

> We get a blank cheque from [the general manager]. We order the meals and we order drinks and it is just one cheque and the receipt comes back to the office. The names are recorded of the people who went on that bus trip and they work out ... how much is owed [and then it is taken from the accounts].

Removing access to cash and valuables is an appropriate practice for protecting older people's assets and property and reducing the likelihood of allegations against the staff, but it pays scant attention to the residents' independence. Some staff, however, recognised the importance of access to cash for some residents. As one carer said:

> But if they get very worried about that then I usually get the office to ... give them a bit of cash so they do have some money and it stops playing on their mind that they have got nothing ... it could just be $5 or $20 ... as long as they have some money there in their pocket, that seems to be important.

This was particularly apparent in one facility that accommodated people from culturally and linguistically diverse backgrounds where it was understood that having cash was especially important for post-World War II refugees who had arrived in Australia with few possessions. Over all the facilities, however, practice indicated that the priority was to manage risks by protecting assets and protecting staff from allegations of misconduct. One care manager recognised some of the moral and ethical dilemmas of encouraging capable residents to remain involved with their assets:

> We are aware that in a lot of cases you are taking away people's independence and their ability to manage. It is done from, hopefully, you know, taking the high moral ground that this is the best thing for that [managing concerns about loss and allegations of theft].

A manager in an extra-services facility that charged higher fees and provided for residents with significant assets also noted the challenges to independence in current policies and the variation is resident responses:

> I mean they lose their homes, they lose their life and they also to a degree lose their money. Some of them are quite happy to. Some are quite happy to come and act like it is a bank and some – I think – there should be more of an avenue where they can have some sort of banking structure [independent access to a bank] so that they can maintain that financial independence, especially for the boys. It is very important for the men.

Discussion

Across the four case studies, there were two consistent findings about older people's involvement in financial decision making in residential aged-care settings. Firstly, that constraints were placed upon their ability to be involved in decision making, both at the level of managing assets and in the day-to-day handling of money and valuables. Secondly, that only limited support was provided for the residents who were capable and wanted to be involved. The frequent outcome was the use of substitute decision makers as the easier option. These findings indicated the impediments to implementing a task-specific approach to the assessment of the capacity to make financial decisions. The analysis of the case studies suggested that the opportunities and constraints in residential settings for implementing the current legislative principles that promote assisted decision making are defined by three intersecting factors: staff attitudes towards older people's rights to manage their assets, staff levels of knowledge of how to support substitute decision making, and the level of resources required to implement supported decision making.

The primary drivers of current policies and practices in the four ACFs were risk minimisation and resource constraints, together with a view that managing residents' financial assets is primarily the concern of family members. Staff involvement in supporting residents with their financial

assets was generally viewed as a risky and resource-intensive area of care practice. For some, it was simply was not regarded as part of their role. As a result, protection of staff time and reputation and the older person's assets were prioritised over empowerment and inclusion of the older person in decision making about their resources.

Substitute decision making mechanisms such as EPAs facilitate ease of asset management on behalf of older people and the identification of people with authority to act as proxy decision makers. This was an important resource for care providers, family members and for residents who were unwilling or unable to participate in decisions about financial matters, but the case studies show the limited understanding of the legislation and the principles underpinning the EPA instrument. While some staff had a sound understanding, inappropriate interpretations of EPAs were also noted. Some staff viewed the attorney as the primary decision maker regardless of any assessment of the nature of the asset management task or decision and the resident's capacity to make that decision or complete that task. In these situations, the older person's preferences were not explored. This misunderstanding and misuse of EPAs has been noted in earlier research on the practices of family members involved in managing older people's assets (Tilse *et al.* 2007*b*; Wilson *et al.* 2009). Resorting to using a substitute decision maker for all financial decisions provides informal and formal carers with a simple and convenient alternative to the more time-consuming practice of assisting older people to remain involved in decision making. In residential settings it can also reduce the risk of misuse and avoid potential conflict with residents' families at the expense of older people's rights.

The implementation of assisted decision making requires resources and support. The environmental and resource constraints revealed by this study showed the limitations of the support available and that this area of practice is under-developed. Although substitute decision making is well developed in legislation in Queensland, in many cases the strategies to achieve this and the resources associated with promoting assisted decision making and involving older people in asset management are inadequate (Tilse, Wilson and Setterlund 2009; Wilson *et al.* 2009). All facilities in the case studies provided safe areas for valuables. There was only limited evidence, however, of other environmental accommodations to assist older people to stay engaged in the tasks and decisions they were able to make (*e.g.* provision of accounts in large print, access to telephone and computers in aged-care facilities to assist the minority who seek to self-manage, transport to financial institutions and shopping). An understanding of day-to-day assessment of decision-making capacity in relation to a particular task also appears to be limited, with residents often viewed in a

dichotomous way – as either being able to self-manage or as requiring family or trustee assistance.

Resource constraints affected opportunities to include older people in decision making. Taking time to assess capacity to make a decision in relation to a particular task, check that information is understood and communicate preferences creates extra tasks for residential-care staff. There was limited support for such tasks and few resources for innovative or experimental practices. Although the right to remain involved in financial affairs is recognised in the *Charter of Residents' Rights and Responsibilities* (Australian Government Department of Health and Ageing 1997), the regulators do not have specific guidelines on what this means in practice and do not assess this when accreditating facilities. In aged-care facilities where managing costs is a significant issue, providing the additional support needed for residents who wish to remain engaged with managing their financial matters is likely to be low priority and dependent on the particular interest and good will of staff members. In residential care facilities, the staff need the support of management to engage with time-consuming assisted decision making especially in relationship to financial matters where there can be risk of suspicion regarding the motives of care staff and possibly also family discord to be dealt with. Some staff in the smaller facilities provided examples of an individualised approach to assisting residents. Such tasks were often undertaken outside working hours in the staff member's own time.

Conclusions

Protection and risk management dominate current practice in aged-care residents' financial decision making, and limited attention is given to developing the skills and the resources required to assist older people to participate in the decisions they are able to make. Legislative principles are clearly not sufficient to ensure inclusive practice. Effecting change will require diverse strategies and commitment from a range of services and groups. To enact the spirit of substitute decision-making legislation in care contexts, all parties need to be aware of their rights and obligations, and all stakeholders need to be prepared and resourced to attend to older people's individual needs and capacities – in this case in relation to asset management – and to understand and respond to those needs and capacities as an integral part of their wider care. In communal environments such as residential care, providing individual attention, assessment and support in this domain of decision making can be easily overlooked and is poorly resourced.

In the UK, Chapter 3 of the *Mental Capacity Act 2005 Code of Practice* (UK Department of Constitutional Affairs 2007) provides practical guidance on how to support people to make decisions for themselves, or to maximise their role in decision making. This advice needs to be viewed in the wider context of resource allocation and service priorities. Johns (2007) and Manthorpe, Rapaport and Stanley (2008) noted the time and resource issues for professionals and informal carers resulting from their changing roles and responsibilities. Dwyer (2005: 1089) provided one example of time and resource constraints impacting on social workers' ability to work with the decision-making processes of some older people when decisions are to be made about permanent care. This example predates the introduction of the *Mental Capacity Act 2005* in the UK. It does suggest, however, that exploring how supported decision making is practised and resourced in line with the principles of this Act is an important area for further scrutiny by this profession.

Appropriate practice in line with current legislation involves an assessment of the context and the decision, an assessment of capacity to make the decision or the support needed to participate in decision making and the adult's wishes and beliefs and values (Letts 2009). For care providers, the need to be clear about when such practice is a moral and ethical responsibility and when identifying best interests is also a legal duty adds to the complexity of practice in this domain of care. These constraints on carers, paid or otherwise, need to be considered by government in the context of current regulatory requirements and funding arrangements in health and social care.

Practice in relation to assisted decision making involves skills in balancing power and risk, protection and independence in particular contexts. It also requires skills in assessing decisional capacity in relation to particular asset management tasks and resources to support and sustain the desired level of involvement of the older person. Improving practice will therefore need a commitment from residential care providers, funding and regulatory bodies, and adult protective services to challenge environmental and attitudinal barriers to the involvement of older people. In addition, education and support is needed for formal and informal carers in assessing capacity for a particular task and ensuring resources are available to support older people to make decisions or carry them out. Education and services that assist in recognising undue influence and resolving disputes between different players will also form part of an array of responses needed to improve practice.

Current and accurate knowledge of the principles underpinning legislation in relation to capacity and substitute decision making, attention to the attitudes and practices that restrict older people's involvement, and

resources to support innovative practice in residential care are urgently needed. The first steps are to recognise what constitutes inclusive practice in this contentious area of care provision and to develop the resources needed to support such practice. The challenge is to develop a range of practices around assisted and substitute decision making that truly reflect the diverse needs and interests of older people. Listening to the voices of people in their 'fourth age' and therefore treating them as citizens requires special effort (Scourfield 2007). This entails avoiding broad assumptions with respect to older people's interest and capacity to be involved in decision making about their finances and property and instead rising to the challenge of finding ways to represent older people in all their diversity.

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NOTES

1 In presenting the interview data, the formatted paragraphs are direct quotations, with the authors' glosses in square brackets. Some short direct quotes are embedded in the main narrative.

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2011

Enduring Documents

Improving the forms, improving the outcomes

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LPITAF Grant No 45 2009-10

Preface

A large number of people across Queensland made this research possible.

Many people participated in face to face interviews, focus groups and surveys. We thank them all most sincerely. The research done with Torres Strait Islander and Murri Indigenous people was conducted by Dr Noritta Morseu-Diop, a respected member of the Aboriginal and Torres Strait Islander Communities. The team sincerely thanks Dr Morseu-Diop, the Elders she consulted and the Torres Strait Islander and Murri respondents for their careful and detailed feedback on the use of Queensland Government enduring documents in Indigenous communities. Carlie Rocco and Angela Setterlund worked very hard to coordinate and carry out a complex piece of research. Their diligence and perseverance are much appreciated by the team.

Although the research team worked on the project and this report as a group, the QUT members of the team had carriage of Part C (AHDs) of the report and the UQ team had primary responsibility for Parts A, B and D.

The research was very ably supported by a critical reference group that guided the development of the interview and survey instruments and provided their own detailed feedback on the use of Enduring Powers of Attorney and Advance Health Directives. Members of this group were Clinton Miles (PT), Ron Joachim (QCAT), Dimitri Glianos (JP Branch DJAG), Richard Kidd (General Practitioner), Peter Kruger (Intensivist), Annelise van Deth (QADA), Crystal Aitchison (Social Worker, ACAT), Will Cairns (Palliative Care Specialist), Chris Davis (Geriatric and Rehabilitation Specialist) and Lindsay Irons (OAG and Public Advocate).

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Table of Contents

List of Tables and Figures

List of Abbreviations

AHD	Advance Health Directive
ATSI	Aboriginal and Torres Strait Islander
EPA	Enduring Power of Attorney
CALD	Culturally and Linguistically Diverse
CRG	Critical Reference Group
Com.Dec.	Commissioner for Declarations
DJAG	Department of Justice and Attorney General
JP	Justice of the Peace
OAG	Office of the Adult Guardian
PT	Public Trustee
QADA	Queensland Aged and Disability Advocacy Inc.
QCAT	Queensland Civil and Administrative Tribunal
QJA	Queensland Justices Association
QLRC	Queensland Law Reform Commission

Executive Summary

Most Australian states have introduced legislation to provide for enduring documents for financial, personal and health care decision making in the event of incapacity. Since the introduction of Enduring Powers of Attorney (EPAs) and Advance Health Directives (AHDs) in Queensland in 1998, concerns have continued to be raised by service providers, professionals and individuals about the uptake, understanding and appropriate use of these documents. In response to these concerns, the Department of Justice and Attorney-General (DJAG) convened a Practical Guardianship Initiatives Working Party. This group identified the limited evidence base available to address these concerns. In 2009, a multidisciplinary research team from the University of Queensland and the Queensland University of Technology was awarded $90,000 from the Legal Practitioners Interest on Trust Account Fund to undertake a review of the current EPA and AHD forms.

The goal of the research was to gather data on the content and useability of the forms from the perspectives of a range of stakeholders, particularly those completing the EPA and AHD, witnesses of these documents, attorneys appointed under an EPA, and health professionals involved in the completion of an AHD or dealing with it in a clinical context. The researchers also sought to gather information from the perspective of Aboriginal and Torres Strait Islander (ATSI) individuals as well people from culturally and linguistically diverse (CALD) groups. Although the focus of the research was on the forms and the extent to which the current design, content and format represents a barrier to uptake, in the course of the research, some broader issues were identified which have an impact on the effectiveness of the EPA and AHD in achieving the goals of planning for financial and personal and health care in advance of losing capacity.

The data gathered enabled the researchers to achieve the primary goal of the research: to make recommendations to improve the content and useability of the forms which hopefully will lead to an increased uptake and appropriate use of the forms. However, the researchers thought it was important not to ignore broader policy issues that were identified in the course of the research. These broader issues have been highlighted in this Report, and the researchers have responded to them in a variety of ways. For some issues, the researchers have suggested alterations that could be made to the forms to address the particular concerns. For other issues, the researchers have suggested that Government may need to take specific action such as educating the broader community with some attention to strategies that engage particular groups within communities. Other concerns raised can only be dealt with by legislative reform and, in some of these cases,

the researchers have identified issues that Government may wish to consider further. We do note, however, that it is beyond the scope of this Report to recommend changes to the law.

This three stage mixed methods project aimed to provide systematic evidence from a broad range of stakeholders in regard to: (i) which groups use and do not use these documents and why, (ii) the contribution of the length/complexity/format/language of the forms as barriers to their completion and/or effective use, and (iii) the issues raised by the current documents for witnesses and attorneys.

Understanding and use of EPAs and AHDs were generally explored in separate but parallel processes. A purposive sampling strategy included users of the documents as principals and attorneys, and professionals, witnesses and service providers who assist others to execute or use the forms. The first component of this study built on existing knowledge using a Critical Reference Group and material provided by the DJAG Practical Guardianship Initiatives Working Party. This assisted in the development of the data collection tools for subsequent stages. The second component comprised semi-structured interviews and focus groups with a targeted sample of current users of the forms, potential users, witnesses and other professionals to provide in-depth information on critical issues. Outreach to Aboriginal and Torres Strait Islander Elders and individuals and workers with CALD groups ensured a broad sample of potential users of the two documents. Fifty individual interviews and three focus groups were completed. Most interviews and focus groups focused on perceptions of, and experiences with, either the EPA or the AHD form. In the interviews with Indigenous people and the CALD focus groups, however, respondents provided their perceptions and experiences of both documents. In general, these respondents had not used the forms and were responding to the documents made available in the interview or focus group. In total, seventy-seven individuals were involved in interviews or focus groups. The final component comprised on-line surveys for EPA principals, EPA attorneys, AHD principals, witnesses of EPAs and AHDs and medical practitioners with experience of AHDs as nominated and/or treating doctors. The surveys were developed from the initial component and the qualitative analysis of the interview and focus group data. A total of 116 surveys were returned from major cities and regional Queensland. The survey data was analysed descriptively for patterns and trends. It is important to note that the aim of the survey was to gain insight into issues and concerns relating to the documents and not to make generalisations to the broader population.

Summary of the main findings

Enduring Power of Attorney

Overall, the EPA was generally seen to work well for people as principals, witnesses and attorneys who are well informed about the purpose and operation of EPAs. However for those

principals who are less informed or who have appointed attorneys who do not understand or follow the legal duties imposed by EPAs, it is suggested some modifications to the form would be useful for both parties. Some groups in the community, notably CALD and Indigenous peoples, are less likely to be well informed about the EPA but believe with appropriate supporting material, education and assistance this legal mechanism could be very useful personally and to their communities.

Broad principles have been identified which support wider use of the form and seek to improve the integrity of the practices surrounding the execution and use of the EPA, balancing ease of access and use with appropriate safeguards for principals and attorneys.

Recommendations are made in relation to widening knowledge of the EPA legislation and forms and making the forms and their associated information more accessible to the wider community. Most respondents completed the form without legal advice. Those who did access legal advice did not necessarily have a better understanding of the implications of the document as they had not necessarily been 'walked through' the document. However, those principals who understood the powers conferred were more likely to recommend the use of legal advice. The research team supports the current approach that does not require legal advice to complete the form. For those who choose not to access legal advice, the Government may wish to consider the further development of resources and educational strategies to train health and human service workers who currently assist adults to complete an EPA. Linked to this set of recommendations, the data support a greater emphasis on assisting attorneys to understand their powers and obligations and some restructuring of the form and the explanatory notes to emphasise the importance of reading Parts 1 and 3 and understanding the scope of their powers and responsibilities.

A common area of misunderstanding was the meaning of the term 'immediately' in relation to when the power for financial matters comes into effect. The confusion related to whether 'immediately' referred to the completion of the form or on loss of capacity to make financial decisions. Recommendations are made in relation to the use of this term to clarify such misunderstandings. Most people did not use special conditions for a range of reasons. The research team does not support the use of multiple special conditions that would unduly limit the ease of use of the document by the attorney. It does recommend changes to the form that would clarify the circumstances in which special conditions are useful and the provision of appropriate examples. A further area of concern for principals and attorneys was confusion about the language in Clause 7 in relation to how decisions by attorneys are made. It is suggested that the language in this Clause could be simplified, and linked to an information section with the available options illustrated by examples to clarify the implications of the choices made for the attorney and the principal.

The role of witnesses received little comment from principals and attorneys. Lawyers, Justices of the Peace (JPs) and Commissioners of Declaration (Com.Decs.) had various views on the

competence of the other for this role. Lawyers were involved in drawing up as well as witnessing EPAs and therefore had a wider set of responsibilities than assessing capacity and keeping records, as is the case for JPs and Com.Decs. It is recommended that there be ongoing training and the provision of resources to assist with their role of assessing capacity and that the comments on the form in Part 2, instructions for witnesses, reassert that witnesses should refuse to sign if in doubt about the principal's capacity. Including in the instructions for witnesses some reference to appropriate guidelines for assessing capacity is suggested. Greater attention to appropriate record keeping is also highlighted.

On the whole this study reports on the experiences of people who have completed EPAs as principals. However, when people who had not completed an EPA did participate, they reported that they were keen to understand and use the documents. The main barriers to making an EPA were first, not knowing they existed, and second, understanding the wording and implications of the document. This suggests the importance of targeted awareness and information campaigns about EPAs for specific groups in the community who are interested in the concept of an EPA but unaware of its existence. Different groups will require different strategies and resources to make EPAs accessible. They may also require modification of the language and assistance with being 'walked through' the document to ensure they understand the implications of the powers they are giving their attorney(s). This point was made most strongly by the Torres Strait Islanders and Murri respondents, and by the CALD focus group.

A number of specific matters were raised in relation to the structure and content of the material in the EPA form. While many respondents agreed that the information is appropriate, that it is presented in an engaging fashion, and that it should be read by all parties, there is a significant minority who struggle to understand both the meaning of many terms used and the implications of the questions for future decision making. Specific recommendations are made in relation to ATSI people in relation to this point. There are also a number of terms that cause problems, and questions in areas such as how long the power of an attorney continues, how the power ends, how to modify the form, and what to do with a completed document. Specific recommendations are made in relation to a range of such matters.

A consistent point of discussion by respondents was the desirability or otherwise of separating the explanatory notes from the form itself. The research team has come to the view that the current format should be retained with the addition of specific explanatory booklets for particular groups (for example ATSI or CALD groups) and for particular roles (for example attorneys and witnesses). There was also broad discussion around the extent to which the information in the form should be explicit about supporting assisted and substitute decision making, and encouraging principals to share their decisions as outlined in the EPA with relevant people within or outside the family. These processes could be the subject of specific information booklets.

Advance Health Directive

Overall, the AHD form works well for the principals who participated in our research. While the principals noted the form was long, they felt that all the information contained in the form was necessary and could not be deleted. They also reported that it was relatively easy to complete and generally not confusing despite a small number of questions being repetitive. Generally, principals reported that the language of the form was simple and easy to understand.

The researchers are aware that the principals who completed the survey were mostly highly educated (67% with postgraduate education), suggesting they would be better equipped to complete an AHD than many in the wider community. The research also revealed that individuals from CALD and ATSI communities would have significant difficulty in completing the form. However, rather than altering the form to make it easier to complete for more members of the community (which would have implications for legal compliance and effectiveness of the form as an advance planning document), the Report suggests other strategies that can assist with uptake for members of the community who may need assistance to complete the form.

On balance, the current content and level of formality of the form is appropriate and the researchers do not recommend a major overhaul of the form. In this regard, the Report contains recommendations about reordering of some sections, some additional information that could be included in the form, and specific suggestions about clarifying some aspects of the form.

A reasonable amount of assistance exists for those seeking to complete an AHD, both on the form itself and from other sources. The problem appears to be that this information is not accessed by many members of the community. The Report recommends that targeted strategies are needed for different cohorts to publicise the AHD and to assist in completing it. Additional support may be required by some individuals including those from CALD and Indigenous backgrounds. Because of particular challenges faced by Indigenous communities, a specifically designed information booklet should be developed, and designed in a way that is attractive to and accessible by members of those communities.

Despite the publicity given to AHDs when the legislation was originally passed, the research reveals a general lack of knowledge about the AHD as an advance planning tool. This lack of awareness is particularly evident in the Indigenous and CALD communities. Given the increased focus on advance planning over the past decade and the ageing of the Australian population, it is important to again promote the AHD as an important document to be completed as part of planning for our future. The Report makes recommendations about the need to educate the community about the role of AHDs, as well as the need to make hard copies of the document more readily available in a range of locations, and at no cost to individuals wishing to complete

it. Recommendations are also made about the need to involve both doctors and lawyers in encouraging individuals to consider the need to complete (and regularly review) AHDs.

An important tension identified by the research was the different perspectives about the role and use of the AHD that are held by the principals who complete the form, and the doctors who treat them. While principals reported that they complete the form to ensure their life is not prolonged against their wishes, doctors are motivated by the desire to provide good patient care and, in some cases, express concern that the AHD may be a barrier to the provision of such care. More particularly, some doctors expressed concern that the directions contained in the AHD may not reflect the real intention of the principal. Doctors are concerned that the document is (or might be) completed in a situation where the actual medical event that arises is not contemplated, so that the direction is not one based on relevant information.

Reflecting this tension, different views were expressed about whether the AHD should allow a principal only to express their wishes about 'quality of life outcomes', rather than specific directions about particular medical treatment to be received or refused. The researchers grappled with this tension and made recommendations that attempted to strike a balance between providing a sufficient degree of self-determination to a principal who wishes to give specific directions about treatment, while offering safeguards to ensure treatment is not refused in situations not contemplated by the adult.

While the doctors participating in this research generally had a sound understanding and acceptance of the legal and ethical imperative to follow the patient's instructions in the AHD, the Report recommends that doctors receive ongoing education about their legal obligations as treating doctors when a patient has completed an AHD.

The task of assessing a principal's capacity to complete an AHD is also a complex one, and doctors as well as witnesses would benefit from learning more about the nature of the legal test for capacity in this context, as well as how to assess capacity for this purpose. The Report includes recommendations in this regard.

Indigenous and CALD perspectives

Overall, respondents from these two groups agreed with the issues raised in the other interviews about the EPA and AHD forms. They were keen to see that there was greater awareness of the forms in their communities and that appropriate assistance was provided for people who may have difficulty filling them out because of the challenges the English language presented or because of the cultural implications of some of the decisions. Some modification of the forms to give space to outline preferences linked to family structures and decision making processes was suggested. Indigenous respondents offered a range of suggestions about the presentation of the forms to make them more inviting for their community members. They also strongly supported making the forms freely available in services used by Indigenous people.

Indigenous respondents were generally reporting anticipated issues rather than their own experiences. In this context they highlighted difficulties with a larger number of terms than were identified by other respondents. A lack of familiarity with the organisations referred to such as the Adult Guardian or the Public Trustee or other legislation or forms mentioned in the documents suggested the need for further explanations, generally in a booklet targeting Indigenous groups.

Concluding comments

This Report recommends a number of changes in the wording and ordering of the forms. It recognises the difficulties of producing a document in easy English that is also exact in legal terms, but supports further effort in this regard. It supports strategies that will contain the costs of completing the forms and hence proposes that the documents should be in a form that enables people to fill them out with minimal assistance. It also supports strategies that lead to documents that accurately reflect the wishes of people and support attorneys to do a sometimes difficult job well. To these ends it supports the ongoing inclusion of clarifying information in the forms but also suggests the development of additional information booklets, DVDs and training for attorneys and witnesses in particular, and for Indigenous and CALD groups who have requested additional information. The Report recommends a range of ways of publicising the State's enduring documents and of providing assistance to community members to complete and appropriately use the documents. The research team recognise that enduring documents sit within processes and practices surrounding assisted and substitute decision making. Effective use of the documents will require developing understanding and good practice in this area.

A. Introduction

1. Background and context

In many countries, the need to provide for an extended period of older age and increasing numbers and proportions of older people with dementia have highlighted the importance of enduring documents to plan for later life decision making. In response, most Australian states have introduced legislation to provide for financial, personal and health care decision making in the event of incapacity. Despite promotion by government and others, concerns continue to be raised about the take-up and effective use of these documents such as enduring powers of attorney (EPAs) and advance health directives (AHDs). A national survey conducted by UQ researchers (including three of the research team for this project) revealed that 16% of adult Queenslanders had an EPA that was currently valid compared to a national average of 11.5%. An earlier UQ study with older people and carers revealed limited understanding of the purpose of EPAs which varied across social groupings.[1] Since that time, concerns have been raised about limited take-up, limited understanding of the role of the attorney and/or family members in financial management,[2] misuse of EPAs by attorneys[3] and the lack of a consistent national approach in legislation and terminology.[4] In 2007, the Department of Justice and Attorney-General (DJAG) convened a Practical Guardianship Initiatives Working Party in response to concerns about the understanding and use of these forms. These concerns were primarily identified by the Public Trustee of Queensland and the Guardianship and Administration Tribunal (as it then was) in relation to EPAs, and Alzheimer's Australia and the medical profession in relation to AHDs. In 2009, the research team was awarded $90,000 from the Legal Practitioners Interest on Trust Fund Account to undertake a review of the current EPA and AHD forms.

This research occurs against the backdrop of a range of reviews in a number of jurisdictions where comparable forms were under active consideration, either directly, or indirectly as part of a wider review. In Queensland, the law that governs EPAs and AHDs was part of the

[1] Setterlund, D, Tilse, C & Wilson, J 2003, "Older people and substitute decision making: limits to informed choice", *Australian Journal on Ageing,* vol. 21,no.2, pp. 128-133.

[2] Tilse, C, Wilson, J, Setterlund, D & Rosenman, L 2005, " Older people's assets: a contested site", *Australian Journal on Ageing,* vol. 24, Special issue, pp. S51-56.

[3] McCawley, A, Tilse, C,, Wilson, J, Rosenman, L & Setterlund, D 2006, "Access to assets: older people with impaired capacity and financial abuse", *The Journal of Adult Protection,* vol. 8, no. 1, pp.20-32.

[4] The Parliament of the Commonwealth of Australia 2007, *Older People and the Law.* Available at http://www.aph.gov.au/house/committee/laca/olderpeople/report/front.pdf.

Queensland Law Reform Commission's (QLRC) terms of reference in its recently completed Guardianship Review.[5] Although that reform exercise focused on the law rather than the forms, the QLRC made a number of recommendations relating to the forms. Some of these recommendations related to ensuring that the form adequately reflected the relevant law, for example, changing the example given of a 'conflict transaction' in the EPA form so that it is legally accurate. The QLRC also made recommendations directed at promoting informed decision making in relation to AHDs such as prompting principals to consider unforeseen circumstances and regularly reviewing their choices. Another set of recommendations relate to the witnessing and execution of EPAs and AHDs. Examples include making reference to relevant capacity assessment guidelines in the forms and advising principals to ensure that any copies are properly certified in accordance with the legislation. These recommendations, where relevant to this project, are referred to in the Report that follows. We note, however, that the QLRC has recommended a range of reforms to the law that governs EPAs and AHDs. The recommendations contained in this Report have generally not sought to pre-empt whether those proposed changes would become law and so are premised on the current legal position.

Other policy work in Queensland has focused on promoting advance care planning. Queensland Health's initial efforts were directed towards planning for acute events that may require resuscitation[6] but a wider advance care planning program has also begun.[7] Although not focused on the EPA and AHD forms, these initiatives are designed to enhance awareness of advance care planning amongst health professionals and the public.

Advance care planning has also been the subject of recent review at national level. The Australian Health Ministers' Advisory Council has expressed a wish to develop a 'national framework' for 'advance care directives' (which in that context is defined broadly to include AHDs and EPAs for health matters) and has issued a consultation document seeking views.[8] This is, at least partly, in response to concerns about the wide variation of laws in this area across Australia. One of the issues the consultation document addresses is 'Best practice standards for policy, law, forms and guidelines'. Provisional recommendations include making forms available at no cost and accessible. They should be accompanied by guidelines to assist

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[5] Queensland Law Reform Commission, *A Review of Queensland's Guardianship Laws,* Report No 67 (2010) Vol 1-4.

[6] Queensland Health, Resuscitation Planning. Available at http://apps.health.qld.gov.au/acp/Public_Section/Resuscitation_Planning/resuscitationPlanning3.aspx.

[7] Queensland Health, Advance Care Planning. Available at http://apps.health.qld.gov.au/acp/HOME.aspx.

[8] Clinical, Technical and Ethical Principal Committee of the Australian Health Ministers' Advisory Council, *A National Framework for Advance Care Directives: Consultation Draft* (2010). Available at: http://www.hwlebsworth.com.au/acdframework/ACD%20Draft%20Framework%20complete%20document.PDF .

principals completing them. Other matters considered are the importance of 'goals of treatment' as opposed to just refusing specific medical treatment, distinguishing between directions given in relation to temporary and permanent loss of capacity, and broadening directives to include situations other than just end of life decision making.

Recent reviews in Australia and the United Kingdom have explored the effectiveness of enduring forms and the information provided. A 2009 South Australian review[9] of advanced directive forms and guidelines recommended that forms/guidelines be readily available and free, be in simple, non legal language that is easily understood by people with different language and cultural background and different levels of education, and be sufficiently flexible to accommodate those who wish to appoint an attorney without writing specific instructions and those who want to write a range of instructions for different attorneys. The review noted that comprehensive guidelines for principals, attorneys and witnesses are the basis for effective use. The South Australian review suggested the forms should be separate from the guidelines but logically linked and distributed together as a kit and that advice for principals, attorneys and witnesses should all be within the same guidelines with all parties signing a declaration that they have read the guidelines. Suggestions were also made about checklists, prompts and anecdotes to generate discussion and a 'decision making pathway' developed. This review also recommended that witnesses be JPs who have completed an accredited training course.

A consultation paper in the United Kingdom (Ministry of Justice UK 2009),[10] reviewing the lasting power of attorney forms of the UK *Mental Capacity Act 2005*, noted that the forms were designed to strike a balance between useability and protection. This paper highlighted the difficult choices posed by seeking to balance (i) conciseness and the inclusion of critical information and (ii) legal accuracy and accessible language. These are challenges to the current review of the forms in Queensland. In the UK, criticisms of the forms included the length, complexity related to legal language, and poor design that led to some sections being overlooked.

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[9] 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). Available at <http://www.agd.sa.gov.au/news/pdfs/2009/AG_Report_1_final_300808.pdf> accessed April 2010 and South Australian Advance Directives Review Committee, *Advance Directives Review — Planning Ahead: Your Health, Your Money, Your Life. Second Report of the Review of 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> accessed April 2010.

[10] Ministry of Justice (UK),2009, *Reviewing the Mental Capacity Act 2005: forms, supervision and fees*. Response to consultation. 2009. Available at

http://webarchive nationalarchives.gov.uk/+/http://www.justice.gov.uk/docs/reviewing-mental-capacity-act.pdf

Recommendations in the responses included the use of plain English, avoidance of complex language and legal jargon where possible and the combination of the forms with the guidance notes. It is interesting to note that the review reverted to legal language of 'jointly' and 'severally' rather than a plain English version citing a concern that the plain English version was legally imprecise.

Recent reviews, research and practice in relation to EPAs are concerned with finding the best way to ensure the information and the forms are accessed, executed and used appropriately. A tension also exists between promoting access to legal advice to execute an EPA and ensuring the document is accessible and affordable to a range of population groups.

In Queensland, systematic evidence from a broad range of stakeholders is currently lacking in regard to: (i) which groups use and do not use these documents and why (ii) the contribution of the length/complexity/format of the forms as barriers to their completion and/or effective use and (iii) the issues raised by the current documents for witnesses and attorneys. The research project aimed to provide evidence in all three areas as a basis for any revision of the forms. Enduring documents that are easy to understand and to complete are more likely to be executed by individuals. Well designed forms are also more likely to be used effectively and appropriately by professionals, service providers, individuals and families.

2. Research design

2.1. Overview

The three stage mixed methods research design sought to include the concerns of diverse groups of users of EPA and AHD documents. The purposive sampling strategy included (i) consumer groups – people who have used or might use the form as principals or attorneys and (ii) professionals, service providers and witnesses who assist others to complete the form or are involved in helping others use the form, or who rely on the form, for example, when treating a patient. The three stage research design comprised:

Stage 1 **Forming a Critical Reference Group (CRG).** This group provided expert input and assisted in summarising existing knowledge. The project built on existing knowledge by working with this reference group and considering the issues raised by the DJAG Practical Guardianship Initiatives Working Party. The issues raised in these groups provided the foundation for the questions in Stage 2 interviews.

Stage 2 **Semi-structured interviews and focus groups with a purposive sample of key stakeholders.** Semi-structured individual interviews and focus groups provided a depth of information on critical issues. This informed the development of a short, targeted web based survey for Stage 3. Fifty individual interviews and three focus

groups with 27 respondents were completed. The interviews included principals, attorneys, witnesses, medical practitioners and other professionals/service providers. This stage also involved a targeted approach to include Aboriginal and Torres Strait Islander people and Queenslanders from culturally and linguistically diverse backgrounds. Overall, 77 people were involved in interviews and focus groups.

Stage 3 **An on-line survey of a purposive sample of consumer and user groups for EPAs and AHDs.** The survey questions were informed by the analysis of Stage 2 interviews, the issues raised by the DJAG Practical Guardianship Initiatives Working Party and consultation with the reference group members. On-line surveys provided the opportunity to include a broader group of respondents and to explore satisfaction with the current forms, identify areas of agreement/disagreement with the issues raised and note any innovative ideas for change. 116 surveys were completed on-line.

2.2. Stage 1: Critical Reference Group and information from DJAG Practical Guardianship Initiatives Working Party

A Critical Reference Group formed in 2009 included representatives of key service providers and interested parties in relation to EPA and AHDs. The group included representatives from legal and advocacy organisations (Public Trustee of Queensland, Office of the Adult Guardian and Public Advocate, Queensland Civil and Administrative Tribunal, Queensland Aged and Disability Advocacy, Justices of the Peace Branch, DJAG), medical practitioners (an intensive care specialist, a palliative care specialist, a geriatrician and a general practitioner) and social work /ACAT team members. The group made comment on existing documents, raised issues derived from their roles and experience, reviewed the current forms as a basis for developing the questions for Stages 2 and 3 and provided input into the sampling strategy and data collection tools. A copy of the Terms of Reference for the group is attached (Appendix A). The group met with the research team three times and also provided comment and feedback by email.

In 2008, a working party was formed by the DJAG to (i) highlight the main practical obstacles or concerns that have been brought to the attention of the Department in regard to EPA and AHD forms and practices and (ii) suggest a way to progress a review of the EPA and AHD forms. For this group, the purpose of reviewing the EPA and AHD forms was to address the following identified issues:

- witnesses who are to attest to the capacity of the principal may execute the forms when the principal does not possess capacity;
- principals and attorneys not fully grasping the nature and effect of the powers given to the attorney (and when and how those powers can be revoked);

- forms are not user friendly and are too long; and
- reluctance by citizens to execute EPAs and AHDs due to the complex nature of the forms.

The issues paper developed from that working party also informed the data collection tools and the analysis.

2.3. Stage 2: Semi-structured interviews with individuals and groups

Semi-structured interviews allow for detailed examination of the forms and feedback on their content and useability. Copies of the relevant forms were provided in interviews and focus groups and used as the basis for discussion. This allowed for detailed and specific feedback. A copy of the interview guides are attached (Appendix B1- EPA; Appendix B2- AHD). The interviews and focus groups were audio recorded and transcribed by a professional transcriber. The transcripts were analysed descriptively and thematically. A purposive sampling strategy sought to include the perspectives of Aboriginal and Torres Strait Islander people, as this group of people currently appear to have very limited take up of the enduring documents.

Individual Interviews (50 respondents)

The purposive sampling strategy and wide ranging recruitment processes sought to recruit a diverse sample of informants for the interviews. The strategy for the interviews with principals and attorneys included advertising for respondents in organisational newsletters and/or on websites (e.g. National Seniors, Palliative Care Queensland, Alzheimer's Australia Queensland, Huntington's Queensland, Parkinson's Queensland, UQ staff Newsletter, Spinal Injury Association, Carers Queensland, Chronic Pain newsletter); ads in local community newspapers; and a request for volunteers in newsletters attached to UQ data bases (e.g. Over 50's register and Ageing Mind Initiative). An initial attempt to recruit respondents for focus groups had only limited success. Once a preference for individual interviews on these topics rather than a group interview was identified, respondents were offered the choice of individual interviews. Respondents who had completed one of the forms in the past two years were sought in the expectation that they would have reasonable recall of their experiences. All interview respondents had access to the relevant forms at the time of interview so that specific feedback could be given on the language and content of the form and the explanatory notes.

Professionals and witnesses with specialised knowledge about the use of the forms were recruited through individual invitation (e.g. an elder law specialist, a senior investigations officer with the Office of the Adult Guardian) and professional contacts of the research team and the Critical Reference Group members (e.g. a general practitioner, a director of a day respite centre, social workers and specialist medical practitioners in a public hospital, a justice of the peace, a commissioner of declaration).

EPA: Individual interviews were held with 21 people about their experiences with EPAs as health professionals (4), witnesses (7), principals (6) and attorneys (4). The interviewer had the long and short form of the EPA forms with them and questions focused, in one or more of these roles, on

1. Motivations and intentions in relation to having an EPA.
2. Qualifications and experience in relation to EPAs.
3. Capacity assessment of principals.
4. Understanding by principals and attorneys of the powers and obligations being conferred.
5. Use and useability of the forms.
6. Information provided on the EPA form.
7. Keeping records.

AHD: Individual interviews were held with 18 people about their experiences with AHDs as treating doctors (2), nominated doctors (2), other professionals who assist in completion of the forms (3), a witness (1), and principals (10). The interviewer had the AHD form with them and questions focused, in one or more of these roles, on

1. Motivations and intentions in relation to having an AHD.
2. Role of the nominated doctor in completing the AHD.
3. Practice of treating doctors with respect to a completed AHD.
4. The nature of directions for end of life decision making.
5. Use and useability of the forms.
6. Information provided on the AHD form.

EPA/AHD: Aboriginal and Torres Strait Islander people: Individual interviews were held with five Aboriginal and six Torres Strait Islander people. Respondents were recruited and interviewed by an Indigenous researcher who first undertook an extensive consultation process with Elders from the Murri community and senior representatives of the Torres Strait Islander community in Brisbane. The Elders provided valuable feedback on the forms and their use. After gaining permission from the Elders eleven Aboriginal and Torres Strait Islander people were interviewed. Each respondent was asked to comment in detail on the EPA short form and the AHD form. The interviews explored understanding the content and intention of the forms. Those interviewed had not used EPAs or AHDs. Respondents spoke about their own understanding and issues they considered relevant to their communities more broadly. This sample included men and women, an age range from 34 to over 60 and education levels from primary school to University. A separate section dealing with issues for this group is available in Section D of this Report.

Focus groups (27 respondents)

Social workers: Two focus groups were held with social workers in health/mental health settings. One focused on EPAs and the other on AHDs. Eight social workers reported on their experience with assisting patients with EPAs. Such workers generally become involved when there is a perceived need to have an EPA in place arising from illness/disability and/or hospitalisation or when misuse of an EPA is suspected. Four social workers commented on their experiences with AHDS. Social workers were recruited from a major public hospital.

CALD groups*:* One focus group with fifteen people from culturally and linguistically diverse (CALD) backgrounds explored issues of particular concern for such groups in relation to EPAs and AHDs. The use of three facilitators allowed for the large groups to operate as three smaller groups. The groups had access to the relevant forms. The respondents were service providers to CALD groups in south east Queensland through health services, family planning and/or the Ethnic Communities Council. The respondents were recruited through a coordinator with the Ethnic Communities Council.

2.4. Stage 3: On-line surveys

Surveys of a purposive sample of representatives of consumer and user groups were distributed in an on-line format using a web based survey tool (Survey Monkey). Two surveys were developed for EPAs to be completed as principals or attorneys. Copies of the long and short EPA forms were attached to the surveys so that respondents had the opportunity to consult the forms as they completed the survey. Two surveys were developed for AHDs to be completed as principals or as a treating and/or nominated doctor. One survey was developed for witnesses of EPA and AHDs. The survey questions were developed from issues raised in the Stage 2 interviews and in consultation with the Critical Reference Group. Descriptive statistics report on patterns and trends in the survey data. Copies of the five surveys are attached (Appendices C1-5).

The on-line surveys were distributed through e-newsletters and contacts in a broad range of organizations, including: National Seniors; Carers Queensland; Palliative Care Queensland; QUT Alumni; Womensport Queensland; Spinal Injury Association; and rural women's health network. Professional networks approached included: GP partners, Seniors Legal and Support Services across Queensland and networks of the Critical Reference Group members (e.g. health staff in a major public hospital, Queensland Justices of Peace Association, Queensland Civil and Administrative Tribunal, Elder Law Committee of Queensland Law Society; Australian Medical Association of Queensland). Flyers with information about the on-line surveys were also distributed at a consumer health forum in Brisbane and a regional forum on later life decision making hosted by the Public Trustee of Queensland. The on-line survey allowed for participation

of regional and remote informants as well as those in major urban centres. Across all groups, 116 surveys were returned.

Survey sample EPAs

In relation to EPAs, 53 surveys were completed (30 as principals, 23 as attorneys). The sample is generally of well educated users of the documents with an overrepresentation of tertiary education for principals and attorneys, some of whom also have relevant professional backgrounds in health, finance or law. Although there is a broad age range, there is also an overrepresentation of women, people born in Australia and with English as the first language. No Aboriginal or Torres Strait Islander person completed the survey as a principal; one attorney identified as Aboriginal or Torres Strait Islander. To describe geographic distribution, the postcodes provided were categorised using ABS categories for major cities, inner regional, outer regional and remote areas. As the numbers are small and there is some overlap where respondents lived in post codes areas that contain parts of regional or urban centres, location is simply reported as major city or regional. It is of interest to note that 35% of principals and 44.5% of attorneys were from regional areas.

The sample group of principals and attorneys primarily comprises people who are least likely to have difficulties in reading and interpreting the form. Any problems they identify in reading, interpreting and/or using the form are likely to be much greater for those in the population with more limited education and English language skills.

Table 1. Survey sample: EPA principals and attorneys

Sample characteristics	**Principals n=30**	**Attorneys n=23**
Gender % Women Men	79 21	81 19
Age Range Median age	27-72 55 years	24-72 50 years
Education: % with tertiary degree	79	81
Birthplace: % born in Australia	79	94
First language: % English	92	94
Location % Major cities Regional	65 35	55.5 44.5

Survey sample AHDs

Two surveys were developed for AHDs to be completed as principals or as medical practitioners acting as nominated or treating doctors. 37 surveys were completed (26 principals, 11 doctors as nominated or treating doctor).

Table 2. Survey sample: AHD principals

Sample characteristics	**Principals n=26***
Gender % Women Men	94% 6
Age Range Median age	43-77 60 years
Education: % with tertiary degree	72
Birthplace: % born in Australia	72
First language: % English	83
Location: % Major cities Regional	67 33

* Note: only 18 provided demographic details

The sample of principals for AHDs is of generally well educated users of the documents with an overrepresentation of tertiary education. Some also had other experience of AHDs as an attorney, a witness or as part of work or training. More than half of respondents (11 of 18) also had relevant professional backgrounds in health or law. The age range was from middle to later years with an overrepresentation of women, people born in Australia and English as the first language. No Aboriginal or Torres Strait Islander person responded to the survey. The respondent group is again generally a group very unlikely to have difficulties in reading and interpreting the form. Any problems they identify in reading, interpreting and/or using the form are likely to be much greater for those in the population with more limited education and English language skills.

Respondents included a mix of partnered and single respondents, two-thirds of whom had children aged over 18 years. Care must be taken in interpreting theses results as, although twenty six people responded, only 18 completed the full survey.

As only eleven doctors completed the survey, results should not be considered representative of this group; rather they provide insight into the range of attitudes and approaches. Of the six doctors who provided demographic information, five reported over ten years of practice experience, 68% were located in major cities

Survey sample of witnesses

The witness group of 23 respondents completed the surveys in relation to EPAs and/or AHDs. The mix of qualifications included: 20% lawyers and 80% Justices of the Peace (JPs), Commissioners of Declaration (Com.Decs.) and Notary Publics. Most witnesses (60%) were JPs.

Figure 1. Background of witnesses of EPAs and AHDs

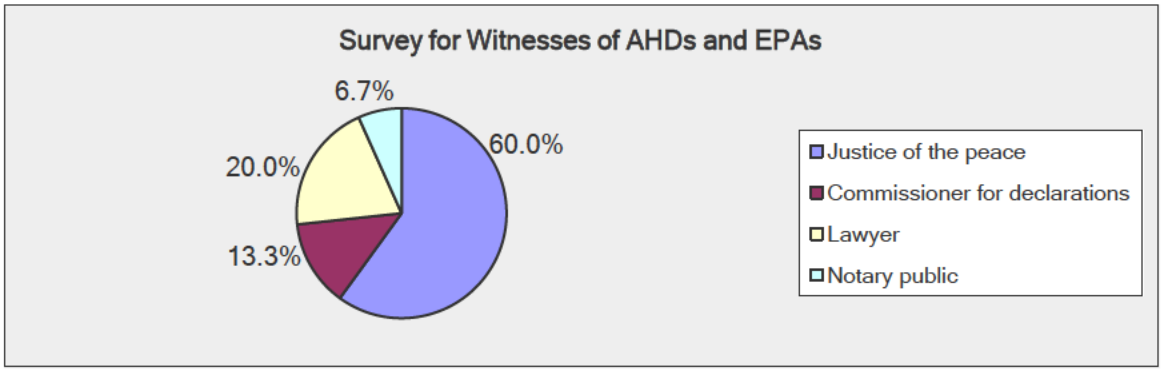


Table 3. Survey sample: Witnesses of EPAs and AHDs

Sample characteristics	**Witnesses n=23**
Gender % Women Men	53 47
Age Range	25-80
Education: % with a tertiary degree	93
Birthplace: % born in Australia	88
First language: % English	100
Location % Major cities Regional	46 54

All 23 witnesses had experience in witnessing EPAs; 13 had experience in witnessing AHDs. Most witnesses had a university education and all had English as a first language. Witnesses varied in professional background, experience and location with some operating out of legal firms and others located in local shopping centres as JPs. Forty-six percent were located in a major city and 54% in regional Queensland. Just over half (53%) of the witnesses had received formal training as a witness with 55% of that group receiving it less than a year ago; others (41%) had information but no formal training and one person reported having no training or

information. It is of interest to note that that more than half of the witnesses responded from regional locations.

2.5. Strengths and limitations of the research approach

As in all research, there are strengths and limitations in the research design that must be considered when interpreting the findings reported in Sections B, C, and D.

The major strengths of the research design are:

- Building on existing knowledge and ensuring cross-sectoral input through a multidisciplinary research team, working with a cross-disciplinary and cross-sectoral Critical Reference Group and including data from the DJAG Practical Guardianship Initiatives Working Party.
- Separating the data collection on EPA and AHD components to avoid adding to already existing confusion among some groups as to the purpose of these documents. This strategy enabled the identification of some specific concerns that should be addressed separately.
- Ensuring inclusion of a wide range of stakeholders. These include (i) consumer groups – people who have used or might use the form as principals or attorneys and (ii) professionals, service providers and witnesses who assist others to complete the form or are involved in operationalising its use. Outreach to representatives of specific groups, for example Indigenous people and people from CALD backgrounds, who might not respond to typical recruitment strategies and the inclusion of regional and remote informants through the on-line survey ensures recommendations for change are based on a wide range of perspectives and experiences.
- Using multiple methods to ensure that data collection is efficient and appropriate for the group being interviewed. The use of semi-structured interviews and focus groups as a preliminary stage to a survey ensures that the survey questions are meaningful to respondents and allows for the inclusion of the perspectives of informants who are unlikely to respond to a survey.
- Using a multistage design so that the survey instrument is targeted to key issues and includes a sample that is sufficiently informed to provide comment on the content, structure and useability of the forms.
- A broadly based strategy of inclusion and consultation that provides the opportunity to engage a wide range of stakeholders in considering any recommended changes.

The major limitations of the research design are:

- The purposive sampling strategy allows for an identification of the range of issues to be raised by various groups but does not allow for generalisation to all members of those groups or to the population of Queensland.
- Difficulties in recruiting those who do not know about the forms or the legislation. For example, although the survey sought to explore why people did not complete the forms as well as those who could comment on their experiences of completing the forms, no survey respondents were non completers of AHDs/EPAs. This proved to be a very difficult group to interest in participation in interviews or surveys, through general recruitment strategies. All Indigenous people interviewed and many of the CALD focus group respondents, however, were not current users of the documents.
- Web based surveys need to be short. The advantage is the opportunity for a broad and low cost distribution; the disadvantages are that only a limited range of questions can be asked and the sample will over-represent those who are computer literate. Although the relevant forms were attached to the surveys, there is no information on whether respondents made their comments based on a detailed reading of the form or relied primarily on recall.

3. Report overview

The findings from the three stages have been organised around whether they primarily refer to EPAs or AHDs. There is some overlap, however, in that Indigenous people and CALD groups commented on both documents as part of the interviews and focus groups. In addition, all witnesses in the surveys were witnesses to EPAs; over half of these respondents also reported experience as witnesses to AHDs.

The remainder of this Report is set out as follows:

Section B	Presents the findings and recommendations in relation to EPAs.
Section C	Presents the findings and recommendations in relation to AHDs.
Section D	Presents the findings and recommendations from the consultation and interviews with Indigenous people.

Appendices

A	Terms of reference of the Critical Reference Group

B Semi-structured interview guides for:

B1 EPA principals, attorneys, witnesses, health providers and other professionals

B2 AHD principals, witnesses, nominated doctors, other health providers.

C On-line surveys

C1 Principals – EPAs

C2 Attorneys – EPAs

C3 Witnesses – EPAs and AHDs

C4 Principals – AHDs

C5 Nominated and treating doctors – AHDs

D Detailed tables of responses, comments and suggestions regarding EPAs and AHDs from Indigenous respondents.

B. Enduring Powers of Attorney

1. Introduction

The research focus is on the content and useability of the current EPA forms and barriers to their completion. Overall, the comments made relate to both the long and short forms of the EPA. Although data collection focused primarily on these issues, the forms themselves sit within a set of processes and practices that affect their appropriate execution and use. The data contain considerable comment on these broader issues; some of these relate to improving the form and others are concerned with the effectiveness of the form in balancing accessibility with protection for all stakeholders. These comments have been reported, reflecting the view of the research team that any form (as a legal document available to the community), should be considered in the context of the processes and practices that surround it. These include consideration of accessibility, information, advice, witnessing, recognition and appropriate use. In addition to providing the necessary context for the research, these broader issues may also signal to Government some areas in need of legislative reform, policy development or community education.

The inclusive sampling strategies of the research have captured different perspectives on the forms and related practices. These different perspectives exist across and within user groups of principals, attorneys, witnesses, professionals and service providers and at times reflect differing views on what changes in the current forms should be made. Some emphasise accessibility and ease of use, while others focus on enhancing protection and preserving legal precision. These differing views provide a considerable challenge to any project seeking to draft recommendations to improve the forms. This section of the Report summarises the contextual issues, reports on findings from interviews and focus groups, the surveys of principals, attorneys and witnesses and details recommendations drawing on these data sources and the comments of the reference group.

2. Stage 1: Scoping the issues

The Department of Justice and Attorney General (DJAG) Practical Guardianship Initiatives Working Group and the Critical Reference Group (CRG) identified a range of problematic areas. The issues raised by these groups have been subject to further research and consideration in the course of this project. Some aspects have been explicitly explored in the interviews and surveys; others have been reviewed through the analysis of the interview and focus group data to ascertain if these issues were raised by particular users without prompting by the interviewer.

Interviews with specialist service providers in elder law and guardianship also raised very specific concerns in relation to the form. Some of the issues raised that are summarised below relate to broader policy matters; others relate more specifically to the EPA form and information. The researchers have considered all of these issues and determined whether they raised points for further exploration in the interviews, focus groups and surveys, or were more appropriately dealt with in another way, such as in recommendations for policy development, targeted or specific education, or to inform any legislative review.

2.1. Broader contextual matters

- Concerns about the actions and accountability of attorneys and the potential for financial abuse
    - Forms need to provide more guidance (e.g. information of types of potential abuse) and be more prescriptive in order to prevent abuse of the principal by the attorney/attorneys.
    - The responsibilities of the attorney need to be made clearer as attorneys are often unaware of their responsibilities and/or are unwilling to act on them.
- Concerns about witnessing of EPAs
    - Some witnesses do not understand their roles, including the complexities of determining capacity of a principal to make an EPA.
    - JPs are concerned about their responsibilities, the use of capacity guidelines and the importance of written records.
    - Should there be a requirement for two rather than one qualified witnesses to an EPA and for the explanation of the EPA to be read out by the principal in front of the witness?
    - There is no requirement for the signing of the document by the attorney/s to be witnessed.
    - The principal can sign when the attorney has not signed.
    - The training of JPs especially self-taught JPs is insufficient for the responsibility undertaken in this context.
- Concerns about appropriate assessment of capacity
    - Some witnesses may not have sufficient training in determining the capacity of the principal.
    - Clearer instructions for the witness in determining the principal's capacity are needed. One suggestion is that guidance should be given to the witness on the types of questions they should ask the principal to determine the principal's capacity and whether they are under duress or have been coached in their answers.
- Concern about the limited use of special conditions

    - Greater guidance should be given on how to set clauses or limitations on the powers of the attorney such as having a series of written safeguards from which the principal can select from. The following clauses are often needed:
        - Capacity (whether the powers become active on physical incapacity or mental incapacity)
        - Start date
        - Substitution (of an attorney)
        - Conflict of interest limitation
        - Consultation (requirement for attorney to discuss decisions/actions with the family)
        - Accountability requirements
- Concerns about understanding when financial power comes into effect
    - People are unaware what it means if powers become active immediately.
    - Issues surrounding selecting when the powers come into effect need to be explored, particularly the issue concerning when they come into effect when capacity is lost. This can make it very difficult for the attorney in having to prove the loss (and continuing loss) of capacity in order to use the document.
- Practical concerns
    - Recognition of the forms by Centrelink and banks is limited.
    - An EPA is sometimes completed but not stored in a place where it is accessible when it is needed.
    - Family and friends are sometimes unaware of the existence of the form or its contents.
    - A principal can execute multiple forms over time. It is not clear if a power has been revoked. These situations create concerns from financial institutions and others about the validity of the document presented and undermine the integrity and use of the form.
    - Currently it is possible to appoint a health attorney in an EPA and in an AHD. Some principals were confused as to the legal effect of appointing different attorneys for health matters in their EPA and AHD.
    - Uncertainty about whether principals are being sufficiently encouraged to discuss the matters involved in making an EPA with their family members.

2.2. Specific matters relating to the EPA form and information

Issues to explore or suggestions about the current form:

- Length: There are three sets of instructions within the document for the principal, attorney and witness as well as examples and instructions within the document. This makes the documents very long and complex and difficult to understand. The long form is 24 pages

and the short form is 18 pages, raising the question whether the form and instructions be separated.

  - If the information is going to be separated from the EPA form, creative ways to ensure that those filling it out are still aware of the information and read it are needed.
  - Having the instructions as an attachment to the form will facilitate ease of certification and copying.

- Format
  - Revision of the first page. The first page of the EPA form does not have provision for the names of the principal and attorney(s) and the date. This information is on separate pages toward the end of the document.
  - Clause 1 names the attorneys but it is not until clause 7 that the document describes how the attorney are to act when making decisions. These should be together so that the attorneys can clearly know how they are to make decisions.
  - The use of multiple attorneys. The form only allows for three named attorneys and the form does not allow for any flexibility to appoint more than 3 attorneys or to describe that the attorneys may be appointed to make different decisions about financial or other affairs.

- Language
  - The language needs to be more user friendly and in easy English. Completing an EPA is particularly difficult for those who have English as a second language and those with a mild intellectual disability who do not have a guardian.
  - Some terms need to be more clearly defined or have accompanying explanations or examples, e.g. the difference between alternate and successive attorneys as to when the powers should end.
  - The statement of understanding is difficult to understand and requires simpler language or an accompanying explanation.

- Witnessing and certification
  - Certification that the EPA was made freely and voluntarily should be included.
  - The signature of the attorney should be witnessed and certified that they 'appeared to understand the nature and effect of the instrument'.
  - JPs should record the questions asked and the answers.
  - The form, on the witness page, tells the witness to make a record of the witnessing if they are in doubt, however, *all* EPA witness proceedings should be recorded.

- Useful additions
    - The form needs to be more specific about what, how and when decisions can be made.
    - An option should be added to allow an annual review of the principal's accounts as part of the appointment although there are cost considerations here.
    - Adding the option to specifically allow or disallow gifting and/or conflict transactions.
    - Including some examples in the forms to clarify 'gift' and 'conflict' transactions.
    - Clearer instructions about limitations of powers and consistency between setting terms and indicating wishes and limiting powers. There needs to be something on the form to help attorneys and principals interpret responsibilities under the legislation.

- Specific issues with the form
    - In Part 3 (attorney's acceptance) the definition of 'current paid carer' causes confusion
    - There is no definition for 'health care provider'
    - Some concern was raised in relation to the attorney signing and dating the form before the principal has signed, raising issues as to the validity of the appointment. A warning on the form could alert the attorney not to sign prior to the principal.

The issues raised by the DJAG Practical Guardianship Initiatives Working Group and the Critical Reference Group have been the subject of further research and consideration in the course of this project. The recent review of guardianship laws undertaken by the Queensland Law Reform Commission (QLRC) is also relevant to this research. The QLRC made a range of recommendations relating to the law that should govern EPAs and, to a lesser extent, about the EPA form and explanatory notes.[11] The recommendations that are of particular significance to this research in relation to EPAs are the following:[12]

- The definition of 'eligible witness' in section 31(1) (a) of the *Powers of Attorney Act 1998* be amended to delete reference to the 'commissioner for declarations'.

[11] See Queensland Law Reform Commission, *A Review of Queensland's Guardianship Laws* Report No 67 (2010) Vol 3, chap 16.

[12] For a summary of all of the recommendations relating to EPAs, see Queensland Law Reform Commission, *A Review of Queensland's Guardianship Laws* Report No 67 (2010) Vol 3, chap 16, pp 219-223.

- The approved form for the EPA should be redrafted to take into account a range of recommendations of the QLRC:
    - A commissioner for declarations should not be an eligible witness (see above), and the approved form would need to reflect that amendment.
    - The approved form should specifically refer to the guidelines developed by the Adult Guardian, the Queensland Law Society and the Justices of the Peace Branch of the Department of Justice and Attorney-General, and recommend their use in witnessing the document.
    - The clause in the approved forms that deals with the commencement of the attorney's power should include various examples of standard words for the commencement of power for a financial matter on the principal's loss of capacity. These examples should particularly draw the principal's attention to the type of evidence that will be required to establish his or her incapacity (for example, a report by the adult's general practitioner, by the adult's treating psychiatrist or geriatrician or by two independent health professionals).
    - The approved forms for an enduring power of attorney should explain that the principal may give a specific instruction in his or her enduring power of attorney which expresses the principal's wishes about notification. For example, the principal may express the wish that the attorney notify one or more persons, nominated by the principal, of all decisions made or transactions undertaken as the principal's attorney in relation to the matters for which they have been appointed.
    - The approved forms for making an enduring power of attorney should explain that a person's ability to seek a medical certificate as to the principal's capacity or a declaration from the Tribunal or the Supreme Court if there is some doubt about whether an attorney's authority has commenced.
    - The current example of a conflict transaction in the approved forms for an enduring power of attorney is misleading and should be revised as a matter of priority so that it is made consistent with the example provided in section 73 of the *Powers of Attorney Act 1998* (Qld) and section 37 of the *Guardianship and Administration Act 2000* (Qld).
    - The explanatory information and notes about the key features of the enduring power of attorney document and the roles, functions and duties of the principal, attorney and the witness should continue to be included in the approved forms. It should also be included in a separate booklet.
    - The explanatory notes for the approved forms for an enduring power of attorney should:

        (a) encourage the principal to give a certified copy of the form to the principal's attorney, doctor, solicitor, accountant and stockbroker; and

(b) explain how a copy of the enduring power of attorney should be certified in order to comply with section 45 of the *Powers of Attorney Act 1998* (Qld).

At the time of writing this Report the recommendations of the QLRC have not yet been endorsed by Government, and the extent to which Government plans to implement these recommendations is not known. The researchers have undertaken this review on the basis of existing law and the current approved EPA long and short form.[13]

3. Stage 2: Interviews and focus groups

Stage 2 comprises interviews with Torres Strait Islander and Murri respondents, principals, attorneys, and witnesses, as well as focus groups with social workers and people from culturally and linguistically diverse backgrounds. Indigenous perspectives have been reported separately in Part D. This section reports on the findings in relation to EPAs from interviews with principals, attorneys, and witnesses and a focus group with social workers. The focus group with CALD respondents explored accessibility and useability of EPAs and AHDs and there is some overlap of information. For the CALD group, general comments on both forms and specific comments on EPAs are reported in this section; specific comments on AHDs are reported in Part C.

3.1. Individual interviews

Individual interviews were held with 21 people about their experiences with EPAs as health professionals (4), witnesses (7), principals (6) and attorneys (4). The interviewer had the long and short form of the EPA forms with them. Service providers interviewed included doctors, aged care workers, justices of the peace and lawyers. Some service providers had extensive experience in providing advice in relation to EPAs and in policy formulation on matters that impact on EPAs. However the witnesses who were not lawyers were less experienced in this particular area.

This section is organised into two intersecting parts: the processes surrounding the drawing up and use of EPAs (points 1-6) and more specific comments about the form itself.

[13] While the researchers are aware of some confusion within the broader community about the different functions performed by the long and short forms, within the current legislative framework, both forms are necessary. Accordingly, the researchers did not expressly explore the views of participants about the precise reason for the confusion, or the desirability of having only one form.

3.1.1. Motivations and intentions in drawing up an EPA

In the introduction to the questions, interviewees were asked why they thought people completed EPAs. In this group, health professionals suggested an EPA when people were faced with a diagnosis that could threaten capacity:

> Dementia has become more of an issue for people. They're aware that they could develop dementia or they could lose capacity and if they do somebody needs to manage their financial affairs. I think financial is more the driving force for enduring powers of attorney than health and so the elderly are often afraid that somebody is going to manage their money inappropriately. EPA16

Lawyers suggested that people draw up an EPA in conjunction with making a will to assist with asset management in the future. Principals drew up EPAs following changes in the family such as a separation, to strengthen their capacity to have their needs met in the future or because personal experiences with family or friends had raised their awareness of EPAs and the negative experiences that could flow if there was no EPA or it was used inappropriately:

> My partner and I felt that being a lesbian couple and not married that it was important for us to make sure that legally we had every protection that we could. EPA11

> After we saw what happened with [a friend], I could see that it was so important. It was so traumatic. I knew that we just had to do something so that we didn't put our kids in that situation. EPA6

3.1.2. Assessing capacity of principals

Interviewees had a wide range of views in relation to understanding their role in capacity assessment and the processes to be used. Sources of information on assessing capacity ranged from professional judgement to referencing a range of material including material prepared by DJAG and the Queensland Law Society or material developed 'in-house'. One interviewee described a process of using a brief assessment of capacity, then, if still uncertain using the Queensland Law Society Guidelines and finally referring clients to their doctor if they were still unsure. The cost of these assessments to the client was raised as an issue as well as the difficulty of negotiation with their client the need for such an assessment.

An opinion was expressed by doctors, lawyers and some witnesses that assessing capacity should not be part of the witness role – they should simply witness the signature:

> Then there is the burden of assuming that the witness is capable of assessing capacity, and I think that is a bit different from most other legal documents, where you are only witnessing that the person signing is who they say they are and not that they have capacity to sign it. I don't see that it is reasonable to have every witness take on the responsibility of certifying that every person has capacity... I do think that the issue

> about the witness saying the person is capable is a lot beyond the scope of any other legal document. EPA21

Those health and legal service providers who participated in these interviews had a great deal of experience in assessing capacity. There was a difference of opinion between health and legal professionals on the capacity of lawyers to assess capacity for this matter and vice versa.

One respondent working in a statutory setting was clear that their role was collating information on capacity rather than gathering data to do assess capacity themselves. This respondent sees their role as requesting information that either confirms or disconfirms capacity as well as collating information from a range of sources to form an opinion on capacity:

> From an investigation point of view we don't assess capacity as such. We rely on the information that is there. ... looking at the specific areas of decision making such as personal, breaking up the personal accommodation decisions, lifestyle decisions, healthcare and all of those things and breaking that down as far as possible to see whether a capacity opinion can be given by the professional who is completing it. EPA1.

Resources to gather information in this way are not easily available for service providers in many human services Most develop their own strategies.

One respondent, a worker in community aged care, responded to the question of processes for assessing capacity with the following:

> Oh we wouldn't. I mean we do it on a basic premise and basic observation and knowledge of the client but we would certainly take it to a relevant professional to get something, especially if it is a little suspect. EPA20

One JP witness, with considerable experience in this role, said of capacity:

> There are actually two things. It's not only capacity but it's also; we're looking for the absence of duress. That is particularly where the attorneys are putting pressure on the principals. Those two things - capacity I assess by asking open questions. Things like what is your address? …. The more important problem, the more frequent problem we have is duress. We often get … parents (being wheeled in) in the wheelchair by the offspring, and as soon as that happens the first thing I do is say to the offspring this is going to take about 20 minutes, would you like to go shopping? We're in a shopping centre…. and that gives me a better opportunity to assess the principal's capacity because they don't have somebody else answering their questions for them or prodding them with answers. EPA4

3.1.3. The need for assistance in drawing up an EPA

Almost all interviewees suggested that legal practitioners should be used in making an EPA. Two perspectives were evident. Some principals thought that getting legal advice was the 'right' thing to do rather than a response to having any problems with understanding the form:

> I just thought okay it's a legal thing I need to get a solicitor. EPA11

> It's very difficult to get that information for free. EPA1

The second group, primarily health and aged care practitioners, believed there were a number of potential pitfalls in drawing up an EPA and in this context advice should be sought:

> I tell them that they can get the form at the post office or newsagent, but I always suggest to them that they go to a solicitor. EPA5

While all except one person interviewed recommended the use of legal advice, there was recognition that this advice could be costly and the form should be able to be completed without advice, suggesting some ways in which the format of the forms could be improved to make self-completion of a form that reflects their wishes easier. One health professional said:

> I do worry for parts of the community whose language skills, reading skills and things like that may not be strong, that it could be very off-putting with the size of it and I think it needs to be even more step-by-step. EPA16

A principal commented:

> Even a page, some flow-chart sort of thing or something to show that this is the steps you take. EPA6

Perceptions of the need for legal assistance were largely linked to how clearly interviewees understood the implications of EPAs for principals and attorneys. The better the understanding of the powers conferred, the more likely people were to recommend the use of legal advice. However, the more trust principals had in their lawyer the less likely they were to try and develop a thorough understanding of what was involved in appointing an attorney, as outlined in the next section.

3.1.4. Understanding the powers and obligations to be conferred by an EPA

Principals

Principals' understanding of the powers and obligations given to attorneys in their EPAs varied a great deal. This Principal had drawn up their EPA after extensive research and finally used a solicitor to draw up the document:

> For the attorney, I'm not sure that they fully understand that they are held accountable and that they could be involved in acting legally for the person. I think they understand the concept of paying the bills, but I'm not sure that they really understand that they are the legal representative and would be involved in any difficult or conflictual arrangements, and would have to continue with that. I'm also not clear, and I've never really thought about this much, but once or twice, we've had an attorney say they won't do it anymore, and how they get out of it. EPA7

Other principals relied on their relationship with the person nominated as an attorney to do 'the right thing' rather than attempting to spell out what they expected, and hence did not put a great deal of energy into understanding this themselves:

> I did not set any conditions or read any information about setting conditions or potential abuse because I trust my attorneys. EPA12

Understandably most principals who used solicitors tended to rely on them to tell them what they needed to know and to interpret their wishes correctly in the form. Hence they were not very concerned about understanding the form itself. One principal said:

> [the solicitor] just explained it all to us and basically asked us everything that she needed in order to complete it and then she emailed it back and we didn't make any edits. It was just as we wanted when she emailed it to us. EPA11

Principals who used solicitors to draw up their EPAs tended to be less involved in understanding what powers they were conferring. One respondent did not feel appropriately consulted on the terms or understand the implications of what the EPA meant to himself or his attorneys. The following interchanges may not be typical but suggests that using a solicitor may not necessarily improve the principal's understanding of what is involved:

> *Interviewer:* Did the solicitor go through the form with you?
> *EPA10*: No
> Interviewer: Did you access other information?
> *EPA10:* No
> Interviewer: Have you looked through the form?
> *EPA10:* Yes, I needed to explain it to my sons. I am not sure who to give it to. I was surprised at its simplicity.

> *Interviewer:* Is there enough information on the form about how to fill out an Enduring Power of Attorney?
> *EPA10:* No, but the solicitor helped me. I am a bit wary of forms. I need guidance.

Most principals interviewed who had consulted a lawyer were happy to leave the details of the EPA to them, and hence did not make many suggestions on how the form could be helpfully modified. They were concerned, however, about the attorneys' level of understanding of their powers and obligations.

Attorneys

The attorneys interviewed fell into two groups – two very experienced JPs who responded with their comments on their roles as attorneys, and two family members who were 'feeling their way' through the process. The experienced JPs considered the relevant web pages provided sufficient information on the form but that it was not easily accessed, read, or understood by people who had little background information. On the whole attorneys did not have their responsibilities outlined to them by the principal or any intermediary who helped the principal draw up the form:

> [The form] is very useful; but it didn't stress, once again, perhaps the limits of being an attorney, and the duties and the responsibilities. EPA18

This is a gap in the forms/process that is agreed to by all attorneys who were interviewed and is implied in most of the principals' interviews. Some were concerned about their understanding of the commitment they were undertaking and where to leave the form once it was completed.

Witnesses

The witnesses fell into two groups, those with a legal background (lawyers, JPs) and those with a health background (doctors, aged care workers). Lawyers acted to assist in the drawing up of the EPA as well as acting as a witness and their practice varied in how much they made specific recommendations for the content, or explored the implications of decisions that were made by the principal. The other witnesses were less likely to be involved in the actual drawing up of the form but still explored, to some degree, the principal's understanding of the impact of the EPA.

One witness with extensive experience in relation to EPAs that become problematic noted that principals did not fully understand the implications of the document for their attorneys:

> I get a sense a bit that (principals are told) 'oh your attorney has to do these things, don't worry about that. Just appoint someone without getting into too much details to well what it is they can and cannot do without reading it'…Well generally if you are the principal you are not thinking about it too much, or you are struggling with the whole document. If you see that, you say, 'well that is for the attorney, it's not my issue'. EPA4

Across both groups there was a range of views in relation to their responsibility to make sure principals understood the powers they were giving attorneys, but in general they did not see they had a responsibility to attorneys to ensure they understood what they were taking on. This was left to the principal to explain to their attorneys.

Overall, they were concerned that principals did not completely understand a number of important issues: the commencement of powers; meaning of 'loss of capacity'; the use of special terms and conditions; and making changes to the document. Witnesses also considered that

attorneys may not always understand how to activate or terminate their powers or indeed what those powers and associated responsibilities were:

> [T]he main issues are that the attorney doesn't understand their responsibility and they think it's just a piece of paper that Mum or Dad wrote to give them the ability to manage their affairs or manage their health if they want to but they don't have to do it if they don't want to. … In relation to mismanagement of funds, there is an inability to make decisions and willingness to make decisions….There's a small proportion that manipulate their form but the majority of people I think it is a lack of understanding of their obligation. EPA16

While most witnesses interviewed had a very clear understanding that their role was to assess the capacity of the witness for this matter, to ensure the principal knew the implications of what they were signing and to witness their signature, other respondents were less sure that witnesses were clear about their roles.

3.1.5. Keeping records

The obligation to keep records is an important area of concern raised by principals and attorneys. The form is seen to be largely silent or ineffective in accurately telling attorneys what is required in this area or what the implications of inadequate record keeping might be. One respondent, interviewed as a witness, with extensive experience in situations where the EPA is linked to abuse, noted that failure to keep adequate records was a significant feature in attorney behaviour that came to the attention of authorities.

This issue was predominately answered by attorneys. An attorney with an extensive background in the finance industry reported that when he started to act as an attorney when his mother went to hospital, he reread the document and said, 'one of the things it really highlighted for me was you must keep records'. However, he was unable to find guidelines on what records to keep:

> So I set it up on my computer and that is the information that I keep. … so I give her a copy of this every two to three months. She is losing interest in it now but I give it to her and my brother gets records and then she can then …go to the cent of what has been done. EPA8

Another attorney, with much less background in managing other people's money, agreed:

> There should be more guidance given to attorneys on what records to keep and how to keep them. EPA14

In addition she added that there should be much more warning given to attorneys on what might happen if abuse occurs, or they do not meet their obligations. One respondent held an active EPA for her father and had been reminded of her report-keeping responsibilities when she was contacted for this survey. She noted that larger amounts used to pay bills are linked to accounts

for organisations, but she has not kept accurate records for smaller amounts of money drawn from his account to pay for minor items.

In general, respondents felt the requirement to keep records is clear on the form but that attorneys may well forget about this when they begin to act on behalf of principals. There was clear agreement that what records should be kept and how they should be kept is not outlined anywhere in the form and this should be remedied.

3.1.6. Satisfaction with the form

3.1.6.1. General comments

All respondents emphasised the importance of the form being presented in a user-friendly manner – both in terms of how it presents information and how it and its supporting documentation are accessed. Opinion varied on how well the form and its presentation achieved these goals, though generally it is seen as being appropriate:

> I think the form is basically a good form. It is certainly better than many other states' forms. … It needs to cover other issues and in fact I am going to be saying it needs to be bigger but it is a good form. It's stood the test of time. It's over ten years old. EPA3

3.1.6.2. Layout and order

Currently the documents are organised into three parts: Part 1- Principal, Part 2 -Witness and Part 3 - Attorney. The order of these parts was queried:

> Well the form goes through principal, witness and then attorney. Normally the witness will witness the principal and the attorney's documents so I initially thought that was a little bit strange in the fact that the information goes through and tells the principal what it is all about and then the form goes through and tells the witness what it is all about. And then it goes through and tells the attorney. So to me the witness was more important that the attorney. EPA8

It was noted that people only tend to read the section that is labelled for them, so the attorney may only read the current Part 3, whereas they are legally required to have read and understood the entire document. Inserting the witness section between the principal and attorney sections may discourage the principal from reading the attorney section and vice versa. Several respondents suggested that the witness section be moved to the end.

Some of these issues may be addressed by requiring the principal, attorney and witness to affirm that they have read the whole form. Some concerns were raised about the location of the review page, with suggestions that it be moved to the front of the document.

3.1.6.3. Length

Length was mentioned by almost all interviewees but was emphasised most by JPs with regard to having to certify the document, and by principals and attorneys with regard to understanding the document as a whole and finding the length intimidating.

At the same time it was recognised by most respondents that the topics raised in the form were all needed. Suggestions in relation to shortening the form were focused on separating the health and finance sections of the EPA into separate forms and separating out at least some of the information spelling out what was involved in each decision into a separate information booklet – rather like the income tax pack. Each of these suggestions is discussed below.

3.1.6.4. Separating the personal/health and financial sections of the form

The arguments advanced for this proposal were outlined as:

- Having separate forms may help clarify the role of the attorney in both capacities thus making enacting the documents clearer with regard to clarifying the limits of power.
- Certification and copying of the documents would be easier.
- Separate forms would ensure greater privacy for the principal, if for example in hospital a record of the EPA needs to be taken, they may only need to know about the health and personal attorney arrangements, but not need to know about the financial affairs of the person.

The arguments against this position were:

- People can already use the short and long form if they wish to have separate forms.
- Multiple forms are confusing and hard to keep track of for both principals and attorneys.
- Some people did not believe principals should be encouraged to appoint multiple attorneys. The short form was seen by this group as encouraging the appointment of single attorneys, a practice this group considered should be encouraged:

  > Where does one stop and one take over? If someone is looking after health and wants to… put him into a home…We need money to put him in there but the other guy is looking after the money. It is a can of worms as far as I am concerned. EPA2

3.1.6.5. Separating the information provided from the form itself.

The arguments for such a separation were:

- Reducing the length of the form in this way would make it more comprehensible as a whole and less daunting to fill out. It would also provide an opportunity to organise the information in a more discursive and integrated way that would be more helpful in

educating the attorney about the responsibilities they were signing for, in helping the principal be clear about the powers they were conferring and the points they may wish to consider, and ensuring the witness is clear about their roles. An attorney said:

> I think I would rather see it in an information booklet and you get that as a booklet and there's the forms. Just read them in conjunction and fill them out in conjunction. But I think a little booklet by itself or a kit, whatever you want to call it. If you want to have the forms at the back perforated so that they can be pulled out so you can keep the whole thing together that's not a bad idea I guess. EPA14

A young principal, who consulted a solicitor to draw up her EPA made the following comment:

> If I had been given a comprehensive booklet with the form and I'd known that it existed it might have given me the confidence to do it myself rather than one document which is all legalistic and has a lot of jargon and looks very formal and going 'oh that looks like I need to talk to a solicitor to help me fill that in'.

- Finally, one respondent suggested that a separate booklet might give the opportunity to provide more direction to attorneys administering more complicated financial matters.
- Those who advocated for separating the information into a booklet often commented that there would need to be a declaration of some form in the document that the principal and attorney had read the information booklet and that the witness had checked with them that this was so.

The arguments against such a separation hinge on whether or not the explanations would be read if they were separated from the form:

> When you have a separate booklet, and then you only have the bits to fill out, people tend to fill out the bits and they don't read the booklet. 'Have you read the booklet?'; 'Ah, yeah I've read the booklet, I've read the booklet.' But then when you ask them questions you find that they haven't (really) read it. EPA18

It is interesting that this attorney later said what you need is someone to go through the form with you – as in this case the social worker at the hospital had done. This contrasted to their own experiences of filling out EPAs nominating children as attorneys where the lawyer had filled it out:

> 'Here's the form. I've filled it all out'. He explained globally to us which we agreed to. But we didn't read it … and I think all too often that would happen. EPA18

Another respondent, a witness who was a lawyer, was also against separation but suggested a reordering so that the notes were together and placed at one end of the document.

> [It would be like] real estate contracts have 'disclosure information' separate from the contract. This never gets passed on. EPA17

While one respondent, an attorney and witness, agreed the information may be separated, his concern was that with downloading the form from the internet you could not be sure that people had looked at it – they noted a sealed pack bought at the newsagent might be appropriate.

Overall, there is agreement that the current form is cumbersome for witnessing purposes, can be intimidating in terms of its length but generally provides appropriate information that should be read by all parties. However, the majority of those interviewed were in favour of separating the information provided by the form itself to allow for a more compressive information package for the principal, witness, and particularly the attorney and to make the form itself 'flow better' and be less intimidating. The problem of ensuring the information is read and understood for participants exists for both arguments, but is stronger for those arguing for its retention in the form.

3.1.6.6. Language and wording

In general it was thought that significant terms were too 'legalistic' particularly in the information sections. While the use of this type of terminology may have been to achieve more precision, the outcome was that for many it was misunderstood. The major terms that caused confusion were:

- The manner of deciding – 'severally' in particular;
- Commencement of powers – 'immediately' in particular;
- Capacity – 'losing capacity';
- What is meant by 'reasonable records';
- What is meant by 'conflict of interest'; and
- What is meant by 'prefer' (page 9, Clause 7 Short form)

The use of the term 'severally' was consistently raised as being difficult to understand by people in all roles and could be reworded. A lawyer witness said:

> No, I have to admit people don't—when they sit here they don't understand what severally means; they don't understand what jointly means but those words are explained to the extent they are and then of course we explain further.EPA 3

This interviewee commented that the explanations in the form were useful, but acknowledged that people would need to know what 'unanimous' meant. One health professional pointed out that 'severally' and 'jointly' were not necessarily difficult terms to understand, but the decision to be made might be difficult:

> I think probably some of them still have decisions with things like severally, jointly and they don't know which way to go. EPA 5

Considerable discussion centred on the sections of the forms that dealt with when the powers of attorney commenced. There are two issues here. One is in understanding the impact of ticking the 'immediately' box and the second is considering the desirability of using that box in relation to financial matters. One respondent, a legal witness, outlines issues in relation to the second point:

> They come in with a preconception, quite reasonable, that this document is to be used when you lose your marbles and suddenly it says oh hang on you can actually appoint someone to make decisions for you even if you still have your marbles so far as your financial affairs are concerned. They find that difficult to comprehend and they're resistant to ticking the box 'Immediately'… we try to convince (spouses but not where the attorney is a child) to tick 'Immediately' because our view is that is the best box to tick when it comes to financial matters… for two reasons: one because it can be used as a standard type Power of Attorney. And secondly, it is just easier to convince institutions. If I walk down to the bank now with this and say I'm the attorney for my spouse, here it is and they read it and they see your financial power starts when she loses capacity, how are you going to prove to me that she has lost capacity? Not only that, you have got to prove it every time you use it where as with 'immediately' you don't have to prove it. Obviously that ups the ante in terms of trust and that is why we only say do it within spouses. Never give your children immediate financial power. EPA 3

3.1.6.7. Information provided

The form requires three groups of respondents - the principal, attorney(s) and witnesses - to understand the implications of decisions made. Comments in previous sections have discussed a number of issues that relate to the placing, accuracy and usefulness of information on the short and long versions of the EPA. This section explores what are seen as some of the tensions within the nature and expression of the information provided. These tensions appear to arise from a desire to make the form, and an understanding of the responsibilities it confers, clear but not intimidating to principals and attorneys. One witness said:

> I think it is going to be that balancing act - make it accessible for everyone but at the same time not deny them the opportunity of knowing the full ins and outs of it and empowering people to make them aware of what it could do and what they want it to do. ...Instead of – I get the sense a bit that - your attorney has to do these things. Don't worry about that, just appoint someone without going into too much detail as to well what is it they can do and they can't do without reading it. EPA1

This witness went on to answer a question on whether they thought there was enough, insufficient or too much information:

> I would say there is enough information. I think it can be more effective with tightening some information and adding ...information in terms of accountability for all of the parties and more awareness for both the principal and the attorney of the jobs that they are in. ...I premise everything I say on what I have seen of the matters that aren't working. EPA1

However, an alternate view was put:

> I think if they (attorneys) read it there would be less misconduct. So that's no excuse. The form does what it needs to do to tell attorneys what their responsibilities are as opposed to other states' forms that don't, within the form. EPA3

This suggests that the issues lie in getting people to carefully read the form rather than a lack of information in the form. One suggested reason for a lack of optimal engagement with the material on the form suggested by respondents was that there are two types of information:

1. An outline of legal responsibilities; and
2. Advice on how to be a competent substitute decision-maker.

Both require a different style of presentation – the first to inform the parties and the second to engage them in thinking through approaches to expressing their wishes (principals) and directions to attorneys. The way they are currently mixed on the form means that neither task is done ideally. Comments were made that the legal responsibilities are not made to sound as serious as they in fact are, that reference is made to the Acts but not to details of the essential points in the Act or drawing attention to sections of the Acts. Principals might not understand the tasks their attorney would have and hence do not always consider the skills the attorney will need.

Additionally, there is not a great deal of information on the form to direct the witness. It was suggested that, at a minimal level, eligible witnesses be required to sign off that they have read the relevant guidelines for JPs or solicitors.

3.1.7. Focus group with social workers

In the focus group on EPAs held with eight social workers at a major hospital, the social workers contextualised their comments by saying they usually saw situations that were unusual, or where it was a crisis and something had to be done quickly or there was concern about the motivations of potential attorneys. Most people they assisted were also elderly and ill.

Structure of form and language used

Most thought the language in the form was accessible but that many people did not read the explanations because they thought they understood it without the explanations, or they trusted the potential attorney who was assisting them to do the right thing. In part, they thought

principals might not read it because the form appeared 'too daunting'. Some terms were identified as problematic: who is a 'paid carer'- some thought that it excluded family members in receipt of carer allowances; the meaning of 'assessing capacity' and what this might involve. The terms 'notary public' and 'commissioner for declarations' were not commonly used; hence knowing how to locate such witnesses was not well understood. The issue of providing the form in the top 20 languages in use (alongside English) was also raised.

A number of suggestions for changes were made:

- a separate explanatory booklet, particularly for attorneys;
- structures to try to ensure that the form was complete before the attorney signed;
- clear instructions for the witness;
- a verbal component that required 'someone' to go through the document with the principal and the attorney to ensure they understood the implications of the document;
- provision for principals who are unable to sign e.g. a person with spinal injuries. (We note that there is such provision on the form but this comment suggests it is not well understood in some areas of practice); and
- a requirement to witness every page to prevent the substitution of other pages at a later time.

When the form takes effect

The social workers considered that there was a common view in the community that the form came into effect when the person lost capacity, rather than when the principal indicated that it should take effect. They also indicated that principals were often encouraged to tick the 'immediately' box. They noted that banks sometimes operated as if an EPA were a PA, refusing to accept the attorney's signature when the person had lost consciousness. Alternatively, they refused to accept the attorney's signature because the person had capacity and was overseas. These comments suggest a need for wider community education.

Where the form is stored

Appropriate storage that safeguarded the original form and also made it accessible when needed was raised as an issue. They agreed some repository for EPAs would be useful to ensure availability and some confidence that it was the latest form.

3.1.8. Focus group with CALD respondents – EPAs and AHDs

The focus group comments on EPAs and AHDs overlapped in many areas relating to knowledge, understanding, language and education. The focus group clearly indicated a limited knowledge of, and for some groups, limited understanding of parts of the form/information. Language, translation, interpretation and access to information and advice were important issues to be

considered for both EPA and AHD documents. The overall comments on both documents are reported in this section as well as comments specifically relating to EPAs. Comments that specifically relate to AHDs are included in Part C of this Report.

Language

Areas of concern in relation to EPAs were the length, which was considered overwhelming, and the need for clearer definition of terms, the use of simpler language and more examples. Specific recommendations included:

- an enhanced explanation of 'jointly' and 'severally' that included an explanation of 'unanimously';
- the use of more examples in the specification of terms and the circumstances where decision making power is retained by principals or ceded to attorneys;
- a clearer indication that attorneys could be relatives as some thought the form implied it should be a lawyer; and
- a glossary for people to easily refer to that could be translated into different languages.

Structure of the form

*C*omments here mostly related to the role of interpreters for EPAs and AHDs. It was suggested that:

- under the heading 'Who is involved in completing this document?' space should be made for an interpreter;
- the term 'translator' on the front of the form and the role of the interpreter should be clearly defined;
- the 'Signed Statement of Interpreter' should be a part of the form; and
- it would be useful to add what level of certification people need to be able to sign the interpreter form and translate the EPA and the AHD as this was not clear.

Understanding terms

The interest was primarily in writing in terms relating to the need for the attorney/s to consult with certain specified people before making certain types of decisions.

Access to information and advice

This was not seen as simply having translations of EPAs and AHDs available in a range of languages. Simplifying the language will not be enough for many people with limited English skills. It was suggested the only way they will come to fully understand the forms is having someone sit down with them and explain the form and answer any questions. Some people from

other countries would also need extra information sessions to explain more about what their legal rights were and the systems (legal, medical, etc.) underlying the form.

Translation and interpretation

Core concerns were that interpreters should be trained in legal and medical issues relating to the EPA and AHD and that translations and legal advice should be available to both the principal and the person appointed. Any interpreters used should be accredited interpreters reflecting concerns about the legal ramifications if misinterpretations are made.

Community awareness and education

Targeted community education programs for culturally and linguistically diverse communities are very important to make people aware of the purpose and use of enduring documents and begin to build trust between the community and the Government. Targeted support services to assist people to understand and complete the forms are also important. It was suggested that these support services should be run by a unit of DJAG rather than other community organisations. This would guarantee that the correct advice is being given and mistakes are not made on the explanations of the role, function and use of the forms. Community education resources need to include information about the underlying legal system such as who is responsible for these matters and where to go/who to ask for more information. One respondent commented that audio/DVD information about the forms would be helpful (in English and/or in other languages) because some people from the community are illiterate and many others find it easier to listen than to read.

4. Stage 3: Survey

4.1. EPA surveys for principals and attorneys

4.1.1. Motivations and intentions

Principals reported being primarily motivated to take out an EPA as part of planning for future illness or accident, estate planning, going overseas or having observed in others the negative consequences of not having a valid EPA in place. Most (80%) had completed the form within the last five years. The short form was completed by 43%; the long form completed by 40% and the remainder were unsure. Over one third (69%) had additional experience of EPA forms as an attorney, a witness or as part of a work role. Only 52% of principals reported discussing the role/responsibilities of the attorney with the attorney at length. Only 17% had revoked or changed an EPA. Principals overwhelmingly agreed on the importance of communication within families about decision making.

Respondents became attorneys because they had been asked by the principal (50%), had suggested it to the principal (19%) or had observed relatives in need of help, were concerned about abuse, had a partner overseas in the defence forces or had made an arrangement with a partner prior to an overseas trip. Attorneys (100%) all thought principals should have an EPA because of age. Most (68%) were an attorney for only one person; all had been an attorney for less than five years. Only 41% had discussed the role and responsibilities with the principal at length before signing the document. Only seven attorneys had acted on the EPA. The reasons for activating the EPA included illness of the principal, the principal was overseas, to address concerns about abuse of an EPA or to challenge a medical decision.

4.1.2. Access to the form, advice and information

- Almost half (48%) of the principals and few (25%) attorneys accessed legal advice before signing the document.

Survey respondents are mostly a well educated group with English as their first language. They are thus likely to be able to actively seek out information/advice from professionals, the internet and organisations. Despite this, some still expressed concern about access to appropriate information.

Figure 2 Access to form: Principals.

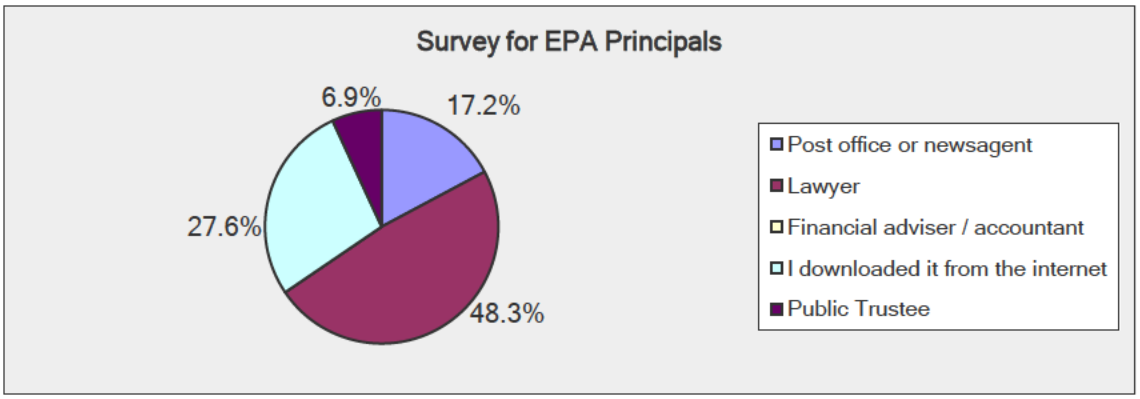
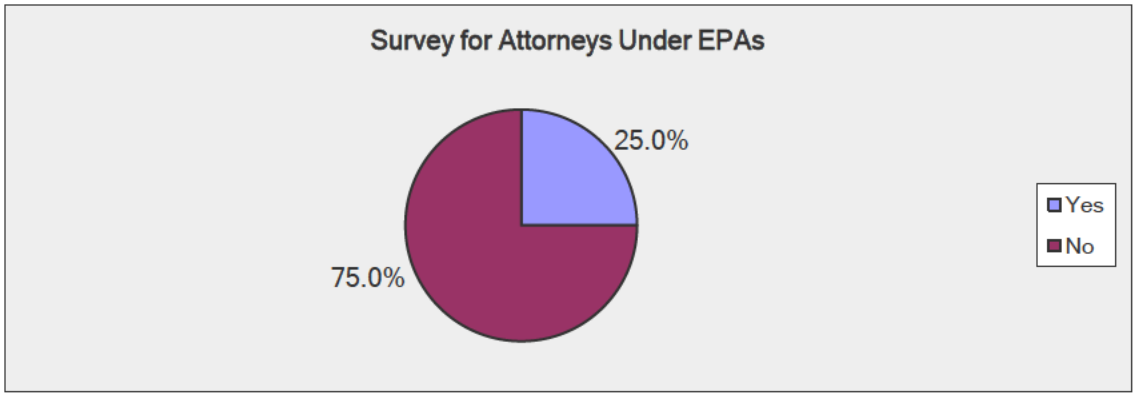


Figure 2 illustrates principals' access to the EPA form. Forty-eight per cent of this group of principals accessed the form through a lawyer and used legal assistance to complete it. Principals who sought legal advice were more likely to agree that the form adequately alerts people to the serious nature of the decision and provided enough information on the possible implications of decisions than those who did not seek legal advice. The other principals used the internet (27.5%), the post office or newsagent (17%) or the Public Trustee (7%) to obtain the form. It is of interest to note that no respondent obtained the form from a financial adviser or accountant. Some principals (41.5%) also consulted other organisations to obtain more information on the

role of attorneys (7), revoking an EPA (6), which institutions recognise the document (5), the meaning of a term (4) or issues of safe custody(1) and accountability(1). Of the principals (46%) who used the internet or booklets to seek further information, the majority (92%) reported that the search was successful. Of this group, most (75%) reported looking at DJAG sites; only one person reported that the information located there was not useful to their enquiry.

Most attorneys (75%) did not have any legal assistance before signing the document (Figure 3). Only four attorneys sought legal advice before signing the form. Of those four attorneys, only two agreed that the form had been discussed with them at length. A few (25%) talked to other organisations about one or more of the following: the role of an attorney (3), who recognises document (1), the meaning of a term (2), accountability for abuse (1), when the EPA comes into effect (1), what type of decisions can still be made by principal (1) and what type of decisions should be made by attorney (1). Of those attorneys (44%) who sought information from the internet or booklets, only 57% reported locating appropriate information. Of this group 75% had sought information from DJAG sites with most reporting that they had found it somewhat useful.

Figure 3. Access to legal advice: Attorneys



4.1.3. Understanding of the powers and obligations being conferred

In the surveys, principals and attorneys were asked a series of questions to explore whether the forms adequately alert principals and attorneys to the serious nature of the decision they were making (in executing an EPA or becoming an attorney under an EPA) and the scope of the powers being conferred on an attorney. Principals and attorneys were also asked about the adequacy of the explanation of the role and responsibilities of an attorney.

4.1.3.1. Nature of the decision to execute an EPA and scope of the powers

- Principals and attorneys differed on whether the serious nature of the decision to execute an EPA or become an attorney was clear.

Most principals (73%) reported that they were adequately alerted to the serious nature of the decision to appoint an attorney. Only 37% of principals considered there was enough information on possible implications of this decision. Concerns were expressed about how substitute decision making worked in practice and the nature of the attorneys' access to bank accounts and finances. Attorneys were much less sure than principals that the seriousness of the appointment is clear, with only 24% agreeing that they were adequately alerted to the seriousness of the appointment (60% disagreed and 18% were unsure).

4.1.3.2. Scope of the powers conferred on an attorney

Almost all principals (93%) agreed that the scope of the powers conferred on an attorney is clear. Attorneys differed on this with nearly one quarter (23%) disagreeing that the scope of the power was clear for attorneys. Attorneys who had sought legal assistance before signing were more likely to agree that the scope was clear than the attorneys who did not seek such assistance.

4.1.3.3. Adequacy of explanation of role and responsibilities of an attorney

- Principals and attorneys expressed concern about the adequacy of explanation of the role and responsibilities of attorneys (Figure 4).

Only 52% of principals agreed that the role and responsibilities of the attorney was adequately explained. What was missing was reported to be:

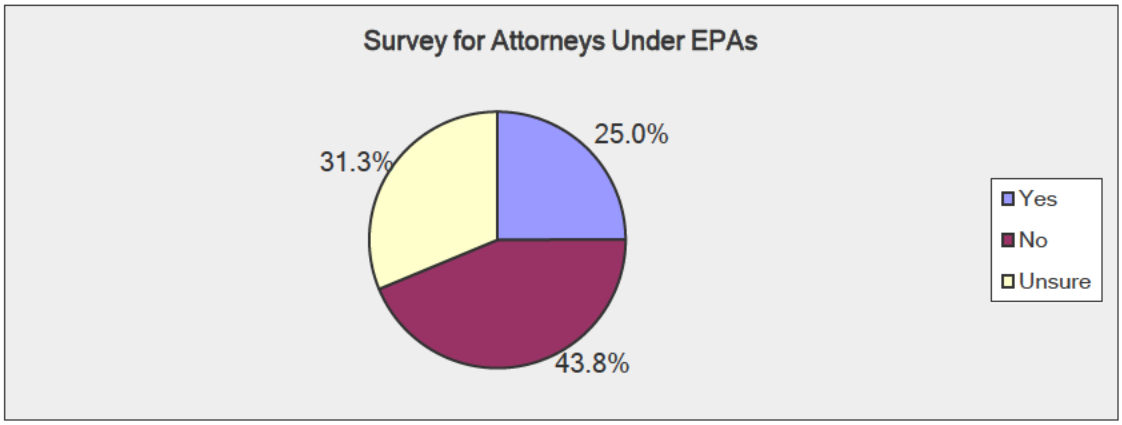
- an understanding of:
    - conflicts of interest;
    - accountability and record keeping;
    - decision specific capacity; and
    - what control is retained;
- examples of 'real life situations so attorneys can get a feel for the role';
- simpler explanations so attorneys can understand, the need to encourage conversation about choices and wishes especially for health care; and
- more instructions for service providers on the types of decision attorneys can make.

Attorneys did not consider that there was an adequate explanation of their role with only 25% agreeing it was adequate, 44% disagreeing and 31% unsure.

What was missing was reported to be: descriptions and explanation about activation of EPA, timelines and expenses; worst case scenarios – 'at present the forms assumes everything will go smoothly in families'; 'how to do the role' – make decisions and keep records; explanations of real life situations about when it commences, who makes this decisions, and how to make decisions about capacity for a matter, an explanation of the advocacy role of an EPA attorney, or

what happens if the attorney abuses power. Of the four attorneys who sought legal advice before signing the form, only two agreed that the form had alerted them to the seriousness of their role.

Figure 4. Adequacy of the explanation of the attorney's role on the form



4.1.3.4. How decisions are made

- Some principals and attorneys wanted more guidance on how decisions will be made.

The communication of decisions to other family members was important to the majority of principals (91%). Principals (43%) wanted more guidance to consider how the attorney will make decisions, how attorneys should consult with other attorneys where the decision is to be 'by majority', how to prove consultations have taken place, and what happens if a joint appointment is not workable. One principal suggested that the possibility of successive attorneys needs to be clearer. Six attorneys wanted more guidance on how to make decisions when more than one attorney is involved.

4.1.3.5. When the financial power comes into effect

- Confusion exists around what 'immediately' means in relation to the commencement of the financial power.

Over half the principals (60%) wrote in an occasion when the financial power was to begin with 26% selecting 'immediately' and 12 % being unsure of what they had nominated. Of those who selected 'immediately', only 50% intended that this power should take effect on completion of the form. Only 31% of attorneys understood that when the principal selected 'immediately', the attorney's power began on the completion of the form. Two attorneys did not have an accurate understanding despite having legal assistance.

4.1.4. Satisfaction with the forms

The survey results indicated satisfaction with the ease of use of the forms. However, this should be viewed in the context of the generally well educated and computer literate respondents in the survey sample.

4.1.4.1. Information provided on the form and in the explanatory notes

- Most principals and attorneys reported reading the explanatory notes and considered them easy to understand. Attorneys in particular, however, sought more examples.

Over 80% of principals and attorneys reported reading the explanatory notes. Although most thought the notes were useful and easy to understand, one third of attorneys did not agree that the information was useful or easy to understand and only 28.5% of attorneys agreed that the notes provided them with all the information they wanted to know. Attorneys (78.5%) more than principals (43.5%) thought more examples would assist with understanding.

Table 4. Importance of further information: Principals EPAs

Answer Options	Very important	Important	Unsure	Unimportant	Very Unimportant	Response Count
Further guiding instructions to help you complete the form	3	12	4	8	0	27
What to do with the form once it's complete	7	16	1	4	0	28
Whether financial institutions or government agencies will recognise the EPA	12	15	0	1	0	28
Who to contact if you require further information	6	17	3	2	0	28
Whether your EPA will be recognised if you travel interstate or overseas	14	12	2	0	0	28
Advice on discussing your EPA with your family	11	9	3	4	0	27
When and how your EPA will come into effect	12	11	0	5	0	28
More information about how to write specific conditions or restrictions into the EPA modifying the way the attorney's powers can be used	9	9	5	5	0	28
More information on the types of personal decisions your attorney/s can make for you in the event that you lose capacity	9	11	3	4	0	27
Answered question ***Skipped question***						**28** **2**

Only six principals and one attorney had referred back to the explanatory notes. The attorney and two of the six principals reported that the information they sought was not available in the notes. Concerns about what was missing were: validity of the document in other states, the importance of appointment of spouses, the consequences of appointing a solicitor who might not be around when the document comes into effect and dealing with abuse.

In response to questions about further information to be provided in the notes, areas of greatest importance to principals (Table 4) were information on: whether financial institutions or government agencies will recognise an EPA, overseas recognition and when and how the EPA will come into effect. Attorneys (Table 5) considered these areas even more important and also wanted information on who to contact for more information.

Table 5. Importance of further information: Attorneys EPAs

Answer Options	Very important	Important	Unsure	Unimportant	Very unimportant	Response Count
Whether financial institutions or government agencies will recognise the EPA	13	3	0	1	0	17
Who to contact if you require further information	12	5	0	0	0	17
Whether your EPA will be recognised if the principal travels interstate or overseas	11	5	0	1	0	17
When and how the EPA will come into effect	12	4	1	0	0	17
Answered question						**17**
Skipped question						**6**

4.1.4.2. Format

- Only one principal reported that the form was difficult to complete. Most survey respondents reported that they did not find difficulties with the presentation, font size and language. Most survey respondents were satisfied with the overall format of the form. Attorneys were less sure than principals that the language used was simple and easy to follow and that the use of legal terminology was necessary. Tables 6 and 7 present an overview of the comments of principals and attorneys on the presentation, language and instructions.

Table 6. Format of EPAs: Principals

Answer Options	Strongly agree/ agree	Unsure	Strongly disagree/ disagree	Response Count
It is well presented	22	3	2	27
I have no problem with the text size or font used	25	1	1	27
Overall, the language used is simple and easy to follow	22	4	1	27
There was an unnecessary amount of legal terminology	4	5	17	27
The definitions of terms provided were clear and easy to understand	22	4	1	27
The instructions for completing the form were confusing	4	5	18	27
Answered question				**27**
Skipped question				**3**

- Principals and attorneys reported few problems with the length of the form.

Most principals (84.6%) and attorneys (75%) agree or strongly agree that the current form was an acceptable length. However, more than half of the principals (52%) and attorneys (62.5%) thought the forms and explanatory notes should be separated.

- Although most principals and 56% of attorneys did not find the inclusion of financial and personal/health matters in one form confusing, some principals (60%) and some attorneys (50%) supported separating the forms.
- Survey respondents were asked direct questions about the inclusion of financial and personal/heath matters in the one form. Although most principals (78%) did not report this as confusing, 60% thought the two matters should be separated into different forms and 44% thought that EPA should be for financial matters only. A smaller proportion of attorneys (56.3%) did not find the inclusion of both matters confusing, with 50% agreeing that the forms should be separated and 43.8% agreeing that EPAs should be for financial matters only.

4.1.4.3. Language and wording

- Principals were generally more satisfied with the language, clarity of definitions and use of legal terminology than attorneys. It is important to note again that this group was generally well educated and computer literate.

Table 7. Format of EPAs: Attorneys

Answer Options	Strongly agree/ agree	Unsure	Strongly disagree/ disagree	Response Count
It is well presented	13	3	0	16
I have no problem with the text size or font used	13	3	0	16
Overall, the language used is simple and easy to follow	10	4	2	16
There was an unnecessary amount of legal terminology	8	5	3	16
The definitions of terms provided were clear and easy to understand	9	5	2	16
Answered question				**16**
Skipped question				**7**

Although most principals (80.7%) reported the language was simple and easy to follow, fewer attorneys (63.6%) agreed with this. The pattern was similar for the clarity of definitions with principals (80.7%) much more likely than attorneys (56.3%) to agree that the definitions were clear. For principals, 63% thought a glossary might help understanding key terms but most thought definitions should still remain part of the form.

Attorneys were concerned about legal terminology. Attorneys were much more likely to agree (50%) or be unsure (31%) that there was an unnecessary amount of legal terminology than principals with only 15% agreeing and a further 15% being unsure.

4.1.5. Other issues relating to the form

Specific issues that were explored in response to the Stages 1 and 2 findings were: accountability of attorneys (keeping records, conflicts of interest and investigation) and the inclusion of special conditions by principals.

Record keeping and accountability: Most principals (85%) and attorneys (94%) agreed that more information on the responsibility to keep records was important. Attorneys also wanted more information on gifts and conflicts of interests (100%) and when the Office of the Adult Guardian will investigate (94%).

Use of special conditions: Most principals did not use special conditions. Of those (34%) who did, the conditions were initiated by themselves rather than on the advice of legal practitioners and they reported that it was not difficult to include. Most principals (92%) wanted more information on how to include special conditions to add specific additional powers; 80% wanted more information on how to restrict powers in relation to gifts, conflicts of interest, consulting

with others, annual accounting and preventing some decisions about property. Only 50% thought pre-worded conditions and tick boxes would assist in including or restricting powers.

Appropriate certification and copies of the form: Not all principals (68%) reported having copies of the EPA. Of these, only 47% reported appropriate certification of copies. Of the attorneys, 22% reported that they did not have a copy of the EPA. Although only five principals had revoked an EPA, two of the five reported that the prior attorney retained a copy of the revoked EPA.

4.2. EPA survey for witnesses

All 23 witnesses in the sample had experience of witnessing EPAs; 13 also had experience in witnessing AHDs. Where comments relate primarily to witnessing EPAs they are reported here; where comments relate to AHD they are reported in Part C of this Report. Where the discussion refers to EPA and AHDs, for example the section on assessment of capacity, it is reported in this section and not repeated in Section C. To recap on information presented in Section A, witnesses varied in professional background (lawyers, JPs and Com.Decs.), experience and location with some operating out of legal firms and others located in local shopping centres as JPs. Forty-six percent were located in a major city, 54% were located in regional Queensland. The small sample size does not allow for any analysis that separates the different qualifications of witnesses. Experience of witnesses of EPAs in the past year varied widely from 0–150 cases with more than half (53%) witnessing five or fewer EPAs in the past year and three witnesses witnessing over 100 in the past year. Years of experience ranged from 1-30 years with a median of 5 years. Most witnesses (87%) reported being adequately or very prepared for their role.

4.2.1. Understanding by principals and attorneys of the powers and obligations

The most common problems observed by witnesses for principals were: understanding when the financial power begins (82.5%), the meaning of an instruction or a term (59%), the role of attorney (41%) and how to revoke the power (41%). Other areas raised were: possible conflicts of interest, what special instructions to insert, understanding about capacity (‘they react angrily if capacity is questioned’), the difference between long and short form, and accountability – ‘the policing’ of the attorney.

4.2.2. Witness understanding of role and terms of the EPA

Of the witnesses, 94% reported the role of the witness to be to witness the signature of principal, explain the nature and effect of the document and assess capacity of the principal. Some confusion was apparent in understanding of what ‘immediately’ meant in relation to when the financial power commenced, with only 59% correctly nominating that it commences on completion of the form.

4.2.3. Preparation and training of witnesses

Most witnesses (87.5%) reported feeling adequately prepared in terms of understanding their legal obligations when witnessing EPAs. Specific training in relation to EPAs varied, with 53% reporting formal training, 41% reporting information but no formal training and one witness indicating no information or formal training had been received. Of those who had received formal training, all except two witnesses had received it in the last five years.

Professional training and seminars (100%) and training DVD or written information (56%) were considered the most effective forms of training.

4.2.4. Satisfaction with the form

4.2.4.1. Information provided on the Enduring Power of Attorney form and in the explanatory notes

- Witnesses were less sure than principals that the form helps principals to understand the nature and effect of the power.

Only 53% of witnesses agreed that the design /content of the form helps witnesses ensure that the principal understands the nature and effect of the power. Most (93%) thought a list of suggested questions would help, but differed as to whether the questions should be separate (60%) or part of the form (33%).

4.2.4.2. Format and language

- Witnesses generally agreed that the form is well presented and the overall language is simple and easy to follow. They differed from principals in their responses to the definitions, use of legal terminology and the length.

Most witnesses agreed that the EPA form is well presented (87.6%), there was no problem with the text size and font (94%) and that overall the language is simple and easy to use (87.6%). Witnesses differed from principals in that more than half (59%) thought that the form is too long. Witnesses also expressed some concern about the language and use of legal terminology with only 69% agreeing that the terms were generally clear and more than half either agreeing (29%) or being unsure (29%) whether there is an unnecessary amount of legal terminology.

Table 8. Format and language: Witnesses of EPAs

Answer Options	Strongly agree/ agree	Unsure	Strongly disagree/ disagree	Response Count
It is well presented	14	1	1	16
I have no problem with the text size or font used	16	0	1	17
Overall, the language used is simple and easy to follow	14	2		16
There was an unnecessary amount of legal terminology	5	5	7	17
The definitions of terms provided were clear and easy to understand	11	2	3	16
Answered question				**17**
Skipped question				**6**

4.2.5. Assessing capacity

Assessing capacity is a core area of contention in terms of what qualifications and/or training are necessary to assess capacity, how it is assessed and what guidelines should be in use. As noted above, this section refers to practices surrounding capacity assessment for either an EPA or AHD.

4.2.5.1. Checking principal's understanding of the nature and effect of the power

- Only 53% of witnesses agreed that the design and content of the forms assists to ensure the principal understands the nature and effect of the power

Witnesses used a range of strategies to check that the principal understood the nature and effect of the EPA. Common methods involved asking the principal to explain what it means (88%), talking generally about the form (80%), discussing it at length (60%) or discussing it briefly (40%). The context matters here with some witnesses assessing capacity as part of a large legal practice and some assessing capacity in a space provided in a busy shopping centre.

4.2.5.2. Practices and guidelines

Usual practices: Nearly all (93%) witnesses suggested that assessing capacity was usually or always straightforward. All witnesses had, as part of their practice, asked specific questions to determine the capacity of principals completing EPA/AHD forms. Of those who only sometimes asked questions to determine capacity, their reasons for not asking questions were prior knowledge of the principal, no reason to doubt capacity or a recent test.

Use of guidelines to assess capacity: All except two witnesses had read guidelines to assess capacity and most thought them to be an acceptable length (77%). Most witnesses (all except 2) reported having drawn on suggested questions provided in guidelines (from the Office of Adult Guardian - 77%; from the Duties of Justices of the Peace (Qualified) manual - 54%; or from the Queensland Law Society- 31%) to assess capacity.

Six witnesses suggested changes to the guidelines. These included comments that: Com.Decs. and untrained JPs do not have sufficient knowledge to assess capacity and that the QJA Guide to JPs is more up to date than the branch manual.

Declining to witness: Nearly half (47%) of the witnesses had declined to witness on at least one occasion because of concerns about capacity. If doubtful, witnesses would request an independent assessment (60%), refuse to witness the form (20%), or seek expert advice from a treating doctor or GP (20%). Reasons provided for requesting an independent assessment were: the person was vague, unable to answer questions, had short term memory issues, or could not recount the explanation given about the form; or the witness considered the principal was being coerced or had a concern about an existing diagnosis. Some sought independent advice routinely if the principal was in a hospital/aged care facility or there was a diagnosis of dementia.

Table 9. Witness use of guidelines in capacity assessment: reading guidelines

Have you read any of the following guidelines? Please select all answers that apply.		
Answer Options	**Response Percent**	**Response Count**
Office of the Adult Guardian's 'Capacity guidelines for witnesses of Enduring Powers of Attorney'	80	12
Queensland Law Society's 'Guide for EPA witnesses'	40	6
Department of Justice and Attorney-General's Bulletin 'Witnessing Enduring Powers of Attorney (EPA) and Advance Health Directive (AHD) documents'	73.3	11
Section of 'Duties of Justices of the Peace (Qualified)' manual relating to witnessing EPAs and AHDs	60	9
Section of 'Administrative Duties of Commissioners for Declarations' manual relating to witnessing EPAs and AHDs	13.3	2
None of the above	13.3	2
Unsure	0	0
Answered question		**15**
Skipped question		**8**

Table 10. Witness use of guidelines in capacity assessment: use of suggested questions

Have you used or drawn from the suggested questions in any of the following guidelines to assess capacity? Please select all answers that apply.		
Answer Options	**Response Percent**	**Response Count**
Office of the Adult Guardian's 'Capacity guidelines for witnesses of Enduring Powers of Attorney'	76.9	10
Queensland Law Society's 'Guide for EPA witnesses'	30.8	4
Department of Justice and Attorney-General's Bulletin 'Witnessing Enduring Powers of Attorney (EPA) and Advance Health Directive (AHD) documents'	53.8	7
None of the above	7.7	1
Unsure	7.7	1
Answered question		**13**
Skipped question		**10**

4.2.6. Accountability and records

Most witnesses (80%) wanted more information about their responsibility to keep records. Some suggested that log books were in use and that experienced JPs always keep records; another suggested that a list of questions was needed with an extra page for recording and clear advice about what information is required for QCAT hearings, should the validity of the EPA be challenged on the basis of the principal's capacity.

A long-term JP commented, 'we did not have log books and it is too easy not to make notes' but was concerned about how it would be policed. One witness commented that he used to keep records but became concerned about privacy and security of files in the open space provided in a shopping centre.

4.2.7. Additional comments

Some witnesses made suggestions about further information on the forms that included: stating upfront the difference between long and short forms, placing more emphasis on the risks of conferring an immediate financial power on an attorney, and adding details of record keeping for attorneys with reference to Tribunal requirements for hearings.

5. Key findings and recommendations: Enduring Powers of Attorney

Participants in the interviews, the focus groups and surveys came from diverse groups and had a range of user interests as principals, attorneys, witnesses, professionals and service providers and/or investigations officers. All agreed that the form should be user friendly, but what constitutes user friendly for such a variety of groups and users is a challenge for any review of

the form. In some cases different groups held very different views. For example, the highly educated principals and attorneys in the surveys were more likely to find the form and information easier to use than the Aboriginal and Torres Strait Islander and CALD groups consulted. Professionals (e.g. social workers) and service providers (e.g. OAG, Public Trustee, QCAT, Land Titles Office of the Department of Environment and Resource Management) are more likely to see EPA cases with problems and hence identified a range of specific responses to address these problems. Additionally, some professionals raised issues that were not identified by other groups. Legal practitioners highlighted the tensions between being user friendly and having the appropriate legal terminology. Lawyers also sometimes differed in their views from other witnesses such as JPs and Com.Decs. Despite this, areas of common agreement as well as variation in views can be identified.

The findings and recommendations below should be viewed with the caveat that the research primarily presents the perspectives of individuals and groups with an interest in discussing EPAs, not the views of those currently not using the form and not willing to engage with the research.

5.1. Broad contextual issues

A. The integrity of the form and the processes surrounding it

Although some groups considered the form and the processes surrounding it worked well for many people, others expressed concerns about: access to the form; level of understanding the information provided, particularly in the context of diverse cultural groups; understanding fully the powers it confers and how and when these come into effect; understanding the role and responsibilities of attorneys and witnesses; and the possibility of tampering with the form after it is completed. It is the view of the research team that the form as a legal document should:

- Be accessible to a broad range of population groups.
- Have appropriate information, education and advice strategies attached to it to ensure that the nature and scope of the document and the responsibilities it gives rise to are understood by all user groups.
- Balance ease of access with appropriate protection for principals, attorneys and witnesses.
- Encourage practices that reflect the spirit of the legislation relating to assisted and substitute decision making.
- Promote discussion with and involvement of attorneys in the execution of the document.
- Alert attorneys and witnesses to their responsibility to keep records and provide examples and tools to assist them.

- Highlight available tools that can be used by witnesses in assessing capacity.
- Have a system that addresses concerns about substitution of pages and limited knowledge of roles and responsibilities of various parties.

The following areas of this Report identify the issues that need attention to enhance the use and usefulness of Enduring Power of Attorney forms.

B. Knowledge of the legislation and use of the forms

Findings:

- Individuals execute an EPA with a range of motivations and intentions, differing abilities and within diverse contexts. This affects how they engage with information, the form and communication strategies around it. It creates tension in determining the role and use of EPAs and the information strategies that surround its promotion and use.
- Highly educated people in the survey sought to complete an EPA as part of later life planning, were generally well informed about the document and reported only a few difficulties with the form and the information provided.
- Some interview respondents, particularly attorneys, identified a range of problems in understanding the form and its use.
- In contrast, none of the Aboriginal or Torres Strait Islander interview respondents were well informed about the document despite some respondents having tertiary education. Although they held the view that the document was highly relevant to their communities, they raised concerns about the language, access to advice and information, cost and cultural issues.
- People from CALD communities had a range of understanding and sought access to information and advice that presented the form and the legislation within a cultural and systems context. For example, what constitutes 'family' and who should have a say in decisions about individuals can have many cultural interpretations. The use of EPAs for some groups needs to be presented in the context of how EPAs relate to broader systems of government (e.g. legal and medical systems and frameworks for substitute decision making and assessment of capacity, Centrelink nominee arrangements and the roles of QCAT and the Public Trustee) and approaches to later life planning for managing financial assets and making personal and health care decisions.
- Witnesses and service providers also provided examples from their practice of limited knowledge and/or misunderstanding by a range of groups. At times misuse of the powers that the form confers are attributed to a lack of understanding of the responsibilities of attorneys.
- Multiple points of access (post offices, newsagents, internet, and legal offices) are well used.

Recommendations:

B1. Although many people did not experience any difficulty in understanding or using the forms, the limited uptake by some groups and the identified areas of limited knowledge or confusion suggest that a more targeted awareness, information and education strategy is required.

B2. Community awareness and wider community education campaigns targeting particular groups including ATSI and CALD communities should be based on outreach to service providers, involvement and training of intermediaries in Indigenous health and legal services, Indigenous communities and CALD services.

B3. Recognition that the document has to be explained in a cultural context and in the context of broader systems is fundamental to the approach to information dissemination and training of intermediaries. Further recommendations that relate specifically to Indigenous people are contained in Section D of this Report.

B4. Maintain flexibility in a range of ways to access the form.

B5. Cost as a barrier to take up was raised as an issue by the Indigenous respondents. The forms should be available free in paper format as well as downloadable from the internet.

C. Access to assistance and advice

Accessibility issues are raised by the considerable variation across informant groups in reports on knowledge of EPAs, access to information and advice and understanding of the information and the form.

Findings:

- Self completion was the most common approach to accessing and completing the forms. This highlights the importance of easy access to information and a user friendly form.
- ATSI and CALD groups as well as social workers and some witnesses emphasised the importance of having someone talk through the form with principals and with attorneys and being able to do this in the context of understanding culture and explaining systems.
- Perceptions of the need for legal assistance were largely linked to how clearly interviewees understood the implications of EPAs for principals and attorneys. The better the understanding of the powers conferred, the more likely people were to recommend the use of legal advice.
- Accessing legal advice did not necessarily mean that the principal understood the scope of the powers or that attorneys were involved in the process of executing the document. The more trust principals had in their lawyer the less likely they were to try and develop a thorough understanding of what was involved in appointing an attorney.

- Some respondents reported that limited advice was available for attorneys.

Recommendations:

B6. The current approach that an EPA is capable of being completed without legal advice is supported.

B7. Develop an educational strategy to train workers who can talk through the document with particular groups.

B8. The EPA form should include a recommendation for a witness, a health or human services worker or community representative to go through the form with the principal and attorney to ensure all parties understand the implications of completing it. This could include a strongly worded recommendation that principals and attorneys should seek advice or information if they do not understand the nature and scope of the power and the duties of attorneys.

D. Understanding of the powers and obligations of the attorney

Concerns consistently arose across user groups and data collection methods about the level of understanding of the responsibilities undertaken by and accountability required of attorneys. Attorneys are also asking for more information, advice and direction. This is a priority area for change as attorneys are identified in prior research and practice as key actors in the misuse and abuse of EPAs.

Findings:

- All groups identified that the form and information do not assist attorneys and principals to fully understand the role and accountability of attorneys. Such problems were linked to the information provided, the language and structure of the form itself and the practices surrounding the execution of the document.
- It was mainly left to principals to explain the nature and scope of the powers to attorneys. There is no one responsible for ensuring that the attorney understands the role and obligations and has the skills to fulfil them.
- Attorneys, principals and service providers clearly identified a need for greater understanding of the role and obligations of attorneys.
- The layout of the form does not necessarily encourage attorneys to read all parts of the form.
- Although the form indicates a responsibility to keep records, limited understanding of how to enact this responsibility was consistently reported across principals, attorneys, service providers and witnesses.

- The information does not specify what constitutes reasonable records or when the OAG will investigate.

Recommendations:

B9. Education and support targeting the role of attorneys is a priority. This should include a targeted information booklet for attorneys and access to advice and assistance.

B10. The information package should include greater detail on

- the obligations attached to the power;
- when it comes into effect;
- who recognises it;
- how decisions are to be made;
- the nature of substitute and assisted decision making;
- managing conflict of interest transactions and gifting;
- accountability;
- what constitutes reasonable records;
- how records might be kept; and
- what might be required in the event of an investigation.

Suggestions included the provision of case scenarios of substitute and assisted decision making and conflicts of interest, and an Excel spreadsheet to assist with record keeping.

B11. As part of the Government's current review of the guardianship legislation, the current law should be examined to determine whether there are options for further enhancing accountability of attorneys particularly in relation to financial matters and for holding to account attorneys who are not acting appropriately.

B12. The obligations of attorneys need to be highlighted in the structure and witnessing of the forms. Attorneys and principals should be required to read Part 1 and Part 3 of the document and indicate their understanding of the scope, nature and obligations of the power being conferred. This could be achieved by altering the principal's 'Statement of Understanding' and the 'Attorney's Acceptance'.

B13. Information for attorneys should strongly recommend that they consult with principals when they start to use the power. This includes consulting, to the extent possible, with principals who have impaired capacity.

B14. As part of promoting accountability of attorneys, principals should be encouraged to give more direct and detailed instruction on processes and expectations in relation to gifts, property and other financial transactions. Principals may also wish to impose

an annual reporting obligation on attorneys. The use of special conditions is one way to do this and these conditions are discussed further below at Heading F.

E. Understanding of when the power for financial matters comes into effect

Findings:

- Misunderstanding of what 'immediately' means in relation to financial matters was present in the surveys of principals, attorneys and witnesses, in interviews and in the social worker focus group. Even within highly educated groups such as the survey respondents, there was some level of misunderstanding. The confusion was around whether 'immediately' referred to on completion of the form or on loss of capacity to make financial decisions.

Recommendations:

B15. Replacing current use of 'immediately' in Clause 5 with options that differentiate more clearly coming into effect on completion of the document and coming into effect when there is evidence of a loss of capacity to make the financial decision.

B16. Extending the section in Part 1 'When does the attorney's power begin' to include a more extensive discussion on the consequences of selecting 'immediately'.

F. Limited use of special instructions

Findings:

- Most people did not use special conditions. This was attributed to a lack of understanding of what could be included, the design of the form and the information provided.
- The current form actively discourages the use of conditions or terms in the note linked to 'How much control will my attorney have?'
- Principals wanted more information on how and why to include special conditions. Areas of interest included conditions on gifts, conflicts of interest, consulting with others, annual accounting and preventing some decisions about property. The use of such conditions was also strongly supported by the OAG and the Land Titles Office of the Department of Environment and Resource Management. There was variation in views about the value of examples and tick boxes to assist in including conditions. Some warned examples limited what people would consider; others thought that examples opened areas for consideration.
- A structural problem is that currently the clause giving an example (Clause 3) of a special condition is not sufficiently linked to the preceding clause (Clause 2) about including special conditions.

Recommendations:

The research team does not support the use of multiple special conditions that would unduly limit the ease of use of the document. The team, however, recognizes the value of principals and attorneys having greater knowledge of how and why to include conditions and queries whether the discouragement of conditions is the right policy response.

B17. More extensive information on the use of special conditions should be provided with some more detailed examples of how some conditions might be worded and what implications these conditions are likely to have.

B18. The structural problem in the current form should be addressed by linking examples to the question in clause 2.

B19. Remove the statement on the form discouraging the use of special conditions and replace with some examples and a discussion of the implications of the use of special conditions and situations that might make this useful. Examples might include the attorney to have regard to the maintenance of an adult child with a disability or conditions placed on gifting or the sale of property. As noted above, another special condition principals may wish to consider is to require an attorney to participate in annual financial auditing.

G. Understanding how decisions are made

Findings

- Many respondents were unsure about the language used in Clause 7 relating to how decisions by attorneys are made. The use of terms such as 'jointly', 'severally', 'by majority' and 'successively' present problems in understanding and there is only limited information available on the various options and what they might mean.
- Clause 7 uses 'prefer' when it is more accurate to use 'require'.

Recommendations

B20. Simplify and clarify the language relating to how decisions are made and include a more detailed discussion in the information with examples to clarify options and their implications. For example, 'unanimous' could be explained as meaning 'all must agree' and the explanation of 'severally' could be clarified by adding the word 'alone' after 'any one of them may decide'. Such definitions or explanations should be accompanied by examples and perhaps be included in a glossary of terms.

B21. In Clause 7 change 'prefer' to 'require'.

H. The role of witnesses

This is an area of some contention with little comment from principals and attorneys and conflicting views from differing service and professional groups.

Findings:

- Most witnesses demonstrated a clear understanding of their role and reported they felt adequately or well prepared in understanding their legal obligations. In contrast to the views of JPs and Com.Decs. interviewed in this study, some respondents (mostly legal practitioners and service providers) were less sure that JPs and Com.Decs. understood their role.
- Witnesses who were JPs and Com.Decs. raised a number of concerns about their responsibility to keep records with most indicating a need for more information and clear instructions. Some witnesses did not consistently keep records when they doubted capacity of the principal.
- Inconsistencies in the instructions and the form create confusion in relation to responsibilities and actions. Page 7 states that the witness should refuse to sign the document if he/she is not sure that principal understands the nature and effect of the appointment whereas the Part 2 instruction for the witness strongly recommends that if he or she in any doubt as to capacity, a written record should be kept.
- Some respondents reported that some lawyers seem to consider the signing of an EPA as part of routine practice in estate planning and had completed it without an extensive discussion with the principal about the seriousness of the decision, the nature and scope of the powers being conferred and the potential implications of decisions made about who and how to appoint attorneys and use special conditions.
- Appropriate qualification to assess capacity is an area of differing views. Some doctors, lawyers and witnesses considered assessing capacity should not be part of the witness role. Some difference was also evident in whether lawyers or doctors are the most appropriate to assess capacity.
- There are a range of guidelines in use to assess capacity.

Recommendations:

B22. Further development of the information and training available to JPs, Com.Decs. and legal practitioners is needed particularly in relation to explaining the form, record keeping and assessment of capacity. Professional development seminars, information kits and card and flow charts should assist in moving through appropriate steps.

B23. Part 2 instructions for the witness should recommend that there be recording of all assessments of capacity not just those when capacity is in doubt. This could be

assisted by the provision of sample records and log books. This change to the form could be achieved by deleting the words 'if you are in any doubt' in the second paragraph of the instructions to Part 2.

B24. Part 2 instructions for the witness should reassert (as in page 7) that the witness should refuse to sign if in doubt about the principal's capacity (after making appropriate inquiries as to capacity as the instructions suggest).

B25. In Part 2 instructions for the witness, there should be a clear statement about the obligation of the witness to ensure the principal has capacity to compete the EPA and this should be accompanied by a specific reference to guidelines that are publically available to assist in this regard.

5.2. Specific matters relating to the EPA form and instructions

I. Need for improved information and instructions

A mix of views on the information provided related primarily to level of education, role (principal, attorney, witness, professional) and/or cultural grouping.

Findings:

- Most respondents agreed that the information provided on the form is appropriate and should be read by all parties. Some thought the form was very well designed, had stood the test of time and that the use of headings as questions was effective.
- Some groups had suggestions for change that included: the inclusion of additional information, further examples and/or case scenarios; changes in the structure of the form to separate the form and the information provided; the inclusion of a glossary of terms and attention to targeting the information for particular user and cultural groups. Details are provided under Section K in this section of the Report.
- For some groups, the concern was not so much about a lack of information but rather not reading or engaging with it. These respondents argued that the current system works well with legal advice or someone talking through the form with the principal. Other respondents suggested it was more about having information in an appropriate format.
- Limitations in the information provided included comment on the following sections:
    - How long does the power continue? The information relating to financial matters suggests the power continues until it is revoked. It does not consider that if loss of capacity is the trigger for financial decisions, the power will stop if capacity is regained.
    - Is there anything else that will end this power? Information on revocation and changing an EPA by marriage, separation or death does not consider in-depth all of the possibilities. A lack of understanding that separation did not revoke the

power was evident in some interviews and focus groups. Confusion was also reported by lawyers and demonstrated by the CALD groups as to the need to execute a new form if there is a substantial change in circumstance such as a marriage of the principal or a desire to change the attorney.

- What happens to this document when it is completed? This section does not suggest discussion with family although this is a strong theme throughout many of the interviews. It also does not indicate that copies should be certified.
- Where can I go for advice? The comment here was about the limited range of resources in booklets and websites.
- Duty to avoid transactions that involve conflict of interest. Wrong information is provided in the example used as it incorrectly suggests that it is not a conflict of interest if market value is paid by an attorney for the principal's car.

Recommendations:

B26. Add a more extensive discussion of when an attorney's power ends and what attorneys who no longer wish to act in this role should do.

B27. Add information in the section on revocation to be clearer about when an EPA will be revoked or a new form should be executed (e.g. when a couple separate but do not divorce).

B28. In the section 'Where can I go for advice?', remove the comment about the principal notifying his or her doctor as the need for the principal to consider giving his or her doctor a copy is already dealt with in the next section.

B29. Both the 'advice' section and the 'What happens to this document when it is completed?' section should include a discussion of the importance of involving family in decision making and discussing the principal's wishes with them.

B30. In relation to the 'What happens to this document when it is completed?' section, the researchers note and endorse the recommendations of the QLRC that the notes in the EPA should encourage the principal to provide a 'certified' copy of the EPA, and to explain the process of certifying an EPA.[14]

B31. Change the example used in the section on duty to avoid conflict of interest so that it accurately reflects the law.

[14] Queensland Law Reform Commission, *A Review of Queensland's Guardianship Laws,* Report No 67 (2010) Vol 3, Recommendation 16.14.

J. Useability of the form and information

Views on the useability of the form relate primarily to the language, wording, use of legal terminology and the structure of the form.

a) *Format*

Findings:

- Most respondents agreed that the form and information were well presented. There were few problems with the text size, font and overall appearance.
- There is a typographical error on page 7. 'The witness must state....'
- Note on page 13 needs to be updated to replace GAAT with QCAT.

Recommendations:

B32. Retain current text size, font and overall appearance.
B33. Amend and update as noted above.

b) Length and comprehensiveness of the form

Findings:

- While some respondents thought the length of the document was intimidating, most were satisfied with the length, agreeing that the topics raised in the form were important.
- Suggestions for shortening the form included separation of the health/personal sections from financial matters by having two forms; separating the notes from the form and moving the notes together and placing at either end of the form so the form has a stronger logic and is shorter. There were cogent arguments for and against all of these proposals.

Recommendations:

In designing the EPA, there is an inevitable tension between having a form that is too long and deters people from completing it, and ensuring that it contains sufficient information so that principals and attorneys are aware of the scope and obligations of the power. The researchers are of the view that the length is not a major concern. The focus should be on enhancing the useability of the information as detailed in other recommendations.

B34. The length of the EPA form is acceptable. The information that is currently in the form is desirable, and should not be removed although suggestions for improvement are made in other recommendations.

c) Language

Findings:

- Although some were satisfied with the language used, others reported that significant terms were too legalistic and definitions were not clear. This diversity in the responses to the language used was related to education, cultural grouping and familiarity.
- The language in the examples in Part 1 relating to what types of decisions could be made is confusing.
- The terms used for how decisions are made are not clearly explained. This issue has been dealt with in Section G.
- Indigenous and CALD respondents identified a range of concerns not simply about legal terminology but also about the meaning of key terms such as 'statute', 'paid carer', 'notary public' and 'losing capacity'.
- Some terms are vague. An example is 'in the ordinary way' on page 14.

Recommendations:

B35. Revise the examples given in Part 1 to better reflect everyday and simple language.

B36. Although some definitions are provided, a glossary of terms would be a useful additional tool. A glossary needs to not only define and explain terms in easy English but also place such terms in the context of an explanation of current systems of substitute decision making and guardianship.

B37. More extensive use of examples to explain some terms. One such term is 'paid carer'. Despite there being some explanation in the form as to what this term means, it continued to cause confusion and further guidance would be useful. A simple explanation such as 'The attorney cannot be someone who is paid to look after you' would be helpful.

d) Confusing aspects of the form

Findings:

- The presentation of signatures in Clause 8 is confusing as currently, it is unclear that the witness is witnessing that the person is signing for the principal.

Recommendations:

B38. Alignment of signatures in Clause 8 Statement of understanding so that it is clearer who is signing where and what is being witnessed.

e) Ordering of the form

Findings:

- Most respondents had little comment on the order of the sections in the documents.
- Some witnesses suggested the need to enhance the link between the section on the responsibilities of attorneys and where they accept their appointment. Currently, the last page where the attorneys accept their appointment and are required to tick boxes does not actually refer to or link with Part 3, the part that tells the attorney what all of their responsibilities are. The suggestion is to also include a declaration that the attorney has read Part 3 and understands their responsibilities.
- Some witnesses and professionals suggested changing the order to enhance the logic of the form from the point of view of the attorney. The suggestion is that the witness section should be placed in the last part of the form. The section for attorneys should follow that for principals and precede that for the witness for the principal.
- In some situations, there was a considerable time delay between the execution of the document by the principal and the witness, and when attorneys signed the forms.

Recommendations:

We note that some of the concerns raised here about attorneys' understanding their responsibilities have been addressed by way of other recommendations under heading D above.

B39. Improve the useability of the form by inserting the names of the principal and attorney(s), dates, and when the form comes into effect at the front of the form.

B40. Improve the logic of the form for the attorney by linking the attorney and principal sections more closely. This could be achieved by putting the witness section at the end and having the attorney section following that for the principal.

f) Certification and witnessing

Findings:

- Service providers/professionals expressed some concerns about current signing and witnessing arrangements and practices. Concerns included: the ability to complete and witness an EPA in the absence of the attorney; the potential to substitute pages of an EPA when downloaded from the web; and the limited specificity of the statements being signed.

Recommendations:

B41. Require the principal to sign or initial those pages which define or limit the powers of the attorney(s) to prevent substitution

K. Structural issues

a) Separation of explanatory notes and form

Findings:

- There were mixed views on the suggestion to separate the information provided from the form itself to enhance the flow of the form and have the information in a more discursive and comprehensive form in a booklet with examples. This would require some certification on the form that the information had been read. Arguments against this reflected a concern that the information would not be downloaded and/or read.
- Major concerns were whether information is read at the time of execution and at the time of activation and whether both the principal and attorney read the whole form. A tendency to trust others (professionals, proposed attorneys) rather than finely detailed reading was apparent in many responses.

Recommendations:

B42. Retain the current form and information format with the addition of specific explanatory booklets for particular groups e.g. ATSI and CALD groups or roles e.g. attorneys, witnesses.

B43. Explore a range of approaches to information provision with target groups e.g. flow charts to provide a step by step working through, workbooks, drop down menu, case scenarios and examples, sample accounting sheet, prompts and tick boxes, cultural designs and external packaging to attract ATSI people.

b) Separate form for Indigenous communities

Findings:

- Indigenous respondents generally thought the form was a good idea but needed to be presented in a culturally appropriate way. Culturally appropriate packaging with Indigenous designs, and an explanatory booklet in plain and simple language, explanations of key terms and an information strategy that targets Indigenous people and relevant workers are considered more important than pursuing a separate form.

Recommendations:

B44. Extensive consultation with ATSI groups to develop appropriate designs, information packs and a training and information strategy while retaining the form as used by all Queenslanders.

L. Other matters relating to the form

a) Processes and practices around drawing up and use of the form

Some respondents drew attention to the processes and practices surrounding the execution and use of an EPA.

Findings:

- The importance of communicating with families is consistently reported by all groups.
- A systematic approach to copying and storage is needed. There is some confusion about who holds valid documents and where.

Recommendations

B45. The form should emphasise the importance of sharing the decisions made in relation to who is appointed as attorneys, when the EPA comes into effect and any conditions around making decisions. It is acknowledged that for some individuals or cultural groups, it may not always be family members who are informed. In these situations, the form might offer guidance as to with whom these discussions should be had. An important issue to be discussed is where the EPA is going to be stored.

b) *Information strategies*

Findings:

- There is variation in understanding the language and concepts in the form.
- For CALD and Indigenous groups it is not solely a matter of simplifying language to improve understanding and uptake. Such groups need to have the document explained in the context of broader systems, have access to well trained support people to ensure accurate information, culturally appropriate formats, and a family centred approach.
- The role of translator and interpreter needs to be clearly defined.

Recommendations

B46. DJAG should develop a broad information strategy that targets the wider community and particular groups and/or stakeholders within it. This should include media campaigns, information kits, workshops, worker training and professional seminars.

B47. Information should be provided in a range of formats including paper based kits, websites, audio tapes and DVD presentations.

B48. DJAG should develop workshops to promote and train Indigenous and CALD workers to support members of their communities to complete an EPA.

B49. DJAG should work with Indigenous groups to develop culturally appropriate information kits and designs.

C. Advance Health Directives

1. Introduction

The findings and recommendations that are made in this Report in relation to AHDs have been informed by pre-existing data to which the researchers have had access, as well as by data gathered over the past 18 months in the course of this research. The data gathered from these sources will be described in this section of the Report.

Before describing that data, it is important to make some observations about the nature and scope of this research. As set out earlier in this Report, one of the motivations for the research was to review the AHD form itself and determine if there were aspects of the form such as length, format, order, language used and instructions given that represent barriers to its completion. Much of the data collected addresses these specific issues. However, a significant portion of the data relates to broader issues concerning statutory regulation including why people complete AHDs, views about the effectiveness of the regime and how it could be improved and perceived barriers to the uptake of AHDs that are unrelated to the form itself. While not all of this data is directly relevant to the central research question of the useability of the AHD form, it is relevant to provide context and background to the research, so will be reported. In addition to providing the necessary context for the research, these broader issues may also signal to the Government some areas in need of legislative reform, policy development or community education.

Finally, two general observations should be made which are relevant in interpreting the research findings. First, there are different perspectives when considering the role that should be played by AHDs, and these perspectives influence both views about what the law should be and how the AHD form should be drafted. A doctor who is treating a patient who has completed an AHD may have a different perspective on the usefulness or otherwise of the form than the patient who completed it. Secondly, even if individuals have a shared understanding of the role of the AHD, there may be divergent views about its desirable form and content. These different perspectives and different views make it a challenging exercise to draft recommendations to improve the form in a way that will increase its uptake.

2. Stage 1: Scoping the issues

A range of problematic aspects of AHD regulation was identified by the DJAG Practical Guardianship Initiatives Working Group and the CRG. These are set out below. Some of these issues relate to broader policy matters, and some specifically to the AHD form, Form 4, itself. The researchers have considered all of these issues and determined whether they raised points for further exploration in the interviews, focus groups and surveys, or were more appropriately dealt

with in another way, such as in recommendations for policy development, targeted or specific education, or to inform any legislative review.

2.1. Broader contextual matters

- Philosophical concerns about AHDs constituting consent to or refusal of medical treatment:
  - A patient who writes an AHD when he or she is well may have different views about treatment when he or she becomes ill.
  - A patient may request treatment that is futile or may refuse treatment when such treatment is consistent with good medical practice.
  - A patient may make an AHD without properly understanding what he or she wants to achieve from such a document.
- Practical concerns about AHDs constituting consent to or refusal of medical treatment:
  - Difficulties for medical professionals determining the validity of AHDs (which is particularly important given the legal implications of not following a valid AHD or following an invalid one).
  - Completing an AHD may result in unintended outcomes for the patient.
  - A directive in an AHD may be difficult to interpret.
  - An AHD is sometimes completed but not stored in a place where it is accessible when it is needed.
  - Family and friends are sometimes unaware of the existence of the form or its contents.

2.2. Specific matters relating to Form 4

- Issues to explore or suggestions about the current form:
  - Should the form encourage an individual to write details about their goals of medical treatment (sometimes referred to as an 'outcomes approach') (along the lines of clauses 7 and 15 on the current AHD) rather than specific directives about particular types of treatment (as in clauses 8–11)? For example, would a question exploring the circumstances in which an individual would like active treatment to stop elicit useful information?
  - Is it desirable to have two separate forms – one for a person who has a pre-existing illness or disease (and would therefore have more knowledge about potential treatment options), and one for a person who does not?
  - There is potential for confusion by including sections about appointing an attorney (Sections 6 and 7 in the form), given that an individual may have previously appointed an attorney under an EPA. There is also potential for a person who has previously appointed an attorney under an EPA and completes

Section 6 to provide responses which are inconsistent with the responses in the earlier EPA.
    - There is confusion about the meaning of 'current paid carer' (clause 36).
    - The form should facilitate or prompt a regular review of the directives in the form by the principal. Such a review is particularly important when a person becomes sick, as there is research suggesting that previously expressed preferences may change in such circumstances.
    - Does the form allow sufficient room to indicate preferred medical treatments for a specific injury or illness?
    - Would it be useful to include examples of potential treatment options?
    - Is there sufficient room on the form for a person to write any extra information they want included in the AHD?
    - Can the order of the sections in the form be improved? For example, should the attorney's acceptance (Section 10) be after the EPA sections (Sections 6 and 7), and should the statement of the principal's understanding (Section 8) and witness's certificate (Section 9) fall after the statement of the doctor's involvement (Section 5).
- Individuals may be intimidated by the form due to its complexity and technicality. Further information may need to be provided to make the form more accessible and easier to complete. Such information may include the following:
    - Clear guidelines, possibly in the form of a separate booklet, to guide completion of the AHD.
    - Information indicating that some medical treatment may be futile, and that there are times when an appropriate option may be to limit treatment.
    - Should the form state the effect of a directive on a substitute decision-maker's powers to make decisions about treatment?
    - Should the form state the implications of the AHD for the treating medical professional, including a statement that a medical professional is protected in some cases if he or she does not follow the directive?

With only one exception, all of the issues raised by the DJAG Practical Guardianship Initiatives Working Group and the Critical Reference Group have been the subject of further research and consideration in the course of this project. That exception relates to the broader contextual matters listed above that represent philosophical concerns about AHDs as an appropriate instrument to determine medical treatment. The brief of the researchers is to investigate why the uptake of AHDs is low, with particular focus on shortcomings of the form itself. Whether AHDs are a desirable component of health care generally is outside our brief, and we make no comment or recommendations in this regard.

The recent review of guardianship laws undertaken by the Queensland Law Reform Commission (QLRC) is also relevant to this research. The QLRC made a range of recommendations relating to the law that should govern AHDs and, to a lesser extent, about the AHD form itself.[15] The recommendations that are of particular significance to this research are the following:[16]

- An AHD must be in the approved form;
- The definition of 'eligible witness' in section 31(1)(a) of the *Powers of Attorney Act 1998* be amended to delete reference to the 'commissioner for declarations';
- The approved form for the AHD should be redrafted to take into account a range of recommendations of the QLRC:
    - A commissioner for declarations should not be an eligible witness (see above), and the approved form would need to reflect that amendment.
    - The approved form should specifically refer to the guidelines developed by the Adult Guardian, the Queensland Law Society and the Justices of the Peace Branch of the Department of Justice and Attorney-General, and recommend their use in witnessing the document.
    - The QLRC observed that section 35(1)(c) of the *Powers of Attorney Act 1998* refers to the appointment of an attorney for 'health matters' only in the AHD. It therefore recommends that Section 7 of the AHD be amended to refer to appointing an attorney for 'health matters' only, not 'personal/health matters'.
    - An AHD that directs the withholding or withdrawal of a life-sustaining measure currently only operates in situations listed in section 36(2)(a). The QLRC has recommended that this restriction be removed. Section 3 of the AHD form will need to be amended to accommodate this legislative change.
    - Include questions that draw the principal's attention to whether a direction refusing treatment is intended to operate in unforeseen circumstances, where the need for the health care does not arise as a result of an existing condition or the natural progression of such a condition.
    - Give consideration to incorporating the 'outcome-based approach' as well as making continued provision for a principal to give specific directions about specific health care.
    - Make provision for the principal to sign or initial each page that includes a statement or direction of the principal.
    - Continue to encourage the principal to review the AHD periodically.

[15] See Queensland Law Reform Commission, *A Review of Queensland's Guardianship Laws* Report No 67 (2010) Vol 2, chap 9.

[16] For a summary of all of the recommendations relating to AHDs, see Queensland Law Reform Commission, *A Review of Queensland's Guardianship Laws* Report No 67 (2010) Vol 2, chap 9, pp 109-118.

    - Continue to include information about the various ways in which the principal may bring the existence of the AHD to the attention of relevant people.
    - The Explanatory notes should encourage the principal to give a certified copy of the AHD to the principal's doctor, attorney, family member or friend and solicitor, and explain how the form can be certified as a true and complete copy.
- The excuse for not complying with an AHD on the basis that a doctor has reasonable grounds to believe that a direction is inconsistent with good medical practice should be removed.
- The legislation should be amended to make it clear that common law advance directives continue to operate alongside the statutory AHD regime.

The researchers have considered the matters explored and recommendations made by the QLRC, and some of these recommendations have been adopted in our Report.

At the time of writing this Report, the recommendations of the QLRC have not yet been endorsed by the Government, and the extent to which the Government plans to implement these recommendations is not known. The researchers have undertaken this review on the basis of the existing law, and the current approved AHD form. However, almost all of the key findings and recommendations will continue to be relevant if the recommendations of the QLRC are implemented.

3. Stage 2: Interviews and focus groups

The number of respondents and the group they belonged to were detailed in Section A of this Report. To recap, 18 people were interviewed in relation to AHDs: principals (10), nominated doctors (2), treating doctors (2), other health professionals who assist principals to complete the AHD (3) and a witness (1). Two focus groups commented on AHDs: one group of health professionals who worked in the health or mental health setting (4 respondents) and one group of people from CALD backgrounds (15 respondents). Interviews were also conducted with 11 Aboriginal (n=5) and Torres Strait Islander (n=6) people about both the EPA and the AHD.

One observation should be made about this section of the Report. A small proportion of the data that was collected did not differentiate between EPAs and AHDs but arose from discussion about both documents. The following data falls into this category:

- Responses from Aboriginal and Torres Strait Islander peoples;
- General comments made about both forms by respondents in the CALD focus group; and
- Some responses to questions in the survey by witnesses of EPAs and AHDs.

This data is reported in Section D in relation to Indigenous perspectives and Section B for CALD groups. Some of Section B which relates to the responses of witnesses also applies to witnesses of AHDs. This data will not be included again in this of the Report.

3.1. Motivations and intentions

The primary motivation for completing an AHD given by all principals was to prevent having their life prolonged if there were in a situation where the ensuing quality of life was unacceptable to the principal.

There were a range of other motivations revealed by some of the principals:

- Witnessing unsatisfactory experiences of a family member or friend at the end of their life, and the belief that having an AHD would have helped to avoid these outcomes;
- Having very clear views on how they wanted to be treated, and the belief that AHDs provided security around having their wishes met:

> 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. AHD7

- Prompting by her solicitor when she was making her will;
- Teaching in an aged care course;
- Giving their same sex partner more legal rights to speak for them in future health care situations. An AHD was suggested to them when they went to make their wills:

> We're in the position we can't get married. It's always at the back of your mind that without these legal guarantees you're at the mercy of your more legally recognized next-of-kin, so your parents. If your parents are not totally kosher with your relationship then there is a possibility they could completely override your partner's wishes in that kind of situation. That's a real worry you know. ADH9

- Lacking family, and the belief that an AHD would ensure that friends would have the appropriate authority;
- One interviewee suggested that the Commonwealth funded health review of those aged 75 plus which includes questions about whether they have an AHD may be a motivation for this group.

In summary, for a range of reasons, 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 address this.

However, it was also suggested that not all people for whom an AHD might be useful because of their life circumstances were interested in doing so:

> I have spoken to a number of people saying it would be a good idea to have an AHD and their eyes just glaze over and they don't want to talk to you any more on that subject. AHD5

Principals also indicated that the directions in their AHDs were intended for their family, friends and attorneys, more than for treating health professionals. In this context, there was also a perception that expressing their wishes to family members through an AHD would help family deal with any feelings of guilt that they otherwise might experience about making health decisions that limited life.

The social workers in the focus group had only limited experience in assisting people complete an AHD. One social worker suggested to a patient that an AHD be completed when he was about to have surgery for advanced cancer and his wife was mentally unwell. The social worker was of the view that completing the AHD would provide guidance to the patient's son and daughter.

3.2. Role of nominated doctor in completing an AHD

Doctors can play different roles with respect to AHDs. For an AHD to be valid, a doctor is required to certify that the principal has capacity to complete the AHD. The doctor who undertakes this role is referred to in the AHD (and in this research project) as the 'nominated doctor'.

Two nominated doctors, both general practitioners, were interviewed. These doctors had seen between 8 and 20 patients in relation to AHDs in the previous 12 months. Neither provided the form to patients, though they usually drew a patient's attention to the existence of the forms either on the web or at newsagents. They both described their role as explaining the medical terminology to their patients.

The nominated doctors were of the view that people should discuss the form with their doctor to ensure they understood the implications of the choices they had made. Without that advice, they felt that a directive might be given which could prevent a doctor providing appropriate care to the patient. Similar views were expressed in the focus group of social workers.

Respondents in the CALD focus group expressed the view that principals should have an opportunity to discuss completing the AHD with a general practitioner, but had some reservations about the ability of individuals from ethnic backgrounds to talk to their doctor as most do not use interpreters. They expressed concern that many doctors may not realize how much of the form the principal really understands.

Different kinds of consultations

In the experience of the doctors, patients desired different things from their consultations. Sometimes the patient simply requested the doctor's signature, and some patients required a consultation that ranged in length from 15-40 minutes. Patients varied in terms of how much of the AHD was completed prior to the consultation and their overall understanding of the document, and there was also variation in their understanding of medical terminology and requests for clarification. These factors all influenced the length of the consultation that was necessary.

Assessment of capacity

One of the nominated doctors interviewed did not consider undertaking a capacity assessment to be a necessary part of the role as nominated doctor. This doctor had never undertaken a formal assessment of capacity while completing the nominated doctor statement because all of the patients she has previously assisted had been regular patients and their capacity was not in doubt. This doctor stated that if she felt a capacity assessment was indicated, she would conduct a capacity assessment using the 'cognitive impairment test' or the basic 'mini-mental state examination'. She was not aware of guidelines for assessing capacity released by GP Partners entitled 'Understanding Capacity', and was of the opinion that a short set of questions in the AHD itself would assist the nominated doctor in performing a basic capacity test.

In contrast, the other nominated doctor considered capacity assessment to be a key part of his role as nominated doctor, and he regularly performed such assessment. In addition, he records notes of this assessment procedure that can be referred to if questions concerning the principal's capacity arise in the future. This doctor had considerable professional experience with capacity assessment, and assisted formulate the 'Understanding Capacity' guidelines. As such, he is confident using his own protocols and does not strictly follow any guidelines. This doctor felt that a separate document to guide doctors in assessing capacity would be useful.

Consultation as a separate Medicare item

A few principals raised the issue of the expense involved in seeking a doctor's assistance in completing the form, as completing an AHD does not constitute a separate Medicare item.

3.3. Practice of treating doctors with respect to completed AHDs

The two treating doctors that were interviewed supported the use of AHDs in principle, but observed that they are often difficult to implement in practice. A reason given for this concern is that it is difficult for people to understand the implications of their directions, and this can lead to internal inconsistencies within the document:

> It is very difficult to cover in detail what principals wanted in areas such as 'artificial nutrition' or 'terminal phase of an incurable illness'. ADH17

The same treating doctor gave an example in relation to a directive about antibiotics, the suggestion being that there were inconsistent directives within the one AHD regarding whether antibiotics should be provided. In such a case, the view was expressed that doctors need to turn to the family for guidance:

> 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. AHD17

3.4. Access to the form, advice and information

The principals interviewed had accessed the form via the internet or a newsagent. They had been told where to find it on the web by others, and did not necessarily consider it was easy to locate without assistance.

Indigenous respondents suggested that the AHD forms should be available in the offices of Indigenous services as well as in the offices of general practitioners. These respondents also suggested that the forms should be available free of charge in paper form to improve accessibility.

One principal and one health professional commented that the pink background made printing the form more expensive in terms of the amount of ink that was required, and that if printed in black and white, it was more difficult to read than if it was on a white background.

Principals received differing levels of assistance and advice in completing their AHDs. Some completed it themselves after discussions with their lawyer. For example:

> The solicitor went through it with both of us first and explained what everything was and then we took them away and filled them out ourselves. AHD9

Most principals saw their doctors simply to obtain their signature rather than to receive assistance with filling out the form. In response to a question about whether any advice was obtained in addition to that of the solicitor, one principal commented:

> No. Obviously we took it to a doctor to get it signed but it was all completed by that stage. AHD9

However, some principals reported that their doctors checked that they understood what the form meant. For example:

> And she (doctor) said to me before she signed it- she looked me squarely in the eye and said, 'Now tell me what are your wishes in the event that you are temporarily incapacitated?' And I told her. And then 'in the event that you are permanently incapacitated and no hope of gaining consciousness, what do you want?' And then she signed it. AHD12

Those interviewed had gone to considerable trouble to ensure that they understood the implications of what they were signing. However, the legal requirements, for example that the form had to be signed by a doctor to be valid, and that a new form had to be completed if the principal wished to change his or her attorney, were not as well known.

A respondent in the CALD focus group suggested inserting a link on the front page of the AHD to a website where people could access further information about completing the form. This group also suggested that it would be helpful to have information about AHD forms and where they can be located at churches.

3.5. Satisfaction with the form

3.5.1. General comments on the form

Principals who were interviewed had completed an AHD and they did not find the form confronting to the extent that they did not complete it. However some respondents raised its confronting nature as an issue for them in completing it.

Interview respondents who play a role in assisting people to complete the document were able to identify some of the barriers to completing the form. An admissions and discharge nurse who encourages and advises people about completing AHDs said:

> Yeah, I like page 9, but once you start to go into pages 10 and 11, you frighten people and you confuse people, and that's when most of them stop. AHD13

One treating doctor was more forthright:

> [Completing an AHD is] a very intimidating process and one that is deferred forever … so I think that many of them don't make a decision NOT to do it, but they just can't quite get around to it … it's overwhelming. AHD17

Another perspective was provided by the nominated doctors who both thought that the design of the form was helpful in carrying out their role as nominated doctor.

The interviews with Indigenous respondents revealed a number of issues similar to those raised in relation to EPAs (discussed in Part D). In general, the AHD was seen as a more straightforward document than the EPA. However, there was little community awareness and knowledge of the form. Respondents were all unaware of the existence of these forms, but many

could cite instances from their experience where such a form may have been helpful in resolving family disputes or indecision.

To promote the chance of uptake of AHDs within Indigenous communities, respondents were of the view that the look and the content of the form itself needed to be modified for Indigenous people. In general, respondents agreed that the forms should be presented in a way that encouraged Indigenous people to use them, and to understand the implications of filling out the form. Furthermore, AHDs, more so than EPAs, were seen as raising a taboo topic – the discussion of death. While respondents all believed the form was useful, these cultural considerations need attention if the form is to be used by community members in a constructive way. Detailed suggestions on the structure and content appropriate to accommodate the needs of Indigenous communities are contained in the Report in Appendix D.

Respondents in the CALD focus group also spoke of the reluctance of people from some cultures to complete the form, as it could be seen as a 'curse' to complete such a document. Again, the need to educate the community was recommended. This group was also of the view that the form should reflect a greater consideration of cultural issues.

3.5.2. Information provided in the explanatory notes

People were generally happy about the quality of the information provided in the explanatory notes in the AHD, but most had suggestions about additional information that would be useful:

- advice about storing and accessing the form once it is completed;
- the nature of the obligation of health professionals to follow the directives in the form, and whether they can be overridden by doctors if they are inconsistent with good medical practice;
- the extent to which it would be wise to involve family and friends in discussions about their AHD, including about their attitudes on treatment at the end of their life, and advice on how to discuss these matters;
- advice about the serious nature and implications of the decisions made in the document;
- information about likely medical scenarios and possible complications that can arise;
- advice about things that should be considered before making certain decisions;
- information and advice about the nature of palliative care, and possible treatment options for palliative care;
- advice about how to select a health attorney;
- clearer advice about the need to complete a new form should your instructions change.

3.5.3. Format

A range of issues that relate to the format of the AHD were explored with respondents and are reported below.

Placement of information

On the current form, there are 3 pages of explanatory notes which provide general information about aspects of the AHD. Some explanations are also interspersed throughout the remainder of the document. Principals had mixed opinions on whether such information should be removed from the AHD form and included in an information booklet separate from the form.

Health care professionals generally wanted it separated. The main reasons in support of this option were that the AHD would be shorter and easier to read, and more information could be provided in the separate booklet without adding to the length of the AHD. The shorter AHD was considered to be desirable for the treating doctor. The tax-pack model was suggested as a possible model for separating the form from the information.

There was also support for retaining the information in the AHD itself. The nominated doctors found the information, particularly the definitions in Section 3, helpful when going through the form with the principal. Others expressed concern that if the information was in a separate form, fewer people would read it, or they would lose it and not be able to refer back to it.

Usefulness of guiding instructions

'Guiding instructions' is a reference to the instructions on the form that are intended to guide the principal in completing the form. These include instructions such as 'write your name here' and 'go to Section 7'. It is also a reference to the examples provided throughout the form. Overall, principals reported that the guiding instructions were good, and made completing the form easier.

The only reservation that was reported related to the use of examples. As a threshold point, some discussed the fact that other kinds of examples may be more helpful. For example, instead of giving examples about what a principal could write, it would be useful to provide examples of potential future situations that can arise, and about which a directive may need to be given. A member of the CALD focus group felt more examples would be helpful, including sample statements about the level of independence that a person would like to maintain, and whether they would rather stay at home or be taken to hospital in certain situations. There was also a suggestion that if examples were to be used, they were more appropriately placed in the information section at the beginning.

In addition, some of the examples were identified as being problematic:

- the examples given in clause 15 (page 13) about the nature of wishes (reported to be 'unhelpful' and/or 'confusing'), including the meaning of 'mere existence';
- the examples given in clause 31 (page 18) about terms attached to the powers of an appointed attorney (reported to be 'misleading').

Clause 35 on page 19 was identified as confusing by the CALD focus group, particularly the instruction relating to a person signing on behalf of the principal.

Length and repetition

All principals thought the form was very long, although none considered the length made it difficult to complete. Most principals thought it was a long form but felt all of the sections were necessary (apart from minor adjustments) and consequently were not overly concerned with the length itself. Many felt it was repetitive, in that they were asked the same questions at different stages, and some found this repetition made the form difficult to complete.

Respondents with an assisting role and nominated doctors also identified repetition (on pages 10 and 11 in particular) as an issue that made completion difficult for principals. However, it was also seen as helpful to ask about the similar issues more than once because this helped people to think through more carefully what they did mean.

One of the treating doctors identified the length of the form as an issue when it had to be used in an emergency. In this context, this respondent reported that there is not necessarily time to read and understand fine detail. It was suggested that ideally the key treatment issues that were important to the principal and possibly discussions that he or she has had with the doctor should appear on the front page. This respondent also observed that the length is largely due to considering the implications of established terminal conditions rather than responses to acute illness or an accident.

Spacing, text size and font

Mixed views were expressed about the spacing, text size and font. Some principals commented that they found the text size and font to be excellent, while others thought it needed to be improved. Some expressed concerns about the spacing between lines which made it difficult to read and complete. Comments were also made that in its downloaded form, there was insufficient space to express opinions, particularly when the principal had complicated medical histories. Some commented that the color scheme (a pink background and the places where you write in white boxes) was useful and made it easier to read, though others noted that the coloured background makes it more difficult to read when it is downloaded and printed in black and white.

3.5.4. Language

People across all roles had mixed views about the language and wording used in the AHD. Some felt that it was of a high standard. This view was shared by the social workers in the focus group. Others thought that the language was too ambiguous and that legal or other professional assistance was needed in order to be certain about the meaning of some of the clauses. Nevertheless, some respondents reported that formulating unambiguous detailed instructions in such a document was not practical.

Respondents in the CALD focus group thought that the form needed to be more basic, the language (including the medical terminology) needed to be simpler, and the use of symbols may provide assistance. Concern about the language was also expressed by Indigenous respondents. It was observed that much of the existing language needs interpreting for many community members, and there are few interpreters available.

For those who felt that the language could be improved, a number of suggestions were made, although none related to improving the legal terminology. Some respondents suggested only minor changes to the wording were necessary, though all principals felt that the medical terminology could be simplified or amplified, perhaps in an accompanying booklet.

One health care professional considered the terminology to be a significant barrier to individuals wishing to complete an AHD. When asked what impact the legal /medical terms have on people completing or understanding the form, this respondent commented:

> It has a major impact. People are frightened of it; it's a legal document. They are ... in here you have the fact that the tissue donation, you have the Act stated. Well they haven't read the Act and they don't know the Act. So it does again frighten people away from completing them, which is why we've seen less people complete them. AHD13

There was not universal opinion about the medical terminology used. Overall doctors thought the medical terminology was accessible, particularly with assistance from the doctor:

> I think it is in plain English. Most people understand the terms except perhaps artificial hydration. AHD16

On the other hand, there was also criticism of some terms because of variance in possible interpretations, in particular 'terminal, incurable or irreversible conditions':

> But see my reading of this is that it all talks about terminal phase of … an incurable illness, which is—how do you define that? We often deal in well it is likely that you are going to die. But then a terminal phase of an incurable illness, does that mean someone who is old and has got sepsis and pneumonia and is probably going to die and aggressive treatments won't matter? Or does that mean someone who has got

> something else? So I think there is a grey area of whether or not that deals with that very well. AHD3

There was evidence of confusion over clause 2 of the General Instructions (page 7), particularly the reference to 'temporarily lose capacity'. When asked about whether the principal felt he or she had a good understanding of the medical decisions that were being made, that person commented:

> No, no, not really, the; hold on a minute. Section two, where it says 'General instructions' and the first thing it says, 'If you temporarily lose capacity' well I wasn't too sure about that, so I just treated that as if I was going to be permanently losing the capacity. But I put a stipulation here that the treatment I didn't want, the stipulation is only if this situation was the case. I'm thinking, I suppose that might be a bit vague for you to understand. AHD15

Those involved in assisting principals to complete the form agreed that this clause needs to be better explained.

Definitions

Principals and other research respondents had mixed views on the quality of the definitions provided. The nominated doctors in particular liked the definitions for the medical terminology at the beginning of Section 3, as they found them helpful in explaining the form and discussing it with patients.

The major criticism of the definitions was that although they defined the practical meaning of a word clearly, they were not interpretative. That is, they did not explain what the term meant in the real world context (for example, they do not adequately explain what cardiopulmonary resuscitation involves for the person receiving it).

The use of a glossary of terms was suggested by one principal. A suggestion came from the CALD focus group that a separate glossary with greater detail in easy English would be an improvement.

Respondents in the CALD focus group suggested that the definitions should be translated into different languages.

3.6. Other issues relating to the form

3.6.1. Directions for end of life decision making

A key issue explored in the AHD interviews related to directives about medical treatment at the end of life. Researchers were interested to explore the kind of directives that principals preferred to give and why, and the usefulness of the different kind of directives from the perspective of

treating doctors and why. Respondents were asked about the two different techniques used in the AHD to describe their preferences at the end of life. These different approaches are described below.

Quality of life outcomes: This technique refers to the ability of a principal to make a statement in the AHD that indicates what quality of life is acceptable at the end of life, and to describe end of life goals. Acceptable quality of life refers to things such as level of independence, social capabilities, and emotional and physical well being that is acceptable to the principal. These statements may direct that treatment be stopped if quality of life falls below an acceptable standard.

Section 3 (pages 8-12) of the AHD allows principals to make directions about 'terminal, incurable, or irreversible conditions' only. Clause 7 (page 9) allows the principal to make statements about broader treatment preferences in this context. For example, it provides the option for the principal to direct that he or she wishes to receive only measures that are necessary to maintain comfort and dignity and to relieve pain. Section 4 of the AHD is headed 'Personal Statement' and allows a principal to record their general views about health care that is not covered in Section 3. Clause 15 allows the principal to record his or her wishes, such as 'I value life, but not under all conditions. I consider dignity and quality of life to be more important than mere existence.' This Report refers to these kinds of directions as an outcomes approach.

Specific directions about treatment: The other technique in the AHD is to make a more specific statement about medical treatment (such as cardiopulmonary resuscitation or assisted ventilation) that the principal wishes to receive or not receive in specified situations at the end of life.

Clauses 8-11 in Section 3 (pages 10-11) facilitate more specific statements to be made about medical treatment. These clauses invite the principal to tick a box to indicate whether they want to receive or refuse specified treatment if they suffered from a specified medical condition (e.g. the terminal phase of an incurable illness).

Views expressed

The two treating doctors that were interviewed expressed a strong preference for an outcomes approach as opposed to specific directions about treatment, in part because treatments change over time and in part because it is very difficult to anticipate all contingencies when giving specific directions. In the view of these doctors, a general statement outlining the principal's values, goals and attitudes towards the end of life would assist in determining the appropriate course of treatment. They also expressed the view that the directions in pages 10-11 can be difficult to interpret:

> 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, that 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. AHD3

The same doctor commented further:

> I think an overall theme should be a refusal document rather than a request document…Having a clear philosophy of what sort of outcome they want is probably the key thing. AHD3

On the other hand, social workers in the focus group thought that the personal statement in clause 15 (page 13) may be difficult for the principal to complete, and be so vague as to provide limited assistance to the treating doctors.

Concern was expressed by a doctor where treatment was refused if the person was in the 'terminal phase of an incurable illness'. An example provided was where a principal refuses surgery, yet a surgical procedure may increase the patient's comfort and allow him or her to return to their previous lifestyle for some time. An outcomes approach rather than specific directions about treatment approach is more likely to achieve that outcome.

Treating doctors understood that advance directives are often completed because of principals' concerns about receiving treatment that they do not want to receive. Doctors felt that it was unlikely, in the current environment in which they are practising, that principals would receive more treatment than they desired. They continued that the best strategy to avoid this would be to provide a broad statement of what they wanted, and to appoint an attorney. In this regard, they felt that clause 7 on page 9 would be useful. This view was not one universally shared, and the social workers focus group had some reservations about clause 7, suggesting that principals might find it difficult to complete.

The principals interviewed also generally supported an outcomes approach, and emphasised the need to have discussions with their attorney about their view on acceptable quality of life below which they would not wish to receive treatment. One said:

> 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. AHD9

Another principal expressed the view that the specific directions about treatment did not necessarily represent her overall wishes:

> I just didn't think (questions on pages 10 and 11) were representative of my wishes to die with dignity. This just says you know we won't do this, we won't do that, we won't do the other but you know the heck with your dignity. You know these are the things that we won't do. So no, I didn't think it represented my wishes. ADH8

The introduction to Section 4 does not specifically invite a broad statement on how people wish to die, and some principals thought the introduction should invite such a statement in a more express manner.

Table 11. Principals' views on a specific directions approach vs. an outcomes approach

Relevant AHD sections*	Respondent ID
Specific directions	
Pages 10 and 11	
Very happy	AHD 5,6,7,12
Happy but had concerns with listing specific treatment	AHD 9,14
Generally happy but had concerns about medical situations listed	AHD 10,11
Not happy	AHD 8
Not happy but will assist treating doctor	AHD 15
Page 9	
Completely happy	AHD 5,6,7,8,9,10,11,14,15
Happy but should include lifestyle	AHD12
Outcomes approach	
Personal statement	
Completely happy	AHD 9,10,11,12
Happy but it should be longer	AHD 8,15
Outcomes focus	
Need greater emphasis on quality of life outcomes in decisions	
Yes	AHD 7,8,9,10,11,12,15
No	AHD 5,6

*Note. This table summarises the views of principals in relation to pages 9-11 and Section 4 of the AHD.

There were also positive responses from principals in relation to the specific directions about treatment approach. Principals liked completing the specific directions on pages 10-11 for the following reasons:

- It was easy to 'just tick the boxes';
- They considered it made their intentions clearer and that meant the treating doctor would understand their intentions and thus be more likely to follow them.

Both nominated doctors thought that including specific directions to refuse treatment were important, but that pages 10 and 11 could be collapsed so that the question 'Do you want medical intervention/life prolonging treatment?' be asked under the four situations. They commented further that antibiotics should not be one of the treatments that could be refused because they are used in palliative care, as well as for the purpose of prolonging life. One doctor suggested that if a direction to refuse particular treatment is given, an explanation of why they make that direction would be helpful.

Views on the preferable approach were also expressed by an admissions and discharge nurse. This respondent preferred the outcomes approach as s/he believed it would be easier for doctors to interpret the wishes of the principal, and simpler for principals to complete the form. This respondent was also of the view that principals struggle with the directions on pages 10-11 due to their confronting nature. A comment was also made in the social workers focus group that an outcomes approach may give the principal a better focus. Table 11 summarises respondents' views on specific directions and outcomes.

Members of the CALD focus group supported both the general statements on page 9 as well as the opportunity to provide consent or to refuse consent to the treatments as set out in pages 10-11.

3.6.2. Separate AHD for a person with a pre-existing illness or disability

AHDs may be completed by a person who has a pre-existing illness or disability, and by a person who does not. The researchers were interested to explore whether it would be useful to have one form for a principal who had a pre-existing illness or disability, and another for a principal who did not.

Two of the doctors were of the view that it may be useful to have different forms, or different sections of this form for each group. It was considered that the current document was more tailored to people with a known terminal disease, and that a separate section or form may be more useful for people who are currently healthy:

> I know they have tried to make a legal document here that covers as many points as possible but in fact that has actually probably made the thing more confusing. AHD3

Social workers in the focus group also expressed some support for the use of separate forms.

However, one treating doctor commented:

> My main concern is to keep things simple. Alternate forms are not good for treating doctors. One form is better that is suitable for both groups. AHD16

Principals were also less supportive of separate forms or a separate part of a form. Those who considered the form too long and tedious agreed that either having separate forms or dividing the form up may be helpful to simplify it without reducing its effectiveness. Other principals who had found the form easy to use did not favour this change.

3.6.3. Separate AHD for members of Indigenous communities

Earlier in this section, it was suggested that the look and content of the AHD would need to be modified to make it more accessible to Indigenous communities. This raises the issue of whether it would be preferable to develop a completely separate form, and there were mixed opinions on this point.

Regardless of whether the form was a separate one, there are some matters which would need to be addressed in the form. Torres Strait Islander respondents in particular referred to the need to specify who will have control of the body after death.

3.6.4. Inclusion of an option to appoint an attorney for personal/health matters

A principal can appoint an attorney to make decisions about personal matters. Such a power enables the attorney to make decisions about a range of personal matters when the principal loses capacity including where the principal lives, the nature of his or her employment, if any, and also health matters. An appointment can also be made to confer on the attorney a power to make decisions for health matters only. The AHD form facilitates a person appointing an attorney for 'personal/health' matters.

Some respondents perceived the appointment of an attorney in the AHD to be illogical as the overall purpose of the AHD is to provide directions in the event that they are unable to give these themselves, and they would therefore not need to appoint someone to make decisions in the same situation. One health professional said:

> I don't find any parts particularly difficult to understand, but I do think that ... the enduring power of attorney for health matters confuses a lot of people, because what you've got is you're ... in one breath you're saying that, we're going to direct ... and direct my own care, and then in the next breath, well who's ... you've given the power to somebody else to direct your care. So I find that a little bit difficult for them, because they're saying, 'Well what's the point of doing this if I'm now directing somebody else to my care?' ADH13

While there was not a great deal of comment on the point, some raised the possibility of confusion arising due to the possibility of appointing an attorney under both an AHD and an EPA.

In the social workers focus group, there was a suggestion that the AHD should be the only enduring document to deal with health matters, so it should be the only vehicle for the appointment of an attorney.

The appointment of an attorney was particularly important for people who did not have family members or those in same-sex relationships where the authority of their partner as decision maker for health matters may not always be recognised.

3.6.5. Tissue/organ donation

The issue of whether tissue donation should be included in the form was raised by health professionals. These respondents suggested that if this clause continues to appear in the document, the heading should be 'tissue and organ donation' rather than 'tissue donation'. They also suggested that individual tissues and organs should be listed for individual consent for donation. The social workers focus group raised the issue of potential conflict between information in the donor register and the AHD.

Principals interviewed did not express any strong views on this topic.

Respondents in the CALD focus group also felt it would be useful to list individual tissues and organs as there may be cultural reasons that some tissues or organs could not be donated. It was also suggested that there should be the opportunity for people to accept donated tissue or an organ. Concern was expressed about the complexity of the references to the *Transplantation and Anatomy Act 1979.*

3.7. Process and practice issues

3.7.1. Storing and accessing the form

The principals had a range of thoughts on where to store their AHD, and how it would be accessed if it was required:

- one respondent had not told anyone where the form was;
- two principals who were partners travelled at all times with their documents on a CD;
- some principals felt that an electronic record of the AHD would be desirable;
- another was in the process of writing an e-book that enables people to collate all of this information so it can be found by attorneys;
- another suggested a link between the Medicare card and copies of an AHD.

Both nominated doctors expressed the view that an electronic record containing the AHD would be most convenient for them. One of these doctors had suggestions about where electronic copies could be stored including on a patient's shared electronic health record, and about procedures for aged care facilities to ensure that if a resident was admitted to hospital, his or her AHD accompanied them along with the other relevant medical documentation.

The CALD focus group also suggested that the hospital admission form should contain an option for a copy of the AHD to be included on the chart.

3.7.2. Reviewing the form

Most principals realized that it may be necessary to update the information if their health situation changed or the details of their family or friends altered. However it was generally noted that making changes required a new form to be completed, and the involvement of legal and medical professionals made this an expensive process.

It was suggested that amendments of names at least should not require a new form. Two principals mentioned changing their AHD by crossing out names of attorneys appointed in the document.

3.7.3. Training of health professionals

Both of the treating doctors emphasised the importance of encouraging doctors to raise the issue of end of life treatment with their patients where this was relevant, and encouraging patients to share their ideas with their attorneys. In their experience this often did not happen and attorneys were not secure in making decisions on behalf of the principal. A suggestion also came from the CALD focus group that general practitioners and doctors in hospitals should routinely be encouraging patients to complete an AHD.

Another health professional agreed that training was important. When asked whether training about the legal issues surrounding AHDs would be desirable, the respondent said:

> Oh I would, absolutely. Even just to get the information through that there are these Acts and you know even from a—I know it is not in here but from a statutory health attorney point of view that you know being family doesn't necessarily mean that they're the right people to be making decisions or you know anything along those lines. But I would think sort of training to really say well this is exactly what it means. You know to let the person when they come to see you, or if one of these is presented to you, knowing okay this is a legal record of, and therefore you really should be adhering to that rather than okay not worth the paper it is written on so don't really bother. But I think if there is training and an understanding that you are really going against the person's wishes because you might think it's—I mean it is one thing to contravene good medical practice and that kind of thing, but anyway. AHD2

3.7.4. Community education and awareness

Many principals as well as the nominated doctors discussed the need for greater community education and awareness raising about the forms.

Education and awareness was also a strong theme arising from the CALD focus group. The members of the focus group felt that there was very little knowledge about the AHD in many ethnic communities. There was a suggestion that filling in this kind of a form could represent a 'curse', and education would be required to counter that perception. While individuals from various ethnic groups would understand much of the language used in the form, education would be required because some of the interpretations of directives may be different as they come from socially, legally and culturally diverse backgrounds.

Community education and awareness is critical for Indigenous people. None of the respondents interviewed had any familiarity with the form. Therefore, a strategy is needed to promote the forms, and it was suggested that members of the community should be used in this promotion process as education at a very grass roots level is most likely to be successful. Such a strategy must take into account the fact that the AHD is concerned with issues of death, a cultural taboo. Community education must be able to address these cultural concerns so that completing AHDs becomes acceptable within Indigenous communities.

4. Stage 3: Survey

To recap on the figures detailed in Section A of this Report, 53 surveys that related to AHDs were completed: 26 were completed by principals, 11 by nominated or treating doctors, and 23 by witnesses, 16 of whom had witnessed AHDs.

4.1. AHD survey for principals

4.1.1. Motivations and intentions

Most principals (83%) who responded to the survey had completed an AHD within the last five years (54% had completed the AHD within the last 2 years). Most were primarily motivated to complete an AHD because of concern about unnecessary prolongation of life by doctors (66.7%) or family members (39%), or a concern to ease guilt of family members if they refuse life sustaining treatment on behalf of the principal (55.6%). Some were motivated by a negative experience of a family or friend (27.8%). Others valued the opportunity to make wishes known and indicate preferences at the end of life (22%) or followed a recommendation by a professional, family member or friend (22%). Two people (11%) had a specific medical condition and a clear idea of how they wished to be treated, two people (11%) had specific religious beliefs they wished to have respected. Only one person expressed concern that doctors might allow them to die before they were ready for their life to end.

4.1.2. Access to the form, advice and information

Among this group of respondents, only 20.8% obtained legal advice to complete the AHD form. Most used the internet (43.5%) or the post office or newsagent (34.8%) to obtain the form. Only three people obtained it from lawyer (n=2) or doctor.

Only one quarter (n=5) of respondents had talked to other organisations about the AHD. Most asked for explanations of the meaning of a term, the role of a health attorney, or the legal obligations of treating doctors to follow the AHD directions. 39% had sought other information from the internet or booklets, and only one person reported not finding the information that was sought. One person used material from the Department of Justice and Attorney General and found that useful.

In their survey, the nominated doctors were asked to specify from a list provided whether patients had raised any issues when considering the form. The issues reported to be raised by patients, and the response rate, are listed in Table 12.

In addition to the above, one doctor responded that he or she has been asked about the effect of the AHD on the ability of relatives to make health care decisions.

Table 12. Nominated doctors reporting on issues raised by patients

Issues raised by patients	Response %
Where to get a copy of the form	60
The meaning of an instruction or term used on the form	80
The role of the appointed health attorney, if any	60
How to change/revoke the AHD	40
The extent to which treating doctor/s will follow the directions in the AHD	80
The implications of specifying particular medical treatments they do or do not want	60
What happens with the form after completion, including how it is accessed by treating doctors	80
The 'general instructions' section of the AHD (that will apply in any circumstance)	40
What to write in the 'personal statement'	0

4.1.3. Role of nominated doctor and witness in completing an AHD

All of the principals reported that they had visited the doctor only once in relation to completing the AHD, at which time they had discussed the AHD at length (48%); talked generally about the nature and likely effect of the form (38%); briefly discussed the completed form (19%); or the doctor simply signed the form (9.5%).

The AHD also has to be witnessed by an eligible witness other than the doctor. In relation to this witness, 41% had discussed the AHD at length; 32% talked generally about the nature and likely effect of the form; 18% briefly discussed the completed form; and in 18% of the cases, the witness simply signed the form. One third of the principals reported that the witness had clarified a part of the form where they had difficulty in understanding.

4.1.4. Satisfaction with the form

4.1.4.1. Information provided in the explanatory notes

Over 95% of principals reported reading the explanatory notes. Most (90%) thought the notes were straightforward and easy to understand; a minority were unsure or did not agree that all of the information provided in the notes were useful (15%) or provided all the information that was needed (21%). Only 25% wanted more examples to assist in understanding.

Only 23.8% (n=5) of principals had referred back to the explanatory notes at some time after completing the AHD. Of those 5, 2 principals reported that the information they sought was not available in the notes.

Principals were asked what further information they would like to be provided with, and a range of options were provided to them. These options and the principals' responses are set out in Table 13.

One person did not want family involved, but did not know whether there was a legal obligation to involve them. Another wanted more advice about consulting with family, and another wanted more examples that explain some terms such as 'persistent vegetative state'.

Areas of greatest importance for principals to be informed about were: the legal responsibilities of doctors to follow the written directions, when and how the AHD came into effect and whether it will be recognised interstate and overseas.

All agreed that an explanation that doctors may choose not to follow an instruction in an AHD that is not consistent with good medical practice should be included in the explanatory notes. Sixteen individuals commented on this issue. The majority of those who responded believed that an AHD should be binding on doctors, although one respondent commented that many people trust their doctor, and would be confident that the doctor would act in their best interest.

Table 13. Principals' suggestions for further information

Answer Options	Very important	Important	Unsure	Unimportant	Very unimportant	Response Count
Further guiding instructions to help you complete the form	3	9	3	2	0	17
What to do with the form once it's complete	10	7	0	2	0	19
Who to contact if you require further information	7	8	1	2	0	18
Whether your AHD will be recognised if you travel interstate or overseas	13	6	0	1	0	20
Advice on discussing your AHD with your family	6	8	2	1	0	17
When and how your AHD will come into effect	13	3	1	1	0	18
More information about what care and treatment may be provided in specific situations to help you decide what directions to give	10	6	2	0	0	18
The legal responsibilities of the doctors to follow your written directions	17	3	0	0	0	20
Other						3
Answered question						20
Skipped question						**6**

4.1.4.2. Format

The views expressed about the format were overall positive. Only three (out of 19) principals reported that the form was difficult to complete. Most principals reported that the form was well presented with an appropriate text size and font and an acceptable length, and the questions in the form progressed in a logical order. The instructions for completing the form were not regarded as confusing and the definitions provided were generally clear and easy to understand. As observed above, 25% of principals reported that more examples would assist their understanding. There were mixed views about whether some of the questions were too repetitive. Table 14 summarises the responses on these matters.

A majority of principals (78%) reported that the form was not difficult to complete because of the nature of decisions being made. Just under half of the respondents felt that the form was sufficiently flexible to reflect the wishes of the principal, with 28% being unsure. Although most agreed there was sufficient space to state wishes, 33% disagreed that the space was sufficient.

Respondents were asked whether the information provided about how to complete the form should remain part of the form, or be contained in a separate booklet. Principals varied on this issue, with 40% agreeing that the information should be separate from the form and 20% being unsure.

Table 14. Principals' experience of filling in the AHD

Answer Options	Strongly agree	Agree	Unsure	Disagree	Strongly disagree	Response Count
It is well presented	2	11	4	1	0	18
The questions are in logical order, easily flowing from one to the next	2	12	3	1	0	18
I had no problem with the text size or font used	6	12	0	0	0	18
The questions asked were too repetitive	1	6	4	7	0	18
Overall, the language used was simple and easy to follow	1	14	0	3	0	18
There was an unnecessary amount of medical and legal terminology	0	1	2	14	1	18
The definitions of terms provided were clear and easy to understand	1	14	1	1	1	18
The instructions for completing the form were confusing	0	3	1	12	1	17
Answered question						**18**
Skipped question						**8**

4.1.4.3. Language

Again there was generally a positive response by principals about the language used in the form. Most principals (83%) reported that the language was simple and easy to understand and the definitions were clear. Most (83%) also did not think there was an unnecessary amount of legal and medical terminology. Most would like a glossary of terms and conditions (74%) but

principals were evenly divided about whether these should be in a glossary only, or should appear both in a glossary and throughout the form where the terms are used. Most (71%) thought a glossary should be part of the form itself, rather than in a separate document.

4.1.5. Other issues relating to the form

4.1.5.1. Adequate reflection of goals, expectations and communication

Respondents were asked whether the completed AHD clearly reflected the person's goals for future health care. A high majority (88.8%) believed that it did.

The majority expected that doctors would follow their AHD exactly (77.8%), while a minority thought it would be used as a guide only. Most (89%) agreed that the written directions were communicated effectively to their doctors.

Most principals (59%) reported that they intended their AHD to represent communication of their health care decisions to their treating doctor and family and friends equally; 23.5% primarily intended it for their treating doctor; and 17.6% primarily for their family/friends.

Almost all (94%) sought to communicate their wishes to family and friends who might be involved in decision making. Only one person was unsure that the document communicated their wishes effectively, the remaining respondents reporting that the AHD effectively communicated their directions to their family. Two thirds had discussed the AHD fully with family and friends, and a further third had informed family/friends they had an AHD but had not discussed it at length. Most said family discussions did not influence how the form was completed, and all agreed it was important to discuss the AHD with family and friends.

4.1.5.2. Directions for end of life decision making

The survey document explained the different techniques or options in the AHD that allow a principal to give directions about treatment at the end of life: the outcomes approach, and the specific directions about treatment approach.

Having been provided with background about these two approaches, principals were asked questions about their preferences for giving directions for end of life health care: which approach would be easier to write, which approach would provide the greatest assistance to doctors relying on the AHD, and which approach would be most helpful for family and friends. The responses are set out below in Table 15.

The outcomes approach was favoured over the specific directions about treatment approach across all three questions. However, a significant percentage of principals considered both approaches to be equally favourable.

Most (88.9%) agreed that the form should provide principals with an opportunity to describe the quality of life that they consider unacceptable and at which point treatment should stop. Opinions varied on the mechanism for describing the quality of life with 2 respondents preferring to write their own, 5 preferring to choose from a list, and 9 electing to have both methods available.

Principals were also asked whether there was enough detail in the form to enable them to specify the treatment they want or do not want at the end of life. Over half (55.6%) of the respondents were happy with the current amount of detail, 28% thought the detail insufficient and 17% were unsure.

Table 15. Principals' preferences for giving directions for end of life health care

Principals' views	Ease of writing % agree	Will most help doctors follow AHD % agree	Most helpful to family/friends% agree
Statements about quality of life outcomes acceptable/unacceptable	44.4	50	44.4
Statements about what specific medical treatments acceptable/unacceptable	16.7	11.1	5.6
a. and b. equally	33	38.9	50
None of the above	5.6	0	0

Principals were also asked whether they would prefer to make a statement that they did or did not want *life-sustaining treatment generally* in particular situations, rather than listing the *specific treatments* that they wanted or did not want. Nearly one third (61%) of respondents preferred a statement about life-sustaining treatments generally rather than a list of medical treatments, (22%) preferred a list, and (17%) were unsure.

Palliative care considerations

The current AHD does not expressly refer to treatment options that a person may want to receive in the palliative context. The directions about specific medical treatment do not distinguish whether they will be given in a palliative context to keep the principal comfortable in the final days, weeks or months of life, or they represent more active treatment with the primary intention of prolonging life. For example, a principal may indicate that they do not wish to have antibiotics if they are in the terminal phase of an incurable illness. However, the form does not give the principal the option to say that he or she would, however, take antibiotics if they were needed in the palliative context to keep him or her comfortable in the final stages of life.

With this in mind, principals were asked questions about whether the form should refer to medical treatment given in the palliative context. Most (83.3%) thought that the form should give the principal an opportunity to consider specific treatments in a palliative context.

Principals were also asked whether they thought the AHD should allow people in palliative care outside of hospital to indicate their preferred place to receive palliative care. Ninety-four percent thought that the AHD should give the principal such an option.

4.1.5.3. Separate AHD for a person with a pre-existing illness or disability

As mentioned earlier, AHDs may be completed by a person who has a pre-existing illness or disability, and by a person who does not. The survey contained a question that was directed to the principals who had a pre-existing illness or disability to establish whether they would prefer that there be two forms – one designed for a person in such a position, and a different one for a person without an existing illness or disability. Only 3 respondents fell into that category, and only one of those 3 suggested it would be preferable to have separate forms.

4.1.5.4. Inclusion of an option to appoint an attorney for personal/health matters

Most (15 of the 18) of the respondent principals had appointed an attorney for personal and health matters using the AHD (8), EPA (2) or both (5) documents. Only one person appointed a different attorney in both documents, and that respondent was aware that appointing a later, different attorney could revoke the previous appointment.

4.1.5.5. Tissue and organ donation

The AHD (clause 12) facilitates the principal giving consent to the removal of tissue after death. Principals were asked whether it was important to have this clause in the AHD. Seventy-eight percent thought it important to include this, with only one person disagreeing.

4.1.6. Process and practice issues

4.1.6.1. Storing and accessing the form

Principals stored copies of their AHDs in a range of places. Most had copies of the AHD form at home in a location other than a safe (68%), with a family member or friend (50%), with their current doctor (36%), in a safe at home (27%), with a solicitor (13.6%), or on a hospital file (13%). Other locations included with the principal's previous general practitioner, in the car glove box, and with the attorney appointed under an EPA. Most (81.8%) were confident it could be easily accessed if needed. Those who were not confident that it was accessible were concerned that no one would know where it was at home, the family might forget in an emergency, his or her own doctor may not be consulted, and there may not be enough time to check whether an AHD is in place.

Respondents were asked about how to increase the chance of the AHD being accessed. Almost all (95.5%) agreed that a wallet card advising that an AHD exists and where it can be located would be useful. A smaller group (68%) thought an electronic database accessible by health professionals would assist. Another suggestion to increase accessibility of the AHD was to ensure that inquiries about the form become part of regular admission procedures.

4.1.6.2. Reviewing the form

Respondents were asked whether they had ever reviewed their AHD. Half (9 of 18 respondents) had reviewed the AHD, but only four of the nine had signed and dated the back page to indicate that it had been reviewed.

4.2. AHD survey for doctors

As explained earlier, doctors play different roles with respect to AHDs. The doctor involved in certifying that the principal has capacity to complete the AHD is the 'nominated doctor'. The doctor who later relies on the AHD to treat the patient if and when he or she loses capacity is referred to here as the 'treating doctor'.

Only 11 people responded to the survey as either a treating or nominated doctor. As a result, care must be taken in interpreting the results. Nine doctors responded as nominated doctors, and 8 responded as treating doctors. (Some doctors responded both as nominated and treating doctors.)

4.2.1. Role of nominated doctor in completing an AHD

Of the eight nominated doctors who answered the question, four had signed five or fewer AHDs in the last year, two had signed six to ten and a further two had signed 11 to 20. Most (7) routinely recommend to patients that they consider an AHD. Nominated doctors were asked about the circumstances in which they would recommend that a patient complete an AHD. Six doctors responded to this question as follows: because of a pre-existing serious illness or disability (5 doctors), reaching a certain age (2 doctors), if the patient has concerns about future care (1 doctor), if the patient is palliative (1 doctor) or is entering an aged care facility (1 doctor). Two doctors would not recommend completion of an AHD because they do not consider it to be part of their role, or it is too complex in Queensland and 'some patients struggle with the concepts'.

Different kinds of consultations

Most doctors (75%) reported two consultations on average for patients completing AHDs. Most (75%) also reported discussing it at length, with the remainder discussing the nature and effect of the form more generally.

Assessment of capacity

Most (75%) considered the role to be that of witnessing the signature, assessing capacity of the principal and explaining the nature and likely effect of the AHD form. Seventy-five percent always assessed capacity, while the remainder sometimes assessed capacity. About 50% have referred to guidelines or suggested questions to assess capacity. The reasons for not assessing capacity are knowledge of the patient and a lack of reason to doubt capacity.

Consultation as a separate Medicare item

All except one doctor would support consultations related to patients completing AHDs becoming a Medicare item, as it requires considerable medical knowledge, is time consuming, is part of complex decision making, forms part of medical management of a patient, requires regular review and sometimes collateral discussion with relatives. Doctors consider this to be an important consultation that deserves a significant amount of time. The doctor who felt it should not have a Medicare item did so on the grounds that a long consultation item can be used to introduce the form in one session, and then to review the completed form in a separate consultation.

4.2.2. Practice of treating doctors with respect to completed AHDs

Eight respondents had consulted AHDs as treating doctors. Of the seven doctors who responded to this question, two had used AHDs five or fewer times, three had used them 11-20 times, and two doctors had used them more than 20 times. Most considered AHDs to be helpful in managing care and treatment although 1 doctor was unsure. Most doctors thought that AHDs were most helpful in understanding patient's attitudes, goals and values with only 1 doctor suggesting that AHDs were most helpful by giving direction about specific medical treatments. Responses varied regarding the extent to which directions in an AHD were followed. Some doctors (n=3) followed the AHD exactly and some (n=4) used it as only a guide as to how the patient wishes to be treated. One doctor reported that if the patient is non verbal, he consulted with families about which part of the AHD they considered was most important to the patient.

Doctors were also asked about the situations in which they found AHDs to be unhelpful, and a range of responses were provided. Doctors reported that AHDs were unhelpful where patients requested treatments that doctors did not want to offer, where contradictory directions concerning specific medical treatments were given, where the attitudes, values and goals stated by the principal were unclear, and where relatives of a patient with a poor diagnosis do not wish the doctor to follow the AHD and instead request active intervention. Another comment was that the design of the form makes it hard to find vital information.

All treating doctors found the AHD helpful in discussing a patient's preference with family and friends. They reported that these discussions can also assist in clarifying directions in the AHD.

Three doctors had been in a situation where the patient's intentions were not clear in the written directions, and two reported that family or friends had helped interpret the written directions.

All doctors agreed that they would take into account an interstate or overseas AHD, if one was presented to them.

4.2.3. Satisfaction with the form

Both nominated and treating doctors were asked their views about the useability of the form. Most (6 out of 8) thought the form is well presented, the questions are in a logical order and the definitions are accurate and clear, with most (5 out of 8) agreeing that the language is simple and easy to follow. Most (5 out of 7) doctors thought the form is too long, and most (5 out of 8) would prefer the explanatory notes section to be deleted from the form and placed in a separate information booklet. There was some variation in whether the questions are too repetitive (5 out of 8 agreeing). The responses for all questions appear in Table 16.

Table 16. Doctors' views on the useability of the AHD

Answer Options	Strongly agree	Agree	Unsure	Disagree	Strongly disagree	Response Count
It is well presented	0	6	0	2	0	8
The questions are in logical order, easily flowing from one to the next	0	6	0	2	0	8
The questions asked are too repetitive	1	4	1	2	0	8
Overall, the language used is simple and easy to follow	0	5	1	2	0	8
The definitions of terms provided are accurate and clear	0	6	1	1	0	8
Answered question						**18**
Skipped question						**8**

All doctors agreed that the AHD form should include some explanation that the treating doctor may choose not to follow a directive in an AHD if he or she considered it to be inconsistent with good medical practice. Doctors thought this was important because otherwise the patient and/or family might believe that a directive will always be followed.

Doctors were also asked about their views concerning the phrases used to describe the medical conditions for which specific medical treatment might be accepted or refused. Their comments included the following:

- terms such as 'persistent vegetative state' and 'permanently unconscious' need to be clarified;
- the term 'persistent vegetative state' is 'archaic'.

In response to this question about phrases, one doctor suggested the language in the form should be couched in the positive, not negative.

4.2.4. Other issues relating to the form

4.2.4.1. Directions for end of life decision making

As occurred for principals who completed AHDs, doctors were asked about the different kinds of guidance in the end of life decision making context: the outcomes approach compared with specific directions about treatment.

Of the treating doctors, 75% thought that general statements about quality of life outcomes and decisions made about specific medical treatments were equally useful. Most 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. Opinions varied on how this should occur: 4 doctors preferring to allow patients to choose from a pre-determined list, and 5 suggesting a combination of selecting from a list and writing their own was important. No one suggested that a principal should only have the option of writing his or her own quality of life outcomes.

There is mixed opinion on the value of listing specific medical treatments to be accepted or refused, rather than allowing principals to refuse treatment generally in certain situations. Although most (60%) agreed with directions being about life sustaining measures generally, one doctor was unsure and 3 disagreed.

Doctors were asked whether there was enough, too much or not enough detail provided in the AHD for patients to specify medical treatment that they wanted or did not want at the end of their life. Opinions varied on this point with 4 doctors responding that there was enough detail, 4 that there was too much detail, and 1 that there was not enough.

Doctors were also asked whether they thought the AHD provides enough information about what care and treatment may be provided in specific situations to help patients decide what directions to give. Again, opinion was divided on this point, with 50% agreeing and the rest being unsure or disagreeing.

Palliative care considerations

As noted when analysing the data on the surveys of principals, the AHD is currently silent about directions for treatment in a palliative context. Doctors were asked whether it would be helpful for the form to allow principals to consider whether refusal of treatment would be acceptable to them in a palliative context. Most (80%) agreed that there should be an option for some medical treatments to be considered in a palliative context.

Doctors also agreed (100%) that the AHD should allow people to indicate their preferred place to receive palliative care.

4.2.4.2. Separate AHD for a person with a pre-existing illness or disability

Doctors were also asked whether it would be preferable to have a separate AHD for a person with a pre-existing illness. Most (70%) thought that separate forms were not necessary.

4.2.4.3. Tissue/organ donation

The AHD (clause 12) facilitates the principal giving consent to the removal of tissue after death. Nearly all doctors thought that choice in relation to tissue donation (90%) should be included in the form.

4.2.5. Process and practice issues

4.2.5.1. Storing and accessing the form

Doctors were asked how they were made aware that a patient had completed an AHD. Only six doctors answered this question, but multiple responses were allowed. The most common methods were through information provided by a partner or other family to staff (83%), on hospital admission forms (66%), on hospital records (66%), or the patient verbally indicated the existence of an AHD on admission (66%). Only one doctor had asked a patient's general practitioner about the existence of an AHD. All agreed that an electronic version would be useful as part of a shared electronic health record, an on-line database, or from a patient through a disk, USB stick or email.

4.2.5.2. Training of doctors

Doctors were asked about the extent of training they had received regarding AHDs. Three doctors had received information but no formal training, 2 had received neither, and 1 had received formal training. One doctor considered themself inadequately prepared in relation to legal obligations when dealing with a patient completing an AHD. Two doctors considered themselves inadequately prepared or unsure of their legal obligations when treating patients who

had completed an AHD. Professional seminars (83%) and DVDs or written information (33%) were the methods of training on AHDs that doctors considered to be most effective.

4.3. AHD survey for witnesses

4.3.1. Experience, training and understanding of the role of witness

Twenty-three witnesses responded to the survey of witnesses of EPAs and AHDs, with 13 of those respondents having had experience witnessing AHDs. The demographics for the entire witness cohort were described in Section B. It will be recalled that, for the most part, this cohort was well educated with 93% having a university education and all having English as their first language.

The following data relates to the 13 respondents who reported that they had witnessed AHDs. Witnesses were asked about the number of AHDs they had witnessed in the past year. There was a significant variation of responses ranging from 0–40 times, with more than half (61.5%) witnessing 5 or fewer in the past year, 4 witnessing between 6 and 20, and 1 having witnessed 40 AHDs. Six respondents reported an increase in the number of AHDs witnessed over the past year, and speculation for that increase included increasing public awareness, principals wanting to have control over medical instructions, and it being more socially acceptable to speak about such choices.

Most witnesses (92%) felt adequately or well prepared in understanding their legal obligations when witnessing an AHD. This is despite the fact that only 31% of the witnesses had received formal training as a witness, with 50% of those receiving it less than a year ago. A greater number (61.5%) had information but no formal training, and 1 person reported having no training or information. When asked their views about their preferred form of training, all agreed that specific professional training or seminars would be effective, and 54% responded that training DVDs or written information would be useful.

The majority of witnesses (76.9%) described their role to be witnessing the signature of the principal, explaining the nature and likely effect of the AHD form to the principal, and to assess the principal's capacity. Two of the witnesses reported that it was not their role to assess the principal's capacity.

4.3.2. Satisfaction with the form

The views expressed about aspects of the form itself were mixed. Most witnesses agreed that the AHD form is well presented (77%), that overall, the language is simple and easy to follow (69%), and that there is no problem with the text size and font (92%). On the other hand, opinion was divided about whether the definitions were clear (with 38.5% disagreeing), and

about whether there was an unnecessary amount of legal and medical terminology (42% believing this to be the case). More than half (58%) thought that the form is too long.

Witnesses were asked which issues principals had most difficulty with, and were invited to choose from a number of listed options. Those identified most frequently were the following: understanding of the meaning of a term or instruction, the extent to which treating doctors will follow directions in an AHD and the role of an appointed attorney.

5. Key findings and recommendations: Advance Health Directives

As reported in Section B dealing with EPAs, research respondents came from diverse groups and represented a range of perspectives. Contributions to the research included the perspectives of principals, witnesses, health professionals (including nominated and treating doctors) and lawyers. However, the research was not able to engage those who are not currently using AHDs and not interested in discussing them. Accordingly, these findings and recommendations need to be viewed in that light. We also note that some of the broader findings and recommendations in relation to EPAs, particularly those about training and education, are applicable to AHDs as well although they have not been repeated here.

5.1. Broad contextual issues

A. Instructions about medical treatment at the end of life

Findings:

Different perspectives were expressed by different user groups about the role that AHDs should play, and this creates tension in determining how the AHD should be drafted and the kind of directives it should contain.

- Principals are primarily motivated by the need for their life not to be prolonged against their wishes, and this is a key reason for completing an AHD. They 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.
- Doctors are motivated by different factors, and the desire to provide good patient care is critical. In some cases, doctors perceive that AHDs may hinder the provision of good care. Some doctors express a preference for patients to describe outcomes that are acceptable to them and overall goals of treatment, rather than specific statements about what treatment they wish to refuse in particular situations. However, doctors expressed mixed views on this point, and some saw the value of specific directions about treatment being contained in the AHD.

- A number of research respondents, particularly doctors, commented that the listing of specific directions in clauses 8-11 was lengthy and repetitive.

Recommendations:

C1. 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.

C2. Consideration should be given to reducing clauses 8-11 to only one clause. If this occurs, additional space may need to be inserted for a person to specify a different directive in a particular case.

C3. 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 in how these directions apply to a particular decision that needs to be made.

C4. There is currently some overlap between the kinds of directives given in clause 7 (Section 3) and clause 15 (Section 4). There should be only one location in the AHD to provide 'quality of life outcome' kind of statements.

C5. Clearer guidance, perhaps in the form of more examples, regarding what might be useful 'quality of life outcomes' statements would be desirable.

- An option for a 'quality of life outcome' may also include a statement that if the principal reached a particular stage (e.g. unable to recognize family members, or unable to return to independent living), they would not wish to receive particular kinds of treatment or any kind of treatment.

C6. The AHD should provide a principal with an opportunity to express preferences about where they would wish to live during the final stages of their life. For example, if they are living in a high care residential facility, they may prefer to receive palliative care at that facility rather than in a hospital, if that were a feasible option in the circumstances.

B. Concerns about AHDs not reflecting the principal's real intention

Findings:

- Concerns were expressed by doctors and other health professionals that directives in an AHD may not reflect the real intention of the principal, and that the principal would not have made the directive had they predicted the medical situation that ultimately arose. In this regard, the principal not possessing all relevant information before making the directive was identified as a problem. Particular concerns arise in the palliative care context. Principals may refuse life-sustaining treatment as they do not wish their life to be

prolonged if the quality of life is poor. However, a blanket refusal of treatment may prevent a person from receiving necessary palliative care.

Recommendations:

The researchers accept the concerns about the potential for a directive to unintentionally deprive a principal of necessary palliative treatment. They are also aware that a principal may not be able to consider all possible circumstances that might arise in the future which may be relevant to a treatment decision. Risks associated with a blanket refusal of life-sustaining treatment, for example in circumstances where a person would return to good health if provided with treatment for a short time, was identified as a concern. The researchers are also of the view that it is imperative that individuals be able to make a binding directive that refuses treatment. The recommendations below attempt to balance these competing imperatives.

C7. 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.

C8. 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 interests.

C9. The researchers note an alternative approach suggested by the QLRC that it may be prudent to draw the principal's attention to whether a refusal of treatment should operate in unforeseen circumstances.[17] Consideration should also be given to this proposal.

C. Lack of awareness of the AHD as an advance care planning tool

Findings:

- There is a lack of knowledge about the AHD and its role as an advance care planning tool. Despite the publicity given to advance health directives when the legislation was originally passed and the increased emphasis on advance care planning, there remains a general lack of community awareness of AHDs and the role it can play in this process. This lack of awareness exists and is particularly evident in the Indigenous and CALD communities.

[17] Queensland Law Reform Commission, *A Review of Queensland's Guardianship Laws,* Report No 67 (2010) Vol 2, Recommendation 9.8(c).

- There was a general view that the AHD would be of considerable use in Indigenous and CALD communities if it was properly understood and completed.

Recommendations:

There is a need to educate the community generally including the Indigenous and CALD communities, about the existence of AHDs as an advance care planning tool. Such education also needs to address the fact that consideration and completion of such a document raises taboo subjects, and these barriers need to be broken down before uptake in completing the documents will be achieved.

C10. There needs to be extensive community education (similar to that discussed in Section B in relation to EPAs) about the role that AHDs play as an advance care planning tool.

C11. For Indigenous communities, the education needs to be undertaken at a grass roots level to ensure sufficient traction. The education should be given by Indigenous people who are specifically trained to carry out such education.

C12. Hard copies of AHDs should be available at no cost in a range of locations including doctors' surgeries, community health service centres, employment centres, community legal centres, Indigenous legal services and government offices generally. There should be a statement on the front page of the AHD advising where copies of the AHDs are available.

C13. Doctors should be encouraged to discuss advance care planning with their patients and, if appropriate, patients should be advised about the option of completing an AHD and the need to discuss their options for end of life care with their friends and family. Doctors should particularly consider doing so if the patient has a diagnosis where decisions about treatment pathways could be made in advance, or in the context of completing health care plans with older members of the community.

C14. Solicitors should also be encouraged to discuss advance care planning, including the completion of an AHD, with their clients when they give estate planning advice.

D. Level of formality of the AHD

Findings:

- As the AHD form is currently drafted, it can be completed by some people without the need to seek legal or other professional advice. However, some members of the community, e.g. members of Indigenous and CALD communities and those who are unable to read or write English (and perhaps others who are not well educated), will not be

able to complete the form without support. Further, some are of the view that the AHD is unnecessarily formal in terms of the language used.

- On the other hand, doctors have expressed concern that some individuals are unaware of the consequences and gravity of the decisions that they are making. A decrease in formality may send a signal that the AHD is not a serious document.

Recommendations:

The content and appearance of the form must reflect the target audience. It is impossible to draft a form that is ideally pitched to all members of the community. This will mean that there will always be individuals who are unable to complete the form without a level of support.

C15. The form should be capable of being completed by most individuals without the need to access legal advice. The current AHD largely meets this objective, and the current level of formality is appropriate.

C16. There should be support within the community to assist others who need support to complete such a form including CALD and Indigenous members of the community.

C17. Details of such support should be available on the front of the form (as currently exists in relation to obtaining services of a translator for those who do not have English as their first language).

E. Role of doctors and the need for education

Findings:

- Of the doctors involved in the research, there is a general understanding and acceptance of the principle of autonomy and the ethical imperative to follow the patient's instructions, including those that are recorded in an AHD. However, there was some evidence that medical (and other health) professionals have some philosophical concerns about directives in an AHD and their binding nature. An illustration of this is the differing views held by doctors about whether the directions in an AHD should be followed exactly, or be a guide only.
- Some doctors are of the view that AHDs are helpful in assisting with conversations with family.
- Not all doctors may be aware of their role of assessing the principal's capacity when an AHD is completed, and processes and protocols to test that capacity.
- There is variation in consultation times and the role played by a doctor when witnessing AHDs.

- Most doctors are of the view that consultations that relate to a patient completing an AHD should have an allocated Medicare item number.

Recommendations:

C18. Doctors should receive ongoing education about their legal obligations both when witnessing AHDs and when treating patients who have completed an AHD.

C19. Doctors should receive ongoing education about the nature of the legal test for capacity to complete an AHD, and how to assess capacity for this purpose.

C20. Discussions should occur across Governments so that consultations involving the completion of an AHD can be an allocated Medicare item number.

5.2. Specific matters relating to the approved form of the AHD (Form 4)

F. Need for improved information and instructions to complete the AHD

Findings:

- Principals obtained information about completing AHDs from a variety of sources, including from legal and medical professionals.
- Some principals also accessed information from internet sources including, for example, websites of the Department of Justice and Attorney General and the Office of the Adult Guardian.
- The AHD also contains information in the explanatory notes at the beginning of the form and throughout the form to assist in its completion. This information contains instructions for completing the form, definitions and examples.
- Some respondents believe that the AHD could provide principals with greater assistance to complete the form by providing examples.
- From some of the comments received from research respondents, it appears that the information that is publicly available, both through government websites and on the form itself, is not always read by those completing the form, or by those assisting others to complete the form. For example, research respondents suggested that the form contain information about what a principal should do with the form once it is completed. However, this information is set out under the heading 'What do I do with the completed document?' in the information section of the AHD.

Recommendations:

Overall, there exists a reasonable amount of assistance available to individuals who wish to complete an AHD. This assistance comes from information on the internet and other sources, as well as information on the form itself. However, this information does not always seem to be read by individuals completing the form or by those assisting them. It is possible that the information which is available is not in the format that is most desirable or accessible to prospective principals. This may be a barrier to the uptake and completion of AHDs. Further, increased information should be provided to doctors and witnesses about how to assess the capacity of a principal to complete an AHD.

C21. Targeted strategies are required for the different cohorts who may wish to complete AHDs. There are a range of different strategies that could be used to inform potential participants and different media may be attractive to different audiences. Options may include interactive media that is available on-line.

C22. Because of the challenges of completing AHDs in Indigenous communities, a specifically designed information booklet should be developed. Such a booklet should address issues that relate particularly to Indigenous communities including the taboo that can be associated with discussions about death, and should have a presentation that is attractive to members of these communities.

C23. It may also be helpful to insert on the AHD form a link to the website of the Department of Justice and Attorney General as that site contains useful information about completing an AHD.

C24. In the introduction to Sections 5 and 9, there should be clear statements about the obligation on the doctor and witness respectively to ensure that the principal has capacity to complete the AHD. In addition, the introductions should specifically refer to guidelines that are publicly available to assist in this regard.[18]

G. **Useability of the form**

a) Format

Findings:

- Overall, research respondents were satisfied with the format of the AHD including how the guiding instructions were used and the use of examples, and found the form easy to

[18] See also Queensland Law Reform Commission, *A Review of Queensland's Guardianship Laws,* Report No 67 (2010) Vol 1, Recommendation 8.13.

complete. There was general satisfaction with the spacing, text size and font and overall appearance of the form. Some liked the colour scheme of the pink background and the white boxes, while others observed that some problems were caused when the form was printed out in black and white.

- Some respondents commented on the repetitive nature of some of the clauses, particularly those on pages 10-11.
- There was also comment about the lack of space for principals to record general directives about desired treatment.

Recommendations:

C25. Subject to the recommendation below about reordering some sections in the form, no fundamental alteration to the format of the AHD is required. (See also recommendation C2 above in relation to addressing the concerns about repetition in clauses 8-11.)

C26. Consideration should be given to providing sufficient space for a person to make general directives that do not relate to specific clauses already in the standard form.

b) Length of the form

Findings:

- While some respondents were of the view that the form was long, the majority of principals thought that it was an acceptable length. For the most part, people thought that the information in the form was useful and should remain.

Recommendation:

In designing an AHD, there is an inevitable tension between having a form that is too long and deters people from completing it, and ensuring that the AHD contains sufficient information so that an informed direction about treatment can be made. The researchers are of the view that the current AHD has largely struck the correct balance in this regard. They further note that the AHD will be reduced in length if the clauses on pages 10-11 are collapsed (see recommendation C2 above), and clauses 25, 26 and 27 are deleted (see recommendation C41 below).

C27. The length of the AHD is acceptable. The information that is currently in the form is desirable, and should not be removed.

c) Language

Findings:

- The qualitative data provided mixed opinions about the language used. While some thought that the language was of a high standard, others thought that it was ambiguous and assistance was required to complete the form. Particular concern was raised that the language was inaccessible to Indigenous people and those from CALD backgrounds. There were also mixed views of the quality of the definitions provided in the document.
- The quantitative data was more positive with the majority of the principals reporting that the language was simple and easy to understand, and the definitions were clear. Most were of the view that a glossary of terms should be included in the form.

Recommendations:

While the language used may be inaccessible to members of the broader community including members of Indigenous and CALD communities, generally the language used is appropriate. As observed earlier, it is impossible for a form which deals with relatively complex subject matter to contain language that is accessible to all members of the community, and appropriate support should be provided to individuals who are unable to complete the form without assistance.

C28. The existing language is appropriate for this kind of document, and medical and legal terminology are used only where necessary.

C29. A glossary of terms may be a useful addition to the explanatory notes.

C30. A definition of 'special health matters' should be inserted in the introduction to Sections 4 and 6 as this term is used in clause 14 and the introduction to Section 6.

d) Confusing aspects of the form

Findings:

- There were no clauses in the AHD that received widespread criticism. There were isolated clauses that were singled out by individual respondents as causing confusion, and these clauses were identified in the body of the Report.
- However, doctors did express some concern about terms relating to the end of life, such as 'persistent vegetative state' and 'permanently unconscious', and regarded those terms as unclear or archaic.

Recommendations:

Overall, there were not many clauses in the AHD that caused confusion. While doctors expressed some reservations about the terms that relate to conditions or illnesses at the end of life, these terms are used to reflect the wording of the Powers of Attorney Act 1998. It may lead to greater problems if terms were given definitions that were inconsistent with those

used in the legislation. The recommendations below attempt to address some of the aspects of the AHD that have been identified as confusing.

C31. The current drafting of clause 35 is confusing as the layout of the clause does not make it clear that the witness is witnessing the signature of a person signing on behalf of the principal. The circumstances in which the witness should sign and insert a date are not clear. This ambiguity should be clarified.

C32. Some research respondents had difficulty understanding the reference to 'temporary' loss of capacity. The circumstances in which a principal would complete clause 2 should be more clearly explained.

C33. Consideration should be given to the AHD containing a clause, equivalent to clause 2, but relating to a 'permanent' loss of capacity. Such a clause would be relevant, for example, if a principal is diagnosed with dementia and wishes to give directions about health care.

H. Structural issues

a) Order

Findings:

- Although some members of the Critical Reference Group queried the order of some of the sections in the AHD, the order used in the document was not an issue raised by research respondents.

Recommendations:

Subject to one comment, the researchers were of the view that the order of the AHD was logical and should not alter. The exception relates to the medical directives contained in Sections 2 General instructions, 3 Terminal, incurable, or irreversible conditions and 4 Personal statement.

The researchers are of the view that it would be more logical for these 3 sections to be collapsed into 2 sections – one relating to directives about end of life medical treatment, and one relating to more general instructions. The first of these sections would logically relate to general instructions which would include statements along the lines of those contained in Section 2 and statements along the lines of those contained in clauses 14, 16 and 17. The next section would relate to directives governing the end of life and would include statements similar to those that are currently contained in Section 3 as well as a directive such as that referred to in clause 15 of Section 4.

C34. Reorganising Sections 2-4 of the AHD as indicated in the preceding paragraph.

C35. With the exception of that recommended above, no further alteration to the order is recommended.

b) Separate form if pre-existing illness

Findings:

- Strong views were not expressed about the need to have two AHD forms – one for a principal who has a pre-existing illness, and one for a principal who has not. While there was some support for the idea from doctors and social workers, principals did not generally support such a position.

Recommendations:

C36. There should not be a separate AHD, or a separate part of an AHD form, for a principal with a pre-existing illness. The existing form can accommodate health directions relevant to a pre-existing illness.

C37. The AHD should provide a space for a principal to record a pre-existing illness and his or her medical history. Recording an illness will inform doctors that the principal made the directive in the knowledge that he or she was already suffering from the illness.

c) Separate form for Indigenous communities

Findings:

- As observed above, there is a problem with the uptake of AHDs in Indigenous communities, and a general lack of awareness about the AHD form, and the role that it can play in a person's health care.
- Some respondents were of the view that members of Indigenous communities would be more likely to complete an AHD if it had a different look and feel.

Recommendation:

C38. On balance, the researchers are of the view that a different AHD should not be designed specifically for use by Indigenous individuals. However, we re-iterate the need to develop an information booklet specifically designed to appeal to members of Indigenous communities which would assist with the uptake and completion of AHDs. (See further recommendation C22.)

d) AHD containing an ability to appoint an attorney for personal/health matters

Findings:

- There is an element of confusion about the AHD form which is primarily designed to enable a principal to give directives about medical treatment, also having the role of appointing an attorney for personal/health matters.
- There is also a conceptual issue about an AHD, a document dealing with health matters, facilitating the appointment of an attorney to make decisions about personal matters more broadly. (This is an observation of the researchers which was not raised by research respondents.)
- On the other hand, it is useful for the AHD to be a 'one-stop shop' for all matters relating to decisions about health, including the appointment of an attorney. The attorney will be able to make decisions about health matters if the AHD does not provide assistance in a particular situation.
- Further, the appointment of an attorney may provide additional protection or assistance to the principal by having someone who can advocate for the directives in the AHD being followed. In this regard, appointment of an attorney may assist in the overall advance care planning for the principal.
- Some concerns were expressed about how effectively the AHD appoints an attorney, and how the form deals with a previous appointment of an attorney under another enduring document. Section 6, for example, asks the principal questions about a previously completed EPA. The problem is that the principal may specify answers that do not accord with what is recorded in the EPA. For example, in the original EPA, the principal may state that the attorneys, if more than one, can make decisions 'severally'. In Section 6 of the AHD, the principal may indicate that the attorneys are able to make decisions 'jointly'. This inconsistency understandably leads to confusion. Further, some of the directions contained in Section 6 are unnecessary. For example, clause 26 authorises a previously appointed attorney to act if the principal loses capacity and an AHD directive does not apply. Such an authorization is legally unnecessary as the EPA has already conferred such a power.
- There is also a technical legal point which has potential for confusion. Section 35(1)(c) of the *Powers of Attorney Act 1998* refers to the power of a principal to appoint an attorney for *health* matters in the AHD, yet the approved AHD form provides for the appointment of an attorney for *both personal and health* matters.

Recommendations:

Despite the confusion expressed by some respondents about having the ability to appoint an attorney in the AHD, this ability is useful and should be retained. However, the AHD should attempt to explain how the appointment fits with the AHD overall (and the researchers note that there is currently an explanation in the AHD) and, to the extent possible, recast the form to minimize confusion.

C39. The potential for confusion arising from the inconsistency between s 35(1)(c) of the *Powers of Attorney Act 1998* and the prescribed form (described in the findings above) should be removed by clarifying whether an AHD can be used to appoint an attorney for health matters only or personal matters generally.[19]

C40. The AHD should continue to facilitate the appointment of an attorney for personal or health matters (the nature of the matters will depend on the approach taken by the Government in relation to recommendation C39). Consistent terminology should be used throughout the form – see clause 29 which presently refers to 'personal matters' whereas other references are to 'personal/health matters'.

C41. However, clauses 25, 26 and 27 should be deleted as they are not legally necessary. Further, clause 25 introduces a potential for providing information that conflicts with that in a previously completed EPA.

C42. The AHD should continue to contain information advising the principal of the effect that an appointment of an attorney will have on any previous attorney that has been appointed for personal/health matters. (The researchers note that an explanation of this appears in the current AHD.)

C43. The following instruction should be deleted from clause 31 as it no longer represents a correct statement of the law: 'Do not include any instructions here about withdrawing or withholding life-sustaining medical treatment. These instructions can only be given by you in Section 3 of this form.'

C44. The following alterations should be made to clause 33:

i. Substitute 'require' for 'prefer' because such a specification is binding on attorneys;

ii. In the brackets after 'severally', add the word 'alone' after the words 'any one of them may decide';

iii. In the brackets after 'jointly', substitute 'all must agree' for 'unanimously'

[19] The researchers note the recommendation by the QLRC that this inconsistency be resolved by amending the approved form so that it refers to 'health matters' only.

e) Separate information booklet

Findings:

- One strategy to shorten the length of the form is to separate the information that is currently in the explanatory notes and integrated into the AHD itself into a separate document. The advantage of this is that the current level of information could be retained, or even expanded, without the AHD becoming longer. The disadvantage is that having the information separated from the AHD may mean fewer people read the information.

Recommendation:

While most people commented that the AHD was long, most were of the view that the information in the form was necessary. On balance, the researchers reached the view that it was more important to keep the information on the form to increase the chance that it would be read, despite the fact that the AHD will remain a long document.

C45. The information should remain in the AHD form and not be separated into a separate information booklet. (Note, however, recommendation C22 above about the need to develop a separate information booklet for use by Indigenous communities.)

I. Other matters relating to the form

a) Additional information to be included in the AHD

Findings:

- Research respondents identified different types of information that should be included in the AHD. These suggestions are detailed above.
- In some cases, the information that respondents suggested should be inserted into the AHD was already in the document, but they were unaware that this was the case.

Recommendations:

Overall, the AHD achieves a good balance of providing enough, but not too much, information to the principal. However, the researchers recommend information be provided on the issues mentioned below.

C46. The AHD should contain a clause advising a principal that a doctor does not have to comply with a directive if he or she has reasonable grounds to believe that: it is

inconsistent with good medical practice; it is uncertain; or there has been a change of circumstances so that the terms of the directive are no longer appropriate.

C47. The AHD should contain a statement about the extent to which their AHD will be enforceable in other jurisdictions. The statement will necessarily be in general terms, advising that the extent to which an AHD completed in Queensland is binding outside Queensland will depend on the law of that other jurisdiction.

C48. The fact that an AHD document can be downloaded from the internet electronically should be included on the front page of the AHD where availability of the document is listed.

b) Organ and tissue donation

Findings:

- Strong views were not expressed about whether the clause giving the principal's preference for tissue donation should remain in the AHD. Nevertheless, most agreed that the form should facilitate the principal expressing a view about donation.
- Some, including those in the CALD focus group, were of the view that tissues and organs should be listed separately as there may be religious or other reasons that the principal may wish to donate some, but not all, organs or tissue.

Recommendations:

The researchers note that there may be conceptual reasons that an AHD should not contain an option for the principal to specify donation preferences. The AHD is a document that is designed to apply when the principal is alive, whereas donation preferences are relevant only when the principal has died. Nevertheless, the researchers also recognize the practical imperative for including such clauses in an AHD.

C49. The AHD should retain an option for the principal to indicate preparedness to donate tissues and/or organs.

C50. There should also be a space provided so that a principal could indicate any tissue or organs that he or she does not want to donate.

c) Regular review of the form by the principal

Findings:

- There was general acceptance that regular review of directives in an AHD was a desirable practice, though concerns were expressed about the cost involved in undertaking this.

- Some of the principals had reviewed their AHD, but had not recorded in Section 11 of the AHD that they had done so.

Recommendations:

The introductory words to Section 11 of the current AHD recommend that the principal regularly review the document. The researchers endorse this advice, and how it is written. The researchers also note that the Explanatory Notes at the beginning of the AHD encourage the principal to regularly review the AHD.

C51. Section 11 of the AHD in which principals are encouraged to review the AHD, and to record that such review has occurred should be retained.

C52. The explanatory notes under the headings 'Can I change or revoke my Advance Health Directive' and 'How often should I update my Advance Health Directive' should be reviewed to remove the repetition about the need to periodically review the AHD.

C53. Doctors should encourage patients who have completed an AHD to regularly review the document, and to record on the AHD that such a review has occurred.

C54. Community education about AHDs should include the need for principals to regularly review the AHD, and to sign that it has been reviewed.

d) Storage, provision of copies and access to AHD

Findings:

- Principals stored their AHDs in a range of ways. In many cases, principals had had conversations with family and friends about where the AHD was located, and there was a reasonable amount of confidence that the form would be located when necessary. There was also wide-ranging support amongst different user groups for an AHD being stored electronically.
- There was also support for principals to carry a card in their wallet to advise others of the existence of the AHD.

Recommendations:

Electronic storage of AHDs and attaching the AHD to a patient's electronic health records is a desirable goal. While current technology, practice and legislative framework may not yet completely facilitate this practice, it would be a desirable outcome to achieve. If an AHD forms part of a patient's health record, a patient will have confidence that the medical and health professionals will have access to their medical instructions if he or she loses capacity.

The researchers also note that the current legal requirement (section 45(2) of the Powers of Attorney Act 1998) about proving the authenticity of a copy of an AHD is quite onerous, and the QLRC has recommended amendment to the existing provisions.[20] *The issue of authentication may be relevant when a health professional is seeking to rely on the direction in an AHD.*

C55. The AHD should contain a clause advising principals to keep the original of the AHD in a secure location that can be easily accessed by family, friends and any attorney for personal/health matters. (We note such a clause exists on page 5 of the current AHD.)

C56. The AHD should contain a clause that emphasizes the need to discuss the AHD with the principal's family, friends and any attorney for personal/health matters, and to advise them where the original is located.

C57. The clause should also advise the principal to consider giving a copy of the AHD to those individuals. (We note that some of this information is already contained on page 5 of the current AHD.) The researchers also note and endorse the recommendations of the QLRC that notes in the AHD should encourage the principal to provide a 'certified' copy of the AHD, and to explain the process of certifying an AHD.[21]

C58. To the extent that it is possible, AHDs should be stored electronically and attached to a patient's electronic health record.

e) Sundry drafting issues

Findings:

- The researchers have carefully reviewed the AHD and are of the view that the form could be improved by addressing the following, relatively minor, drafting issues.

[20] Queensland Law Reform Commission, *A Review of Queensland's Guardianship Laws,* Report No 67 (2010) Vol 2, Recommendation 9.9.

[21] Queensland Law Reform Commission, *A Review of Queensland's Guardianship Laws,* Report No 67 (2010) Vol 2, Recommendation 9.10.

Recommendations:

C59. The reference to 'depression' in the introductory words to Section 1 (page 6) and Section 5 (page 14) should be removed as suffering from depression does not of itself mean a person is lacking capacity to complete an AHD.

C60. In clause 1 (page 6), substitute 'wish to accept or refuse' for 'require' before the sentence in bold.

C61. In clauses 5 and 6 (on page 7), the words 'or other' should be inserted after 'religious' to reflect the fact that there might be reasons other than religious ones that may affect treatment preferences.

C62. The definition of 'artificial feeding and hydration' (page 8) should be renamed 'artificial nutrition and hydration' as this is the term that is used in the AHD and is sought to be defined.

C63. In addition, in that definition, the words 'hydration and' should be included before 'feeding' in the words in brackets at the end of the definition to make clear that hydration will also be provided to keep a person's mouth moist.

C64. In the introductory wording to Section 6, under the heading 'Note', substitute 'under the Powers of Attorney Act 1998' for 'since the Powers of Attorney Act 1998 was proclaimed' as this uses less technical language.

C65. In the introductory wording to Section 9 in the sentence commencing 'It is strongly recommended that …', delete the words 'if you are in any doubt' because it is generally recommended that records be kept regardless of whether doubts are held about the principal's capacity.

C66. Instructions for both the witness and the doctor should make clear that they should refuse to witness the AHD if in doubt about principal's capacity (although the form notes that a witness should make appropriate inquiries prior to reaching this conclusion).

C67. The researchers also note and endorse the recommendation of the QLRC that there should be provision for the principal to sign or initial each page of the AHD that includes a statement or direction of the principal.[22]

[22] Queensland Law Reform Commission, *A Review of Queensland's Guardianship Laws,* Report No 67 (2010) Vol 2, Recommendation 9.8(e).

D. Indigenous Perspectives: Enduring Powers of Attorney and Advance Health Directives

1. Introduction

The research sought to specifically include the perspectives of Indigenous people. The focus in these interviews and consultations was on the respondents' views on both forms for themselves and their perceptions of their use in their Indigenous community. This section of the Report combines impressions of the EPA and AHD forms.

Formal consultations were held with Aboriginal Councils of Elders and senior representatives of the Torres Strait Islander community in Brisbane. The Elders provided valuable feedback on the forms and their use and their comments form the first part of this section. After gaining permission from the Elders, Aboriginal and Torres Strait Islanders were interviewed in relation to their views of the accessibility and useability of the short form of the EPA and the AHD form. During the consultation meetings and interviews the forms were handed out for comment.

Interviews were held with six people from the Torres Strait Islands and five Murri people all of whom currently live in the Brisbane area. Respondents were recruited based on their willingness to discuss both forms in detail with Dr Morseu-Diop. Only one of these informants had heard of EPAs or AHDs and none had used them. The interviewer used the same interview schedule as was used with other principals, attorneys and witnesses, but the interview process was modified to reflect the different role of these interviewees as people giving their views on what community members would want in relation to these forms in addition to their personal views. They provided detailed feedback after reading through the forms with the interviewer. This section provides an overview of comments made. Details of the specific issues with language and meaning are provided in Appendix D.

2. Summary of comments from community Elders

The Aboriginal and Torres Strait Islander Elders expressed strong, consensual views after reading the EPA and AHD forms. Categorised below are the key areas of concern arising from the discussions with elder groups during the consultation meetings in Brisbane. These headings are also used in reporting on the interviews with Indigenous Queenslanders.

- Community awareness of the EPA and AHD forms
- Promotion, dissemination and accessibility

- Presentation of the forms
- Language and terminology

2.1. Community awareness of the EPA and AHD forms

- Many people in the Indigenous community have not seen or heard about these forms.
- Many have died without the knowledge of these forms, and the powers they give would have been helpful.
- There has been a lot of fighting between families in terms of family members' health care and treatment which may have been avoided by knowledge of and understanding about these forms.
- Some Murri people are aware of the general Power of Attorney forms but have never heard of the Enduring Power of Attorney forms.

2.2. Promotion, dissemination and accessibility

- There should be a community information forum run by the Department of Justice and Attorney General and key stakeholders to inform the grassroots community about the forms and have adequate people there to explain it properly to community members.
- Education about the forms should be delivered by sending people with Aboriginal and Torres Strait Islander background out to people's homes to meet with the whole family. Trained health care providers should teach Indigenous people about the forms and assist people in filling them out.
- Provide more information about EPAs and AHDs to the community through doctors in hospitals, legal services and through the public arena. Doctors and health professionals should be informing Indigenous people about these forms.
- The EPA and AHD forms should be made readily available in hospitals, Indigenous community health centres and Indigenous legal services.
- Doctors should keep these forms and when patients are diagnosed with a terminal or life-threatening illness, the doctor should explain to the patient about the EPA and AHD forms and show them the forms, so that they know about them and are able to make the decision about filling them out.
- Resources need to be spent on educating the Indigenous community about the forms and protecting yourself from elder abuse as well as helping people understand it as they fill it out.
- The forms currently are too expensive - why do you have to pay to get them?

2.3. Presentation and content of the forms

- Indigenous designs should be on the forms, to make them more relevant and welcoming.

- The form should be specifically geared for Indigenous people.
- A good thing to investigate would be whether Aboriginal and Torres Strait Islanders want a separate form offered to them that is culturally appropriate to their needs.
- Most thought the forms were a great idea, but it needed to be culturally conducive to Indigenous peoples' understanding.

2.4. Language and terminology

- The forms need to be in plain and simple English.
- Forms should be made as simple as possible
- There is a lack of Indigenous Interpreters to assist those who have difficulty with the English language. This needs to be addressed.
- Old people might need an interpreter to fill out the form. The form requires a qualified interpreter, not many interpreters speak the language. It would be more practical to just let a family member do it.
- It would be too difficult to re-write the forms in Torres Strait Islander language and this always causes issues with legality.

2.5. General information from the Elders' discussions about the forms

- Interviews may be more successful when other family members are also present - this way family members can help each other understand the content when they need to use the forms and they are family decisions that are being made.
- Elders stressed the importance of government recognizing cultural differences between Aboriginal people and Torres Strait Islanders.
- Elders expressed support for the research project stressing the need to protect older people and incorporate Aboriginal and Torres Strait Islander perspectives into the research.
- From looking at the forms, it looks like there needs to be more information about the underpinning legislation.

3. Interviews with Torres Strait Islander and Murri respondents.

The findings in this section highlight some of the direct responses of the Aboriginal and Torres Strait respondents. Respondents were aged 34 to 70 and 6 of this group of 11 were women. The majority had tertiary education and spoke Indigenous languages as well as English. Educational background is not linked to greater or less knowledge of the existence of the EPA and AHD, although it does have an impact on the individual's understanding of the implications of the forms and the assumptions that sit behind the questions asked on both forms. However

respondents all made similar comments in relation to what they saw as the likely responses of community members to the forms.

The interviews used Indigenous yarning modalities, Indigenous Speak when necessary, and the use of Torres Strait Islander Creole when communicating with the Torres Strait Islander respondents. During the interviewing process, each respondent was asked to carefully read both the Enduring Power of Attorney Short Form *[Form 2]* and the Advance Health Directive Form *[Form 4]*. After reading the forms the respondents were then asked to give their feedback or perspective on the forms' content, wording, terminology, language and layout. Reading the forms was the basis of comments on the extent to which the forms were user-friendly or culturally acceptable and appropriate for Aboriginal and Torres Strait Islander peoples. While the major comments made have been summarised for Torres Strait Islander and Murri groups, there were some distinctions between the two groups identified below. There are significant cultural variations between the two groups which impact on motivations for filling out these documents, the process of completing the forms and the way in which they are used.

Particular issues with language, content and presentation are summarised in Section D of this Report.

3.1. Torres Strait Islanders' viewpoints

None of the 6 respondents had ever heard of or seen the EPA *[Long Form and Short Form]* or the AHD Form *[Form 4]* before. Four participants had heard of the term 'power of attorney' but did not have a clear understanding of the role of the attorney. The core issues arising from the discussions with Torres Strait Islander respondents were accessing the forms and the forms themselves, in terms of the language and terminology used in the document.

Although 4 respondents had a good understanding of the language used in the forms linked to their level of education, all of them identified the difficulties that members of their communities would have in terms of their understanding and interpretation of the forms, primarily owing to their command of the English language and in some cases their age. One person said:

> I wish we knew about these forms before. Now that we are old we don't understand. It would have been good to have people come around and show us these papers before…for me, because I read many books, I can understand but many Islander people will have trouble understanding it. I've thought about this for a long time but I've never done it. Yes, I will fill out these forms. TSI2

Most respondents linked issues with using the form to a lack of education, particularly for older community members. One Torres Strait Island respondent pointed out that illness could also be a factor limiting the take-up of the forms:

> A lot of us, we start getting chronic illnesses at the age in our late thirties and forties and by the time we lose that capacity. We don't even know these things exist until we get really sick. TSI1

Asked to summarise their impressions of the EPA form, another person commented:

> I think … again like I mentioned with the last form, the language, I can understand it, but I don't think a lot of our Torres Strait Islander people particularly in the remote areas are gonna find it easy to understand and that's because of the language used in the form, the terminology used in the form. I think that the form should be set out in simple terms. Some of the reasons why our people may not understand it is just lack of exposure to government forms and that could be for a lot of different reasons, like they could be trades people that are not reading government forms all day, just as simple as that. That's why I think that might be a bit harder. …. The other thing to consider too is that our Torres Strait Islander people, English is not our first language, you know, it could be our third language, that's considering Torres Strait language, Creole and then English, so that makes it even harder and also attributes to the lack of exposure. I think even the definitions in here need to be defined. TSI4

A lack of familiarity with government forms, as well as language issues were suggested as barriers. Education in relation to the concept of attorney was seen as an essential step in promoting the use of either form.

3.2. Murri viewpoints

Five Murri people from diverse clan groups (but not including Inala and Stradbroke Island) and educational and professional backgrounds participated in the study. All live in and around Greater Brisbane. One respondent had seen the forms in the context of doing JP training. Overall Murri respondents made similar comments to those expressed by respondents from the Torres Strait. Two additional points were made. The first was the impact of chronic ill health on people's willingness to think about their future care – either because thinking about the need for these directives was difficult or there was not energy available for this:

> Because there's so many with poor health, chronic disease, how would the person be thinking this far ahead, you know, into advanced directives. M1

The status of the documents as legal directions was also suggested as an issue:

> The mere fact that it is a legal document can be very off putting to people and I think they would hesitate or they'd need help, just to make sure they have done the right thing. M2

4. Summary of Findings across Torres Strait Islander and Murri respondents

All respondents considered that the communities should have access to the legal mechanisms provided by the forms, which they should be widely promoted and that assistance should be available to help Indigenous people to complete the forms. One Murri person said:

> With these types of documents in place, our people can feel safer that their wishes are being carried out, yeah, I think they're very important for our people to have, but I think firstly they need to understand the contents of what's here and not be sort of railroaded into filling out stuff, because they really need to understand it before they sign any papers or whatever and just be advised by. M5

Respondents reported a range of views regarding the value of separate forms for Indigenous communities or the need to substantially modify the forms so that they would be more accessible.

The following summarises the conclusions of Indigenous respondents in relation to EPAs and AHDs under the headings of:

- Community awareness and knowledge of the forms
- Promotion, dissemination and accessibility of the forms
- Presentation and content of the forms
- Language and terminology

4.1. Community awareness and knowledge of the forms

All respondents agreed that very few Indigenous Queenslanders have ever heard of either form but they could well be a useful device in the lives of both Murri and Torres Strait Island Queenslanders. One Torres Strait Islander said:

> There's not enough public information out there for our people to be aware of, to target the Indigenous community about these forms, the existence of these forms. Maybe the health centres, the medical centres or wherever else they go to, maybe the Queensland government should be making some public campaign. We all know about Wills, everybody knows about Wills, but we don't know about the Enduring Power of Attorney or Advance Health Directive. …when you're involved in a situation where you have someone that's close to you, a close relative that's terminally ill, you don't think, there are some things that don't enter your mind that you have to take care of, in terms of their legal needs and financial and health needs and sometimes you need someone there to make you aware that you need to take care of this. TSI1

The use of these forms was linked by one respondent to elder abuse if principals were not fully aware of the powers they would be conferring by giving someone an EPA.

4.2. Some Murri respondents had heard of the general Power of Attorney but many do not have a clear understanding of the duties of an attorney, the processes to appoint one nor the limits of its use once capacity is lost.

4.2. Promotion, dissemination and accessibility of the forms

It followed that all respondents supported a range of education campaigns in the community. These campaigns should be very grass roots and family focused as well as being linked to existing health and legal services where staff should be encouraged to inform people about EPAs. The use of existing Indigenous Health services was recommended by a number of respondents. For example:

> *Interviewer*: How do you think would be the best way to make sure that the Indigenous community knows about these documents?
>
> *M5*: Yeah, I was thinking about both documents as I was reading them you know and I wonder if these documents were given to an Indigenous person, is there an impact on them by giving them these documents, they're relating to something happening to them personally, dying or, illnesses or whatever, so before even reading it are they fearful of what's wrong, the unknown. I think for the Advance Health stuff, I think, if this was sort of introduced to them through their GPs, if they're going through a medical visit to the doctor or whatever, if the doctor can maybe have a yarn with them regarding this sort of stuff and then introduce this literature to them through that visit.
>
> *Interviewer:* And what about the Enduring Power of Attorney?
>
> *M5:* The Enduring Power of Attorney, that sort of the legal sort of stuff, you know a lot of our mob go to the legal services for various reasons and I don't think it could be introduced while you're going to the solicitor about a criminal offence or something like that, gee that's pretty hard that one. … a non-threatening avenue would be through the GP I think, cause our people are going there for their health reasons, if the GP can just have a talk about it and introduce it during the consultation and that could be the beginning. And once they get a better understanding of what this is all about, maybe then they will access the legal services and find out more or whatever. I think they really need a soft approach.

It was suggested that the forms would be more accessible if they were available free in paper format as is the case with most government forms. It was pointed out that many people in the Aboriginal and Torres Strait Islander communities do not have easy access to computers and printer facilities.

A number of respondents commented that people were very aware of their mortality and that thinking about the issues raised in both forms could be 'tempting fate'. For example:

> A lot of our people drink, a lot of our people got diabetes; it's almost like signing your death warrant. M3

Responses suggested to this issue was education and information about what could be achieved by filling in the forms and the appropriate presentation of the forms all done with the active involvement of Aboriginal and Torres Strait Islander peoples in communities.

4.3. Presentation and content of the forms

All of those interviewed agreed it should be clear in the presentation of the document that this was applicable to both Murri and Torres Strait Islander peoples by the use of, for example, appropriate designs, pictures, watermarks and external packaging. One suggestion was to have a kit with external packaging with Indigenous packaging and the generic form enclosed. A further suggestion was to have a specific form for the use of Indigenous Queenslanders but that this would need further exploration:

> *Interviewer:* And in terms of being culturally appropriate to Indigenous people, is it something that would be eye-catching for them?
>
> *M4:* Not in their current state, but like I said, the whole idea of what the forms are for needs to be promoted and how it relates to Aboriginal people because of our health concerns that we do have …

Making the forms more attractive to all people who are non-English speaking was also suggested:

> it needs to be visual in order to attract our people to pick it up, cause we have non-English speaking people in our community and for the wider community as well, so visuals and make it pretty clear about where you can actually get it as well, where you can pick it up, that's the other thing. If they want to be inclusive then they need to encourage our people to fill out these forms. TSI6

There were a few comments on the overall organisation of the form. For example, a Torres Strait Islander respondent noted in relation to the question 'Whom should I appoint as my Attorney?':

> The information is too late. It should be placed on page 3 so it is the first information the person reads when they open the form. TSI1

Some areas raised in the form were seen as very helpful. In relation to the AHD Page 13, point 4 'Do you wish to mention any people who are not to be contacted about your treatment?':

> I think this is a good one actually because …there are people out there that you don't want to be contacted… Yeah, family always has politics. TSI3

The same respondent noted in relation to the EPA Page 6 Part 1 'Is there anything else that will end this power?' and referring to the attorney becoming incapable of understanding the nature

and effects of a decision and communicating that decision, that the point could be expanded to take into account cultural issues:

> I can see that in communities where you might give your enduring power of attorney to a family member and with family politics, things change and they make a decision where they're incapable of understanding or communicating that decision to you. TSI3

References to other Acts or authorities in the forms was seen as discouraging to people who do not know what they do or how to find out. While it is recognised that providing a lot of detail could make the form more bulky, some way needs to be found to outlining the significance of organisations such as the Land Titles Office of the Department of Environment and Resource Management, the Adult Guardian, the Public Trustee and/or other enduring document such as the AHD (when completing the EPA). One suggestion is an extended information booklet separate to the form but with reference to it in the form. The bulk of comments on the overall useability of the form related to the language used, not surprisingly given that responses were given after a first reading of the form.

4.4. Language and terminology

This was a core issue in the useability of the forms for Indigenous community members. The point was made that for most Torres Strait Islander people English is their second or third language and a significant group of Murri people speak Aboriginal English. A generally lower level of education for Indigenous people than the community average, particularly for older Indigenous peoples, combined with the English language used in the form was consistently seen as creating difficulties for many Indigenous people. These difficulties can be summarised as knowing what specific words meant and identifying the underlying meanings of sections of the form for the authority the completed form would give attorneys.

One Torres Strait Islander respondent with expertise in linguistics gave detailed feedback on the language used. In relation to the Explanatory notes for the AHD this respondent commented on 'Who is involved in completing this document?':

> It says, 'You are referred to as the principal because you are the person principally involved'. If you don't know English, it hasn't defined the word 'principal' there. If you're going to go and give a definition, you don't use that word again to define it, because it just confuses the reader. TSI1

Two Torres Strait respondents experienced difficulty themselves in understanding the content of both the Enduring Power of Attorney Short Form *[Form 2]* and the Advance Health Directive Form *[Form 4]*. The definitions provided did not necessarily clarify the meaning for them.

In relation to page 10, Section 3 of the AHD 'I do not want artificial nutrition'. TSI3 noted:

> I don't know what that means. Does that mean you are going to have a pipe down your throat and people feeding you? But I know that a lot of Murris and Torres Strait Islanders they won't understand that. they don't even know what the word 'artificial' means let alone 'nutrition', All these words are fairly big words, assisted ventilation, artificial hydration …what is artificial hydration? Nobody would understand that.

It was noted that there are almost no formal Indigenous translators to assist people fill out these forms if their English proficiency is very limited. It follows that a combination of recognizing the language skills and abilities of nonprofessional translators who could assist in translating the forms and the simplification and clarification of the language used in the forms in their English form are ways of addressing this issue.

The terms that were consistently seen as causing confusion are listed in Table 17.

Table 17. Terms identified as causing confusion for Indigenous people

Advance Health Directive	Enduring Powers of Attorney
Technology Omission Special health decisions Revoke Clause Paid carer Capacity Medical terminologies: • prognosis • cardiopulmonary resuscitation, assisted ventilation • Artificial hydration and artificial nutrition • persistent vegetative state • terminal, incurable or irreversible • euthanasia Tissue donation (what tissue?) 'direction stated in this directive' Notary public, Commissioner for declarations Review of the document Affirm	Jointly, majority and severally On the other hand Immediately Revoked Restrictive Paid carer Impaired A management plan Special personal matters, special health matters, sterilization Adult Guardian 'For instance' rather than 'for example' Statute Deregister Entirety Conclusive evidence

All thought there needed to be fuller information on a large number of terms that are not currently defined. Examples include: specific legal terms such as 'jointly' and 'severally' and 'notary public' and more generic language that was seen as unnecessarily difficult such as 'statute', 'explicitly', 'conclusive' and 'restrictive'. The meaning of many sentences was difficult to discern. In general it was seen as too complicated. Even this generally well educated group of respondents concluded:

When it comes to reading stuff like this, for me I would ask for help. Yeah. M3

Some areas were also seen as difficult for a broad range of community members to deal with because of cultural considerations. For example, defining who dependents were or who should be an attorney has cultural as well as legal implications. It was noted that the forms were culturally challenging in terms of thinking about the issues of dying, dealing with family members around substitute decision making and entering into legal agreements on these topics in the context of a range of family structures and changing family politics over time

5. Key findings and recommendations

This section draws together some of the key recommendations that emerge from the research conducted with Indigenous respondents. A number of these recommendations have already been flagged in Sections B and C but we considered it worthwhile including them separately here as well. We note, however, that these recommendations are not all that emerged from the Indigenous component of the research. Many of the concerns Indigenous people expressed about the EPA and AHD forms were reflective of wider concerns and so supported the wider findings reached in Sections B and C.

Recommendations:

D1. Aboriginal and Torres Strait Islander peoples are unaware of AHDs and EPAs but consider they are valuable tools for community members. Respondents suggest that the forms should be widely available and promoted through a range of Health Services and Community Centres.

D2. Many government forms are free and this should extend to EPA and AHD forms.

D3. The current packaging of the forms needs to be modified to make them more inviting and user friendly for Indigenous people. Options to consider include:

- introducing packaging and design to attract the attention of Indigenous people (e.g. enclosing the current form in a kit with Indigenous designs)
- developing an information booklet and separate glossary with extended examples of relevance to Indigenous peoples. This material could also reflect simplified language in line with earlier recommendations to make the meaning of the documents clearer. It could also include information that takes account of different family structures and family decision making processes in Indigenous communities.

D4. A grass roots approach needs to inform Aboriginal and Torres Strait Islander communities of the usefulness of these documents in their lives and support people with any cultural and practical challenges raised in filling in these forms.

Appendix A: Terms of Reference of Critical Reference Group

The Research Project

Individuals in our community are being encouraged to complete Enduring Powers of Attorney and Advance Health Directives. By completing these forms, adults can put in place mechanisms for dealing with financial and personal matters if they later lose capacity to make decisions. However, concerns have been raised that the forms for these enduring documents may present a barrier to their uptake. The goal of this research project is to gather data on the content and useability of the forms from the perspective of a range of stakeholders. This empirical research will then provide a basis for the Government to consider whether any changes to the forms are needed. (The power to make any such changes resides with the Government; the research team will not be producing new forms. The research focuses only on the useability of the forms, not on the law that underpins them. Accordingly, recommendations made by the research team must ensure continued compliance of the forms with existing legislative requirements.)

The research is being conducted by an interdisciplinary team from the University of Queensland and the Queensland University of Technology. The research team is comprised of: Associate Professor Cheryl Tilse (UQ), Professor Jill Wilson (UQ), Dr Anne-Louise McCawley (UQ), Associate Professor Ben White (QUT) and Professor Lindy Willmott (QUT). Funding for the project has been provided by the Queensland Government through its Legal Practitioner Interest on Trust Accounts Fund Grant Scheme.

Role of Critical Reference Group

The role of the Critical Reference Group is to assist the research team to build on existing knowledge and expertise. In particular, it is intended that the CRG will assist the team by:

- Identifying current problems with the EPA and AHD forms (including how they are used in practice);
- Making suggestions as to how the EPA and AHD forms could be improved;
- Assisting the research team to identify groups of people who are likely to use EPAs and AHDs as potential research respondents;
- Commenting on the data collection tools and the research findings as they emerge..

Membership

The team seeks to involve a broad cross-section of practitioners and service providers who have first-hand experience with the EPA and/or AHD forms. The research team recognises that some members may have experience with both types of enduring documents and others may have experience with only EPAs *or* AHDs. We invite members to undertake this role in their capacity as individuals with practical experience and expertise in this field, rather than as a representative of any particular group. Ultimate responsibility for the research findings rests with the research team.

Meetings

It is intended that the Critical Reference Group will meet at least two but possibly up to four times during the project. These meetings will involve reading and discussing written material provided in advance, as well as raising for consideration other issues that warrant attention. The research team may also ask for your advice on ad hoc matters at other times during the project.

Procedures

The Critical Reference Group will operate on a relatively informal basis. An agenda will circulated prior to the meeting along with written material for comment. The research team will keep notes of what is said for its own purposes but formal minutes will not be kept.
In order to promote full and frank discussion, meetings will be run according to the 'Chatham House Rule'. That rule provides that the research team may use the information received in meetings, but neither the identity nor affiliation of the source of that information will be revealed. Similar obligations also apply to other members of the Critical Reference Group.
The research team also requests that any written material you receive be treated confidentially.

Appendix B1: Semi-structured Interview Guides – Enduring Powers of Attorney

EPA Witnesses - Interview Guide

1. **Qualifications and experience**
   b) Could you please outline your qualifications for being a witness to the completion of an EPA document
   c) Could you estimate how many EPA documents you have witnessed in the past year?
      i. Before that, were you involved with more or less EPA documents than in the last 12 months?
         1) Why do you think that is the case?

2. **Capacity Assessment**
   a) What processes do you go through, and what factor do you take in to account, in determining the capacity of the principal to appoint an attorney?
      i) Have you ever asked for an independent assessment of the capacity of the principal? Can you briefly outline the circumstances?
   b) Are you aware of the Office for the Adult Guardian's or the Queensland Law Society's 'Capacity guidelines for witnesses of enduring power of attorney'?
      i) Do you use either of them?
      ii) In what ways are the guidelines helpful?
      iii) Do you use the guideline's suggested questions to ask the principal in determining their capacity?

3. **Understanding powers and obligations being conferred**
   a) What steps do you take to ensure that the principal understands the powers and obligations being conferred to their attorney by completing an EPA?
   b) Have you ever asked to see the principal and the attorney(s) separately prior to witnessing the document?
   c) Do you read the completed form?
      i. When do you do this? (e.g. before seeing the principal and attorney or while you and the principal/attorney are together?)

4. **Keeping records**
   a) What records do you keep?
   b) Is there anything that would assist you in keeping records of the witnessing proceedings?

5. **Use of the forms**
   a) What comments would you make on the proposal that there should be a separate form for financial matters and for health and personal matters?
   b) How useful is the form in helping you to be sure the principal understands what powers and obligations are being conferred?
      i) How useful would it be for witnesses to have a set of suggested questions to ask the principal?

c) Overall, do you think the form provides enough protection for the principal?
    i) Is there anything that you think could be changed about the form, or added to the form to provide greater protection for the principal?
d) Are there any parts of the form that principals have difficulty in understanding?
    i) In your experience, what impact does the use of the legal terms (such as 'attorney', 'clause' or 'jointly') have on people completing and/or understanding the form?
    ii) Is the 'Statement of understanding' (p.10/11) straightforward and easy to understand?
        1. What, if any, changes would you suggest?
e) What general comments would you like to make on the ease of use of the forms for you as a witness? Can you comment on the format of the form in terms of:
    i) The ordering or flow of information
    ii) How the form is structured
    iii) The language used
    iv) The length of the form (short? long form?)
    v) The instructions on the form (helpful? Confusing?)
f) What would you like to change about the form to make it easier for you as a witness to complete?
g) What would you like to change about the form to make it easier for principals and attorneys to complete?

6. Information provided

a) Any there any important matters not discussed in the information provided on the form? What should be added?
b) Do you feel there is sufficient information provided for principals?
c) Do you feel there is sufficient information provided for attorneys?
d) Do you feel there is sufficient information provided for the witness?
e) Do you have any comments to make on the placement or ordering of the information?
f) Should the information be provided as part of the form or as a separate booklet that accompanies the form?
    i. Why?
g) In general, do you think that there is not enough information provided, sufficient information provided or too much information provided?

Is there anything else you would like to add?

EPA Attorneys - Interview Guide

1. **Qualifications and Experience**
   a) Outline the qualifications/family/friendship situations that led you into this role.
   b) How long have you been an attorney appointed by an EPA?
   c) Are you, or have you been an attorney under an enduring power of attorney for more than one person?
   d) How many Enduring Powers of Attorney are currently active for which you are an attorney?
   e) Have you been a sole attorney? What are the problems and benefits of this position?
   f) Have you been an attorney in company with others for a particular person? What are the problems and benefits of this position?
   g) Overall, can you outline what has worked well for you as an attorney?

2. **Understanding powers and obligations being conferred**
   a) In your opinion, did the principal fully understand the powers being conferred?
      i. Who or what helped the principal to understand this?
   b) Do you think, at the time that you completed the EPA, that you fully understood the responsibilities involved in being an appointed attorney?
   c) Do you think, at the time that you completed the EPA, that you fully understood the limitations on your powers as an attorney?
   d) Do you ever go back to the form and the information that comes with it to check the details of your duties and role as an attorney?
      i. Why/ Why not?
   e) Have you sought any other sources of information about your duties and roles as an attorney?
      i. Who or what did you consult?
      ii. At what stage did you access this information? (Before you became an attorney, when you became an attorney or later)
      iii. How useful was this information?

3. **Keeping records**
   a) What records do you keep?
   b) Is there anything that would assist you in keeping records of your actions as an attorney?

4. **Use of the forms**
   a) What comments would you make on the proposal that there should be a separate form for financial matters and for health and personal matters?
   b) Overall, do you think the form provides enough protection for the principal?
      i) Is there anything that you think could be changed about the form or added to the form to provide greater protection for the principal**?**
   c) How useful is the form in helping you understand your duties and roles as an attorney?
   d) How useful is the form in helping you understand the limitations of your powers as an attorney?

e) What general comments would you like to make on the ease of use of the forms for you as an attorney? Can you comment on the format of the form in terms of:
    i) The ordering or flow of information
    ii) The Structure of the form
        1. Do you think the sections of the form are in logical order?
        2. Do they flow easily?
    iii) The language used
        a) Did you find any of the following legal terms confusing or difficult to understand: attorney, principal, clause, jointly, severally, simple majority?
        b) Overall, did you find that the wording of the form made it difficult to understand?
    iv) The length of the form
        1) Did you think the form was too long or too short?
        2) Are sections of the form unnecessary?
        3) Is any of the information provided not necessary?
    v) The instructions on the form
        1) Did you find any of the instructions were confusing or misleading?
    vi) The font used (was it large/bold enough to make it easy to read?)
b) What would you like to change about the form to make it more useful to you as an attorney?
c) What would you like to change about the form to make it more useful to principals?
d) Do you have any comments to make about the processes around filling out the form?
e) Do you have any comments to make about the processes around using the form in your role as an attorney?

5. Information Provided

a) Did you read the information provided for the attorney/s? (p. 12/13)
    i. How long ago did you read it?
b) Did you read the information provided for the principal and the witness?
    i. How long ago did you read it?
c) Did you find the information straightforward and easy to understand?
d) Was there enough information provided about:
    i. Your role and responsibilities?
    ii. The roles and responsibilities of the principal and the witness?
    iii. General information about enduring powers of attorney?
    iv. The limitations of your powers (what you cannot do) under the Act?
    v. How to keep records?
e) Are there any other important matters that you felt were not covered in the information in the form?
f) In general, do you think that there is not enough information provided, sufficient information provided or too much information provided?
g) Do you have any comments to make on the placement or ordering of the information?
h) Should the information be incorporated into the form, or would have you preferred it as a separate booklet that accompanies the form?
    i. Why?

Is there anything else you would like to add?

EPA Principals - Interview Guide

1. **Accessing and completing the EPA**
    a) What prompted you to fill out an EPA?
    b) How did you access the form? Did you obtain a hard copy or download it from the internet?
        i. If you obtained a hard copy, where did you get it from?
    c) Did you complete the short form or the long form?
        i. If you completed the long form, why did you do this?
    d) How long ago did you complete your EPA?
    e) Who acted as a witness for your EPA? (A JP, lawyer, commissioner for declarations?)
    f) Did the witness explain and go through the form with you?
    g) Did you have professional assistance in filling out the form?
        i. Why did you feel you needed professional assistance?
    h) Did anyone else assist you in completing the form?
        i. Who (family? Friends?)
    i) What information other than the information on the form did you have to assist you to fill out the form?
    j) Who has copies of your EPA?

2. **Setting conditions**
    a) What conditions did you set for attorneys in making decisions about financial, health and personal matters?
    b) Was there sufficient space on the form to write conditions/limitations?
    c) Did you set a time when you wanted the power of attorney to begin around financial matters?
    d) Did you think that sufficient information/instruction was given to assist you in writing a statement concerning when the powers begin?

3. **Appointing Attorneys**
    a) How did you select your attorneys to be appointed in your EPA?
    b) If you decided on more than one attorney, how do you want them to make decisions – just one can decide, they must decide together or the majority will make the decisions?

4. **Revoking an EPA**
    a) Have you ever revoked an EPA?
        i. If so, can you tell me what prompted this action?
        ii. Was the process of revoking it easy to understand?

5. **Use of the forms**
    a) How long did it take you to complete the form?
    b) Did you complete the form successfully on your first attempt or were mistakes made?
    c) What did you find easy about filling out the form?
    d) What was more difficult in filling out the form?
    e) Would you consider it easy to fill out without professional assistance?

f) What comments would you make on the proposal that there should be a separate form for financial matters and for health and personal matters?
g) Overall, did you feel that the form included enough conditions to ensure that your attorney would act in your best interests?
    i. Is there anything that you think could be changed about the form or added to the form to provide greater protection for the principal?
h) Did you find any parts of the form particularly confusing and/or difficult?
    i. Did you find the 'Statement of understanding' (p. 10/11) straightforward and easy to understand?
        1. What, if any, changes would you suggest?
i) What general comments would you like to make on the ease and use of the forms for you? Can you comment on the format of the form in terms of:
i) The ordering or flow of information
ii) The Structure of the form
    i. Do you think the sections of the form are in logical order?
    ii. Do they flow easily?
iii) The language used
    i. Did you find any of the following legal terms confusing or difficult to understand: attorney, principal, clause, jointly, severally, simple majority
    ii. Overall, did you find that the wording of the form made it difficult to understand?
iv) The font used (was it large/bold enough to make it easy to read?)
v) The length of the form
    i. Did you think the form was too long or too short?
    ii. Did you think that any sections of the form were unnecessary?
    iii. Did you think that any of the information that was provided was not necessary?
vi) The instructions on the form
    i. Did you feel that any of the instructions were confusing or misleading?
j) What would you like to change about the form to make it more useful to you as a principal?
k) Do you have any comments to make about the processes around filling out the form?

6. Information provided

a) Did you read the information provided for the principal?
    i) How long ago did you read it?
b) Did you read the information provided for the attorney/s and the witness?
    i) How long ago did you read it?
c) Did you find the information straightforward and easy to understand?
d) Did you feel that enough information was provided about:
    i) The scope and nature of the powers of your attorney, including how to put limitations on the scope of your attorney's power?
    ii) Your role and responsibilities?
    iii) The roles and responsibilities of the attorney/s and the witness?
    iv) General information about enduring powers of attorney?
    v) Guiding information to assist you in completing the form?
    vi) Avoiding situations where intentional or unintentional financial abuse may occur?

vii) Are there any other important matters that you felt were not covered in the form?

e) In general, do you think that there is not enough information provided, sufficient information provided or too much information provided?
f) Do you have any comments to make on the placement or ordering of the information?
g) Did you like having the information incorporated into the form, or would have you preferred it as a separate booklet that accompanies the form?
    a) Why?

Is there anything else you would like to add?

EPA Health Providers and Other Professionals - Interview Guide

This section relates to people who may offer support to fill out EPAs, work with Principals or Attorneys in implementing EPAs or deal with issues that relate to the misuse of EPAs

1. **Qualifications and experience**
    a) Could you please outline your role/qualifications that relate to your involvement with EPAs?
    b) Could you please outline your experience in supporting people to fill out EPAs, implementing EPAs or dealing with misuse?
    c) Could you estimate how many EPAs you have been involved with in the past year? What has been your primary role in these cases?
        i. Before that, were you involved with more or less EPA documents than in the last 12 months?
            1) Why do you think that is the case?

2. **Assessing capacity**
    a) Have you ever been involved in some way in assessing the capacity, or arranging an assessment of capacity of a principal or an attorney?
        i) What process did/ do you go through?

3. **Questioning the actions of the attorney**
    a) Have you had experience of being involved in questioning the actions of an attorney?
        i) What issues have been raised with you?
        ii)To what extent did the form and accompanying information contribute to the issues faced?
        iii) Did a lack of clarity in the form or in the accompanying information contribute to the issues arising when:
            1) More than one EPA has been completed?
            2) The principal did not intend the outcome that has emerged?

4. **Use of the form**
    a) Overall, do you think the form provides enough protection for the principal?
        i. Is there anything that you think could be changed about the form or added to the form to provide greater protection for the principal?
    b) What are the issues principals, witnesses or attorneys raise with you in filling out EPAs
        i. issues around understanding the topic areas in the form
        ii. issues around the way the form is structured
        iii. issues around linking substitute decision making for financial matters with issues around health or personal matters
    c) What are the issues principals or attorneys raise in putting an EPA into effect in relation to:
        i. financial matters
        ii. health matters
        iii. personal matters.
    d) Can you comment generally on the useability of the current long and short forms of the EPA?

e) Do you think it would assist to have separate forms for financial matters and for health and personal matters?
f) What general comments would you like to make on the ease of use of the forms for you? Can you comment on the format of the form in terms of:
    i. The ordering or flow of information
    ii. The Structure of the form
        1) Do you think the sections of the form are in logical order?
        2) Do they flow easily?
    iii. The language used
        1) Did you think that any of the following legal terms are confusing or difficult to understand: attorney, principal, clause, jointly, severally, simple majority?
        2) Overall, do you think that the wording of the form makes it difficult to understand?
    iv. The font used (was it large/bold enough to make it easy to read?)
    v. The length of the form
        1) Do you think the form is too long or too short?
        2) Do you think that any sections of the form are unnecessary?
        3) Do you think that any of the information that was provided is not necessary?
    vi. The instructions on the form
        1) Do you think that any of the instructions are confusing or misleading?
i. What would you like to change about the form to make it more useful to you?
ii. What would you like to change about the form to make it more useful to principals and attorneys?
g) Do you have any comments to make about the processes around filling out the form?

5. Information provided

a) Do you find the information straightforward and easy to understand?
b) Do you think that enough information is provided about:
    i) The scope and nature of the powers of the attorney, including how to put limitations on the scope of the attorney's power?
    ii) The roles and responsibilities of the principal?
    iii) The roles and responsibilities of the attorney?
    iv) The roles and responsibilities of the witness?
    v) General information about enduring powers of attorney?
    vi) Guiding information to assist the principal in completing the form?
h) Do you feel that there are any important matters not discussed in the information provided that you feel should be discussed in the information?
i) In general, do you think that there is not enough information provided, sufficient information provided or too much information provided?
j) Do you have any comments to make on the placement or ordering of the information?
k) Do you think that the information should be incorporated into the form, or as a separate booklet that accompanies the form?
    a) Why?

Is there anything else you would like to add?

Appendix B2: Semi-structured Interview Guides – Advance Health Directives

AHD Witnesses - Interview Guide

1.Qualifications and experience

a) Could you please outline your qualifications for being a witness and the extent of your experience as a witness
b) Could you estimate how many AHD documents you have witnessed in the past 12 months?
    i) Before that, were you involved with more or less AHD documents than in the last 12 months?
        (1) Why do you think that is the case?

2.Capacity assessment

a) How do you assess the capacity of the principal to complete an AHD? Could you take us through the process?
b) Have you ever asked for an independent assessment of the capacity of the principal? Can you briefly outline the circumstances?
c) Do you use any guidelines or other information to assist you in assessing the capacity of the principal?
    i. What do you use?
    ii. How useful do you find it?

3.Understanding the effect of an AHD

a) What steps do you take to ensure that the principal understands the effect of directions given in an AHD?
b) Do you read the completed form?
    i. When do you do this? (e.g. before seeing the principal or while you and the principal are together?)

4.Keeping records

a) What records do you keep?
b) Is there anything that would assist you in keeping records of the witnessing proceedings?

5.Use of the form

a) In your opinion, does the form require the principal to be too specific about medical preferences in the terminal phase of illness?
    i. Can you comment on the part of the form that asks the principal to tick boxes to indicate their specific preferences in the terminal phase of illness (pages 10-11)?
    i. Are there any changes to this section that you would suggest?
b) Can you comment on the proposal that the form should primarily encourage the principal to state life goals (such as the extent of loss of capacity, dignity or comfort that is tolerable to the principal) and general preferences for medical treatments rather than making specific medical decisions?

i. Can you comment on the general statement selections on page 9 of the form?
ii. Can you comment on section 4 'Personal Statement' (page 13) of the form?
i. Are there any changes to these sections that you would suggest?

c) What comments would you make on the proposal that there should be two separate forms, one for people with a known serious illness/ disability who may have a good idea of the future medical decisions they will most likely have to make and one for people not in this position?
d) How useful is the form in helping you to be sure that the principal understands the effect of completing an AHD?
ii) How useful would it be for witnesses to have a set of suggested questions to ask the principal?
1) Should such questions be on the form or within the information that accompanies the form?
e) Are there any parts of the form that you find confusing or have difficulty in understanding?
f) Are there any parts of the form that principals find confusing or have difficulty in understanding?
i. Can you comment on Section 7 (p.17) of the form that allows the principal to appoint an attorney?
ii. Do you think the 'Statement of understanding' (p.19) is straightforward and easy to understand?
1. What, if any, changes would you suggest?
iii. In your experience, what impact does the use of medical terms (such as 'cardiopulmonary resuscitation', 'artificial hydration' or 'palliative care') have on people completing and/or understanding the form?
iv. In your experience, what impact does the use of the legal terms (such as 'attorney', 'clause' or 'jointly') have on people completing and/or understanding the form?
g) Overall, do you think the requirements of the form achieve the right balance between representing the principal's wishes and making the form as simple as possible to complete?
i. Why/ why not?
h) What general comments would you like to make on the ease of use of the forms for you as a witness? Can you comment on the format of the form in terms of:
i. The ordering or flow of information
ii. How the form is structured
iii. The language used
iv. The length of the form (short? long?)
v. The nature of the information provided
vi. The instructions on the form (helpful? Confusing?)
i) What would you like to change about the form to make it easier for you as a witness?
j) What would you like to change about the form to make easier for the principal to complete?

6.Information provided

a) Are there are any important matters not discussed in the information provided on the form? What should be added?
b) Do you have any comments to make on the placement or ordering of the information?
c) Should the information be provided as part of the form or as a separate booklet that accompanies the form?
d) In general, do you think that there is not enough information provided, sufficient information provided or too much information provided?

Is there anything else you would like to add?

AHD Nominated Doctor - Interview Guide

1. **Qualifications and experience**
    a) Could you estimate how many AHD documents for which you have been the nominated doctor in the past 12 months?
        i) Before that, were you involved with more or less AHD documents than in the last 12 months?
            (1) Why do you think that is the case?
    b) For the AHD document/s for which you have been the nominated doctor, have you also been the usual GP for the principal/s?
        i. If not, what led you to your appointment as the nominated doctor in an AHD?

2. **Capacity assessment**
    a) What factors do you take into account in determining the capacity of the principal to complete an AHD?
    b) Do you normally conduct a capacity assessment of the principal as part of the AHD consultation?
        i. What processes do you go through?
    c) Do you use any guidelines or other information to assist you in assessing the capacity of the principal?
        i. What do you use?
        ii. How useful do you find it?

3. **Understanding the nature of the directions made about medical treatment**
    a) To what extent do you discuss the content of the AHD with the principal?
        i. Do you read through the form and discuss each of the medical decisions being made with the principal or do you discuss the nature of the medical decisions more generally?
        ii. What questions does the principal ask of you, if any, when discussing the form?
        iii. Approximately how long does the meeting with the principal usually last?

4. **Keeping records**
    a) What records do you keep?
    b) Is there anything that would assist you in keeping records of your involvement with AHDs?

5. **Use of the form**
    a) How useful is the form in helping you to be sure that the principal understands the effect of completing an AHD?
        i. How useful would it be for doctors certifying capacity to have a set of suggested questions to ask the principal?
            1) Should such questions be on the form or within the information that accompanies the form?
    b) In your opinion, does the form require the principal to be too specific about medical preferences in the terminal phase of illness?

i. Can you comment on the part of the form that asks the principal to tick boxes to indicate their specific preferences in the terminal phase of illness (pages 10-11)?
    1) Can you comment on the nature of the medical interventions listed in this section?
i. Are there any changes to this section that you would suggest?

c) Can you comment on the proposal that the form should primarily encourage the principal to state life goals (such as the extent of loss of capacity, dignity or comfort that is tolerable to the principal) and general preferences for medical treatments rather than making specific medical decisions?
    i. Can you comment on the general statement selections on page 9 of the form?
    ii. Can you comment on section 4 'Personal Statement' (page 13) of the form?
    i. Are there any changes to these sections that you would suggest?
d) What comments would you make on the proposal that there should be two separate forms, one for people with a known serious illness/ disability who may have a good idea of the future medical decisions they will most likely have to make and one for people who are not in this position?
e) Are there any parts of the form that you find confusing or have difficulty in understanding?
f) Are there any parts of the form that principals find confusing or have difficulty in understanding?
    i. In your experience, what impact does the use of medical terms (such as 'cardiopulmonary resuscitation', 'artificial hydration' or 'palliative care') have on people completing and/or understanding the form?
    ii. In your experience, what impact does the use of the legal terms have on people completing and/or understanding the form?
    iii. Can you comment on the part of the form that asks about tissue donation (page 12)?
g) Overall, do you think the requirements of the form achieve the right balance between representing the principal's wishes and making the form as simple as possible to complete?
    i. Why/ why not?
h) Overall, do you think the requirements of the form achieve the right balance between representing the principal's wishes accurately and making the principal's directions easy to follow for the medical professionals and other people involved?
        i. Why/ why not?
i) What general comments would you like to make on the ease of use of the forms for you as the nominated doctor signing the statement of involvement? Can you comment on the format of the form in terms of:
    i. The ordering or flow of information
    ii. The Structure of the form
        1) Do you think the sections of the form are in logical order?
        2) Do they flow easily?
    iii. The language used
    iv. The length of the form (too short? too long?)
    v. The nature of the information provided
    vi. The instructions on the form (helpful? Confusing?)

i) What would you like to change about the form to make it easier for you as the nominated doctor signing the statement of involvement?
j) What would you like to change about the form to make easier for the principal to complete?

6. Information provided

a) Are there are any important matters not discussed in the information provided on the form? What should be added?
b) Do you have any comments to make on the placement or ordering of the information?
c) Should the information be provided as part of the form, or as a separate booklet that accompanies the form?
d) Do you think that there is enough information provided to help you understand your role as the nominated doctor?
e) In general, do you think that there is not enough information provided, sufficient information provided or too much information provided?

Is there anything else you would like to add?

AHD Principals - Interview Guide

1. **Accessing and completing an AHD**
    a) What prompted you to fill out an AHD?
        i) Did you have a known medical condition or disability at the time when you completed the form?
    b) How did you access the form? Did you obtain a hard copy or download it from the internet?
        i. If you obtained a hard copy, where did you get if from?
    c) How long ago did you complete your AHD?
    d) Did you have professional assistance in filling out the form?
        i. Why did you feel you needed professional assistance?
    e) Was it your usual doctor that signed the form as your 'nominated doctor'?
    f) To what extent did the doctor go through the form with you?
    g) Did anyone else assist you in completing the form?
        i. Who (family? Friends?)
    h) Did you access any other information other than the information given on the form to assist you to fill out the form?
    i) Did you feel you understood the nature of the medical decisions being made when completing the form?
    j) Does anyone have a copy of your AHD?
        i. Who?
    k) Who else is aware that you have completed an AHD?
    l) In the case of an emergency, could your AHD be easily accessed?
        i. How would it be accessed?

2. **Appointing an attorney and setting conditions**
    a) Did you appoint an attorney/s for personal/health matters when completing your AHD?
    b) How did you select your attorney/s?
    c) If you decided on more than one attorney, how do you want them to make decisions – just one can decide, they must decide together or the majority will make the decisions?

3. **Reviewing and revoking an AHD**
    a) Have you ever reviewed your AHD and signed the last page attesting that there is nothing you wish to change?
    b) How often do you review your AHD?
    c) Have you ever updated or revoked your AHD?
        i. If so, can you tell me what prompted this action?

4. **Use of form**
    a) How long did it take you to complete the form?
    b) Did you complete the form successfully on your first attempt or were mistakes made?
    c) What did you find easy about filling out the form?
    d) What was more difficult in filling out the form?
    e) Would you consider it easy to fill out without professional assistance?

f) Did you feel the form required you to be too specific about future medical treatments or that it was not specific enough?
g) Were you satisfied that the form was flexible enough to allow you to state your personal preferences clearly?
    i. Why/ why not?
h) Can you comment on the proposal that the form should primarily encourage the principal to state life goals (such as the extent of loss of capacity, dignity or comfort that is tolerable to the principal) and general preferences for medical treatments rather than making specific medical decisions?
    i. Can you comment on the part of the form that asks you to tick boxes to indicate your specific preferences in the terminal phase of illness (pages 10-11)?
    ii. Can you comment on the general statement selections on page 9 of the form?
    iii. Can you comment on section 4 'Personal Statement' (page 13) of the form?
i) Do you think the form is well designed for going through it and discussing with your family and friends what your future health care wishes are, including your attitudes towards end-of-life?
    a. How does it do this/ why doesn't it do this?
j) Do you think the form is well designed for informing your treating doctor of your wishes?
    a. How does it do this/ why doesn't it do this?
k) What comments would you make on the proposal that there should be two separate forms, one for people with a known serious illness/ disability who may have a good idea of the future medical decisions they will most likely have to make, and one for people who are not in this position?
l) Are there any parts of the form that you find confusing?
    i. Can you comment on the section in the form that allows the principal to appoint an attorney?
    ii. Can you comment on the part of the form that asks about tissue donation (page 12)?
    iii) Did you find the 'Statement of understanding' (p.19) straightforward and easy to understand?
        (1) What, if any, changes would you suggest?
m) Overall, do you think the requirements of the form achieve the right balance between representing your wishes and making the form as simple as possible to complete?
n) Overall, do you think the requirements of the form achieve the right balance between representing your wishes accurately and making your directions easy to follow for the medical professionals and other people involved?
        i. Why/ why not?
o) What general comments would you like to make on the ease of use of the AHD form for you? Can you comment on the format of the form in terms of:
    i. The Structure of the form
        1. Do you think the sections of the form are in logical order?
        2. Do they flow easily?
    ii. The language used
        1. Did you find any of the legal terms (particularly if you appointed an attorney) confusing or difficult to understand?

2. Did you find any of the medical terms confusing or difficult to understand? (such as ‘cardiopulmonary resuscitation’, ‘artificial hydration’ or ‘palliative care’) have on people completing and/or understanding the form?
3. Overall, what impact did the use of medical and/or legal terms have on your understanding of the form?

iii. The length of the form
1. Did you think the form was too long or too short?
2. Did you think that any sections of the form were unnecessary?
3. Did you think that any of the information that was provided was not necessary?

iv. The instructions on the form
1. Did you find that any of the instructions on the form were confusing or misleading?

p) What would you like to change about the form to make it more useful to you or easier to complete?
q) Was there any information that you wanted to provide, but could not find a place to write it?
r) Do you think the form is well-suited and meets the needs of people with an existing medical condition?
s) Do you think the form is well-suited and meets the needs of people without an existing medical condition?

5. Information provided

a) Did you read the information provided on the form?
   i. How long ago did you read it?
b) Did you find the information straightforward and easy to understand?
c) Did you feel there was enough information provided about:
   i. The nature and effect of the medical decisions being made?
   ii. General information about advance health directives?
   iii. General information on the types of end of life decisions you might have to make?
   iv. Guiding instruction to help you fill out the form?
   v. What to do with the form once it has been completed?
   vi. Are there any other important matters that you felt were not sufficiently covered in the information?
d) In general, do you think that there is not enough information provided, sufficient information provided or too much information provided?
e) Do you have any comments to make on the placement or ordering of the information?
f) Should the information be incorporated into the form, or would have you preferred it as a separate booklet that accompanies the form?

Is there anything else you would like to add?

AHD Health Providers (following AHD directions) - Interview Guide

1. **Qualifications and experience**
    a) Please outline your qualifications and role that led you to have experience with AHDs
    b) Approximately how many AHDs have you encountered in your medical practice over the past 12 months?
        i) Before that, were you involved with more or less AHD documents than in the last 12 months?
            (1) Why do you think that is the case?
    c) What situations prompt you to seek information from patients about whether they have completed an AHD?

2. **Understanding the nature of the directions made about medical treatment**
    a) What level of understanding do you think that the principal had of the directions made about medical treatment contained in their AHD when they completed it?
        i. Why do you think that?

3. **Use of the form**
    a) How helpful is the AHD in providing you with information about treatment to provide or to withhold from your patient?
        i. Which of the directions about medical treatment have been useful?
        ii. Which of the directions about medical treatment have not been useful?
        iii. What kind of information do you think would be helpful for the form to contain-
            1) For you?
            2) For the principal?
    b) Can you comment on the proposal that the form should primarily encourage the principal to state life goals (such as the extent of loss of capacity, dignity or comfort that is tolerable to the principal) and general preferences for medical treatments rather than making specific medical decisions?
        i. Can you comment on the part of the form that asks the principal to tick boxes to indicate their specific preferences in the terminal phase of illness (pages 10-11)?
            1) Can you comment on the nature of the medical interventions listed in this section?
        i. Are there any changes to this section that you would suggest?
        ii. Can you comment on the general statement selections on page 9 of the form?
        iii. Can you comment on section 4 'Personal Statement' (page 13) of the form?
        i. Are there any changes to these sections that you would suggest?
    c) What comments would you make on the proposal that there should be two separate forms, one for people with a known serious illness/ disability who may have a good idea of the future medical decisions they will most likely have to make and one for people who are not in this position?
    d) What problems, if any, do you have with the form that is used?
        i. Are there any parts of the form that you find confusing or difficult to understand?
        ii. Can you comment on the section in the form that allows the principal to appoint an attorney?
        iii. Can you comment on the part of the form that asks about tissue donation (page 12)?

e) Overall, do you think the requirements of the form achieve the right balance between representing the principal's wishes and making the form as simple as possible to complete?
f) Overall, do you think the requirements of the form achieve the right balance between representing the principal's wishes accurately and making the principal's directions easy to follow for the medical professionals and other people involved?
    i. Why/ why not?
g) What suggestions do you have, if any, that would make the AHD form easier to use for your patients?
h) What general comments would you like to make on the ease of use of the forms for you and other health care staff? Can you comment on the format of the form in terms of:
    i. The ordering or flow of information
    ii. How the form is structured
    iii. The language used
    iv. The length of the form (too long? Too short?)
    v. The nature of the information provided
    vi. The instructions on the form (confusing? Misleading?)
i) How helpful would it be for you if there was an electronic version of the form?
j) Are there are any important matters not discussed in the information provided on the form? What should be added?
    vii. Do you think the form is well-suited and meets the needs of people with an existing medical condition?
    viii. Do you think the form is well-suited and meets the needs of people without an existing medical condition?
k) What other suggestions, if any, do you have that would make the AHD form more useful for you as a health professional?

Is there anything else you would like to add?

AHD Other Health Providers and Professionals - Interview Guide

1. **Qualifications and experience**
    a) Could you please outline your qualifications and role that has led you to assist in the completion of AHDs or be involved in their use in some other way?
    b) Could you estimate how many AHD documents that you have been involved with in the past 12 months?
        i) Before that, were you involved with more or less AHD documents than in the last 12 months?
            (1) Why do you think that is the case?

2. **Understanding the nature of the directions made about medical treatment (if assisting)**
    a) To what extent do you discuss the content of the AHD with the principal?
        i. Do you only speak about the AHD in general terms on do you go through the form with the principal and discuss the specific sections?
        ii. What factors and issues do you discuss with the principal?
        iii. What questions does the principal ask of you, if any, when discussing the form?
        iv. Approximately how long does the meeting with the principal usually last?
    b) How useful is the form in helping you to be sure that the principal understands the effect of completing an AHD?

3. **Use of the form**
    a) In your opinion, does the form require the principal to be too specific about medical preferences in the terminal phase of illness?
        i. Can you comment on the part of the form that asks the principal to tick boxes to indicate their specific preferences in the terminal phase of illness (pages 10-11)?
        i. Are there any changes to this section that you would suggest?
    b) Can you comment on the proposal that the form should primarily encourage the principal to state life goals (such as the extent of loss of capacity, dignity or comfort that is tolerable to the principal) and general preferences for medical treatments rather than making specific medical decisions?
        i. Can you comment on the general statement selections on page 9 of the form?
        ii. Can you comment on section 4 'Personal Statement' (page 13) of the form?
        iii. Are there any changes to these sections that you would suggest?
    c) What comments would you make on the proposal that there should be two separate forms, one for people with a known serious illness/ disability who may have a good idea of the future medical decisions they will most likely have to make and one for people who are not in this position?
    d) Are there any parts of the form that you find confusing or have difficulty in understanding?
    e) Are there any parts of the form that principals or other people involved in the use of form find confusing or have difficulty in understanding?
        i. Can you comment on the part of the form that asks about tissue donation (page 12)?
        ii. Can you comment on Section 7 (p.17) of the form that allows the principal to appoint an attorney?

iii. In your experience, what impact does the use of medical terms (such as 'cardiopulmonary resuscitation', 'artificial hydration' or 'palliative care') have on people completing and/or understanding the form?
iv. In your experience, what impact does the use of the legal terms have on people completing and/or understanding the form?

f) Overall, do you think the requirements of the form achieve the right balance between representing the principal's wishes and making the forms as simple as possible to complete?
   i. Why/ why not?

g) Overall, do you think the requirements of the form achieve the right balance between representing the principal's wishes accurately and making the principal's directions easy to follow for the medical professionals and other people involved?
   i. Why/ why not?

h) What general comments would you like to make on the ease of use of the forms? Can you comment on the format of the form in terms of:
   i. The ordering or flow of information
   ii. The language used
   iii. The length of the form (too short? too long?)
   iv. The instructions on the form (helpful? Confusing?)?

i) What would you like to change about the form to make easier for the principal to complete?

4. Information provided

a) Do you think the information provided on the form is straightforward and easy to understand?

b) Do you think there is enough information provided about:
   i. The nature and effect of the medical decisions being made?
   ii. The principal's role and responsibilities?
   iii. General information about advance health directives?
   iv. General information on common end of life decisions that may have to be made?
   v. Guiding information to assist filling out the form?
   vi. What to do with the form once it has been completed?

c) Are there are any other important matters not discussed in the information provided on the form? What should be added?

d) Do you have any comments to make on the placement or ordering of the information?

e) Should the information be provided as part of the form or as a separate booklet that accompanies the form?

f) In general, do you think that there is not enough information provided, sufficient information provided or too much information provided?

Is there anything else you would like to add?

Appendix C1: Survey for Principals – EPAs

These appendices provide the questions in the surveys. As an on-line survey, the presentation is different from that seen on screen by respondents.

Please note: These surveys should not be reproduced and used without permission from the research team.

ABOUT THIS SURVEY
The Enduring Power of Attorney (EPA) is an important tool for your future personal, financial and health planning and the Queensland community as a whole. Your completion of this survey will provide valuable feedback about the current EPA form (long and short) and help the research team make recommendations to the Queensland Government about the usefulness of the form.

A BRIEF SURVEY OPEN UNTIL 28 FEBRUARY
The survey will take about 10-15 minutes to complete. We have spent a lot of time thinking about the questions we want to ask you and we hope you will find it easy to finish.

SURVEY REQUIREMENTS
All questions relate directly to the Queensland Enduring Power of Attorney form. Most are multiple choice questions (simply select your answer or more than one if applicable). For a few questions you type in what you want to tell us. For most of the multiple choice questions, you must select a response in order to continue.
Surveys aren't perfect. Sometimes the answers presented might not exactly match your situation. When that happens, please select the one that is the best fit for you or leave it blank if possible.

ETHICAL CONDUCT OF RESEARCH
The University of Queensland conducts research in accordance with the National Statement on Ethical Conduct in Research Involving Humans. If potential respondents have any concerns or complaints about the ethical conduct of this research project, please contact the UQ Ethics Officer on (07) 3365 3924.

CONFIDENTIALITY AND ANONYMITY
All answers provided will remain confidential. We are not asking you for your name or other information that could identify you. The survey results will be collated before being published.

DIFFICULTIES?
If you have received this survey on your work email, and you encounter any difficulties completing it, try forwarding it to your home email address.
If you have any problems with this survey, please contact Angela Setterlund: a.setterlund@uq.edu.au.

1. Have you completed an Enduring Power of Attorney (EPA)?

    i. Yes →(skips to Section 1)
    ii. No

    a. We are interested in why people do not complete EPAs. Please indicate which reason best represents why you have not completed one:
        i. I would not consider completing an EPA as I do not like the concept (survey ends)
        ii. I might consider completing one, but have not yet obtained a form
        iii. I decided not to complete one after looking at the form (skips to c)

    b. Please select any relevant reasons why you have never obtained a form:
        i. I did not know where to get a form
        ii. I could not download the form from the internet
        iii. My local newsagent / post office did not have any in stock
        iv. I did not want to pay for a form

    c. Please select any reason(s) below that contributed to your decision not to complete the form:
        i. It was hard to follow what the instructions in the form meant overall
        ii. I had trouble understanding the legal terminology
        iii. I felt uncomfortable with the serious nature of the decisions I was making
        iv. I felt uncomfortable answering some of the questions
        v. I was unsure about the implications of appointing an attorney
        vi. The form was too long
        vii. Other (please give details)
        _____

(This concludes the survey for the 'no' respondents from Question 1.)

Section 1: Completing and Storing Your Enduring Power of Attorney

1. When did you complete your most recent EPA?
    a. Less than 1 year ago
    b. 1 to 2 years ago
    c. 3 to 5 years ago
    d. More than 5 years ago

2. How did you access your EPA form?
    a. Post office or newsagent
    b. Lawyer
    c. Financial adviser / accountant
    d. I downloaded it from the internet

e. Other (please specify) _____

3. Did you complete the EPA short form or the EPA long form?
    a. EPA short form
    b. EPA long form
    c. Unsure

4. Did you obtain legal assistance to help you complete the form?
    a. Yes
    b. No

5. Do you think legal assistance was necessary to help you complete the form?
    a. Yes
    b. No
    c. Unsure

6. Before your signature on the form was witnessed, did you discuss the form with the witness? Please select all answers that apply.
    a. Yes, we discussed the completed form at length
    b. Yes, we briefly discussed the completed form
    c. Yes, we talked generally about the nature and effect of the form
    d. No, the witness simply witnessed my signature

7. Did the witness clarify any parts of the form you had difficulty understanding?
    a. Yes
    b. No
    c. Unsure

8. Before your attorney(s) signed the form, did you discuss his/her roles and responsibilities?
    a. Yes, we discussed them at length
    b. Yes, we briefly discussed them
    c. No, my attorney(s) simply signed the form
    d. Other (please specify) _____

9. Does your attorney have either your original EPA or a copy of it?
    a. The original (skips to 11)
    b. A copy
        i. Has someone such as a commissioner for declarations or justice of the peace signed each page to certify that it is a copy of the original document?
            1. Yes
            2. No
            3. Unsure

c. Neither of the above

10. Does your attorney know the exact location of your original EPA form?
    a. Yes
    b. No
    c. Unsure

11. Where else are copies of your EPA currently located? Please select all answers that apply.
    a. With the bank or a financial adviser / accountant
    b. With a family member / friend who is not an attorney
    c. With a solicitor
    d. At home in a safe
    e. At home in another location
    f. Other (please specify)_____

12. Have you ever revoked or changed your EPA?
    a. Yes
        i. Did you keep an original or copy of your old form? Yes/No/Unsure
        ii. Does your attorney(s) still have an original or copy of your old form? Yes/No/Unsure
    b. No

Section 2: Enduring Power of Attorney Information

1. The EPA form includes explanatory notes providing information to assist with the completion of the form. Did you read the explanatory notes **BEFORE** completing the form?
    a. Yes (skips to 3)
    b. No

2. Please select which of the following options best describes why you did not read them:
    a. My lawyer helped me complete the form and explained everything to me
    b. My accountant / financial adviser helped me complete the form and explained everything to me
    c. The form was self explanatory
    d. The information was too long
    e. The information was too difficult to understand
    f. Other (please give details) _____
    (skips to 7)
3. The explanatory notes were straightforward and easy to understand
    a. Strongly agree
    b. Agree
    c. Unsure
    d. Disagree

e. Strongly disagree

4. All of the information provided in the explanatory notes was useful
    a. Strongly agree
    b. Agree
    c. Unsure
    d. Disagree
    e. Strongly disagree

5. The explanatory notes provided me with all of the information I wanted to know
    a. Strongly agree
    b. Agree
    c. Unsure
    d. Disagree
    e. Strongly disagree

6. I would have liked more examples to help me understand the matters discussed
    a. Strongly agree
    b. Agree
    c. Unsure
    d. Disagree
    e. Strongly disagree

7. Since completing the EPA form, have you ever referred back to the explanatory notes?
    a. Yes
        iii. Were the explanatory notes sufficient for finding the information you were looking for?
        Yes
        No → What did you feel was missing from the explanatory notes? Please give details _____
    b. No
    c. Unsure
8. Would you prefer to have the explanatory notes separated from the form and placed in a separate information booklet that accompanies the form?
    a. Yes
    b. No
    c. Unsure
9. What further information would you like to be provided in the explanatory notes, if any? Please indicate the level of importance these options are to you: (1 = Very important; 2 = Important; 3 = Unsure; 4 = Unimportant; 5 = Very unimportant)
    a. Further guiding instructions to help you complete the form
    b. What to do with the form once it's complete
    c. Whether financial institutions or government agencies will recognise the EPA
    d. Who to contact if you require further information

a. Whether your EPA will be recognised if you travel interstate or overseas
e. Advice on discussing your EPA with your family
f. When and how your EPA will come into effect
g. More information about how to write specific conditions or restrictions into the EPA modifying the way the attorney's powers can be used
h. More information on the types of personal decisions your attorney/s can make for you in the event that you lose capacity
i. Other (please specify) _____

10. Overall, do you think the form adequately alerts people to the serious nature of the decisions they are making?
    a. Strongly agree
    b. Agree
    c. Unsure
    d. Disagree
    e. Strongly disagree

11. Did the form provide enough information on the possible implications of certain decisions?
    a. Yes
    b. No
    c. Unsure

    Please give any comments _____
12. Is the scope of the powers of your attorney(s) clear to you?
    a. Very clear
    b. Clear
    c. Unsure
    d. Somewhat unclear
    e. Very unclear

13. In your opinion, does the EPA form provide an adequate explanation of the role and responsibilities of an attorney under the EPA?
    a. Yes
    b. No
        i. What do you feel is missing? Please give any comments _____
    c. Unsure

14. Would you like to see more information in the form about the attorney's responsibility to keep records?
    a. Yes
    b. No

15. Before, during or after completing your EPA, did you talk to any organisation (other than a lawyer) to seek further information?
    a. Yes – before completing my EPA

b. Yes – while I was completing my EPA
c. Yes – after I had completed my EPA
d. No (skips to 17)

16. What did you ask about? Please select all answers that apply.
    a. Where to get a copy of the form
    b. The meaning of an instruction or term used on the form
    c. The role of the attorney(s)
    d. Revoking or changing your EPA
    e. Whether financial institutions or government agencies will recognise the EPA
    f. Other (please specify)_____

17. Before, during or after completing your EPA, did you seek further information material (such as information available on the internet or in information booklets)?
    1. Yes – before completing my EPA
    2. Yes – while I was completing my EPA
    3. Yes – after I had completed my EPA
    4. No (skips to section 3)

18. Were you successful in finding further information materials?
    1. Yes
    2. No (skips to section 3)

19. Were any of the information materials you accessed from the Department of Justice and Attorney General (including the Office of the Adult Guardian)?
    1. Yes
        a. Was the information provided by the Department of Justice and Attorney General (including the Office of the Adult Guardian) useful?
            i. Yes
            ii. Somewhat useful
            iii. No
    2. No

Section 3: The Useability of the EPA

1. In your opinion, how easy was the EPA form to complete?
    a. Very easy
    b. Easy
    c. Neither easy nor difficult
    d. Difficult
    e. Very difficult

2. The current EPA form usually defines an unfamiliar term (such as a legal term) when it first appears in the document. This means that terms and definitions are spread throughout the form. Are you satisfied with the current placement of terms and definitions in the form or would you like to see a glossary where all terms and definitions are listed together?

i. I would like a glossary of terms and conditions
ii. No glossary necessary – I am happy with the form the way it is (skips to 3)
iii. Unsure (skips to 3)

a. If a glossary was provided, would you still want definitions of terms throughout the form as well?
    i. Yes, I would prefer to have terms defined where they are first used in the form AND placed in a glossary
    ii. No, I would prefer all the definitions currently spread throughout the form to be moved into a glossary instead
    iii. Unsure

b. If a glossary was provided, would you prefer it to accompany the form or be included as part of the form?
    i. I would like the glossary to be a separate document accompanying the form
    ii. I would like the glossary to be part of the form itself
    iii. Unsure

3. Please consider the length of the form. In your opinion, the form is:
    a. Too long
    b. An acceptable length
    c. Too short

4. Please consider the following statements about how clear the form is and indicate how strongly you agree or disagree with each one. (1 = Strongly agree; 2 = Agree; 3 = Unsure; 4 = Disagree; 5 = Strongly disagree)
    a. It is well presented
    b. I have no problem with the text size or font used
    c. Overall, the language used is simple and easy to follow
    d. There was an unnecessary amount of legal terminology
    e. The definitions of terms provided were clear and easy to understand
    f. The instructions for completing the form were confusing

5. In your opinion, does the EPA form provide an adequate explanation of what an attorney can or cannot do under the EPA if no special conditions or restrictions are written into it?
    a. Yes
    b. No
    c. Unsure

6. Legislation gives attorneys the power to make certain decisions under EPAs and controls the way that attorneys can use those powers. The way those powers can be used can also be modified by you writing special conditions or restrictions into your EPA.

These conditions or restrictions can give extra powers that are not granted by the standard EPA form. They can also remove or limit powers that are normally granted by the standard EPA form. Including special conditions or restrictions in your EPA can make your attorney more accountable, give him or her more flexibility in dealing with your assets, or give yourself more protection according to your preferences.

For example, you could write clauses:

1) Preventing the attorney(s) from making decisions in relation to your property
2) Preventing the attorney(s) from making decisions in relation to a particular asset of yours
3) Allowing the attorney(s) to make gifts and/or make any financial decisions on your behalf regardless of any conflict of interest – for example, allowing your attorney to give themselves a gift from your savings
4) Requiring the attorney(s) to consult with nominated people before making any decisions
5) Requiring the attorney(s) to provide an annual accounting report to a nominated person

Did you include any special conditions or restrictions in your EPA on the way your attorney's powers can be used?

a. Yes
b. No (skips to 10)

7. What special conditions or restrictions did you set? Please provide details
_____

8. Were these special conditions or restrictions suggested to you by a solicitor or did you initiate them yourself?
    a. Suggested by a solicitor
    b. Initiated by me
    c. Both

9. How easy or difficult was it to write the special conditions or restrictions? (1 = Very easy; 2 = Easy; 3 = Neither easy nor difficult; 4 = Difficult; 5 = Very difficult)

10. Do you think that the EPA should provide more information on how to include special conditions or restrictions that give the attorney specific additional powers not granted by the standard EPA form?
    a. Yes
    b. No
    c. Unsure

11. Do you think that the EPA should provide more information on how to include special conditions or restrictions that remove or limit powers normally granted to attorneys by the standard EPA form?

a. Yes
b. No
c. Unsure

12. Would you like to see pre-written special conditions or restrictions on the EPA form for the person completing it to choose or reject by ticking/crossing them out?
    a. Yes
    b. No (skips to 14)
    c. Unsure (skips to 14)

13. Please indicate how strongly you agree or disagree with the inclusion of pre-written special conditions / restrictions about: (1 = Strongly agree; 2 = Agree; 3 = Unsure; 4 = Disagree; 5 = Strongly disagree)
    a. Preventing the attorney(s) from making decisions in relation to your property
    b. Preventing the attorney(s) from making decisions in relation to a particular asset of yours
    c. Allowing the attorney(s) to make gifts and/or make any financial decisions on your behalf regardless of any conflict of interest
    d. Requiring the attorney(s) to consult with nominated people before making any decisions
    e. Requiring the attorney(s) to provide an annual accounting report to a nominated person

14. Question 5 of the EPA form asks when you want the power of attorney for financial matters to begin. What did you select?
    a. I did not appoint a power of attorney for financial matters (skips to 16)
    b. 'Immediately'
    c. I wrote in a date when I wanted it to begin (skips to 16)
    d. I wrote in an occasion when I wanted it to begin (skips to 16)
    e. Unsure (skips to 16)

15. What was your intention in selecting 'immediately'?
    a. I wanted my attorney to be able to exercise power of attorney for financial matters immediately following the completion of the EPA form.
    b. I wanted my attorney to be able to exercise power of attorney for financial matters immediately upon any loss of capacity on my part to make financial decisions for myself, including in an emergency situation such as a car accident.
    c. Unsure
    d. Other (please specify) _____

16. The EPA gives you the option of appointing an attorney for personal/health matters. You may also have completed an Advance Health Directive (AHD) form, which also allows you to appoint an attorney for personal/health matters.

    Have you appointed a personal/health attorney in the EPA or in an AHD form?

a. Yes
b. No (skips to 19)
c. Unsure (skips to 19)

17. Did you appoint a personal/health attorney in the AHD, in an EPA form or both?
    a. In the EPA only (skips to 19)
    b. In an AHD form only (skips to 19)
    c. In both documents

18. Did you appoint the same personal/health attorney in both documents?
    a. Yes (skips to 19)
    b. No, I appointed a different attorney in each document
        ii. Are you aware that appointing an attorney in a later document may revoke the earlier appointment of an attorney?
            1. Yes
            2. No
            3. Unsure
    c. Unsure (skips to 19)

19. Have you ever needed your attorney(s) to act under the EPA?
    a. Yes
    b. No (skips to section 4)

20. Please select all reasons why you needed your attorney(s) to act:
    a. I was travelling overseas or interstate
    b. I was ill for 3 months or less
    c. I was ill for more than 3 months
    d. I had a physical injury or disability
    e. Other (please specify) _____

Section 4: The Purpose of Your EPA

The following questions ask you to consider the purpose of your EPA. An EPA allows you to appoint someone to make financial and/or personal/health-related decisions on your behalf.

Unlike under a general power of attorney, under an EPA your attorney can make decisions for you when you are incapacitated by serious illness or accident. Please answer the following questions keeping these features of the EPA in mind.

1. What was your motivation for completing an EPA? Please select any of the following reasons behind your decision:
    a. I have a specific medical condition and wanted to choose who to make decisions for me when I am unable to make them myself
    b. I do not have a specific medical condition, but I wanted my family or friends to be able to make decisions for me if I become ill or have an accident
    c. I am in a same-sex relationship and wanted to improve the legal rights of my partner

d. My lawyer, doctor, family member or friend recommended it to me
e. My partner died and I wanted to appoint someone to make decisions for me if I am unable to do so myself
f. I wanted to have one in place when I am overseas
g. I moved into an aged care facility and was asked to complete one by the staff there
h. I got married and wanted to appoint my partner as an attorney
i. I made an EPA at the same time as I made a will
j. I have experienced negative consequences of not having an EPA or seen someone else experience them
k. Other (please provide details)

_____

2. Did you find it confusing that the form refers to both financial matters and personal/health matters?
    a. Very confusing
    b. A little confusing
    c. No

3. Do you think financial matters and health/personal matters should be separated into two different EPA forms?
    a. Strongly agree
    b. Agree
    c. Unsure
    d. Disagree
    e. Strongly disagree

4. Do you think the EPA should only be for financial matters only, with people only having the option of appointing attorneys for health/personal matters in an Advance Health Directive (AHD) form?
    a. Strongly agree
    b. Agree
    c. Unsure
    d. Disagree
    e. Strongly disagree

5. Do you have more than one attorney for your EPA?
    a. Yes
        i. How many? _____
    b. No (skips to 10)

6. Why did you decide to have more than one attorney? Please select all answers that apply.
    a. I wanted to appoint all my children as attorneys to avoid excluding anyone
    b. Increased accountability
    c. Increased transparency

d. I wished to appoint at least one different attorney for financial matters compared to personal/health matters
e. Other (please specify) _____

7. How did you arrange the appointment of attorneys?
    a. I appointed attorneys for financial matters only
    b. I appointed attorneys for personal/health matters only
    c. I appointed more than one attorney for both financial and personal/health matters
    d. I appointed at least one different attorney for financial matters than for personal/health matters

8. How did you arrange your attorneys to make decisions?
    a. Jointly (attorneys must agree on any decision)
    b. Severally (each attorney has the power to make decisions independently of any other)
    c. Jointly and severally
    d. As a majority (the majority of attorneys must agree on any decision)
    e. Unsure
    f. Other (please specify) _____

9. Would you have liked more guidance in terms of what to consider when deciding how your attorneys will make decisions?
    a. Yes → Why? Please give any comments _____
    b. No
    c. Unsure

10. How important is it to you that your attorney/s consults with and communicates decisions to other family members or people who might be part of your support network?
    a. Very important
    b. Important
    c. Unsure
    d. Unimportant
    e. Very unimportant

Section 5: Personal Information

What is your gender identity? 1 Male
2 Female

From your postcode, we hope to pick up what type of region you live in (e.g. rural, provincial, outer suburban, city). Please type in the postcode of your current residence: _____

What is your current relationship status?

a. Single
b. Married / with partner
c. Widowed

Do you have any children aged over 18 years?

a. Yes

b. No

Are you Aboriginal or Torres Strait Islander?

a. Yes → Please choose the specific group you identify with:
    i. Aboriginal
    ii. Torres Strait Islander
    iii. Aboriginal and Torres Strait Islander
b. No

Please select your country of birth: (drop down box)

Is English your first language? Yes / No

What is your current age? _____

What is your highest completed level of education?

1. Postgraduate
2. Undergraduate
3. High school
4. Primary school

Do you have a financial/accounting background?

1. Yes
2. No

Are you currently practising medicine or do you have a background in a health profession?

1. Yes
2. No

Are you currently practising law or do you have a legal background?

1. Yes
2. No

Do you have any experience with EPAs in another capacity apart from completing one yourself?

a. Yes
    → Please select all answers that apply:
    i. I have been appointed as an attorney under an EPA
    ii. I have signed an EPA as a witness
    iii. Other (please specify) _____

b. No

We would like to thank you for taking the time to complete this survey. When the results are finalised a summary of outcomes will be made available to those who express interest in this research by contacting the University of Queensland – School of Social Work and Human Services.

Appendix C2: Survey for Attorneys – EPAs

Please note: These surveys should not be reproduced and used without permission from the research team.

ABOUT THIS SURVEY
The Enduring Power of Attorney (EPA) is an important tool for personal, financial and health planning and the Queensland community as a whole. Your completion of this survey will provide valuable feedback about the current EPA form (long and short) and help the research team make recommendations to the Queensland Government about the usefulness of the form.

A BRIEF SURVEY OPEN UNTIL 28 FEBRUARY
The survey will take about 10-15 minutes to complete. We have spent a lot of time thinking about the questions we want to ask you and we hope you will find it easy to finish.

SURVEY REQUIREMENTS
All questions relate directly to the Queensland Enduring Power of Attorney form. Most are multiple choice questions (simply select your answer or more than one if applicable). For a few questions you type in what you want to tell us. For most of the multiple choice questions, you must select a response in order to continue.

Surveys aren't perfect. Sometimes the answers presented might not exactly match your situation. When that happens, please select the one that is the best fit for you or leave it blank if possible.

ETHICAL CONDUCT OF RESEARCH
The University of Queensland conducts research in accordance with the National Statement on Ethical Conduct in Research Involving Humans. If potential participants have any concerns or complaints about the ethical conduct of this research project, please contact the UQ Ethics Officer on (07) 3365 3924.

CONFIDENTIALITY AND ANONYMITY
All answers provided will remain confidential. We are not asking you for your name or other information that could identify you. The survey results will be collated before being published.

DIFFICULTIES?
If you have received this survey on your work email, and you encounter any difficulties completing it, try forwarding it to your home email address.
If you have any problems with this survey, please contact Angela Setterlund: a.setterlund@uq.edu.au.

1. Have you ever been an attorney for someone under an Enduring Power of Attorney (EPA)?
    a. Yes
    b. No (survey ends)

Section 1: Your Appointment and Acting Under the EPA

1. Have you been an attorney under an EPA for more than one person?
    a. Yes
    b. No (skips to 4)

2. How many currently active Enduring Powers of Attorney are there for which you are an attorney? _____

3. What is the longest period of time you have been an attorney under an EPA?
    a. Less than 1 year
    b. 1 to 2 years
    c. 3 to 5 years
    d. More than 5 years

4. Have you been the sole attorney appointed under an EPA?
    a. Yes
    b. No

5. Have you been appointed with one or more other attorneys under an EPA?
    a. Yes
    b. No (skips to 8)

6. How do you make decisions under the EPA? If you are an attorney under only one EPA, please select one answer. If you are an attorney under more than one EPA, please select all answers that apply.
    a. Jointly (attorneys must agree on any decision)
    b. Severally (each attorney has the power to make decisions independently of any other)
    c. Jointly and severally
    d. As a majority (the majority of attorneys must agree on any decision)
    e. Unsure
    f. Other (please specify) _____

7. Would you have liked more guidance in terms of how to make decisions when more than one attorney has been appointed?
    a. Yes → If so, why? Please give any comments _____
    b. No
    c. Unsure

8. Before you signed the form(s), did you discuss your roles and responsibilities with the principal(s)? If you are an attorney under more than one EPA, please select all answers that apply.
    a. Yes, we discussed them at length
    b. Yes, we briefly discussed them
    c. No, I simply signed the form
    d. Other (please specify) _____

9. Did you keep the original EPA or a copy of it? If you are an attorney under more than one EPA, please select all answers that apply.
    a. The original
    b. A copy
        i. Has someone such as a commissioner for declarations or justice of the peace signed each page to certify that it is a copy of the original document? Yes/No/Unsure
    c. Neither of the above

10. Do you hold the original of each EPA form on which you are an attorney?
    a. Yes
    b. No
        i. Do you know the exact location of any original ones you do not hold?
            1. Yes
            2. No
            3. Unsure
    c. Unsure

11. Have you ever needed to act under an EPA?
    c. Yes
    d. No (skips to section 2)

12. Please select any reasons why you needed to act:
    a. The principal was travelling overseas or interstate
    b. The principal was ill for 3 months or less
    c. The principal was ill for more than 3 months
    d. The principal had a physical injury or disability
    a. Other (please specify) _____

Section 2: EPA Information

1. Pages 12-16 of the EPA form give explanatory notes for attorneys. Did you read these notes **BEFORE** completing the attorney's acceptance in the form?
    a. Yes (skips to 3)
    b. No
    c. Unsure (skips to 3)

2. Please select which of the following options best describes why you did not read them:
    g. The form was self explanatory
    a. The information was too long
    b. The information was too difficult to understand
    c. Other (please specify) _____
    (skips to 7)
3. The explanatory notes were straightforward and easy to understand
    (Strongly agree/Agree/Unsure/Disagree/Strongly disagree)

4. All of the information provided was useful
    (Strongly agree/Agree/Unsure/Disagree/Strongly disagree)

5. The explanatory notes provided me with all of the information I wanted to know
    (Strongly agree/Agree/Unsure/Disagree/Strongly disagree)

6. I would have liked more examples to help me understand the matters discussed
    (Strongly agree/Agree/Unsure/Disagree/Strongly disagree)

7. Since signing an EPA form, have you ever referred back to the explanatory notes?
    a. Yes
        i. Were the explanatory notes sufficient for finding the information you were looking for?
        Yes
        No → What did you feel was missing from the explanatory notes? Please give details: _____
    b. No

8. Would you prefer to have the explanatory notes separated from the form and placed in a separate information booklet that accompanies the form?
    a. Yes
    b. No
    c. Unsure

9. What further information would you like to be provided in the explanatory notes, if any? Please indicate the level of importance these options are to you (1 = Very important; 2 = Important; 3 = Unsure; 4 = Unimportant; 5 = Very unimportant)
    a. Whether financial institutions or government agencies will recognise the EPA
    b. Who to contact if you require further information
    c. Whether the EPA will be recognised if the principal travels interstate or overseas
    d. When and how the EPA will come into effect
    e. Other (please specify)_____

10. Overall, do you think the form adequately alerts people to the serious nature of being an attorney under an EPA?

a. Strongly agree
b. Agree
c. Unsure
d. Disagree
e. Strongly disagree

11. Is the scope of your powers clear to you?
    a. Very clear
    b. Clear
    c. Unsure
    d. Somewhat unclear
    e. Very unclear

12. Legislation gives attorneys the power to make certain decisions under EPAs and controls the way that attorneys can use those powers. The way those powers can be used can also be modified by writing special conditions or restrictions into the EPA. These conditions or restrictions can give extra powers that are not granted by the standard EPA form. They can also remove or limit powers that are normally granted by the standard EPA form.

Has a principal included any special conditions or restrictions on your powers in an EPA?
    a. Yes
        i. Please give details: _____
    b. No
    c. Unsure

13. In your opinion, does the EPA form provide an adequate explanation of the role and responsibilities of an attorney under the EPA?
    a. Yes
    b. No
        i. What do you feel is missing? Please give any comments: _____
    c. Unsure

14. Would you like to see more information in the form about your responsibility to keep records?
    a. Yes
    b. No

15. Would you like to see more information in the form about your responsibilities with regard to 'gifts' and conflicts of interest?
    a. Yes
    b. No

16. Would you like to see more information in the form about situations in which the Adult Guardian may investigate decision making by attorneys under EPAs?
    a. Yes

b. No

17. Have you obtained legal assistance before signing an EPA form?
    a. Yes
    b. No

18. Before or after signing an EPA, have you talked to any organisation (other than a lawyer) to seek further information?
    a. Yes – before signing an EPA
    b. Yes – after signing an EPA
    c. Yes – before and after signing an EPA
    d. No (skips to 20)

19. What did you ask about? Please select all answers that apply.
    g. The meaning of an instruction or term used on the form
    h. Your role as an attorney
    i. Whether financial institutions or government agencies will recognise the EPA
    j. Other (please specify) _____

20. Before or after signing an EPA, have you sought further information material (such as information available on the internet or in information booklets)?
        1. Yes – before signing an EPA
        2. Yes – after signing an EPA
        3. Yes – before and after signing an EPA
        4. No (skips to section 3)

21. Were you successful in finding further information materials?
        1. Yes
        2. No (skips to section 3)

22. Were any of the information materials you accessed from the Department of Justice and Attorney General (including the Office of the Adult Guardian)?
    3. Yes
        a. Was the information provided by the Department of Justice and Attorney General (including the Office of the Adult Guardian) useful?
            i. Yes
            ii. Somewhat useful
            iii. No
    4. No
    5. Unsure

Section 3: The Useability of the EPA

1. Please consider the length of the form. In your opinion, the form is:
    a. Too long
    b. An acceptable length

c. Too short

2. Please consider the following statements about how clear the form is and indicate how strongly you agree or disagree with each one. (1 = Strongly agree; 2 = Agree; 3 = Unsure; 4 = Disagree; 5 = Strongly disagree)
    a. It is well presented
    b. I have no problem with the text size or font used
    c. Overall, the language used is simple and easy to follow
    d. The definitions of terms provided were clear and easy to understand
    e. There was an unnecessary amount of legal terminology

Section 4: The Purpose of the EPA

1. The following questions ask you to consider the purpose of EPAs. An EPA allows people to appoint someone to make financial and/or personal/health-related decisions on their behalf. Unlike under a general power of attorney, under an EPA an attorney can make decisions for the principal when he or she is incapacitated by serious illness or accident.

Please answer the following questions keeping these features of the EPA in mind.

How did you become an attorney under an EPA? Please select all answers that apply.

- a. The principal decided to complete an EPA and asked me to be an attorney
- b. I am in a same-sex relationship and my partner and I decided to become attorneys for each other to improve our legal rights
- c. I got married and my partner and I decided to become attorneys for each other
- d. I thought the principal should have one so I suggested it to him/her and he/she was happy for me to be his/her attorney
    - i. Why did you think the principal should have one?
        1. Because he/she reached a certain age
        2. Because of his/her serious pre-existing illness and/or disability
        3. Other (please specify) _____
- e. My lawyer, doctor, family member or friend (other than the principal) suggested it to me
- f. Other (please provide details) _____

2. An attorney for personal/health matters may also be appointed under an Advance Health Directive (AHD) form. Have you been appointed as a personal/health attorney IN AN EPA FORM?
    a. Yes
    b. No
    c. Unsure

3. Did you find it confusing that the EPA form refers to both financial matters and personal/health matters?
    a. Very confusing
    b. A little confusing

c. No

4. Do you think financial matters and health/personal matters should be separated into two different EPA forms?
    a. Strongly agree
    b. Agree
    c. Unsure
    d. Disagree
    e. Strongly disagree

5. Do you think the EPA should only be for financial matters only, with people only having the option of appointing attorneys for health/personal matters in an Advance Health Directive (AHD) form?
    a. Strongly agree
    b. Agree
    c. Unsure
    d. Disagree
    e. Strongly disagree

6. Have you been appointed as an attorney for financial matters in an EPA form?
    a. Yes
    b. No (skips to section 5)

7. Question 5 of the EPA form asks when the principal wants the power of attorney for financial matters to begin. What did the principal select?

If you are an attorney for financial matters under only one EPA, please select one answer. If you are an attorney for financial matters under more than one EPA, please select all answers that apply.

    a. 'Immediately'
    b. The principal wrote in a date for it to begin
    c. The principal wrote in an occasion for it to begin
    d. Unsure

8. If a principal selects 'immediately', when do you think the attorney's power to make decisions under the EPA begins?
    a. Immediately following the completion of the EPA form
    b. Immediately upon the principal losing the capacity to make financial decisions for himself/herself including in an emergency situation such as a car accident
    c. Either a or b
    d. Unsure
    e. Other (please specify)_____

Section 5: Personal Information

What is your gender identity? 1 Male
2 Female

From your postcode, we hope to pick up what type of region you live in (e.g. rural, provincial, outer suburban, city). Please type in the postcode of your current residence: _____

What is your current relationship status?

a. Single
b. Married / with partner
c. Widowed

Do you have any children aged over 18 years?

a. Yes
b. No

Are you Aboriginal or Torres Strait Islander?

a. Yes → Please choose the specific group you identify with:
    i. Aboriginal
    ii. Torres Strait Islander
    iii. Aboriginal and Torres Strait Islander
b. No

Please select your country of birth: (drop down box)

Is English your first language? Yes/No

What is your current age? _____

What is your highest completed level of education?

1. Postgraduate
2. Undergraduate
3. High school
4. Primary school

Do you have a financial/accounting background?

1. Yes
2. No

Are you currently practising law or do you have a legal background?

1. Yes
2. No

Are you currently practising medicine or do you have a background in a health profession?

1. Yes
2. No

Do you have any experience with EPAs in another capacity apart from being an attorney?

c. Yes
→ Please select all answers that apply:
    i. I have completed an EPA for myself
    ii. I have signed an EPA as a witness
    iii. Other (please specify) _____

d. No

Appendix C3: Survey for Witnesses – EPAs and AHDs

Please note: These surveys should not be reproduced and used without permission from the research team.

ABOUT THIS SURVEY

The Enduring Power of Attorney (EPA) is a tool for personal, financial and health planning, while the Advance Health Directive (AHD) provides a mechanism for people to participate in advance care planning and discussion about their future health care.

We are interested in your opinion and experiences of EPA and AHD forms as a witness. Your completion of this survey will provide valuable feedback about the current EPA form (long and short) as well as the AHD form. This feedback will help the research team make recommendations to the Queensland Government about the usefulness of the forms.

A BRIEF SURVEY OPEN UNTIL 28 FEBRUARY

The survey will take about 10-15 minutes to complete. We have spent a lot of time thinking about the questions we want to ask you and we hope you will find it easy to finish.

SURVEY REQUIREMENTS

Most are multiple choice questions (simply select your answer or more than one if applicable). For a few questions you type in what you want to tell us. For most of the multiple choice questions, you must select a response in order to continue.

Surveys aren't perfect. Sometimes the answers presented might not exactly match your situation. When that happens, please select the one that is the best fit for you or leave it blank if possible.

ETHICAL CONDUCT OF RESEARCH

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CONFIDENTIALITY AND ANONYMITY

All answers provided will remain confidential. We are not asking you for your name or other information that could identify you. The survey results will be collated before being published.

DIFFICULTIES?

If you have received this survey on your work email, and you encounter any difficulties completing it, try forwarding it to your home email address.

If you have any problems with this survey, please contact Angela Setterlund: a.setterlund@uq.edu.au.

Section 1: Experience Witnessing EPAs

1. Have you ever been a witness for the completion of an Enduring Power of Attorney (EPA) form?
    a. Yes
    b. No (skips to section 4)

2. How many years have you been witnessing EPA forms? _____

3. Please estimate how many EPA forms you have witnessed in the past year: _____

4. Compared with previous years, have you been asked to witness more, fewer or about the same number of EPAs over the past year?
    a. More
        ii. Why do you think you are being asked to witness more EPAs? Please give any comments:
    b. Fewer
        iii. Why do you think you are being asked to witness fewer EPAs? Please give any comments:
    c. About the same
    d. Unsure

5. What do you consider to be the role of the witness in relation to EPAs?
    a. To witness the signature of the principal
    b. To explain the nature and effect of the EPA form to the principal
    c. To assess the capacity of the principal to make the EPA
    d. Both a and b
    e. Both b and c
    f. A, b and c

Section 2: The Useability of the EPA

1. In your experience, what issues, if any, have principals had difficulties with in relation to the EPA form? Please select all answers that apply.
    a. The meaning of an instruction or term used on the form
    b. The role of the attorney(s)
    c. When the attorney's power to make decisions regarding financial matters would begin
    d. How to change/revoke the EPA
    e. Other (please specify)_____

2. Please consider the length of the EPA form. In your opinion, the form is:
    a. Too long
    b. An acceptable length

c. Too short

3. Please consider the following statements about how clear the EPA form is and indicate how strongly you agree or disagree with each one. (1 = Strongly agree; 2 = Agree; 3 = Unsure; 4 = Disagree; 5 = Strongly disagree)
    a. It is well presented
    b. I have no problem with the text size or font used
    c. Overall, the language used is simple and easy to follow
    d. The definitions of terms provided are clear and easy to understand
    e. There is an unnecessary amount of legal terminology

4. Question 5 of the EPA form asks when the principal wants the power of attorney for financial matters to begin. If the principal selects 'immediately', when do you think the attorney's power to make decisions under the EPA begins?
    a. Immediately following the completion of the EPA form
    b. Immediately upon the principal losing the capacity to make financial decisions for himself/herself including in an emergency situation such as a car accident
    c. Either a or b
    d. Unsure
    e. Other (please specify) _____

Section 3: EPA Training

1. Please indicate any training you have received specifically on witnessing EPAs.
    a. I have received formal training about witnessing EPAs
    b. I have received information about witnessing EPAs but no formal training (skips to 3)
    c. I have not received any training or information about it (skips to 3)

2. When was the most recent training you received?
    a. Less than 1 year ago
    b. 1 to 5 years ago
    c. More than 5 years ago

3. Do you feel you are adequately prepared in terms of understanding your legal obligations when witnessing EPAs? Please rate your level of preparedness.
    1) Very prepared
    2) Adequately prepared
    3) Unsure
    4) Inadequately prepared
    5) Very unprepared

4. What forms of training on EPAs do you think would be effective for witnesses? Please select all answers that apply.
    a. Specific professional training / seminars
    b. Training DVDs or written information

c. No specific training is needed
d. Other (please specify) _____

Section 4: Experience Witnessing AHDs

1. Have you ever been a witness for the completion of an Advance Health Directive (AHD) form?
    a. Yes
    b. No (skips to section 7)

2. How many years have you been witnessing AHD forms? _____

3. Please estimate how many AHD forms you have witnessed in the past year: _____

4. Compared with previous years, have you been asked to witness more, fewer or about the same number of AHDs over the past year?
    a. More
        iv. Why do you think you are being asked to witness more AHDs? Please give any comments
    b. Fewer
        v. Why do you think you are being asked to witness fewer AHDs? Please give any comments
    c. About the same
    d. Unsure

5. What do you consider to be the role of the witness in relation to AHDs?
    a. To witness the signature of the principal
    b. To explain the nature and likely effect of the AHD form to the principal
    c. To assess the capacity of the principal to make the AHD
    d. Both a and b
    e. Both b and c
    f. A, b and c

Section 5: The Useability of the AHD

1. In your experience, what issues, if any, have principals had difficulties with in relation to the AHD form? Please select all answers that apply.
    a. The meaning of an instruction or term used on the form
    b. The role of the appointed health attorney, if any
    c. How to change/revoke the AHD
    d. The extent to which treating doctors will follow directions in the AHD
    e. Other (please specify)_____

2. Please consider the length of the AHD form. In your opinion, the form is:
    a. Too long
    b. An acceptable length

c. Too short

3. Please consider the following statements about how clear the AHD form is and indicate how strongly you agree or disagree with each one. (1 = Strongly Agree; 2 = Agree; 3 = Unsure; 4 = Disagree; 5 = Strongly Disagree)
    a. It is well presented
    b. I have no problem with the text size or font used
    c. Overall, the language used is simple and easy to follow
    d. The definitions of terms provided are clear and easy to understand
    e. There is an unnecessary amount of medical and legal terminology

Section 6: AHD Training

1. Please indicate any training you have received specifically on witnessing AHDs:
    a. I have received formal training about it
    b. I have received information about it but no formal training (skips to 3)
    c. I have not received any training or information about it (skips to 3)

2. When was the most recent training you received?
    a. Less than 1 year ago
    b. 1 to 5 years ago
    c. More than 5 years ago

3. Do you feel you are adequately prepared in terms of understanding your legal obligations when witnessing AHDs? Please rate your level of preparedness:
    1) Very prepared
    2) Adequately prepared
    3) Unsure
    4) Inadequately prepared
    5) Very unprepared

4. What forms of training on AHDs do you think would be effective for witnesses? Please select all answers that apply.
    a. Specific professional training / seminars
    b. Training DVDs or written information
    c. No specific training is needed
    d. Other (please specify) _____

Section 7: Other Aspects of Witnessing

1. Have you ever been approached to witness an EPA/AHD form by a principal accompanied by one or more other people?
    a. Yes
    b. No (skips to 3)
    c. Unsure (skips to 3)

2. In that situation, have you ever asked to see the principal alone prior to witnessing the form?
    a. Yes
        i. In what circumstances have you asked to see the principal alone? Please select all answers that apply.
            1. I always talk to the principal alone before witnessing an EPA
            2. I always talk to the principal alone before witnessing an AHD
            3. Whenever I am concerned the principal may be vulnerable to pressure to complete the form
            4. Whenever I am doubtful about the principal's capacity
            5. Other (please give any comments) _____
    b. No
    c. Unsure

3. Before you sign the EPA/AHD form as a witness, what steps do you take to ensure that the principal understands the nature and effect of the form? Please select all answers that apply.
    a. We usually discuss the completed form at length
    b. We usually briefly discuss the completed form
    c. We usually talk generally about the nature and effect of the form
    d. I usually ask the principal to explain what the EPA/AHD means
    e. I usually engage the principal in general conversation about current events
    f. Other (please specify) _____

4. In your opinion, is the design and content of the forms helpful for witnesses attempting to ensure the principal understands the nature and effect of EPAs/AHDs?
    a. Strongly agree
    b. Agree
    c. Unsure
    d. Disagree
    e. Strongly disagree

5. Do you think a list of suggested questions for witnesses to ask the principal should be provided?
    a. Yes
    b. No
    c. Unsure

6. If suggested questions were provided, would you prefer them to accompany the form or be included as part of the form?
    a. I would like the questions to be in a separate document/card accompanying the form
    b. I would like the questions to be part of the form itself
    c. Unsure

7. How often have you asked specific questions to determine the capacity of the person completing the EPA/AHD?
    a. Always (skips to 9)
    b. Sometimes
    c. Never

8. Please indicate reasons why you have not at least in some cases asked specific questions to determine a principal's capacity:
    a. I knew the principal well
    b. Someone else had done a recent assessment of capacity
    c. I was not given any reason to doubt the principal's capacity
    d. Other (please specify) _____

9. Have you read any of the following guidelines? Please select all answers that apply.
    a. Office of the Adult Guardian's 'Capacity guidelines for witnesses of Enduring Powers of Attorney'
    b. Queensland Law Society's 'Guide for EPA witnesses'
    c. Department of Justice and Attorney-General's Bulletin 'Witnessing Enduring Powers of Attorney (EPA) and Advance Health Directive (AHD) documents'
    d. Section of 'Duties of Justices of the Peace (Qualified)' manual relating to witnessing EPAs and AHDs
    e. Section of 'Administrative Duties of Commissioners for Declarations' manual relating to witnessing EPAs and AHDs
    f. None of the above (skips to 13)
    g. Unsure (skips to 13)

10. Have you used or drawn from the suggested questions in any of the following guidelines to assess capacity? Please select all answers that apply.
    a. Office of the Adult Guardian's 'Capacity guidelines for witnesses of Enduring Powers of Attorney'
    b. Queensland Law Society's 'Guide for EPA witnesses'
    c. Department of Justice and Attorney-General's Bulletin 'Witnessing Enduring Powers of Attorney (EPA) and Advance Health Directive (AHD) documents'
    d. None of the above
    e. Unsure

11. Please consider the length of these guidelines. Are they:
    a. Too long
    b. An acceptable length
    c. Too short

12. Are there any other changes you would like to see to these guidelines? Please give any comments: _____

13. Have you referred to any other guidelines or suggested questions to assist you with assessing the capacity of the person completing the EPA/AHD?
    a. Yes
        i. Please give details: _____
    b. No
    c. Unsure

14. Do you find it straightforward to determine whether a principal has capacity?
    a. Always
    b. Usually
    c. Sometimes
    d. Never

15. How would you usually respond to a request to witness an EPA/AHD form if you were doubtful about the capacity of the principal?
    a. I would consider asking for an independent assessment
    b. I would refuse to witness the form
    c. I would witness the form and keep notes of the conversation
    d. Unsure
    e. Other (please specify) _____

16. Have you ever asked for an independent assessment of the capacity of the principal?
    a. Yes
        i. Please briefly outline the circumstances
        _____
    b. No

17. Have you ever declined to witness an EPA/AHD because you believed the person did not have capacity to complete the form?
    a. Yes
    b. No
    c. Unsure

18. Do you keep records if you decline to witness an EPA/AHD for any reason?
    a. Yes
    b. I would, but I have not yet declined to witness one
    c. No
    d. Unsure

19. Would you like to see more information in the form about your responsibility to keep records?
    a. Yes
    b. No
    c. Unsure

20. Is there anything that could be provided to assist witnesses in keeping records of the witnessing proceedings? Please give any comments _____

Section 8: Personal Information

What type of witness are you?

a. Justice of the peace
b. Commissioner for declarations
c. Lawyer
d. Notary public

What is your gender identity? 1 Male
2 Female

From your postcode, we hope to pick up what type of region you live in (e.g. rural, provincial, outer suburban, city). Please type in the postcode of your current residence: _____

Are you Aboriginal or Torres Strait Islander?

c. Yes → Please choose the specific group you identify with:
   i. Aboriginal
   ii. Torres Strait Islander
   iii. Aboriginal and Torres Strait Islander
d. No

Please select your country of birth: (drop down box)

Is English your first language? Yes / No

What is your current age? _____

What is your highest completed level of education?

1. Postgraduate
2. Undergraduate
3. High school
4. Primary school

Do you have a financial/accounting background?

1. Yes
2. No

Are you currently practising medicine or do you have a background in a health profession?

1. Yes
2. No

Do you have any experience with EPAs/AHDs in another capacity apart from being a witness?

a. Yes

→ Please select all answers that apply:

   i. I have completed an EPA/AHD for myself
   ii. I have been appointed as an attorney under an EPA/AHD
   iii. Other (please specify) _____

b. No

We would like to thank you for taking the time to complete this survey. When the results are finalised, a summary of outcomes will be made available to those who express interest in this research by contacting the University of Queensland – School of Social Work and Human Services.

Appendix C4: Survey for Principals – AHDs

Please note: These surveys should not be reproduced and used without permission from the research team.

ABOUT THIS SURVEY
The Advance Health Directive (AHD) is an important tool for future health planning and the Queensland community as a whole. Your completion of this survey will provide valuable feedback about the current AHD form and help the research team make recommendations to the Queensland Government about the usefulness of the form.

A BRIEF SURVEY OPEN UNTIL 28 FEBRUARY
The survey will take about 10-15 minutes to complete. We have spent a lot of time thinking about the questions that we want to ask you and we hope you will find it easy to finish.

SURVEY REQUIREMENTS
Most are multiple choice questions (simply select your answer or more than one if applicable). For one or two questions you type in what you want to tell us. For most of the multiple choice questions, you must select a response in order to continue.
Surveys aren't perfect. Sometimes the answers presented might not exactly match your situation. When that happens, please select the one that is the best fit for you or leave it blank if possible.

ETHICAL CONDUCT OF RESEARCH
The University of Queensland conducts research in accordance with the National Statement on Ethical Conduct in Research Involving Humans. If potential respondents have any concerns or complaints about the ethical conduct of this research project, please contact the UQ Ethics Officer on (07) 3365 3924.

CONFIDENTIALITY AND ANONYMITY
All answers provided will remain confidential. We are not asking you for your name or other information that could identify you. The survey results will be collated before being published.

DIFFICULTIES?
If you have received this survey on your work email, and you encounter any difficulties completing it, try forwarding it to your home email address.
If you have any problems with this survey, please contact Angela Setterlund: a.setterlund@uq.edu.au.

---

1. Have you completed an Advanced Health Directive (AHD)?

    i. Yes →(skips to section 1)
    ii. No

a. We are interested in why people do not complete AHDs. Please indicate which reason best represents why you have not completed one:
    i. I would not consider completing an AHD as I do not like the concept (survey ends)
    ii. I might consider completing one, but have not yet obtained a form
    iii. I decided not to complete one after looking at the form (skips to c)

b. Please select all relevant reasons why you have never obtained a form:
    i. I did not know where to get a form
    ii. I could not download the form from the internet
    iii. My local newsagent / post office did not have any in stock
    iv. I did not want to pay for a form

(survey ends)

c. Please indicate all of the reasons below that contributed to your decision not to complete the form:
    i. It was hard to follow what the instructions meant overall
    ii. I had trouble understanding the medical terminology
    iii. I felt uncomfortable with the serious nature of the decisions I was making
    iv. I found a lot of the form to be unnecessary
    v. I felt uncomfortable answering some of the questions in the form
    vi. The form was too long
    vii. Other (please give details) _____

(This concludes the survey for the 'no' respondents from Question 1.)

Section 1: Completing and Storing Your AHD

1. When did you complete your most recent AHD?
    a. Less than 1 year ago
    b. 1 to 2 years ago
    c. 3 to 5 years ago
    d. More than 5 years ago

2. How did you access your AHD form?
    a. Post office or newsagent
    b. Lawyer
    c. Doctor
    d. Downloaded the form from the internet
    e. Other (please specify) _____

3. Did you obtain legal assistance to help you complete the AHD form?
    a. Yes
    b. No

4. Your AHD was witnessed by two people: a doctor and an independent witness who was either a justice of the peace, commissioner for declarations, lawyer or notary public. The next two questions refer to the independent witness, rather than the doctor.

   Did you discuss the form with the independent witness before he/she witnessed your signature on it? Please select all answers that apply.
   a. Yes, we discussed the completed form at length
   b. Yes, we briefly discussed the completed form
   c. Yes, we talked generally about the nature and likely effect of the form
   d. No, the witness simply witnessed my signature

5. Did the independent witness clarify any parts of the form you had difficulty understanding?
   a. Yes
   b. No
   c. Unsure

6. When completing your AHD, how many times did you visit your doctor to discuss the AHD or get their signature?
   a. Once
   b. Twice
   c. More than twice

7. Did you discuss the form with the doctor before he/she signed it? Please select all answers that apply.
   a. Yes, we discussed the completed form at length
   b. Yes, we briefly discussed the completed form
   c. Yes, we talked generally about the nature and likely effect of the form
   d. No, my doctor simply signed the form

8. Where are copies of your AHD currently located? Please select all answers that apply.
   a. With my doctor
   b. With a family member / friend
   c. With a solicitor
   d. At home in a safe
   e. At home in another location
   f. Other (please specify) _____

9. Are you confident that your AHD will be easily accessed when it is needed?
   a. Yes
   b. No
   c. Unsure

   Why/why not? Please give any comments: _____

10. Which of the following would you like to see implemented to help ensure the AHD can be easily accessed when needed? Please select all answers that apply.
    a. Providing a wallet card with the form, advising that an AHD has been completed and its location
    b. Making an electronic version of your completed form accessible to any registered health professional through a database
    c. Neither of the above
    d. Other (please specify) _____

Section 2: Advance Health Directive Information

1. The AHD includes three pages of 'explanatory notes' at the beginning of the form. These explanatory notes are designed to provide information and advice to the person completing the form. Did you read the explanatory notes BEFORE completing the AHD?
    i. Yes → (skips to 2)
    ii. No
    iii. Unsure (skips to 6)

    a. Please indicate which of the following options best describes your reason for NOT reading the explanatory notes:
        i. My lawyer helped me complete the form and explained everything to me
        ii. The form was self explanatory
        iii. The information was too long
        iv. The information was too difficult to understand
        v. Other (please give comments) _____

    (skips to 6)

2. The explanatory notes were straightforward and easy to understand
    (Strongly agree/Agree/Unsure/Disagree/Strongly disagree)

3. All of the information provided in the explanatory notes was useful
    (Strongly agree/Agree/Unsure/Disagree/Strongly disagree)

4. The explanatory notes provided me with all of the information I wanted to know
    (Strongly agree/Agree/Unsure/Disagree/Strongly disagree)

5. I would have liked more examples to help me understand the matters discussed
    (Strongly agree/Agree/Unsure/Disagree/Strongly disagree)

6. Since completing your AHD, have you ever referred back to the explanatory notes on your form?
    Yes → Did the explanatory notes sufficiently provide you with the information you were looking for?
    Yes
    No → What did you feel was missing from the explanatory notes?

No

7. Would you prefer to have the explanatory notes separated from the form and placed in a separate information booklet that accompanies the form?
    a. Yes
    b. No
    c. Unsure

8. If further information was provided, what information would you like it to include? Please indicate the level of importance these options are to you (1 = Very important; 2 = Important; 3 = Unsure; 4 = Unimportant; 5 = Very unimportant)
    a. Further guiding instructions to help you complete the form
    b. What to do with the form once it's complete
    c. Who to contact if you require further information
    d. Whether your AHD will be recognised if you travel interstate or overseas
    e. Advice on discussing your AHD with your family
    f. When and how your AHD will come into effect
    g. More information about what care and treatment may be provided in specific situations to help you decide what directions to give
    h. The legal responsibilities of the doctors to follow your written directions
    i. Other (please specify) _____

9. The current AHD form does not explain that doctors may choose not to follow an instruction in the AHD if they felt the instruction was inconsistent with good medical practice. Do you think such an explanation would be useful?
    a. Yes
        i. Why? Please give any comments _____
    b. No
        i. Why not? Please give any comments _____
    c. Unsure

10. Before, during or after completing your AHD, did you talk to any organisation (other than your lawyer's or doctor's office) to seek further information?
        1. Yes – before completing my AHD
        2. Yes – while I was completing my AHD
        3. Yes – after I had completed my AHD
        4. No (skips to 11)

    a. What did you ask about? Please select all answers that apply.
        i. Where to get a copy of the form
        ii. The meaning of an instruction or term used on the form
        iii. The role of your appointed health attorney, if any
        iv. Revoking or changing your AHD

v. The legal obligation/s of your treating doctor/s to follow the directions in your AHD
vi. Other (please specify) _____

11. Before, during or after completing your AHD, did you seek further information material (such as information available on the internet or in information booklets)?
    1. Yes – before completing my AHD
    2. Yes – while I was completing my AHD
    3. Yes – after I had completed my AHD
    4. No (skips to Section 3)

12. Were you successful in finding further information materials?
    1. Yes
    2. No (skips to Section 3)

13. Were any of the information materials you accessed from the Department of Justice and Attorney General (including the Office of the Adult Guardian)?
    a. Yes → Was the information provided by the Department of Justice and Attorney General (including the Office of the Adult Guardian) useful?
        i. Yes
        ii. Somewhat useful
        iii. No
    b. No
    c. Unsure

Section 3: The Useability of the Advance Health Directive

1. In your opinion, how easy was the AHD form to complete?
    a. Very easy
    b. Easy
    c. Neither easy nor difficult
    d. Difficult
    e. Very difficult

2. The current AHD form usually defines an unfamiliar term (such as a medical or legal term) when it first appears in the document. This means that terms and definitions are spread throughout the form.

   Are you satisfied with the current placement of terms and definitions in the form or would you like to see a glossary where all terms and definitions are listed together?
    i. I would like a glossary of terms and conditions
    ii. No glossary necessary – I am happy with the form the way it is (skips to 3)

    a. If a glossary was provided, would you still want definitions of terms throughout the form as well?

i. Yes, I would prefer to have terms defined where they are first used in the form AND placed in a glossary
ii. No, I would prefer all the definitions currently spread throughout the form to be moved into a glossary instead

b. If a glossary was provided, would you prefer it to accompany the form or be included as part of the form?
    i. I would like the glossary to be a separate document accompanying the form
    ii. I would like the glossary to be part of the form itself

3. Please consider the length of the form. In your opinion, the form is:
    a. Too long
    b. An acceptable length
    c. Too short

4. Please consider the following statements about how clear the form is and indicate how strongly you agree or disagree with each one. (1 = Strongly agree; 2 = Agree; 3 = Unsure; 4 = Disagree; 5 = Strongly disagree)

    a. It is well presented
    b. The questions are in logical order, easily flowing from one to the next
    c. I had no problem with the text size or font used
    d. The questions asked were too repetitive
    e. Overall, the language used was simple and easy to follow
    f. There was an unnecessary amount of medical and legal terminology
    g. The definitions of terms provided were clear and easy to understand
    h. The instructions for completing the form were confusing

5. Please consider the following statements about your experience of completing the form and indicate how strongly you agree or disagree with each one. (1 = Strongly agree; 2 = Agree; 3 = Unsure; 4 = Disagree; 5 = Strongly disagree)
    a. I found it difficult to complete the form because of the nature of the decisions being made
    b. The form design was flexible allowing me to state my wishes as I wanted to
    c. There was sufficient space provided for me to state my wishes

6. The AHD gives you the option of appointing an attorney for personal/health matters. You may also have completed an Enduring Power of Attorney (EPA) form, which also allows you to appoint an attorney for personal/health matters.

    Have you appointed a personal/health attorney in the AHD or in an EPA form?
    a. Yes
    b. No (skips to section 4)
    c. Unsure (skips to section 4)

7. Did you appoint a personal/health attorney in the AHD, in an EPA form or both?
    a. In the AHD only (skips to section 4)
    b. In an EPA form only (skips to section 4)
    c. In both documents

8. Did you appoint the same attorney in both documents?
    a. Yes (skips to section 4)
    b. No, I appointed a different attorney in each document
        i. Are you aware that appointing an attorney in a later document may revoke the earlier appointment of an attorney?
            4. Yes
            5. No
            6. Unsure
    c. Unsure (skips to section 4)

Section 4: The Purpose of Your AHD

The following questions ask you to consider the purpose of the completed AHD.

1. What was your motivation for completing an AHD? Please select any of the following reasons behind your decision:
    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 want 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. Thinking about your completed AHD, how clearly does it reflect your goals for your future health care? (1 = Very clearly; 2 = Clearly; 3 = Unsure; 4 = Unclearly; 5 = Very unclearly)

3. Did you have any serious pre-existing illness and/or disability when you completed your AHD? (please note: disability such as para- or quadriplegia, cerebral palsy, etc.; debilitating illness such as multiple sclerosis, cancer, kidney disease, etc.)
    a. Yes
    b. No (skips to 5)

4. Would you prefer to have two separate AHD forms, one for completion by a person with a serious pre-existing illness and/or disability and one for completion by a person who is not in that position?
    a. Yes
    b. No
    c. Unsure

5. The current AHD form asks you whether or not you consent to tissue and organ donation. How important is it to you that this section is included within your AHD? (1 = Very important; 2 = Important; 3 = Unsure; 4 = Unimportant; 5 = Very unimportant)

6. How do you expect your treating doctors to respond to your AHD form?
    a. I expect treating doctors to follow my AHD exactly
    b. For treating doctors, I expect my AHD to serve only as a guide to how I wish to be treated

7. How effectively do you think your written directions in your AHD are communicated to your treating doctors? (1 = Very effectively; 2 = Effectively; 3 = Unsure; 4 = Ineffectively; 5 = Very ineffectively)

8. Your AHD provides directions to your treating doctors. Did you also write your AHD intending it to communicate your wishes to family or friends who might be involved in decision making?
    a. Yes, I wrote my AHD partly with my family or friends in mind
    b. No (skips to 11)

9. When you decided to complete an AHD, who did you PRIMARILY intend to communicate your future health care decisions to?
    a. My treating doctors
    b. My family or friends
    c. Both a and b equally

10. How effectively do you think your written directions in your AHD are communicated to family or friends? (1 = Very effectively; 2 = Effectively; 3 = Unsure; 4 = Ineffectively; 5 = Very ineffectively)

11. To what extent have you discussed the directions in your AHD form with your family or friends?
    a. I have not discussed my AHD with anyone
    b. I have not discussed my AHD with anyone other than my doctor
    c. I have told family or friends that I have an AHD but not discussed it at length
    d. I have fully discussed my AHD with family or friends at length

12. Did any discussions with your family or friends influence how you completed the form?
    a. Yes

b. Somewhat
c. No

13. In your opinion, how important is discussing your AHD with your family or friends? (1 = Very important; 2 = Important; 3 = Unsure; 4 = Unimportant; 5 = Very unimportant)

Section 5: End of Life Decision Making

QUALITY OF LIFE OUTCOMES

This survey refers to your 'quality of life outcomes', which means any statement in your AHD that indicates what quality of life is acceptable to you and what your goals are for your end of life care.

Your acceptable quality of life is the level of independence, social capabilities, and emotional and physical well being that is acceptable to you.

In stating or indicating what your quality of life outcomes are, you are giving guidance about whether or not you want life sustaining treatment based on what your treating doctors believe the likely outcome will be. Your quality of life outcomes may be that you value life in all circumstances, regardless of its quality and would not want treatment to be withheld or withdrawn.

SPECIFIC MEDICAL TREATMENTS

This survey also asks you to consider 'specific medical treatments'. 'Specific medical treatments' refer to any part of your AHD where you make a decision about whether you want particular treatment or not (such as cardiopulmonary resuscitation or assisted ventilation) in some or all circumstances.

An AHD can be used to give general guidance as to 'quality of life outcomes' or it can make decisions about 'specific medical treatments', or it can do both. Doctors probably have more discretion about treatment where the AHD contains general guidance as to quality of life outcomes than if the AHD contains decisions about specific medical treatments.

Please answer the following questions keeping these concepts in mind.

1. In your opinion, should the AHD form give you the opportunity to describe the quality of life you consider unacceptable such that you would like life-sustaining treatment stopped?
    a. Yes
    b. No (skips to 3)
    c. Unsure (skips to 3)

2. Would you prefer to be able to write your own statement about your quality of life outcomes or choose from a list of predefined quality of life outcomes?
    a. Write your own
    b. Choose from a list

c. Both

3. Do you think there is enough, too much or not enough detail provided in the AHD form for you to specify medical treatments you want / do not want at the end of life?
    a. I am happy with the current amount of detail
    b. Too much detail
    c. Not enough detail
    d. Unsure

4. Rather than listing specific medical treatments you do want or do not want, would you prefer to simply indicate whether you do / do not want life-sustaining treatment generally in particular situations?
    a. Strongly agree
    b. Agree
    c. Unsure
    d. Disagree
    e. Strongly disagree

5. The current AHD form asks you to indicate whether you do/do not want the following medical treatments in certain situations:
    - Cardiopulmonary resuscitation
    - Assisted ventilation
    - Artificial hydration
    - Artificial nutrition
    - Antibiotics

    Sometimes people completing the form refuse these treatments in general terms.

    In your opinion, should the AHD form give you the opportunity to consider whether these treatments would be acceptable to you in a palliative context?
    a. Yes
    b. No
    c. Unsure

6. Do you think the AHD should allow people in palliative care outside of a hospital or residing in a nursing home to clearly indicate that they wish to stay where they are (and just receive palliative care there) rather than be admitted to hospital?
    a. Yes
    b. No
    c. Unsure

7. What did you find easier writing in your AHD form? Please select the response that best represents your opinion.
    a. Statements about what quality of life outcomes are acceptable or unacceptable to me
    b. Statements about what specific medical treatments I do or do not want

c. A and b equally
d. None of the above

8. What type of statements do you think will most help doctors follow your AHD? Please select the response below that best represents your opinion.
    a. Statements about what quality of life outcomes are acceptable or unacceptable to me
    b. Statements about what specific medical treatments I do or do not want
    c. A and b equally
    d. None of the above

9. What approach do you think will be more helpful for your family and/or friends?
    a. Statements about what quality of life outcomes are acceptable or unacceptable to me
    b. Statements about what specific medical treatments I do or do not want
    c. A and b equally
    d. None of the above

Section 6: Reviewing Your AHD

1. Have you ever reviewed your AHD form?
    a. Yes, and I signed and dated the back page to indicate I had done so
    b. Yes, without signing and dating the back page to indicate I had done so
    c. No

Section 7: Personal Information

What is your gender identity?
    a. Male
    b. Female

From your postcode, we hope to pick up what type of region you live in (e.g. rural, provincial, outer suburban, city). Please type in the postcode of your current residence: _____

What is your current relationship status?
a. Single
b. Married / with partner
c. Widowed

Do you have any children over 18 years?
    a. Yes
    b. No

Are you Aboriginal and/or Torres Strait Islander?
    Yes → Please choose the specific group you identify with:
        a. Aboriginal

b. Torres Strait Islander
c. Aboriginal and Torres Strait Islander

No

Please select your country of birth: (drop down box)

Is English your first language? Yes / No

What is your current age? _____

What is your highest completed level of education?

1. Postgraduate
2. Undergraduate
3. High School
4. PrimarySchool

Are you currently practising medicine or do you have a background in a health profession?

1. Yes
2. No

Are you currently practising law or do you have a legal background?

1. Yes
2. No

Do you have any experience with AHDs in another capacity apart from completing one yourself?

b. Yes

→ Please select all answers that apply:

i. I have been appointed as an attorney under an AHD
ii. I have signed an AHD as a witness
iii. Other (please specify) _____

c. No

We would like to thank you for taking the time to complete this survey. When the results are finalised a summary of outcomes will be made available to those who are interested in this research by contacting the University of Queensland – School of Social Work and Human Services.

Appendix C5: Survey for Nominated and Treating Doctors – AHDs

Please note: These surveys should not be reproduced and used without permission from the research team.

ABOUT THIS SURVEY
The Advance Health Directive (AHD) provides a mechanism for people to participate in advance care planning and discussion about their future health care. We are interested in your opinion and experiences of AHDs as a doctor.
We use the term 'nominated doctors' to refer to doctors involved in the execution of the AHD, while 'treating doctors' are those doctors implementing AHDs of patients they are treating.
Your completion of this survey will provide valuable feedback about the current AHD form and help the research team make recommendations to the Queensland Government about the usefulness of the form.

A BRIEF SURVEY OPEN UNTIL 28 FEBRUARY
The survey will take about 10-15 minutes to complete. Most questions are multiple choice, while a few are open ended. For most of the multiple-choice questions, you must select a response in order to continue.

ETHICAL CONDUCT OF RESEARCH
The University of Queensland conducts research in accordance with the National Statement on Ethical Conduct in Research Involving Humans. If potential respondents have any concerns or complaints about the ethical conduct of this research project, please contact the UQ Ethics Officer on (07) 3365 3924.

CONFIDENTIALITY AND ANONYMITY
All answers provided will remain confidential. We are not asking you for your name or other information that could identify you. The survey results will be collated before being published.

DIFFICULTIES?
If you received this survey on your work email, and you encounter any difficulties completing it, try forwarding it to your home email address.
If you have any problems with this survey, please contact Angela Setterlund: a.setterlund@uq.edu.au.

Section 1: Your Experiences with the AHD Form as a Nominated Doctor

1.Have you ever signed an AHD for a patient as the nominated doctor?
   a. Yes
   b. No (skips to section 2)

2. In the past year, approximately how many AHDs have you signed for patients as the nominated doctor?

a. 5 or fewer
b. 6 to 10
c. 11 to 20
d. More than 20

3. What do you consider to be the role of the nominated doctor?
    a. To witness the signature of the patient
    b. To explain the nature and likely effect of the AHD form to the patient
    c. To assess the capacity of the patient to make the AHD
    d. Both a and b
    e. Both b and c
    f. A, b and c

4. When acting as the nominated doctor, how often have you undertaken a specific assessment of the capacity of the patient(s) completing the AHD?
    a. Always (skips to 8)
    b. Sometimes
    c. Never (skips to 7)

5. Have you referred to guidelines or suggested questions (such as from AMA or GP Partners) to assist you?
    a. Yes
        i. Please give details: _____
    b. No

6. Please indicate reasons why you have sometimes not undertaken a specific assessment of a patient's capacity.
    a. I knew the patient well
    b. Someone else had done a recent assessment of capacity
    c. I was not given any reason to doubt their capacity
    d. I do not see it as my role as the nominated doctor on the AHD form to assess capacity
    e. Other (please specify) _____

    (skips to 9)
7. Please indicate reasons why you have not undertaken a specific assessment of a patient's capacity.
    a. I knew the patient well
    b. Someone else had done a recent assessment of capacity
    c. I was not given any reason to doubt their capacity
    d. I do not see it as my role as the nominated doctor on the AHD form to assess capacity
    e. Other (please specify) _____

    (skips to 9)
8. Have you referred to guidelines or suggested questions (such as from AMA or GP Partners) to assist you?

a. Yes
    i. Please give details: _____
b. No

9. On average, how many consultations do you have with a patient concerning his/her AHD?
    a. One
    b. Two
    c. More than two

10. Do you usually discuss the form with the patient before signing it? Please select all answers that apply.
    a. Yes, we usually discuss the completed form at length
    b. Yes, we usually briefly discuss the completed form
    c. Yes, we usually talk generally about the nature and likely effect of the form
    d. No, I usually simply sign the form

11. Would you support doctors' consultations with patients about their AHD becoming a Medicare item?
    a. Yes
        i. Why? Please give any comments: _____
    b. No
        i. Why not? Please give any comments: _____

12. What issues have patients raised with you in relation to the form? Please select all answers that apply.
    a. Where to get a copy of the form
    b. The meaning of an instruction or term used on the form
    c. The role of the appointed health attorney, if any
    d. How to change/revoke the AHD
    e. The extent to which treating doctor/s will follow the directions in the AHD
    f. The implications of specifying particular medical treatments they do or do not want
    g. What happens with the form after completion, including how it is accessed by treating doctors
    h. The 'general instructions' section of the AHD (that will apply in any circumstance)
    i. What to write in the 'personal statement'
    j. Other (please specify)_____

13. Do you routinely recommend to patients that they consider completing an AHD?
    a. Yes
    b. No
        i. Why not? Please give any comments _____

14. Would you recommend the current AHD form to some or all of your patients?
    a. Yes
        i. Why or when would you recommend an AHD to a patient? Please select all answers that apply.
            1. If the patient had reached a certain age
            2. If the patient had a serious pre-existing illness and/or disability
            3. Other (please give any comments) _____
    b. No
        i. Why not? Please select all answers that apply.
            1. I don't see the form as important
            2. I don't see it as my role to recommend the AHD form to patients
            3. Other (please give any comments) _____

Section 2: The Purpose of AHDs

QUALITY OF LIFE OUTCOMES

This survey refers to 'quality of life outcomes', which means any statement in the AHD that indicates what quality of life is acceptable to the patient and what his or her goals are for his or her end of life care. The patient's acceptable quality of life is the level of independence, social capabilities, and emotional and physical well being that is acceptable to him or her.

In stating or indicating what the patient's quality of life outcomes are, he or she gives guidance about whether or not he or she wants life-sustaining treatment based on what treating doctors believe the likely outcome will be. A patient's quality of life outcomes may be that he or she values life in all circumstances, regardless of its quality and would not want treatment to be withheld or withdrawn.

SPECIFIC MEDICAL TREATMENTS

This survey also asks you to consider 'specific medical treatments'. 'Specific medical treatments' refer to any part of the AHD where the patient makes a decision about whether he or she wants particular treatment or not (such as cardiopulmonary resuscitation or assisted ventilation) in some or all circumstances.

An AHD can be used to give general guidance as to 'quality of life outcomes', make decisions about 'specific medical treatments', or do both. Doctors probably have more discretion about treatment where the AHD contains general guidance as to quality of life outcomes than if the AHD contains decisions about specific medical treatments.

Please answer the following questions keeping these concepts in mind.

2. The current AHD form asks the person completing it to indicate whether they do/do not want the following medical treatments in certain situations:
    - Cardiopulmonary resuscitation
    - Assisted ventilation
    - Artificial hydration

- Artificial nutrition
- Antibiotics

Sometimes patients refuse these treatments in general terms. Would it be helpful for the form to allow them to consider whether these treatments would be acceptable to them in a palliative context?

a. Yes
b. No
c. Unsure

3. Rather than listing specific medical treatments they want or do not want, do you think the patient should simply indicate whether they do / do not want life-sustaining treatments generally in particular situations?
    a. Strongly agree
    b. Agree
    c. Unsure
    d. Disagree
    e. Strongly disagree

4. In your opinion, should the AHD form give a patient the opportunity to describe the quality of life he/she considers unacceptable such that he/she would like life-sustaining treatment stopped?
    a. Yes
    b. No (skips to 5)
    c. Unsure (skips to 5)

5. Would you prefer patients to be able to write their own statements about their quality of life outcomes or choose from a list of predefined quality of life outcomes?
    a. Write their own
    b. Choose from a list
    c. Both

6. Do you think there is enough, too much or not enough detail provided in the AHD form for patients to specify medical treatments they want / do not want at the end of their lives?
    a. I am happy with the current amount of detail
    b. Too much detail
    c. Not enough detail
    d. Unsure

7. Do you think the form provides enough information about what care and treatment may be provided in specific situations to help patients decide what directions to give?
    a. Yes
    b. No
    c. Unsure

8. Do you think the AHD should allow people in palliative care outside of a hospital or residing in a nursing home to clearly indicate that they wish to stay where they are (and just receive palliative care there) rather than be admitted to hospital?
    a. Yes
    b. No
    c. Unsure

9. Would you prefer to have two separate AHD forms, one for completion by a person with a serious pre-existing illness and/or disability and one for completion by a person who is not in that position?
    a. Yes
    b. No
    c. Unsure

10. In your opinion, is it important to include questions concerning tissue donation in the AHD?
    a. Very important
    b. Important
    c. Unsure
    d. Unimportant
    e. Very unimportant

11. Have you ever consulted the AHD form of a patient you are treating?
    a. Yes
    b. No (skips to section 4)

12. What type of statements do you think most help you follow the AHD as a treating doctor? Please select the response below that best represents your opinion.
    a. Statements about what quality of life outcomes are acceptable or unacceptable to the patient
    b. Statements about what specific medical treatments the patient does or does not want
    c. A and b equally
    d. None of the above
13. How do you implement the AHD form as a treating doctor?
    a. I follow the AHD exactly
    b. I use the AHD form only as a guide to how the patient wishes to be treated
    c. Other (please give any comments) _____

Section 3: Your Experiences with the AHD Form as a Treating Doctor

1. In the past year, approximately how many patients with AHDs have you treated?
    a. 5 or fewer
    b. 6 to 10
    c. 11 to 20

d. More than 20

2. Overall, how helpful do you think an AHD is for managing the care and treatment of a patient?
    a. Very helpful
    b. Helpful
    c. Unsure
    d. Somewhat unhelpful
    e. Veryunhelpful

3. In which one of the following ways do you think the AHD is MOST HELPFUL in managing the care and treatment of a patient?
    a. Understanding the patient's attitudes, values and goals concerning end-of-life care
    b. Making decisions about specific medical treatments
    c. Alerting to any allergies, conditions, or religious beliefs that may affect treatment options
    d. Other (please specify)
    _____

4. In what ways or situations have you found the AHD to be unhelpful in managing the care and treatment of a patient? Please select all answers that apply.
    a. Unclear attitudes, values and goals
    b. Contradictory decisions concerning specific medical treatments
    c. The structure and/or design of the document makes it difficult to find vital information
    d. Requests treatment that doctors are not offering
    e. Refuses treatment that is indicated by good medical practice
    f. Other (please specify)
    _____

5. Overall, how helpful have you found an AHD in discussing a patient's preferences with their family or friends?
    a. Very helpful
    b. Helpful
    c. Unsure
    d. Somewhat unhelpful
    e. Very unhelpful

6. Have you ever been involved in a situation where you were not sure what the patient intended by the written directions in their AHD?
    a. Yes
    b. No

7. Have family or friends of the patient ever helped you interpret written directions in an AHD?

a. Yes
b. No
c. Unsure

8. As a treating doctor, how have you been made aware that a patient has an AHD? Please select all answers that apply.
    a. A patient verbally informing hospital staff on admission
    b. Hospital admission forms completed by the patient
    c. A patient's medical records
    d. A partner or family member informs staff
    e. Asking the patient's GP
    f. Other (please specify) _____

9. Would it be useful if there was an electronic version of the form that you could access when needed?
    a. Yes → Please select any of the following options you think would be useful for accessing an electronic version:
        i. An on-line database
        ii. A shared electronic health record
        iii. From the patient (on a disk/USB stick/email)
    b. No

10. Would you take into account an interstate or overseas AHD if one was presented at the time of treatment?
    a. Yes
    b. No
    c. Unsure

Section 4: The Useability of the AHD Form

1. The AHD form includes three pages of 'explanatory notes' at the beginning. These explanatory notes are designed to provide information and advice to the person completing the form.

Would you prefer to have the explanatory notes separated from the form and placed in a separate information booklet accompanying the form?

    a. Yes
    b. No
    c. Unsure

2. Please indicate your opinion on the length of the AHD form:
    a. Too short
    b. An acceptable length
    c. Too long

3. Please consider the following statements about how clear the form is and indicate how strongly you agree or disagree with each one. (1 = Strongly agree; 2 = Agree; 3 = Unsure; 4 = Disagree; 5 = Strongly disagree)
    a. It is well presented
    b. The questions are in logical order, easily flowing from one to the next
    c. The questions asked are too repetitive
    d. Overall, the language used is simple and easy to follow
    e. The definitions of terms provided are accurate and clear

4. The form currently asks the patient about treatment in each of the following four situations:
    a. 'If I am in the terminal phase of an incurable illness'.
    b. 'If I am permanently unconscious (in a coma)'
    c. 'If I am in a persistent vegetative state'
    d. 'If I am so seriously ill or injured that I am unlikely to recover to the extent that I can live without the use of life-sustaining measures'

    We are interested in whether you find these four categories appropriate and useful for understanding and implementing the patient's wishes. Please comment on the clarity or appropriateness of each category and any changes you would like to see to the terminology

    _____

5. The current AHD form does not explain to the person completing it that treating doctors may choose not to follow an instruction in the AHD if they felt the instruction was inconsistent with good medical practice. Do you think such an explanation would be useful?
    a. Yes
        a. Why? Please give any comments _____
    a. No
        b. Why not? Please select all answers that apply.
            i. It would not be relevant to the patient
            ii. It would be too confusing for the patient
            iii. Other (please give comments) _____

Section 5: AHD Training

1. As a medical professional, please indicate any training you have received specifically on the AHD.
    a. I have received formal training about the AHD
    b. I have received information about best practice concerning the AHD but no formal training (skips to 3)
    c. I have not received any training or information about it (skips to 3)
    d. Other (please specify) _____

2. When was the most recent training you received?
    a. Less than 1 year ago
    b. 1 to 5 years ago

c. More than 5 years ago

3. As a medical professional, do you feel you are adequately prepared in terms of understanding your legal obligations WHEN DEALING WITH THE COMPLETION OF AHDS? Please rate your level of preparedness.
   1 = Very prepared
   2 = Adequately prepared
   3 = Unsure
   4 = Inadequately prepared
   5 = Very unprepared
   6 = Not applicable as I am not involved in the completion of AHDs as a nominated doctor

4. As a medical professional, do you feel you are adequately prepared in terms of understanding your legal obligations WHEN TREATING PATIENTS WITH AHDS? Please rate your level of preparedness.
   1 = Very prepared
   2 = Adequately prepared
   3 = Unsure
   4 = Inadequately prepared
   5 = Very unprepared
   6 = Not applicable as I am not involved in treating patients with AHDs

5. What forms of training on AHDs do you think would be effective for doctors? Please select all answers that apply.
   a. Specific professional training / seminars
   b. Training DVDs or written information
   c. No training is needed
   d. Other (please specify) _____

Section 6: Personal Background

What is your gender identity? Male / Female

What is your current age? _____

From the postcode of your hospital or practice, we hope to pick up what type of region it is in (e.g. rural, provincial, outer suburban, city). Please type in the postcode: _____

Number of years as a doctor 5 years or fewer
6 to 10 years
11 to 20 years
Over 20 years

Do you have any experience with AHDs in another capacity apart from being a nominated or treating doctor?

d. Yes

→ Please select all answers that apply:

i. I have completed an AHD for myself
ii. I have been appointed as an attorney under an AHD

iii. Other (please specify) _____

e. No

We would like to thank you for taking the time to complete this survey. When results are finalised a summary of outcomes will be made available to those who express interest by contacting the University of Queensland – School of Social Work and Human Services.

Appendix D: Detailed Comments from Aboriginal and Torres Strait Islander Respondents on EPAs and AHDs

Included in this appendix are the individual views of ATSI respondents expressed in their own words.

Enduring Power of Attorney: Torres Strait Islanders

ENDURING POWER OF ATTORNEY Short Form *[Form 2] – Torres Strait Islander P.1*

EPA PAGE & SECTION	DIFFICULT WORD OR SENTENCE	PROBLEM AREA	RESPONDENT EXPLANATION OR SUGGESTION
Page 3 – PART 1: For the person appointing an attorney ***What types of decisions?***	Decisions about personal and financial matters	Confusing	Needs to be explained clearer
Page 4 - PART 1: For the person appointing an attorney ***Can I appoint more than one attorney?***	Jointly, majority and severally and 'two thirds'	A lot of people would have a problem with that.	Those terms need to be broken down and explained more clearly.
Page 4 - PART 1: For the person appointing an attorney ***Whom should I appoint as my attorney***	Whom should I appoint as my Attorney?	The information is given too late.	It should be placed on page 3, so it is the first information people read when they open up the form.
Page 5 – PART 1: For the person appointing an attorney ***Whom should I appoint as my attorney?***	Note: 'Paid Carer'	The term is confusing	Needs to be defined more clearly
Page 5 – PART 1: For the person appointing an attorney ***When does the attorney's power begin?***	'With financial matters … If you do not name a date or an occasion, it begins immediately. On the other hand…'	You have to be very clear … there's a lot of 'on the other hand unless'. ..the average Joe in the street is bound to get confused. It's very lengthy	It needs to be put in plain language.
Page 5 – PART 1: For the person appointing an attorney ***How long does the power continue?***	The word 'revoked'	The word 'revoked' is used throughout the document.	This needs to be defined.
Page 6 – PART 1: For the person	If you make an inconsistent	What inconsistency?	There needs to be a clear definition of

appointing an attorney ***Is there anything else that will end this power?*** ***[fourth bullet point]***	document. This power is revoked to the extent of any inconsistency with any later document…		inconsistency. What inconsistencies are they talking about?
Page 7 – PART 1: For the person appointing an attorney ***Where can I go for advice?***	It lists the Adult Guardian, The Public Trustee or Solicitor.	What is the Adult Guardian and the Public Trustee? Who are these people?	That needs to be clarified as well.
Page 8 – APPOINTING AN ATTORNEY	The address details	Is it a residential address or is it a postal address, what address do you put there?	Clarify this
Page 9 – APPOINTING AN ATTORNEY ***Write these terms here:[number 3]***	Write these terms here:	There's not enough space there, there's only five lines.	It needs more space for people to fill in, add more lines.
Page 9 – APPOINTING AN ATTORNEY ***When do you want the power of your attorney / s for financial matters to begin?*** ***[number 5]***	'When do you want the power of your attorney … to begin?'	It should be under the 'tick one box only'	So people know what they're doing, before they start ticking the boxes
Page 13 – PART 3: For the attorney ***The health-care principles is:*** ***[second bullet point]***	The term 'restrictive'	Someone who doesn't have a good grasp of English won't understand it.	This word 'restrictive' needs to be defined
Page 13 – PART 3: For the attorney ***Duty to present a management plan and get approval for unauthorised transactions.[bottom section]***	'Duty to present a management plan …'	What is a management plan?	This needs to be clarified/
Page 13 – PART 3: For the attorney ***Duty to avoid transactions that involve conflict of interest.*** ***[last bullet point]***	Duty to avoid transactions that involve conflict of interest.	What exactly is the conflict of interest? The example given is not clear.	Maybe there needs to be more examples there, so people understand properly. Especially when its dealing with the financial arrangements between the principal and the Attorney.
Page 14 – PART 3: For the attorney ***When does my power end?[last paragraph]***	… if the principal regains the ability to make the decision in question	What decision are they talking about?	This needs to be clarified again.

ENDURING POWER OF ATTORNEY Short Form *[Form 2] – Torres Strait Islander P.3*

EPA PAGE & SECTION	DIFFICULT WORD OR SENTENCE	PROBLEM AREA	RESPONDENT EXPLANATION OR SUGGESTION
Page 3 – PART 1: For the person appointing an attorney. ***Why give someone enduring power of attorney?*** ***[second paragraph]***	If you give someone a *general* power of attorney and what is enduring power of attorney?	What I'm saying is you're introducing another term, another process and people will think, what the heck is that? And what is this for? … Actually it's quite surprising you mentioned that this was the short form {laughs}, I hate to think what the long form is like.	
Page 3 – PART 1: For the person appointing an attorney. ***What types of decisions?***			On page three on part one, the person appointing an attorney, it says, what types of decisions. It gives an example here of a financial matter, is deciding how your income is invested. I think maybe that's good in a way, it's giving an example. It probably needs some more of that through the document, because it's a lot of terminology and theory and it probably needs more examples in there. That example there of making an investment decision that makes it a bit more clearer to people.
Page 4 – PART 1: For the person appointing an attorney ***[Note: You cannot give your attorney power to make decisions about:*** ***[first & second bullet point]***	'for special personal matters, special health matters' and 'sterilisation'.	I know what that means, but someone in the Indigenous community wouldn't know what that means. I'm assuming that means getting your family jewels dealt with {laughs}. Yeah, I think someone in the Indigenous community would think it means you to hospital and get sterilised or something, anyway, it's confusing. People wouldn't know what sterilisation is. I know it	

		because I'm a carer …	
Page 5 – PART 1: For the person appointing an attorney: ***[third paragraph]***	Note: 'Paid carer' does not mean someone receiving a carer's pension or similar benefit, so you are free to choose someone who is receiving such a benefit for looking after you.	Well, again, that's confusing right there, but, I guess, I just have a question about why a paid carer is not allowed? Cause if it is someone, like it says on page four, you should appoint someone you trust. What if it is a paid carer? Cause many people choose their spouse or adult child but you may prefer to appoint another family member or a friend with expertise in the area.	So this is a curious question, cause I know that there are some people who will have a closer relationship with their paid carer than their families. People, that is with disabilities, you know.
Page 5 - PART 1: For the person appointing an attorney. ***Should I pay my attorney?***	'Normally payment is not made unless a trust company is acting as attorney'.	I don't know what a trust company is. A lot of people wouldn't know what that is either.	
Page 5 - PART 1: For the person appointing an attorney. ***When does the attorney's power begin?*** ***[first paragraph]***	'…you're attorney's power to make decisions does not begin until if ever you are incapable of understanding the nature and foreseeing the effects of a decision and of communicating that decision'.	What the heck does that mean, that's a real mouthful there. Yeah, big words, long sentence, even for me, it took me a while to digest all of that.	
Page 5 - PART 1: For the person appointing an attorney. ***How can I be sure that my attorney will act as my interests?***	'While (if ever) you are unable to oversee your attorney's decisions, the Adult Guardian and the Court have the power to protect your interests'.	A lot of people wouldn't have a clue, what is the Adult Guardian? I've heard of them, but I still don't quite know what they do.	So a lot of people would just have no idea who they are, you'd have to explain that to them.
Page 6 - PART 1: For the person appointing an attorney. ***Is there anything else that will end this power?*** ***[fourth bullet point]***	'if you make an inconsistent document. This power is revoked at the extent of any inconsistency with any later document you complete, such as an Advance Health Directive'.	Again, it's introducing another form, and even says or another enduring power of attorney. It's introducing another form, the Advance Health Directive, if somebody had read this first, again, what the heck is that form? It's another form you gotta go and dig out.	Maybe there should be something to define that, direct that to that form. I don't know.
Page 6 - PART 1: For the person appointing an attorney.	'If your attorney becomes incapable. It says your attorney's power is	I think that's a good point…, because your relation with your attorney may	I think that's a good point, maybe you can expand a bit on that in a cultural

Is there anything else that will end this power?	revoked if he or she becomes incapable of understanding the nature and foreseeing the effects of a decision, and of communicating that decision'.	change over time, which may be detrimental to your situation. I can see that in communities where you might give your enduring power of attorney to a family member, & with family politics, things change and they make decision, where they're incapable of understanding or communicating that decision to you.	way.
Page 7 - PART 1: For the person appointing an attorney. ***What happens to this document when it is completed? [last paragraph]***	if your attorney will be making decisions about buying or selling land, this document must be registered with the Land Titles Office.	Being a former bureaucrat, I know of the Land Titles Office, a lot of people would not know who those people are. Anyway, the point that I'm trying to make here, as I'm going through it is, it's introducing all these other organisations and other forms. And it's a lot of work for people to go and dig all that information out.	I guess this could become even more bulky if you start trying to define things, so there's a real task there on their hands to try and do that, if they wanna try and simplify it.
Page 8 – APPOINTING AN ATTORNEY.	I guess here in this section, I just have a general comment … for where you list out all your attorneys and then it asks you to say, who do you want to delegate your financial matters, personal health matters, financial and personal health matter.	My only general question … what if you wanna give financial matters to attorney one and personal health matters to Attorney two and personal and health matters to attorney three, that could be difficult to put in a form.	
Page 9 – APPOINTING AN ATTORNEY. ***[number 3]***	I know you've got section three on page nine there that says, write these terms here. For example, my attorney is not authorised to invest in ABC Pty Ltd shares or if I need nursing home care, etc.		But I guess my point there is that there should be something about giving specific powers to certain attorneys, rather than giving all financial matters to all three or the majority or consensus, maybe you wanna give financial matters to number one and number three and just give health matters to number two, the attorneys, anyway, that's a general comment there.

Page 9 – APPOINTING AN ATTORNEY. ***[number 7]***	How do you prefer that they make their decisions … severally, jointly and as a majority…		But again, my point there is, there should be something where you can expand on delegating certain matters to the three different attorneys rather than giving them all of them powers for all of it. If that makes sense. I'm giving you a lot of work here. {laughs}
Page 11 – PART 2: **For the witness.** ***[number 9]***	Another definitional thing on … the witnesses certificate, on point nine.	I know what a justice of the peace is, commissioner for declarations, I don't really know what a commissioner for declarations is, I know what a lawyer is …	notary public, maybe you should just put there, a member of the public, I don't know, maybe it's a bit confusing.
Page 12 – PART 3: **For the Attorney** ***General principles include:*** ***[first bullet point]***	'presuming that the principal has the capacity to make a particular decision until there is conclusive evidence that this is not the case'.	It's just confusing; I don't fully understand that full stop.	
Page 12 – PART 3: **For the Attorney** ***General principles include:*** ***[fifth bullet point]***	'taking into account, the importance of the principal's existing supportive relationships, values, cultural and linguistic environment'.	I think that's a really important one for Indigenous people.	'Values, cultural and linguistic environment', I think that it needs to be expanded a bit, maybe highlighted a bit more for Indigenous people
Page 15 – PART 3: **For the Attorney** **When does my power end?** ***[Becoming incapable]***	'Your power is revoked if you become incapable of understanding the nature and foreseeing the effects of a decision, and of communicating that decision'.	I think that point I made earlier, my only question is how is that decided? When someone is incapable of understanding the nature of a decision that they're making on your behalf? How is that decided? Especially if the relationship that you have with that person has been souring over a number of years? {laughs}.	
Page 15 – PART 3: **For the Attorney** **When does my power end?** ***[Appointing a new attorney to have your powers]***	'If the principal completes a new document giving your powers to another attorney, your powers are revoked to that extent. Because the new document has a later date, it overrides the first.'	I don't know how that works, it's just confusing.	

Page 16 – PART 3: **For the attorney** ***Can I be held liable?***	'Yes you can be held liable if you use the enduring power of attorney knowing that it has been changed or revoked, or knowing of an event that effectively revokes it', etc.	I guess, I just have a question about, can you be liable for just making a bad decision? Cause it seems to be talking about, knowing that your power of attorney authority has been changed or revoked. It's just a question, can you be liable for making a bad decision? That's it.	

ENDURING POWER OF ATTORNEY Short Form *[Form 2] – Torres Strait Islander P.4*

EPA PAGE & SECTION	DIFFICULT WORD OR SENTENCE	PROBLEM AREA	RESPONDENT EXPLANATION OR SUGGESTION
Page 3 – PART 1: **For the person appointing an attorney.** ***Why give someone enduring power of attorney? [second paragraph]***	'for instance to sign documents for you in your absence…'	The word "for instance" is not a common word.	We would say, 'for example'. Little things like that I think help make explanation easier for our people.
Page 5 – PART 1: **For the person appointing an attorney.** ***Whom should I appoint as my Attorney?***	'…statute to look after the rights and interests …'	Words like 'statute' are not common words that people are familiar with in everyday language.	I think, again for our people to understand it, just laid out in steps, like example answers …
Page 5 – PART 1: **For the person appointing an attorney.** ***Should I pay my attorney?***	'Should I pay my attorney?'	If the question is, 'should I pay my attorney?' Then the way to explain that would be, you don't have to pay them any money, this is free, just state it clearly.	I don't know whether the Government would go that far as to put it like that. I think things like that would make it easier. … More simplified language.
Page 6- PART 1 **For the person appointing an attorney** ***Is there anything that will end this***	Is there anything that will end this power? and When does my power end?	I think that repeats itself there, so I think that's making the form a bit longer.	

ENDURING POWER OF ATTORNEY Short Form *[Form 2] – Torres Strait Islander P.5*

EPA PAGE & SECTION	DIFFICULT WORD OR SENTENCE	PROBLEM AREA	RESPONDENT EXPLANATION OR SUGGESTION
Page 6 – PART 1: **For the person appointing an attorney?** ***Can I change or revoke this power of attorney?***	The word 'revoke'.	I didn't quite really understood that word, that I haven't actually used that word in my knowing I guess.	
Page 8 – APPOINTING AND ATTORNEY ***Number 2, Do you want to set any terms for the power given in clause 1…***	That word 'clause'.	I didn't even understand that word… I don't use it everyday, those words stood out to me, that I sort of went, I need a dictionary for that.	… could make it simpler.

ENDURING POWER OF ATTORNEY Short Form *[Form 2] – Torres Strait Islander P.6*

EPA PAGE & SECTION	DIFFICULT WORD OR SENTENCE	PROBLEM AREA	RESPONDENT EXPLANATION OR SUGESTION
Page 3 – PART 1: **For the person appointing an attorney** ***[second bullet point, last sentence]***	'Because you are the person principally concerned you are referred to as the principal'.	But I think that maybe that word shouldn't be there. I think it should be, because you are the person concerned, and don't put principal in there, you are referred to as the 'principal'. That principally shouldn't be there I think.	So in terms of that, those key words that are there, maybe there should be a little glossary at the back or at the front, so people can say, principal means 'you' in brackets or something, to break down those terms in there.
Page 5 – PART 1: **For the person appointing an attorney** ***How long does the power continue?***	… 'it continues so long as you are incapable of understanding the nature and foreseeing the effects of a decision, and of communicating that decision… '	Yeah, I think that's confusing again.	It kinda has to say, that powers to make decisions does not begin until [if ever] you are incapable of understanding the nature and foresee the effects of a decision and of communicating that decision. You've

			gotta say if ever you are incapable of … I think that's the same thing again, I think it needs to be simple. Just in case of something like that or should you become incapable, straight forward.
Page 7 – PART 1: **For the person appointing an attorney** ***How do I register this document?***	'… you must deregister the document …'	I think the word 'deregister', we never use the word deregister, we use 'unregister', you know what I mean, it's like a word that we don't use.	It might be it needs to be made clearer. … either you must unregister or whatever, you know cause we associate with registering and unregistering. Not so much deregister.
TSI P.6 **EPA PAGE & SECTION**	**DIFFICULT WORD OR SENTENCE**	**PROBLEM AREA**	**RESPONDENT EXPLANATION OR SUGGESTION**
Page 8 – APPOINTING AND ATTORNEY ***Number 2, Do you want to set any terms for the power given in clause 1…***	Okay, so they're saying, *'clause 1'*...		If they're saying *'clause 1'* down here, that needs to say up here underneath there, *clause 1*, you know what I mean. Because if it's someone that's never written or read a document, they're gonna be looking for *clause 1*, that word, *clause 1*. So that maybe needs to say underneath there somewhere there next to it. Maybe it needs to be made more clearer.
Page 9 - APPOINTING AND ATTORNEY ***Number 7. How do you prefer that they make their decisions?*** ***[third box]***	'if you are appointing more than three attorneys'	It's the same thing from a couple of pages back that I was making reference to … Yeah, that section is confusing because of the language that's used there, 'jointly, unanimously'. It's the same thing about speak clear English and don't confuse people with other words at	I think it should be just straight forward what they're actually saying … They need to say what they actually mean.

		the end.	
Page 10 – STATEMENT OF UNDERSTANDING ***Number 8, Point (1)***	Yeah, it's because of the clause 1, maybe that needs to be in there, like if they're not familiar with it, maybe they need to say clause 1 and make reference back to that page, whatever page it was on.	It's the same thing of what I picked up here before; I think if they don't carry it through, maybe they need to say on page eight. Cause you know some people are in a hurry, not that you wanna be in a hurry when you're looking at this document.The sentence is confusing.	
Page 10 – STATEMENT OF UNDERSTANDING ***Number 8, Point (5)***	And that word 'impaired' 'My power to make a decision is not impaired'.	Now what do they mean by that? … what do you mean by impaired?	Maybe that needs to be simple English. I understand what it means, it means I'm unable to make the decision, but you know that all it needs to say, not 'impaired'. If I'm unable to make the decision, straight forward plain simple English.
Page 13 – PART 3: For the attorney ***[For all decisions]***	'… as directed in clause 7 …'		I think they need to put a little bracket there to say whatever page that was on. It's making simple, it's almost as if you can colour code it, if that's a colour, it might be whatever colour, and it's the same colour back here, so they know exactly where it is, oh yeah, that's it there. You can almost colour code it too. Yeah you go back down and oh yeah, that's clause 7 there, it's the same colour.
Page 15 - PART 3: For the attorney ***The principal's actions [The principal's death, fifth bullet point]***	On page 15, that word 'entirety' The principal's death, if the principal dies, your enduring power of attorney is revoked in its entirety.		So 'entirety', it needs to say it in simple English there again, and if you were over at the back page here, maybe there needs to be a glossary there, that says, what does 'entirety' mean. Otherwise they're be lookin for that dictionary {laughs}. Now that needs to be in simple language there again.

Enduring Power of attorney: Murri respondents

ENDURING POWER OF ATTORNEY Short Form *[Form 2] – Murri P.1*

EPA PAGE & SECTION	DIFFICULT WORD OR SENTENCE	PROBLEM AREA	RESPONDENT EXPLANATION OR SUGGESTION
Page 4 – For the person appointing an attorney ***What types of decisions? Note: [last paragraph]***	'Your attorney can consent to withdrawing or withholding of life-sustaining medical treatment if, for instance, you become terminally ill or go into a state of permanent or persistent unconsciousness. You can give instructions about this type of decision if you make an Advance Health Directive. These instructions will override any decision of your attorney'.	I didn't really understand that, so this is for the person appointing an attorney, so you can give instructions about this type of decision if you make an Advance Health Directive. Is it if you make a Health Advance?	
Page 9 – APPOINTING AN ATTORNEY ***How do you prefer that they make their decisions [number 7]***	'Severally and Jointly…' Whether you want them on all of those matters or one of them, yeah?	'Severally', I've never heard of that word, anyone of them may decide. Yeah I don't really understand that to tell the truth.	

ENDURING POWER OF ATTORNEY Short Form *[Form 2] – Murri P.2*

EPA PAGE & SECTION	DIFFICULT WORD OR SENTENCE	PROBLEM AREA	RESPONDENT EXPLANATION OR SUGGESTION
Page 7 – PART 1: For the person appointing an attorney ***[first bullet point, 2nd paragraph***	'The witness must be a justice of the peace, commissioner for declarations, lawyer or notary public'	People need to know what 'notary public' is, it's nice to write that down there but Joe Blow in the street, a lot of people that wouldn't even come into their vocabulary. Yeah, that doesn't come into their everyday vocabulary… Maybe put it in brackets	I just think they need to break it down, spell it out, put it in brackets whatever, yeah some people, I don't think they're consulted. Because people some time are too embarrassed to ask, so it's not insulting by breaking it down or condescending.

		'commissioner' what that is,	
Page 8 – APPOINTING AN ATTORNEY ***As my attorney/s, under this enduring power of attorney, for (Tick one box only):***	It says, 'as my attorney or attorneys under this enduring power of attorney, for (tick one box only).	So personal health matters and financial matters, what if you wanted to tick more than one box? Do you need another separate one of these forms, that's what I'm asking. *I guess you would probably tick that one.* Oh, Oh, I see. *The third box.* The third box includes the two, how silly. I find that silly, but anyway, that sorted that out, other than that I don't have any other issues	

Page 9 – APPOINTING AN ATTORNEY ***How do you prefer that they make their decisions? (tick one box only) [Number 7]***	'Severally, jointly'… so how do you prefer that they make their decisions? Anyone of them may decide.	Well no, severally, several, several are many aren't they? I can work that out. Several are many, jointly is all together, so severally, So severally, say if there's about three of them, severally, anyone of them may decide, so there's one out of three, what goes? Jointly, so two out of three. *So does that make sense to you?* No. Severally, so let's sorta have a little scenario, so severally could be three. Any one of them may decide. And it	I think they need to work on the wording, you know I think I'm fairly literate and I can understand things but I find that sometimes words can confuse people, it confused me. It's a bit like when I go to Centrelink or somewhere like that, they have stuff down there that's like, it's almost like it repeats a previous question that's been asked. So there was just a few there.

		goes down here to say, as a majority if you are appointing more than three attorneys please specify, 'simple majority' or 'two-thirds'. Isn't two thirds a simple majority? I would think that two thirds is a majority, well it is. So you got simple majority, two thirds majority, well hello, put quite simply, two thirds is a majority. So that's a wee bit confusing me.	

ENDURING POWER OF ATTORNEY Short Form *[Form 2] – Murri P.3*

EPA PAGE & SECTION	DIFFICULT WORD OR SENTENCE	PROBLEM AREA	RESPONDENT EXPLANATION OR SUGGESTION
Page 4 – PART 1: For the person appointing an attorney ***Can I limit my attorney's powers? [second paragraph]***	'There are also limits set by legislation. For example, the Trust Act names the types of investment that a trustee (in this case your attorney) is authorised to make. If you lose the capacity to make financial decisions, the only investments your attorney can make on your behalf are those that are named in the Act, unless the consent of the Court is obtained'.	I don't understand what all that meant. … I didn't understand what that paragraph meant. Cause you got the Acts and you've got all these things that doesn't make any sense to me.	Make it clearer; break it down a bit more.
Page 6 – PART 1: For the person appointing an attorney ***Is there anything else that will end this document? [fourth bullet point]***	'If you make an inconsistent document. This power is revoked to the extent of any inconsistency with any later document you complete, such as an Advance Health Directive or another enduring power of attorney'.	So all that I don't understand what it was getting at. It is … very confusing. And if you make an inconsistent document, what do they mean by that? I don't understand that.	

Page 7 – PART 1: For the person appointing an attorney ***Who is involved in completing this document?*** ***[first bullet point, second paragraph]***	(a) 'The witness must be a justice of the peace, commissioner for declarations, lawyer or notary public. The witness must not also sign for you and must not be your attorney, or relation of yours or of the person/s you appoint as attorney. If the power includes dealing with health matters, the witness must not be your current paid carer or health-care provider'	That's confusing. So yeah, I don't understand, these two here. Yeah, I don't understand what that means.	Needs more explanation.
Page 7 – PART 1: For the person appointing an attorney ***Who is involved in completing this document?*** ***[first bullet point, second paragraph] (Cont)***	(b) 'The witness must state that you appeared to understand what you were doing. If the witness is not sure that you understand the nature and effect of the appointment, he or she should refuse to sign the document'		
Page 12 – PART 3: For the attorney ***What are these responsibilities?*** ***General principles include:*** ***[first bullet point]***	General principles include: presuming that the principal has the capacity to make a particular decision until there is conclusive evidence that this is not the case.	And I don't know what they mean by that, presuming that the principal has the capacity, so the principal, that's the person who's sick? What do you mean 'conclusive'? Yeah, what's 'conclusive evidence'?	
Page 12 – PART 3: For the attorney ***What are these responsibilities?*** ***General principles include:*** ***[sixth bullet point]***	'ensuring that your decisions are appropriate to the principal's characteristics and needs;'	I don't know what is meant by 'principal's characteristics and needs'. That's confusing too as well.	

Page 14 – PART 3: For the attorney ***How do I complete a document for the principle?***	'If you have the power to execute (complete) a document for the principal, you do so in the ordinary way, but you must note on the document that you are executing it as the principal's attorney under enduring power of attorney'.	That's where I got mixed up you know and then John Smith, but where I got mixed up is this bit here saying, 'but you must note on the document that you are executing it as the principal's attorney under enduring power of attorney'. So yeah, that's a bit confusing there as well .	Yeah make it more clearer, like taking care of the kids, like saying dependants, I would say children or so, I don't know dependants.

ENDURING POWER OF ATTORNEY Short Form *[Form 2] – Murri P.4*

EPA PAGE & SECTION	DIFFICULT WORD OR SENTENCE	PROBLEM AREA	RESPONDENT EXPLANATION OR SUGGESTION
Page 9 – APPOINTING AN ATTORNEY ***When do you want the power of your attorney/s for financial matters to begin? [number 5]***	When do you want the Power of Attorney for financial matters to begin?	It's asking there for dates and occasion, yeah, I'm just wondering how people might determine that within families. … that might be a tricky question. A question that there might be a lot of discussion, conflict about when does that start. And it could be a positive thing as well, letting people know that it's gonna start on this day. I was just thinking that there is the negative side of that as well where it could be used to someone's advantage.	
Page 14 – PART 3: For the attorney ***When does my power to make decisions begin? Financial matters. [second bullet point]***	Again, it's about the financial matters …	It's just my own experience with clients who have been taken advantage of by family members and yeah, I'm just concerned about … the financial matters.	

		For some people I think it would be good … to know that someone is looking after that. Yeah, but I'm just cautious or wary of that question where someone is given that responsibility. For myself, I have read through this and the importance of someone appointed that you trust and you know is gonna look after these things for you, but there are people who do take advantage of people when they're unwell.	
Page 15 – PART 3: For the attorney Your actions, *Becoming the principal's paid carer or health-care provider [second bullet point]*	The carers question	It just highlighted for me something about carers often the carer may not be someone who is a family member. It might be a close friend or and again, it's a flag for me that a person may be taken advantage of in that role as carer.	… there might be somebody else who is more responsible … you know, keeping to the guidelines of this form. But otherwise I think it's a good form, I think if you're hearts in the right place and you wanna get these things in order.

ENDURING POWER OF ATTORNEY Short Form *[Form 2] – Murri P.5*

EPA PAGE & SECTION	DIFFICULT WORD OR SENTENCE	PROBLEM AREA	RESPONDENT EXPLANATION OR SUGGESTION
Page 4 & 5 – For the person appointing an attorney ***Whom should I appoint as my attorney?***	It says, 'the adult guardian is appointed by statute to look after the rights and interest of the people with disabilities... '	I wonder how many of our people would know what the word 'statute' is. There would be people who wouldn't know what it meant; I know it means it's an Act or Legislation whatever. But that word 'statute' I wonder if they can use another word or a more simple word like legislation'. …That could be changed or whatever.	

Page 5 – For the person appointing an attorney ***How much control will my attorney have?***	'… control over that decision unless you have explicitly limited that power in this document. '	'Explicitly' can be difficult word too, it's a word that could scare people.	So I think if they can come up with a simpler version of the meaning of that word. The meaning of that sentence would be helpful, I think. … All the rest seem pretty self explanatory.
Page 12 – PART 3: For the attorney ***What are the responsibilities?*** ***General principles include: [first bullet point]***	Part of the sentence, '… particular decision until there is conclusive evidence that this is not the case'	I wonder about the word 'conclusive' too, people might struggle to understand what conclusive means.	
Page 13 - PART 3: For the attorney ***The health-care principles is: [second bullet point]***	The health-care principles is: '… to be made in a way that is least restrictive to the principal's rights'	Again I wonder if people can understand the meaning behind 'restrictive'.	

Advance Health Directive: Torres Strait Islander respondents

ADVANCE HEALTH DIRECTIVE *[Form 4] – Torres Strait Islander P.1*

AHD PAGE & SECTION	DIFFICULT WORD OR SENTENCE	PROBLEM AREA	RESPONDENT EXPLANATION OR SUGGESTION
Page 3 – EXPLANATORY NOTES: *What do I need to consider before making an Advance Health Directive?* *[third bullet point]*	How will you know what technology is available for use in certain conditions.	What do they mean by 'technology'?	Maybe give an example of the type of technology.
Page 3 – EXPLANATORY NOTES: *What do I need to consider before making an Advance Health Directive?* *[last paragraph, second last sentence]*	Under the Queensland criminal code, it is a criminal offence to accelerate the death of a person by an act or omission.	The term 'omission'	That would need to be defined or maybe put in more simpler terms.
Page 3 – EXPLANATORY NOTES: *Can I cover all possible health-care decisions in this form?* *[last section, last line]*	This person will not be able to make 'special health' decisions.	What is 'special health'?	That needs to be defined.
Page 4 – EXPLANATORY NOTES – *Can I cover all possible health-care decisions in this form?* *[first section]*	If you have already given someone enduring power of attorney …	If you haven't seen or read the Power of Attorney forms, you'll be questioning what is an enduring power of attorney?	Perhaps it could be mentioned in the AHD form that can say, 'before you fill out this form find out this information about the Power of Attorney first'
Page 4 – EXPLANATORY NOTES: *Can I change or revoke my Advance Health Directive?* *[second section]*	Can I change or revoke my Advance Health Directive?	That word 'revoke' again. People with limited English, if they're picking this up for the first time … would have problems understanding that word.	Define it or use another word.
Page 4 – EXPLANATORY NOTES: *Can I change or revoke my Advance Health Directive?* *[second sentence]*	It is wise to review your directive every two years …	I forgot that this was called a Health Directive … so when I came to the term directive', I kept thinking, 'why does this term keep coming up all the time?'	I think they need to define that when we use this word 'directive' we are referring to the Advance Health Directive.
Page 4 – EXPLANATORY NOTES: *Can I change or revoke*	You may also totally revoke your directive at any time. … and the	This leaves it kinda open to just anyone, because it's not being	No suggestion given

my Advance Health Directive? [third last paragraph]	person witnessing your signature does not need to be a justice of the peace, commissioner for declarations, lawyer or notary public.	appropriately witnessed, people can be forced or tricked into signing something. This is very important stuff.	
Page 4 – EXPLANATORY NOTES: *Who is involved in completing this document? [last section]*	Who is involved in completing this document? – the definition for principal	It says, 'You are referred to as the principal because you are the person principally involved'. If you don't know English, it hasn't defined the word 'principal' there. If you're gonna go and give a definition, you don't use that word again to define it, cause it just confuses the reader.	Use another word there instead of saying, 'you are the person principally involved'. You can't define the word 'principal' with the word 'principally'. You could say, 'you are the person who is directly involved in this…'
Page 4 – EXPLANATORY NOTES: *Who is involved in completing this document? [last paragraph*	'Paid carer'	Again, the role of the 'paid carer' is confusing.	It should be clarified in the note section, what a paid carer is, we know who they're not, but who are they?
Page 5 – EXPLANATORY NOTES: *What do I do with the completed document? [last paragraph]*	What do I do with a completed document? You may also wish to carry a card in your purse or wallet stating you have made a directive, and where it can be found.	Is there a specific card they have or is it something that someone makes up?	They need to be clear on that card. What is this card that they're referring to? Is that something that the department issues? … They need to clarify on the form, what they mean by a card, is there an actual official card?
Page 6 – SECTION 1: Your details TO MY FAMILY, FRIENDS AND HEALTH-CARE PROVIDERS			They very clearly state … print the number of your house, name of address and that was absent in the Enduring Power of Attorney form. The print is big which is good.
Page 7 – SECTION 2: General instructions *[number 2]*	'If I temporarily lose capacity …'	What do they mean by 'capacity'	That needs to be clarified.
Page 7 – SECTION 2: General instructions *Are there any special conditions that your health-care*	Are there any special conditions that your health care provider should know about, such as asthma or any	Maybe there needs to be more examples given there, because someone reading this might think,	If this is not spelt out clearly, they might tick the 'no' box, skip question 4 and go straight to question 5.

providers should know about, such as asthma or any allergy to medication? ***[number 3]***	allergy to medication?	they don't have an allergy or asthma and they won't be thinking about all the other conditions like diabetes and blood pressure.	
Page 8 – SECTION 3: **Terminal, incurable, or irreversible conditions** ***Definitions of terms used in this section*** ***[first bullet point]***	Medical terminologies, for example, words such as, 'prognosis'	Many people in the Torres Strait Islander Community do not understand these medical terms.	Words such as 'prognosis' needs to be defined or perhaps put another word there. A word that people would understand.
Page 9 - SECTION 3: **Terminal, incurable, or irreversible conditions** ***Number 7.*** ***I request that:*** ***[first box]***	Everyone responsible for my care, initiate only those measures that are considered necessary to maintain my comfort and dignity.	What 'measures'?	That needs to be clarified, so that people know what do they mean by 'measures'.
Page 9 - SECTION 3: **Terminal, incurable, or irreversible conditions** ***Number 7.*** ***[second box]***	any treatment that might obstruct my natural dying … The word 'obstruct'.	It's one of those words that people might have problems with, understanding the term.	Maybe another word needs to be put in there.
Page 10 - SECTION 3: **Terminal, incurable, or irreversible conditions** ***Number 8.*** ***If I am in the terminal phase of an incurable illness:*** ***[third and fourth box]***	The terms 'artificial hydration and artificial nutrition'	In the definition of terms on page 8 they have the term 'artificial feeding' and on page 10, they have the term 'artificial nutrition'.	They need to be consistent, if they are going to have the term 'artificial feeding' in the definition of terms, then they should use that and not artificial nutrition. This is confusing.
Page 12 – SECTION 3: **Terminal, incurable, or irreversible conditions** ***Tissue donation***	The tissue donation?	What tissue do they mean?	They need to clarify what is tissue donation and what organ donation is.

Page 13 – SECTION 4: Personal statement ***Do you wish to mention any people who are not to be contacted about your treatment? [number 16]***	Do you wish to mention any people who are *not* to be contacted about your treatment?	There needs to be some clarification there, who do they mean by people you don't want to be contacted? Is it just somebody you've got a grudge against or is it because you're sick and you don't want your employer or someone like that.	There needs to be examples put in there, specifically, what kind of people do you not want to know about your health business.
Page 15 – SECTION 6: **Enduring power of attorney for personal/health matters**	Why is there a section about the enduring power of attorney there.		Explain it clearly.
Page 18 – SECTION 7: Appointing an attorney for personal/health matters ***Write these terms here:*** ***[number 31]***	Do not include any instructions about withdrawing or withholding life-sustaining medical treatment.	The two term 'withdrawing or withholding, life sustaining medical treatment'.	They need to be made simpler.
Page 19 – SECTION 8: Statement of understanding and signature ***I understand: [number 35, first bullet point]***	'the nature and the likely effects of each direction stated in this directive'	It's a confusing statement / sentence. The words, 'direction' and 'directive' is confusing; I'm looking through the eyes of someone who would have limited understanding of English.	You need to change terminologies there.
Page 19 – SECTION 8: Statement of understanding and signature ***I understand:*** ***[number 35, fourth bullet point]***	'that at any time I am not capable of revoking a direction in the directive, I am unable to effectively oversee the implementation of the directive.'	It sounds like I'm listening to a comedy line, it's funny. It's almost like listening to politicians who talk in a way that deliberately confuse you and then you go and you turn on the TV and you know the comedy show where these two comedians who send up these politicians and they talk like that. This would be a line out of a comedy show.	They need to write it more in the way that any normal Tom, Dick and Harry in the street will understand.

ADVANCE HEALTH DIRECTIVE *[Form 4] – Torres Strait Islander P.3*

AHD PAGE & SECTION	DIFFICULT WORD OR SENTENCE	PROBLEM AREA	RESPONDENT EXPLANATION OR SUGGESTION
Page 9 – SECTION 3: Terminal, incurable, or irreversible conditions *[number 7, first box]:* **I request that:**	'everyone responsible for my care initiate only those measures that are considered necessary to maintain my comfort and dignity with particular emphasis on the relief of pain.'	I don't know what it means to be quite honest, I don't know. Even when I read it now, it's confusing, I don't know. When you first start reading this document and you come across that sentence and it says, initiate only those measures, the first question is, what measures? That's just confusing that's all.	
Page 10 – SECTION 3: Terminal, incurable, or irreversible conditions *Number 8. If I am in the terminal phase of an incurable illness: [third box]*	'I do not want artificial nutrition'	I don't know what that means, does that mean you're gonna have a pipe down your throat and people feeding you? But I know that a lot of Murris and Torres Strait Islanders they won't understand that. They don't even know what the word 'artificial' means, let alone 'nutrition'. All these words are fairly big words, assisted ventilation, artificial hydration. …what is artificial hydration?. Nobody would understand that at all.	These terms need to be looked at.
Page 10 – SECTION 3: Terminal, incurable, or irreversible conditions *Number 9. If I am permanently unconscious (in a coma): [first box]*	Cardiopulmonary resuscitation, assisted ventilation.	Nobody would understand what that means.	You really have to spell that out in very basic terms, yeah.
Page 11 – SECTION 3 Terminal, incurable, or irreversible conditions *Number 10. If I am in a persistent vegetative state:*	If I'm in a persistent vegetative state.	It's all of them really, it's a definition thing, I understand what that means but I don't thing our old people will understand that at all.	
Page 13- SECTION 4: Personal statement	'Do you wish to mention any people who are not to be contacted about	I think this is a good one actually because, maybe a bit of a positive	

Number 16. Do you wish to mention any people who are not to be contacted about your treatment?	your treatment?'	thing, because there are people out there that you don't want to be contacted. … Yeah, family always has politics …	
Page 14 – SECTION 5: Doctor involvement, ***Number 19. Statement of nominated doctor.***	'statement of nominated doctor'	Now when I first read that, it was confusing because is says, it's a statement by the doctor saying, "I have discussed this document with the principal and in my opinion, he or she is not suffering from any condition". My first reaction to that was, "hang on, isn't this about somebody suffering. Oh, this is a section about the doctor saying you are suffering, but then it's here, the doctor saying that you're not suffering, then I had to read it up the top again. … it's very confusing.	…maybe just make some clear reference to that first paragraph explaining what this section's about. And this section is about him saying that you're not suffering from anything to affect the decision.
Page 16, SECTION 6, Enduring power of attorney for personal/health matters ***Number 25. How do you prefer that your attorneys make their decisions?***	'How do you prefer that your attorneys make their decisions?'	Right at the start, I was confused about Enduring Power of Attorney for personal health matters. What the heck is that? This is an Advance Health Directive and all of a sudden it's going to something foreign	
Page 17 – SECTION 7: Appointing an attorney for personal/health matters	On section 6, you're talking about an Enduring Power of Attorney for personal health matters, then section 7 is appointing an attorney for personal health matters.	What is the difference there? There probably is something that explains it a bit more there, but I'm just looking at it. It's repetitive yeah and that's confusing.	
Page 20 – SECTION 9: Witness's certificate. ***[number 36, box 4]***	'notary public'	I don't know what a notary public is. Notary public, what's a notary public, that's all? I think it means public, but notary, I think it means something else.	So Indigenous people with basic education will be confused.
Page 23 – Section 11: Review of this document	'review of the document'	I've got no idea what it means by review of document 1, review of document 2, review of document 3.	

		I've been through the whole document and I can't see any document 1, document 2, document 3. So I've no idea there, that's very confusing that is, it's not marked properly at all.	

ADVANCE HEALTH DIRECTIVE *[Form 4] – Torres Strait Islander P.4*

AHD PAGE & SECTION	DIFFICULT WORD OR SENTENCE	PROBLEM AREA	RESPONDENT EXPLANATION OR SUGGESTION
Page 8 – SECTION 3 **Terminal, incurable, or irreversible conditions** ***Definitions of terms used in this section***	'terminal, incurable or irreversible…'	One of the definitions of the terms is irreversible, for example our people may not understand that term. The example you've got here on the form itself says, "an example of an irreversible illness is Motor Neurone Disease, which progressively paralyses the body". I don't know if our people would understand that {laughs}.	It would just be easier to have it in more simple terms. A suggestion would be to write it up as, "something's wrong and they can't change it back or they can't fix it". Something as simple like that, would be something our people would understand better. That's just an example.

ADVANCE HEALTH DIRECTIVE *[Form 4] – Torres Strait Islander P.5*

AHD PAGE & SECTION	DIFFICULT WORD OR SENTENCE	PROBLEM AREA	RESPONDENT EXPLANATION OR SUGGESTION
Page 4 – EXPLANATORY NOTES **Page 17 – SECTION 7: Appointing an attorney for personal/health matters** **Page 19 – SECTION 8: Statement of understanding and signature** **Page 20 – SECTION 9:**	The words 'revoke' and 'clause' has been used again.	'Close', see I can't even say it {laughs}	

ADVANCE HEALTH DIRECTIVE *[Form 4] – Torres Strait Islander P.6*

AHD PAGE & SECTION	DIFFICULT WORD OR SENTENCE	PROBLEM AREA	RESPONDENT EXPLANATION OR SUGGESTION
Page 3 – EXPLANATORY NOTES ***What do I need to consider before making an Advance Health Directive?*** ***[last paragraph]***	Where it says 'a request for euthanasia would not be followed'.	They need to say what that is, because for our mob, they may not know what that means.	That needs to be possibly explained somewhere.
Page 5 – EXPLANATORY NOTES ***What do I do with the completed document?*** ***[last sentence]***	In here it says 'you may also wish to carry a card in your purse …'	People are gonna say, 'What card?' What's the card? So it doesn't really say where you get that card from and they're making reference to a card.	They might need to have an image here, a diagram or some sort of image about the card. A picture of the card, cause they're just making reference to a card and then they'll probably wanna know where do you get the card from, where a copy can be obtained. So if they had an image of the card here, so they can see what that card looks like. But I thought this was pretty good…
Page 9 – SECTION 3: Terminal, incurable, or irreversible conditions ***[Definitions of terms used in this section]***		So I really like this number three and it's talking about all that stuff, you know what I was talking about in the previous page as well, it has the definition of terms and that's was what was missing in the other one.	
Page 9 – SECTION 3: Terminal, incurable, or irreversible conditions ***Number 7. I request that:***	'any treatment that might obstruct my natural dying either not be initiated or be stopped.'	I think the same thing, it needs to be straight forward I think, cause that's a bit confusing. Obstruct my natural dying either not be initiated, I don't know, that's like going around in circles there again.	It's not clear yeah.
Page 13 – SECTION 4:	Personal statement, section four, point	Yeah, the example, I think it needs to	So they need to make it simple

Personal Statement ***[Number 15]. Record your wishes here.***	15. Record your wishes here.	be in more simple English than something that's airy fairy, when we're talking about 'mere existence', just the use of that language, 'this hastens my death'.	language, cause I think in some ways kind of like, ..uh, my mere existence, does that mean that I'm not meant to be here and this hastens my death. I think that's a bit insulting in some way, it's demeaning the value of human life in general.
Page 18 – SECTION 7: **Appointing and attorney for personal/health matters.** **Number 33. *Note:** ***The Powers of Attorney Act 1998***	Page 18, number 33.	I just wanted to put that there, you know the Power of Attorney, they had an Act there, they didn't say what it was, there should've been a note in the previous one that said what that Act was.	That's a pretty straight forward document.

Advance Health Directive: Murri respondents

ADVANCE HEALTH DIRECTIVE ***[Form 4] – Murri P.2***

AHD PAGE & SECTION	DIFFICULT WORD OR SENTENCE	PROBLEM AREA	RESPONDENT EXPLANATION OR SUGGESTION
Page 17 – SECTION 7: Appointing an attorney for personal/health matters ***Number 28. Do you wish to appoint an attorney for personal/health matters?***	Note: the person/s you appoint must be over the age of eighteen and must not be your current paid carer or health-care provider.	Well I know what a health care provider is, working in the health field for 30 odd years, but then, not be your current paid carer, does that mean if I'm being paid by Centrelink as a carer for my mum, does that apply to me? I'm not sure about that.	
Page 19 – SECTION 8: Statement of understanding and signature ***[second paragraph]***	You must sign the document in front of qualified witnesses, that is someone who is a justice of the peace, a commissioner for declarations, a lawyer or a notary public.	So I don't know what that is. … I don't even know who I'd go to or where I'd go regarding the commissioner for declarations what's that? … the notary public, I don't know who a notary public is.	The whole lot there needs to just be simplified a little bit more. So just to sort of have it spelt out a little bit, just broken down a little bit, especially for Murri people.

		And then I put again, the witness must be 21 years or over and not your attorney, a relation of yours or of your attorney, your current paid carer or your current health provider. So that can't be my providers, that's what it's saying see, that's what I wanted to clarify, I don't know.	

ADVANCE HEALTH DIRECTIVE *[Form 4] – Murri P.3*

AHD PAGE & SECTION	DIFFICULT WORD OR SENTENCE	PROBLEM AREA	RESPONDENT EXPLANATION OR SUGGESTION
Page 3 – EXPLANATORY NOTES: ***What is an Advance Health Directive?***	What is an Advance Health Directive?	And again, like I said before, Advance Health Directive, I don't really understand what Advance Health Directive means. *So even reading where it says, 'what is an Advance Health Directive? Even reading the explanations for that … you still don't understand what that means?* I still don't understand what this Advance Health Directive document is.	
Page 4 – EXPLANATORY NOTES:	Your witness must be 21 years of age or over and must be the justice of the	I don't know what that is.	

Who is involved in completing this document? [Your witness must complete Section 9].	peace, commissioner for declaration, lawyer or notary public. Yep, notary public or what you call him.		
Page 6 – SECTION 1: Your details ***[number 1]***	This directive should never be used if I have the capacity to speak competently for myself …	So are they're saying if I'm still able to know what's going on with myself then they shouldn't follow through what I said?	Yeah I reckon, that should be said a bit more simple, simplify it more.
Page 16 – SECTION 6: Enduring power of attorney for personal health matters ***How do you prefer that your attorneys make their decisions? [number 25]***	how do you prefer that your attorney make their decisions, severally, jointly …	Just that, I don't know what they mean by that, so I just don't know.	

ADVANCE HEALTH DIRECTIVE ***[Form 4] – Murri P.4***

AHD PAGE & SECTION	DIFFICULT WORD OR SENTENCE	PROBLEM AREA	RESPONDENT EXPLANATION OR SUGGESTION
Page 8 – SECTION 3: Terminal, incurable, or irreversible conditions ***Definition of terms used in this section***	Yeah, I just thought that page 8, section three with all the definitions.	It was really helpful when I was reading it and yeah it will help with other people who are completing the form. *So you think that a Murri off the street can pick this up and read it clearly?* Um, I think people would take some time you know, because it is at a sensitive time for people, yeah it depends on where the person is emotionally at. But yeah if all the families involved in understanding that, I think it would be a good form to have and an easy form to complete.	I think with … page 8, like I mentioned before is a handy page to have. It has the definitions and you can keep referring back to it and going over it, so that's a good thing to have in there. So yeah, I think people would be able to do that, well I did, I referred back.

Page 13 – SECTION 4: Personal statement ***Number 16. Do you wish to mention any people who are not to be contacted about your treatment?***	Just the personal statement, question 16, 'Do you wish to mention any people who are not to be contacted …'	I guess just remembering when this is gonna take effect, people will be quite emotional and if it's already written down clearly then, um, people can't go against the wishes that you've written down. I think just respecting the person's wishes there, you know, at a time when it can be quite emotional for everyone.	Um, yeah I just thought that's a good question to have.

Page 9 – Witness's certificate ***[number 36(b)]***	'notary public' 'commissioner for declarations …'	I'm not sure what that means, the 'notary public'.	*So you think that might need to be made clearer?* Yeah, even any of those terms in that section (b) there, just to be clearer somewhere in the document. *Have like a definition about … who they are?…* Who they are, mmm. But apart from that I think this form would be helpful.

ADVANCE HEALTH DIRECTIVE *[Form 4] – Murri P.5*

AHD PAGE & SECTION	DIFFICULT WORD OR SENTENCE	PROBLEM AREA	RESPONDENT EXPLANATION OR SUGGESTION
Page 3 – EXPLANATORY NOTES ***What do I need to consider before making an Advance Health***	'However a request for euthanasia would not be followed, as this would be in breach of the law'	I don't know if some of our people would understand what that means.. *They wouldn't know what euthanasia*	Yeah, if that could be simplified a bit.

Directive? ***[last paragraph]***		*is?* … I think some people might not understand what that word means.	
Page 4 – EXPLANATORY NOTES ***Who is involved in completing this document?*** ***Your witness must complete Section 9.***	'a notary public'.	I'm not too sure if some people would understand what a 'notary public' is.	Explain what a 'notary public' is. Yeah … somebody who's not familiar with this might look at it and sort of jump back and say, "what's a notary public?". So maybe if that can be explained.
Page 9 – SECTION 3: Terminal, incurable,or irreversible conditions ***The directions you give in this section apply only if, in the opinion of your treating medical practitioner:***	'… the continued use of life-sustaining measures'.	Just clarify it yeah, what are life-sustaining measures yeah, cause some people might be scared to go on machines, I mean not scared but.	I think that could be clarified, whether it's life-sustaining measures with medication or life support machines or um, I don't know.
Page 10 – SECTION 3: Terminal, incurable,or irreversible conditions ***[Number 8. If I am in the terminal phase of an incurable illness: first two boxes]***	'I do not want cardiopulmonary resuscitation. '	Hang on 'cardiopulmonary resuscitation', that's a huge word eh? I know, it's gotta do with the heart and everything, but people are gonna be frightened by that word, I think, you know. That word is used quite a bit through the rest of the document too.	Just put it in simple terms, explain what it is and people can read it and not have to worry. … people can see that and maybe get a fright, what's this word?, what's it mean? So if that can be simplified.
Page 23 – SECTION 11: Review of this document	Review of this document: 1,2 and 3, 'I affirm that I have reviewed this document'…	Some people might not know what the word 'affirm' is … Some people mightn't know what affirmations are.	So they need to explain the word 'affirm' as well.