

LOST IN TRANSLATION: OVERCOMING PRACTICAL BARRIERS IN THE OPERATION OF ADVANCE CARE DIRECTIVES AND ENDURING POWERS OF ATTORNEY IN SOUTH AUSTRALIA

ABSTRACT

Declining capacity can be a companion of the ageing process, and under the historic paternalistic model of healthcare, once capacity was lost so too was the voice of the individual. Both an Advance Care Directive ('ACD') and an Enduring Power of Attorney ('EPA') are legal instruments created to serve as safeguards to ensure an individual's decision-making autonomy is supported and retained for as long as possible. This article begins with a discussion of the policy and recognition of fundamental rights that shaped the development of the ACD and EPA frameworks. Following this, two practical barriers which obstruct the proper function of ACDs and EPAs in South Australia will be examined. First, the distinct language adopted by each instrument hinders community understanding and professional enforcement in clinical settings. Second, the practical barriers associated with capacity and its assessment significantly undermine the enforcement of ACDs and EPAs. This is further exacerbated by clear discrepancies in the legal definition of capacity and the complex interplay of law, medicine, and ethics. In light of these barriers, it is time to consider reforms to legislation and practice to ensure ACDs and EPAs retain their proper purpose and function following activation.

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I INTRODUCTION

With the largest ageing population in Australia, it is unsurprising that future planning for finances and medical interventions is important to South Australians.¹ Both an Advance Care Directive ('ACD') and an Enduring Power of Attorney ('EPA') are legal instruments created for the cognitive decline which may accompany ageing.² In a society that promotes individual autonomy and agency, these legal instruments aim to serve as safeguards to ensure an individual's decision-making autonomy is supported and retained for as long as possible. Striking a balance between realistic future planning, unknown healthcare challenges, autonomy and the complexities of human relationships, represents a significant challenge to any regulatory framework. This article will consider two key instruments, the ACD and the EPA, and ask whether they have effectively risen to this challenge. It will be argued that whilst the underlying rationale for both of these instruments is appropriate and represents a significant advancement in support of autonomous decision-making, they fall short of achieving this goal in a consistent manner. Despite the carefully constructed regulatory framework and underlying principled approach, the purpose of both instruments has been lost in translation, failing to comprehensively protect vulnerable individuals who have lost capacity to make their own decisions.

This analysis begins with a discussion of the policy and recognition of fundamental rights that shaped the development of the ACD and EPA frameworks. Following this, two practical barriers which have served to obstruct the proper function of ACDs and EPAs in South Australia will be examined. It will be demonstrated that despite an appropriately values-driven foundation, both of these instruments have failed to meet their policy and practical objectives. Further, it will be argued that reform is crucial if the operation of these instruments is to coincide with their basic principles. Such reform is long overdue. The current ACD framework is largely procedural and fails to meaningfully engage with the principles it purports to protect. On the other hand, the EPA legislation lacks prescriptive and proscriptive provisions — which has created an inherently vulnerable instrument subject to exploitation. In addition, when considering the instruments together, there are two broad areas of concern.

First, both instruments adopt a distinct language, which ascribes relevant parties and their role in the operation of the instrument. Our discussion will demonstrate that there is a general lack of understanding of terminology and the roles undertaken by relevant parties, which serves as a barrier to both community understanding and professional enforcement in clinical settings. Specifically, the role of a substitute decision-maker ('SDM') for an ACD and an attorney for an EPA, are theoretically quite different. The respective roles are often conflated by the general community

¹ SA Health, *South Australia's Plan for Ageing Well 2020-2025* (Report, 2020) 5.

² It is important to note here, that both instruments apply in all situations where there has been a loss of capacity and are not confined to the cognitive decline that can be associated with ageing.

and legal and medical professionals, leading to negative impacts on the operation of an active ACD or EPA.

Second, the practical barriers associated with capacity and its assessment significantly undermine the enforcement of ACDs and EPAs. This is further exacerbated by clear discrepancies in the definition of capacity. While the ACD legislation includes a statutory definition, the EPA legislation remains completely reliant upon the common law to inform its definition. This has led to different interpretations and assessments of capacity, creating a risk that an individual's ability to actively participate in crucial health and financial decisions will be taken away prematurely, thereby impeding upon their agency and autonomy. From this analysis, it is clear that the time has come for meaningful engagement with these shortcomings and for both instruments to be reviewed. There is a need for legislative clarity and an introduction of measures to improve community and professional understandings of both ACDs and EPAs. Once this occurs, there will be meaningful protection of the interests of some of the most vulnerable members of society.

II THE DEVELOPMENT OF ADVANCE CARE DIRECTIVES AND ENDURING POWERS OF ATTORNEYS

Declining capacity can be a companion of the ageing process, and under the historic paternalistic model of healthcare, once capacity was lost so too was the voice of the individual. It was deemed appropriate for others to step in to make decisions on an individual's behalf under a 'best interests' framework, that was most commonly aligned with biological best interests and guided by professional, clinical assessments. There has, however, been a changing ideological landscape of death, disease and future planning, along with an increasing emphasis on the recognition of individual values and preferences. It is this shift that has prompted legislative reform to enhance the operation and applicability of ACDs and EPAs. Over time, the individual has been placed at the centre of decision-making and the recognition of fundamental rights of autonomy, agency, self-determination, equality and self-participation have combined to form the foundation of advance planning policies and laws.

The policy underpinning ACDs and EPAs is characterised as values-based, and aims to maintain individual autonomy in decisions relating to personal affairs.³ Both instruments aim to facilitate open channels of communication in relation to ageing,

³ See *Advance Care Directives Act 2013* (SA) ss 9–10 ('ACD Act'). Due to the lack of specificity in the *Powers of Attorney and Agency Act 1984* (SA), the values-driven purpose of an EPA is best exemplified through its practical operation: see GE Dal Pont, *Powers of Attorney* (LexisNexis Butterworths, 2nd ed, 2014) 16 [1.26]. Further, EPAs have been characterised as 'an important expression of autonomy': Law Reform Committee, Parliament of Victoria, *Inquiry into Powers of Attorney: Final Report of the Victorian Parliament Law Reform Committee* (Parliamentary Paper No 352, August 2010) 22, citing Evidence to Law Reform Committee, Parliament of Victoria, Melbourne, 1 October 2009, 3 (Laura Helm, Policy Adviser, Law Institute of Victoria).

declining cognition and death. In a society which embraces self-determination and autonomy in decision-making, ACDs and EPAs are vital in promoting these fundamental rights, but without some further reform, they will continue to fall short of meeting their stated objectives.

A *Advance Care Directives*

South Australia has been proactive in the development of a legislative framework for ACDs. In 2007, the South Australian Government commissioned the Advance Directives Review Committee to evaluate the governing law and policy in this area. In order to undertake this assessment, the Advance Directives Review Committee was tasked

[t]o make recommendations for a simpler, more consistent and accessible system of advance directives that will ensure the proper protection of citizens whose mental capacity becomes compromised and increase people's capacity to direct how they want their finances managed, where and how they want to live and what treatment they want to be offered when they are unable to speak for themselves.⁴

Therefore, it can be seen from the outset, a key tenet guiding reform of South Australia's ACDs was to adopt a consistent approach to future healthcare planning, empowering individuals with capacity to exercise autonomy and maintain a voice in medical and lifestyle decision-making when they lose capacity. This was but the first step in the introduction of the *Advance Care Directives Act 2013 (SA)* (*ACD Act*), which aimed to implement a consistent approach to advance care planning and enhance community access to ACDs. This was intended to be achieved through the introduction of a single form that facilitates conversations surrounding an individual's wishes and values with respect to healthcare.⁵ The focus here was to empower individuals through clear communication of their preferences, and in this way, ACDs were designed to provide individuals with a degree of control, certainty and comfort by articulating their autonomous wishes and preferences. This approach is not confined to South Australia, and it is just one example of a global trend, described by Charles Sabatino in his analysis of the evolution of advance care planning in the United States in the following terms: 'formal advance directives have become public policy's choice for championing patient autonomy in

⁴ Margaret Brown, 'The South Australian *Advance Care Directives Act 2013*: How Has the Decision-Making Paradigm Changed?' (2018) 25(2) *Journal of Law and Medicine* 538, 540. See also Advance Directives Review Committee, *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* (Report, 2008) <https://webarchive.nla.gov.au/awa/20111209043434/http://pandora.nla.gov.au/pan/131091/20111209-1502/www.agd.sa.gov.au/news/pdfs/2009/AG_Report_1_final_300808.pdf>.

⁵ See South Australia, *Parliamentary Debates*, House of Assembly, 17 October 2012, 3227 (John David Hill, Minister for Health and Ageing) ('October Debates'). See also *ACD Act* (n 3) s 9(b).

the face of incapacity'.⁶ Similarly, Australia's advance care planning policy has predominantly relied upon the enduring nature of ACDs and EPAs beyond incapacity to promote and safeguard autonomy. This discussion regarding the South Australian experience, whilst narrow in regard to the specific provisions, has broad application given the emphasis on guiding principles and the core goal of enabling participation in future decisions.

Introduced into Parliament in 2012 and formally passed in 2013, the 'new laws' in the *ACD Act* were reinforced by a set of 'overarching principles',⁷ which represent the underlying policy objectives clearly laid out in the *ACD Act*.⁸ These principles enumerated fundamental rights and concepts including:

- the presumption of capacity;⁹
- autonomy in decision-making;¹⁰
- access to supported decision-making when required;¹¹
- self-determination;¹²
- recognition and acknowledgement of cultural values, ethnicity, linguistic differences, religious or spiritual views, background and history;¹³ and
- the 'will, preferences and rights' decision-making model, requiring an SDM to make a decision that the individual would have made, having regard to the available information and wishes and values.¹⁴

The legislation was the first state response to the *National Framework for Advance Care Directives* ('*National Framework*'), a 2011 national initiative aimed at supporting a meaningful approach to advance care planning. The *National Framework* was aptly described as an aspirational document and explained that 'ACDs are founded on respect for personal autonomy and are intended to ensure a person's preferences can be honoured during any period of temporary or permanent impaired decision-making capacity, not only at the end of life'.¹⁵

⁶ Charles P Sabatino, 'The Evolution of Health Care Advance Planning Law and Policy' (2010) 88(2) *The Milbank Quarterly* 211, 219.

⁷ October Debates (n 5) 3228 (John David Hill, Minister for Health and Ageing).

⁸ *ACD Act* (n 3) s 10.

⁹ *Ibid* s 10(c).

¹⁰ *Ibid* ss 10(a)–(b), (d).

¹¹ *Ibid* s 10(d).

¹² *Ibid* s 10(e).

¹³ *Ibid*.

¹⁴ Australian Law Reform Commission, *Equality, Capacity and Disability in Commonwealth Laws: Final Report* (Report No 124, August 2014) 75; *ibid* s 10(g).

¹⁵ The Clinical, Technical and Ethical Principal Committee of the Australian Health Ministers' Advisory Council, *A National Framework for Advance Care Directives* (Report, September 2011) 5 [2.3] ('*National Framework*').

A review commissioned by the South Australian Department of Health and Wellbeing in 2019 revealed ongoing issues of practicality in the enforcement of ACDs.¹⁶ In particular, there was widespread support for public consultation to be undertaken to examine how individuals lacking capacity can engage in the process of creating an ACD.¹⁷ This identified a significant gap in both policy and practice — the implementation of a clear process by which incapacitated individuals can articulate wishes, preferences and values. Despite the review's recommendation for public consultation, there have been no subsequent reforms to address this gap. It is relevant to note that public consultation regarding the Advance Care Directives (Review) Amendment Bill 2021 (SA) recently closed on the 3 August 2021.¹⁸ As part of this consultation, comments were sought on ways in which an incapacitated individual can convey directives.¹⁹ This may be an opportune time for a transition from a substitute decision-making (a model whereby an individual 'steps into the shoes' of another and makes a decision based on known will and preferences) to a supported decision-making model, under which the individual with declining capacity is aided in their decision-making process. It also provides scope to address fluctuating capacity in the context of executing and revoking ACDs.

One particular policy objective will be examined in greater depth — that of safeguarding an individual's autonomy, despite a decline in or total loss of capacity. ACDs are designed to operate when an individual has lost capacity, giving voice to their identified and stated preferences. This is a distinct feature, which also applies to EPAs, enabling the preservation of autonomy beyond the loss of capacity. The central feature of an ACD is the recognition of values and wishes of an individual made at a time when capacity is not lacking and provides the roadmap for an SDM for future medical decisions and lifestyle preferences. In practice, this also translates into a rights-based instrument, whereby an SDM is reasonably equipped with the necessary information to 'step into the shoes' of the incapacitated individual when making decisions.²⁰

An ACD's applicability following the loss of capacity can be likened to a double-edged sword. On the one hand, it ensures the individual's values and wishes are preserved, thereby maintaining a degree of autonomy. On the other, autonomy is endangered as the SDM retains complete authority over decision-making, which may be exploited. Although the legislation advocates for the consideration of values

¹⁶ Wendy Lacey, *Report on the Review of the Advance Care Directives Act 2013 (SA)* (Report, Department of Health and Wellbeing, June 2019).

¹⁷ *Ibid* 89–90.

¹⁸ 'Have Your Say on the Advance Care Directives (Review) Amendment Bill 2021', *yourSay* (Web Page, 2021) <<https://yoursay.sa.gov.au/advance-care-directives>>.

¹⁹ *Ibid*. See also SA Health, 'Advance Care Directives (Review) Amendment Bill 2021' (Discussion Paper, June 2021) 18.

²⁰ It is important to recognise from the outset that this is effectively only a guide as there are specific limits placed on what constitutes a binding decision under the *ACD Act*. The legislation recognises that the only binding directive is a refusal of specific medical treatment: *ACD Act* (n 3) s 19.

and wishes — a ‘step into the shoes’ decision-making approach — one cannot guarantee that this will be the case in practice.²¹ This inherent vulnerability of the instrument introduces the risk of either benign or direct abuse perpetrated by the SDM.²² It is both a risk and practical impediment common to ACDs and EPAs.²³ However, in the context of ACDs, it could be argued the shift away from a substitute decision-making model, to a supported decision-making model negates this risk of abuse. This shift is reinforced in the legislative guiding principles, which advocate for the provision of supports to enable an individual to retain their decision-making autonomy for as long as possible.²⁴ In addition, a medical professional’s clinical judgement and advice may, through the provision of oversight and guidance, act as a safeguard against unfavourable decisions made by an SDM. It must be acknowledged that this does not completely protect against, nor prevent departures from, a patient’s preferences towards a more traditional best interests decision-making model. It is this potential that is afforded some protection by the binding nature of refusal of identified medical treatment.

Another potential challenge to the effective application of an ACD is a situation where an individual has fluctuating capacity, meaning that whilst they may temporarily be unable to make decisions, their loss of capacity is either short-lived or intermittent. A significant advancement in support of individuals in this position was the recognition of ‘impaired decision-making capacity’ under the *ACD Act*.²⁵ For the purposes of the *ACD Act*, it is recognised that ‘a person may fluctuate between having impaired decision-making capacity and full decision-making capacity’,²⁶ meaning the triggering of an ACD and subsequent empowerment of the SDM is not meant as a ‘once and for all’ decision. In contrast to ACDs, the absence of a definition of capacity and failure to recognise fluctuating capacity in the legislative framework

²¹ Indeed, the legislative instrument itself limits the scope of the ACD with its narrow definition of binding provisions. Refusal of a particular health care is characterised as a binding provision, whilst the remaining provisions are taken to be non-binding: see *ACD Act* (n 3) ss 19(1), (3).

²² ‘Benign’ abuse refers to those situations in which an SDM steps in and overrides the preferences of the decision-maker based upon their own values or determination of what is in the best interests of the individual.

²³ In a recent review of Powers of Attorney in South Australia, the South Australian Law Reform Institute (‘SALRI’) revealed EPAs — which are activated at the point in which the principal loses capacity — serve as a vehicle for abuse. SALRI received many examples of financial abuse of EPAs perpetrated by the attorney: Sylvia Villios et al, *Valuable Instrument or the Single Most Abused Legal Document in our Judicial System? A Review of the Role and Operation of Enduring Powers of Attorney in South Australia* (Report No 15, South Australian Law Reform Institute, 2020) 230–8 (‘SALRI’s Final Report’).

²⁴ *ACD Act* (n 3) s 10(d).

²⁵ *Ibid* s 7.

²⁶ *Ibid* s 7(2)(c).

for Powers of Attorney ('POAs') exposes the individual to a risk of ongoing abuse and disempowerment, leading to detrimental practical implications.²⁷

The introduction of the *ACD Act* signalled a shift away from medical paternalism whereby the doctor dictates healthcare, to a new paradigm of advance planning and decision-making models facilitating person-centred care.²⁸ The underlying policy guiding its implementation is a microcosm of a modern, liberal society which embraces and champions autonomy. Further, moral accountability to respect and uphold an individual's autonomy could be argued as the key driving force behind active participation and enforcement of ACDs. However, while ideologically sound, given its procedural nature, there are concerns that the *ACD Act* is a blunt instrument when it comes to protecting or empowering values.

B *Enduring Powers of Attorney*

POAs form part of the advance planning suite of instruments. For the purposes of this article, EPAs will be discussed. An EPA is a legal instrument whereby the principal confers authority upon an appointed attorney to make financial decisions on their behalf. At the point of execution, an EPA may be activated immediately, or upon the loss of the principal's capacity. The issues raised in this article pertain to EPAs activated upon the loss of the principal's capacity.

The common law has recognised POAs for centuries.²⁹ Traditionally, POAs have had a commercial use, enabling one individual to undertake a specified financial transaction on behalf of another.³⁰ The need for statutory codification and governance of POAs was prompted by two factors — an increasingly affluent middle class and greater life expectancy.³¹ These factors highlighted the importance of a POA to act as a necessary safeguard to ensure the financial wellbeing of an individual is not lost or diminished. Increased utility over time led to the introduction of legislation governing the creation, use and termination of a POA. In addition, national reforms were prompted by the high prevalence of community misunderstanding concerning the continued operation of an EPA following loss of the principal's capacity.³² As

²⁷ See below Part IV for a discussion of this in the context of capacity assessments.

²⁸ October Debates (n 5) 3229 (John David Hill, Minister for Health and Ageing).

²⁹ Berna Collier and Chris Coyne, 'An Overview of the Relevant Legal Principles' in Berna Collier, Chris Coyne and Karen Sullivan (eds), *Mental Capacity: Powers of Attorney and Advance Health Directives* (Federation Press, 2005) 1, 2.

³⁰ *Ibid* 3.

³¹ Law Reform Committee, Parliament of Victoria, *Inquiry into Powers of Attorney: Final Report of the Victorian Parliament Law Reform Committee* (Parliamentary Paper No 352, August 2010) 11.

³² Australian Law Reform Commission, *Community Law Reform for the Australian Capital Territory: Third Report: Enduring Powers of Attorney* (Report No 47, 1988) 5 ('*Community Law Reform for the Australian Capital Territory*'); Robin Creyke, 'Enduring Powers of Attorney: Cinderella Story of the 80s' (1991) 21(1) *University of Western Australia Law Review* 122, 124.

a result, the continued validity of an EPA became the practical norm, leading to a number of reviews for reforms of Australian POA laws.³³

The existence of an EPA has been described as a ‘relatively recent statutory innovation’,³⁴ which has ‘served to further extend [a POA’s] utility’.³⁵ The conception of an EPA denoted greater understandings of diminishing capacity as part of the ageing process and pre-empted the need for wealth and asset protection.

Since its enactment in 1984, South Australia’s *Powers of Attorney and Agency Act 1984* (SA) (*POA Act*), has only been subject to three minor amendments.³⁶ Concise in its form — a total of nine pages — its brevity is telling. The absence of statutory clarity with respect to its applicability and enforcement highlights significant gaps. These are often realised in its practical operation. As noted by Gino Dal Pont, ‘the antiquity of the law governing powers of attorney does not shield the need to engage in reform, whether minor or wholesale’.³⁷ This is especially the case for South Australia’s *POA Act*, which is in much need of reform.

Most recently in 2020, the South Australian Law Reform Institute (‘SALRI’) undertook a comprehensive review of the role and operation of EPAs in South Australia (‘SALRI’s Final Report’).³⁸ The findings and recommendations of SALRI’s Final Report reveal the practical barriers impacting the enforcement of ACDs and EPAs are indistinguishable. The review identified a number of issues. Among them, and of relevance to this discussion, the absence of a legislative definition of ‘capacity’ or ‘impaired decision-making capacity’ within the *POA Act* was identified as a significant exclusion.³⁹ In light of an EPA’s continued applicabil-

³³ Robin Creyke, ‘Privatising Guardianship: The EPA Alternative’ (1993) 15(1) *Adelaide Law Review* 79, 85–6. See, eg: *Community Law Reform for the Australian Capital Territory* (n 32); Law Reform Commission of New South Wales, *Powers of Attorney and Unsoundness of Body or Mind* (Report No 20, 1975); Law Reform Committee of South Australia, *Relating to Powers of Attorney* (Report No 47, 1981); Law Reform Commission of Tasmania, *Report on Powers of Attorney* (Report No 39, 1984); Law Reform Commission of Victoria, *Enduring Powers of Management* (Report No 35, 1990).

³⁴ Dal Pont (n 3) 33 [1.58].

³⁵ *Ibid* 4 [1.1].

³⁶ For an in-depth overview of these amendments, see SALRI’s Final Report (n 23) 46 [3.1.3]. Three minor amendments were made in 1988, 2006 and 2013: *Powers of Attorney and Agency Act 1984* (SA) ss 6, 11, as amended by *Powers of Attorney and Agency Act Amendment Act 1988* (SA) ss 2, 3; *Powers of Attorney and Agency Act 1984* (SA) s 9, as amended by *Statutes Amendment (New Rules of Civil Procedure) Act 2006* (SA) s 186; *Powers of Attorney and Agency Act 1984* (SA) s 4, as amended by *Powers of Attorney and Agency (Interstate Powers of Attorney) Amendment Act 2013* (SA) s 3.

³⁷ Dal Pont (n 3) 5 [1.1].

³⁸ See SALRI’s Final Report (n 23): completed in December 2020, it was published in January 2021.

³⁹ See SALRI’s Final Report (n 23) 128.

ity following a principal's loss of capacity, this exclusion causes practical difficulties for timely and necessary activation of EPAs. Further, it creates an opportunity for misuse, as 'financial abuse is contingent upon access to assets. EPAs provide such access'.⁴⁰

Much like ACDs, in principle, an EPA serves to preserve autonomy by allowing an individual to confer authority to an attorney to make specific financial decisions/transactions once capacity is lost. However, its rigid application in practice, combined with the absence of statutory clarity and direction, undermines its utility and diminishes its protective capability. A further complicating factor is the irreversible nature of a determination of incapacity. In practice, capacity at activation of an EPA is treated as a 'once and for all' determination, which directly contravenes the safeguarding purpose of an EPA. This is also contrary to the ACD approach which recognises fluctuating capacity and advocates for supported decision-making.

The importance of ACDs and EPAs is apparent. However, both instruments and their governing legislation have flaws which need to be addressed, such that their purpose is not lost in translation once activated and enforced. Most notably, in the context of ACDs, the procedural nature of legislation and the lack of uniform terminology and laws across Australia compromises their proper function. This is equally applicable to EPAs, in which the absence of legislative clarity and direction governing their use and enforcement renders the same outcome. Both instruments share a common challenge, which is capable of undermining its fundamental policy objectives — the assessment of capacity. When an instrument's activation is contingent upon a subjective variable, in this case capacity or lack thereof, it is inevitable that this variable becomes the primary barrier to its proper function. This strengthens the need for clear and unambiguous governing legislation and established translational pathways to ensure activation of the instrument is necessary.

Reform of law and practice is necessary to address the barriers created by the determinate variable prompting their activation — loss of capacity.

III LANGUAGE AND TERMINOLOGY

Legal terminology can be confusing and ambiguous. This is especially the case for members of the community who have never engaged with this type of language. This is of particular concern in the context of ACDs and EPAs which are purportedly aimed at facilitating effective communication, yet are framed in complicated legal language, unfamiliar to those who are supposed to be or are the target of the protective umbrella of the legislation. ACDs and EPAs each have a distinct set of terms, which form part of a language relevant to the specific instrument. Community understanding of these terms, such as 'substitute decision-maker', 'attorney' and

⁴⁰ Cheryl Tilse et al, 'Enduring Powers of Attorney: Promoting Attorneys' Accountability as Substitute Decision Makers' (2014) 33(3) *Australasian Journal on Ageing* 193, 193 ('Promoting Attorneys' Accountability').

‘enduring powers of attorney’ is lacking.⁴¹ As a result, members of the community have access to an instrument which is aimed at protecting their foundational right of decision-making autonomy, yet lack the necessary tools of understanding to truly benefit from these instruments. This represents a significant regulatory gap which must be addressed.

An understanding of these concepts is crucial to the application of the instrument, as the ‘utility of [the instrument] will depend on whether the people who are involved in these decisions know what the law permits and are able to operationalise those rights and/or duties’.⁴² Consistent with this observation, the utility of ACDs and EPAs are diminished when an SDM or an attorney lacks knowledge and understanding of their role, duties and boundaries.⁴³ This was revealed in SALRI’s Final Report.⁴⁴ In many instances where a duty or duties were breached, this was a product of genuine misunderstanding on behalf of the attorney.⁴⁵

The specific terminology governing ACDs and POAs can be described as the ‘formal law’.⁴⁶ The formal law serves a number of functions, most importantly, it introduces the framework which establishes and regulates the use of the specific legal instrument. If there is a lack of clarity in the language employed by the formal law in the context of end-of-life decision-making, this increases the risk

⁴¹ This was made apparent during a series of interviews conducted by the research team: NHMRC Partnership Grant, *Investigating the Inclusion of Vulnerable Populations in Advance Care Planning: Developing Complex and Sensitive Public Policy* (APP1133407 Partnership Project, 2017–22). In the context of EPAs, see also SALRI’s Final Report (n 23) 380–1, 387, 389–90.

⁴² Cheryl Tilse et al, ‘Community Knowledge of Law on End-of-Life Decision-Making: An Australian Telephone Survey’ (2019) 27(2) *Journal of Law and Medicine* 399, 401 (‘Community Knowledge of Law’).

⁴³ Importantly, this also extends to the differences in the purpose and duties of an SDM and an attorney.

⁴⁴ SALRI’s Final Report (n 23) 71–3.

⁴⁵ Despite this finding, we note that many indiscretions are deliberate actions on behalf of an attorney, who is aware of their misuse of power. During consultation, an example in which a misunderstanding led to a breach of duties was provided:

SALRI was told of one rural example where an adult child who was an attorney for their mother, drove each week a considerable distance to visit their mother in a retirement home (the suggestion was the other siblings were disinterested). The attorney initially charged their weekly petrol expenses to see their mother under the EPA but later changed their car’s tyres and charged it to the EPA as the ‘wear and tear’ was said to be due to driving each week to see their parent and ‘it is what mum would have wanted’. The attorney finally bought a new car to replace their previous car and also charged it to the EPA as the ‘wear and tear’ was due to driving each week to see their parent and again ‘it is what mum would have wanted’.

SALRI’s Final Report (n 23) 72.

⁴⁶ See Katherine Curnow, ‘End-of-Life Decision-Making in a Health Services Setting: An Access to Justice Lens’ (2016) 23(4) *Journal of Law and Medicine* 864, 865.

for error. This point was emphasised by Katherine Curnow in her 2016 article analysing end-of-life decision-making through an ‘access to justice’ lens, where she noted ‘[t]he comprehensibility of formal legal principles to lay people ... [is a] significant factor ... in the certainty with which formal law can be applied in everyday interactions’.⁴⁷ In the absence of accessible language, the formal law around advance care planning becomes ambiguous. This gives rise to a misunderstanding of the relevant legal rules and rights which, in turn, translates into practical barriers in the creation and enforcement of valid ACDs and EPAs. The absence of legislative guidance and clarity, accompanied by a paucity of community educational material⁴⁸ explaining legal concepts and terms, creates an unnecessary barrier to access, whereby the purpose and function of an ACD and EPA is lost.

A *Advance Care Directives*

At its inception, the *National Framework* advocated for nationally consistent terminology.⁴⁹ It was proposed this ‘common language’ or ‘lexicon of common terms’ be uniformly adopted across Australia to promote community understanding and awareness.⁵⁰ Definitions of terms such as ‘advance care plan’, ‘substitute decision-maker’, ‘competence’, and ‘capacity’ are among those featured in the *National Framework*.⁵¹ Despite the inclusion of clear definitions, the prospect of uniform legislative adoption of this language and community understanding was overly ambitious. The fragmentation of advance care planning laws across Australia, coupled with inconsistency in the interpretation of the relevant language has rendered this prospect aspirational at best but in reality, unattainable.

In the absence of clearly defined — and understood — roles and responsibilities of participants in the advance care planning relationship, meaningful engagement in the process cannot be achieved.⁵² As explained by Cheryl Tilse et al, active and productive participation of individuals and their SDMs is ‘integral to achieving “patient-centred care”’ — a fundamental concept underlying the purpose of an ACD.⁵³ Where this does not occur, the core principles of advance care planning cannot be met. Without community understanding of the ACD ‘common language’

⁴⁷ Ibid 881.

⁴⁸ See Tilse et al, ‘Community Knowledge of Law’ (n 42) 411.

⁴⁹ See *National Framework* (n 15) 8.

⁵⁰ Ibid.

⁵¹ Ibid 8–12.

⁵² The *Report on the Review of the Advance Care Directives Act 2013 (SA)* reported that the barriers to translation of the *ACD Act* objectives into practice were primarily attributed to ‘levels of understanding and awareness of ACDs and their operation’: Lacey (n 16) 30 [2.1.17].

⁵³ Tilse et al, ‘Community Knowledge of Law’ (n 42) 401.

there can be no meaningful common process.⁵⁴ This represents a significant barrier that can only be overcome by a careful review of language accompanied by a community education program.

Curnow identified four factors influencing the role and operation of the formal law in medical decision-making — two of which are relevant to this discussion.⁵⁵ First, as raised above, the comprehensibility of relevant laws directly translates to the operationalisation of principles, rights and duties.⁵⁶ For example, the *National Framework* supports a decision-making model which results in a ‘contemporaneous substitute decision’.⁵⁷ Conceptually, this can be simply described as ‘stepping into the shoes’ of the individual. However, it also recognises that the decision considers ‘current or contemporary circumstances’, whilst reflecting the decision which the incapacitated individual would have made, if confronted with the same circumstances and provided with the same information.⁵⁸ Enforcement of this decision-making model is predicated on the assumption that an SDM understands this model, its enumeration and binding force within the formal law⁵⁹ and the means by which a contemporaneous decision can be achieved in practice. It could be argued this assumption is misplaced, whereby the SDM is unaware or lacks understanding of their duties. If this is the case, it emphasises the need to tailor legislative language to lay people. The use of simple, descriptive terms can provide clarity and certainty in the implementation of relevant laws.⁶⁰

Lack of understanding or knowledge of laws and principles is further complicated within a medical setting, as a medical professional must consider and balance a number of factors when making a decision on behalf of a patient with an ACD. Most notably, the complex interplay between clinical judgement, medical necessity and urgency, ethics, morals and legal obligations can create ambivalence, impacting on the enforcement of the formal law. Legal liability and risk of a lawsuit may have an impact on a medical professional’s execution of duties. This introduces additional ethical and legal issues to the medical decision-making paradigm. This is especially the case when clinical judgement, determined to be in the patient’s

⁵⁴ This was highlighted in the *Report on the Review of the Advance Care Directives Act 2013 (SA)*, whereby the community’s general understanding of ACDs was characterised as ‘low’: Lacey (n 16) 35 [3.1.5]. In response to this finding, the report recommended the reinstatement of one (or preferably two) positions within the Department for Health and Wellbeing, serving to promote community awareness and understanding of ACDs, offering education and professional development programs to employees of the ‘Local Health Networks’ and facilitating productive collaboration and consultation with key stakeholder groups: at 40.

⁵⁵ Curnow (n 46) 881–3.

⁵⁶ *Ibid* 881.

⁵⁷ *National Framework* (n 15) 10.

⁵⁸ *Ibid*.

⁵⁹ See *ACD Act* (n 3) s 10(g).

⁶⁰ Curnow (n 46) 881.

best interest, is in conflict with a directive contained within a valid ACD.⁶¹ In cases where the ACD is valid, the directive should prevail over the medical professional's clinical judgement.⁶² However, if the prevailing directive, for example refusal of treatment, will result in the patient's death, this creates an ethical dilemma for the medical professional,⁶³ whose default position of '[a]bove all [or first] do no harm'⁶⁴ is in conflict with allowing a patient to die. These cases produce a conflict between respect for patient autonomy — namely the directive to refuse treatment — and nonmaleficence and beneficence — two fundamental principles underpinning the role of a medical professional.⁶⁵ The product of this conflict creates a hierarchical structure of rights/principles, whereby the prevailing right/principle will be entirely dependent on the existence of a valid ACD. This may potentially give rise to defensive medicine.⁶⁶

The second challenge highlighted by Curnow is the fact that widespread lack of knowledge concerning applicable laws often means that the law is not properly enforced.⁶⁷ This extends to all medical professionals, in addition to family members or friends acting as the appointed SDM. Despite the risk of defensive medicine, there is evidence that indicates the formal law has a very tenuous role in medical professional decision-making.⁶⁸ This may be attributed to the possible influence of personal ethical, moral, social and religious values, uncertainty in the application of laws and their translation into practice and lack of knowledge of the law.⁶⁹ In addition, the decision-making paradigm of the medical professional incorporates clinical judgement about diagnosis and treatment. Therefore, for medical professionals, clinical judgement must be considered alongside the decision-making principles enumerated in the formal law and where there is a lack of familiarity or understanding of the formal law, then the predominant paradigm will be clinical judgement. The imperative that underpins the exercise of clinical judgement is unsurprisingly, the best interests of the patient, which may be confined to 'biological' best interests — that is, active clinical intervention and treatment. However, as discussed, this may not reflect the patient's view of their own best interests which could be the cessation

⁶¹ DL Denniss, 'Legal and Ethical Issues Associated with Advance Care Directives in an Australian Context' (2016) 46(12) *Internal Medicine Journal* 1375, 1378.

⁶² See *ibid.*

⁶³ *Ibid.*

⁶⁴ Ben A Rich, *Strange Bedfellows: How Medical Jurisprudence Has Influenced Medical Ethics and Medical Practice* (Kluwer Academic Publishers, 1st ed, 2002) 10.

⁶⁵ For a more detailed discussion of beneficence and nonmaleficence within a medical law context, see *ibid.*

⁶⁶ The term defensive medicine refers to the provision of healthcare where decisions are influenced by the perceived potential of litigation. This mode of medical decision-making removes the patient from the centre of the relationship.

⁶⁷ Curnow (n 46) 881–2. This may also extend to the specific practices adopted by hospitals when dealing with ACDs and their enforcement: see, eg, Lacey (n 16) 45–6.

⁶⁸ Curnow (n 46) 873.

⁶⁹ *Ibid* 872–3.

of treatment. In the absence of clear and carefully explained advance care planning, this preference is at risk of either being poorly articulated or ignored.

Despite the well-intentioned reforms to introduce nationally consistent and simple language, community and professional misunderstandings of ACDs highlight the need for further review and reform. Given an ACD is premised on communication and is specifically targeted to benefit lay members of the community, language and terminology must be tailored to ensure understanding.

B *Enduring Powers of Attorney*

Much like ACDs, the language and terminology concerning EPAs is met with confusion, concern and a lack of understanding.⁷⁰ This is especially the case for Aboriginal peoples,⁷¹ members of culturally and linguistically diverse communities, persons with a disability and older persons.⁷² SALRI's consultation revealed significant shortfalls in the understanding of the term 'attorney' and 'enduring power of attorney'.⁷³ As discussed in the context of ACDs above, where there is

⁷⁰ The following discussion pertaining to EPAs relies on our involvement as co-authors in SALRI's Final Report.

⁷¹ This article refers to 'Aboriginal peoples', as this discussion relates to both Aboriginal and Torres Strait Islander peoples. As noted by the Australian Institute of Aboriginal and Torres Strait Islander Studies in *The Little Red Yellow Black Book: An Introduction to Indigenous Australia*, we respect and acknowledge that Aboriginal peoples come from many different nations and use a variety of labels ... [for example] in South Australia we may use Nunga or Nyoongars in south-west Australia ... because they are names we gave ourselves and have meaning to us, as opposed to 'aboriginal' or 'indigenous' which were imposed on us and have only a very generic meaning in the English language.

Bruce Pascoe, David Horton and Australian Institute of Aboriginal and Torres Strait Islander Studies, *The Little Red Yellow Black Book: An Introduction to Indigenous Australia* (Aboriginal Studies Press, 4th ed, 2018) 9.

⁷² For a detailed discussion of the issues and barriers facing South Australia's vulnerable populations, see SALRI's Final Report (n 23) pt 9.

⁷³ It was noted [d]uring SALRI's consultation, a meeting with community representatives at the MCCA [Multicultural Communities Council of South Australia] highlighted significant gaps in understanding, awareness and engagement with CALD [culturally and linguistically diverse] communities in the area of EPAs. Representatives from the Chinese, Iranian, Sierra Leone[an], Serbian, Armenian, Pakista[ni]/Muslim, Italian, Greek, Spanish and Lebanese/Maronite communities were in attendance. There was an overwhelming consensus that CALD communities have a limited or complete lack of knowledge regarding EPAs.

SALRI's Final Report (n 23) ii, 389 [9.1.82].

In August 2021, the Law Council of Australia supported uniformity in the use of common terms associated with EPAs, noting terms 'should be able to be understood by lay-persons': Law Council of Australia, 'National Roundtable: Enduring Power of Attorney Law Reforms' (Communiqué, 6 August 2021) 3.

poor understanding of key terms, roles and responsibilities, the instrument becomes an ineffective tool. Under the current law, there is a lack of linguistic clarity and an absence of cultural awareness. The concept of an EPA is premised on Anglo-Saxon ideas of health, ageing, disease or impairment, money, decision-making and family obligations.⁷⁴ In the context of Aboriginal peoples, SALRI concluded that the operation of an EPA must be adaptable to accommodate cultural differences:

the EPA arrangement lacks the structure and ability to deal with kinship- and collective-based decision-making. Flexibility in arrangements for an EPA may produce a system better suited to Aboriginal culture and values, by ensuring kinship and other cultural obligations are embraced and adhered to. Further, acknowledgment of differences in understanding key concepts such as ‘relative’, ‘attorney’ or ‘money’ can improve the cultural relevance of EPAs in Aboriginal communities. These changes can also be enforced and better understood through productive engagement with Aboriginal communities.⁷⁵

The absence, or minimal understanding, of these terms creates a significant risk that the EPA will not be enforced or applied appropriately, leading to abuses of power on behalf of the attorney, whether it is unintended or deliberate.⁷⁶ In addition to these challenges, the essence of the role of an attorney is poorly understood, having been described as an ‘unscripted role’.⁷⁷ This was reinforced in Victoria’s *Inquiry into Powers of Attorney*, which revealed attorneys had a ‘rudimentary understanding’ of their role.⁷⁸ In the context of vulnerable populations, this problem is magnified. SALRI found that ‘Aboriginal and CALD communities have minimal to no understanding of EPAs. This [was] compounded by limited access to culturally and linguistically appropriate information and legal services.’⁷⁹

In the context of older persons, a study conducted by Deborah Setterlund, Cheryl Tilse and Jill Wilson examined knowledge of the law relating to substitute

⁷⁴ This was reinforced during SALRI’s consultation by Dr Kris Wilson:

Aboriginal peoples aren’t the problem here, the issue is the provision of care and granting of capacity to make binding decisions isn’t structured to deal with collective and kinship based decision making authority, and that’s where a flexible EPA might be of use for the system. Aboriginal culture doesn’t need [an] EPA.

SALRI’s Final Report (n 23) 381 [9.1.51].

⁷⁵ Ibid.

⁷⁶ See *ibid* 71–2; Office of the Public Advocate Queensland, Submission No 361 to the Australian Law Reform Commission, *Elder Abuse* (2016) 7, 18; Law Reform Committee (n 31) 29.

⁷⁷ Carolyn L Dessin, ‘Acting as Agent under Financial Durable Power of Attorney: An Unscripted Role’ (1996) 75(3) *Nebraska Law Review* 574, 584; see also Tilse et al, ‘Promoting Attorneys’ Accountability’ (n 40) 193.

⁷⁸ Law Reform Committee (n 31) 175.

⁷⁹ SALRI’s Final Report (n 23) 400 [9.1.138].

decision-making, which included POA.⁸⁰ In a total of 48 focus groups, comprising of older persons living in the community, aged care facilities and retirement villages, family members and carers — 23 groups had a ‘low understanding’.⁸¹ A ‘low understanding’ was characterised as: the participants ‘did not understand the differences between an EPA and power of attorney, could not articulate any other details, or did not know about the concept of substitute decision making’.⁸²

The authors aptly noted that the primary purpose of an EPA — to protect the principal — can only be realised if the principal has an ‘adequate level of understanding of the relevant legal concepts and provisions’.⁸³ Therefore, a lack of understanding endangers the autonomy of the principal and their ability to make an informed decision.⁸⁴

In conclusion, much like ACDs, the relevant language associated with EPAs must be accessible to all members of the community. This means the language must be adaptable to the specific demographic to ensure cultural appropriateness and sensitivity. It also highlights that language should remain consistent. The fragmentation of state laws governing EPAs further complicates efforts to achieve an adequate understanding of terminology. As interstate travel and relocation across Australia becomes more frequent, consistency in advance care planning legislation is necessary to ensure EPAs are enforced and applied appropriately.

In their current form, ACDs and EPAs remain relatively inaccessible to the community. Reforms to ACDs have made improvements with respect to community understanding surrounding the introduction of a single form aimed to prompt future planning discussions. However, key terms such as an SDM, remain largely misunderstood meaning that there needs to be appropriate engagement with the public if these instruments are to provide clarity and support to those vulnerable members of society who have lost capacity. This was also observed in the context of EPAs.

If the stakeholders involved in the execution, activation and enforcement of an ACD or EPA do not understand key terms, the instrument will not retain its proper function and of particular concern, cannot safeguard individuals when they become vulnerable. Greater resources are required to implement targeted communication and educational strategies for all South Australians. Education will improve knowledge and understanding of ACDs and EPAs, such that individuals who engage in future planning can operationalise their rights and perform their duties lawfully.

⁸⁰ Deborah Setterlund, Cheryl Tilse and Jill Wilson, ‘Older People and Substitute Decision Making Legislation: Limits to Informed Choice’ (2002) 21(3) *Australasian Journal on Ageing* 128. See also Tilse et al, ‘Promoting Attorneys’ Accountability’ (n 40) 193.

⁸¹ Setterlund, Tilse and Wilson (n 80) 129–30.

⁸² Ibid 129.

⁸³ Ibid 128.

⁸⁴ See *ibid*.

IV CAPACITY AND ITS ASSESSMENT

A *The Definition of Capacity*

Capacity is the legal chameleon of advance care planning, it has been and continues to be at the forefront of policy development and reform. Capacity represents the intersection of the legal, medical and psychological disciplines, creating a grey area within law and practice for ACDs and EPAs. The complexity attached to capacity is attributable to the fact that it is a legal, medical, psychological and neuropsychological construct. With advances in medical and neuropsychological knowledge and understanding of capacity, the law must be able to adapt in response.

As a result of its multidisciplinary nature, the definition of capacity can be difficult to ascertain. Whether in a medical or legal context, its definition is underpinned by a number of principles, aimed to guide its definition and assessment.⁸⁵ These principles function as a safeguard for the individual whose capacity is questioned and highlights the importance of preserving autonomy.

The fundamental principles⁸⁶ include:

1. The individual is presumed to have capacity.⁸⁷ This is the fundamental presumption of capacity, which represents the starting position for its assessment. As noted in SALRI's Final Report, the presence of this presumption 'shifts away from a paternalistic view of autonomy to one which acknowledges the importance of maintaining the individual's autonomy to retain capacity'.⁸⁸

⁸⁵ SALRI's consultation revealed the importance of retaining and enumerating a set of guiding principles to define and assess capacity: SALRI's Final Report (n 23) 168–9 [4.5.88]–[4.5.95]. In August 2021, the Law Council of Australia acknowledged different approaches to defining capacity which impacts its assessment. To achieve consistency and understanding, the implementation of 'nationally consistent capacity assessment guidelines' were proposed: Law Council of Australia (n 73) 3.

⁸⁶ These guiding principles are reflected in various toolkits introduced in Australia. See, eg, NSW Department of Communities and Justice, *Capacity Toolkit* (Guide, 2008) 27 ('NSW Capacity Toolkit') <<https://www.justice.nsw.gov.au/diversityservices/Documents/CapacityToolkit2020ElectronicAccessible.pdf>>. The NSW Capacity Toolkit is the most established resource and has been adopted in Victoria and Queensland. The guiding principles are also derived from well-established common law principles: see, eg, *Gibbons v Wright* (1954) 91 CLR 423, 437 (Dixon CJ, Kitto and Taylor JJ) ('*Gibbons*') where it was held an individual with capacity must understand the general nature of the legal transaction; *Re K (Enduring Powers of Attorney)* [1988] Ch 310, 313 ('*Re K*'), where Hoffman J identified four matters which an individual must understand concerning the magnitude of conferring complete financial authority to the appointed attorney, the continued operation of the EPA following the principal's loss of capacity and the revocable nature of an EPA; *Szoda v Szoda* [2010] NSWSC 804 ('*Szoda*'); *Ranclaud v Cabban* (1988) NSW ConvR 57 ('*Ranclaud*').

⁸⁷ *NSW Capacity Toolkit* (n 86) 10.

⁸⁸ SALRI's Final Report (n 23) 154 [4.5.14].

2. Capacity is decision-specific,⁸⁹ which means it must be determined based on the type or nature of the decision.
3. Capacity is time-specific,⁹⁰ which means it is determined at the time of the assessment.⁹¹
4. The assessment of capacity is not influenced or determined based upon the physical and verbal appearance of the individual.⁹² Appearance refers to non-verbal cues, behaviour and communication skills and encompasses impairments such as Parkinson's Disease, Autism Spectrum Disorder and Multiple Sclerosis.⁹³
5. The merits or outcome of the decision does not determine capacity — rather, capacity is assessed on the decision-making ability of the individual.⁹⁴
6. Privacy of the individual is to be respected and upheld.⁹⁵
7. Substitute decision-making is treated as an option of 'last resort'.⁹⁶

It is important to note that, as autonomous agents, we have a right to make mistakes or decisions which lead to unfavourable outcomes.⁹⁷ Further, mere disagreement with the decisions made by an individual has no bearing on their decision-making capacity. Often, these value judgements are informed by a number of factors, such as personal moral values, ethics, culture/ethnicity, socio-economic status and religion.

Currently, South Australia's *POA Act* does not include a legislative definition of capacity or incapacity. Over time, reliance on the common law has shaped the definition of capacity.⁹⁸ However, capacity has only been judicially interrogated in the context of EPA execution, but not at the point of activation.⁹⁹ The absence

⁸⁹ *NSW Capacity Toolkit* (n 86) 32. This principle may also be expressed as context-specific — which refers to the particular decision.

⁹⁰ *Ibid.*

⁹¹ *Ibid.*

⁹² *Ibid* 33–4.

⁹³ *Ibid.*

⁹⁴ *Ibid* 27.

⁹⁵ *Ibid.*

⁹⁶ *Ibid.*

⁹⁷ See: *ACD Act* (n 3) s 7(d); *Re T (Adult: Refusal of Medical Treatment)* [1992] 4 All ER 649, 662 (Lord Donaldson): 'the patient's right of choice exists whether the reasons for making that choice are rational, irrational, unknown or even non-existent'. Lord Donaldson's position was endorsed in the subsequent case of *Re MB (Medical Treatment)* [1997] 2 FLR 426, 432. See also: *Re C (Adult: Refusal of Medical Treatment)* [1994] 1 WLR 290; SALRI's Final Report (n 23) 149–50 [4.5.3].

⁹⁸ See, eg: *Gibbons* (n 86) 437; *Re K* (n 86) 313; *Dalle-Molle v Manos* (2004) 88 SASR 193, 198 (Debelle J); *Szoda* (n 86); *Ranclaud* (n 86).

⁹⁹ For the purposes of this article, the relevant case law will not be discussed. Rather, the absence of judicial interrogation of 'capacity' at the point of activation is argued to support the need for the enumeration of a legislative definition of capacity.

of a legislative definition and judicial guidance has prompted greater reliance on clinical capacity assessments. This medicalisation of capacity requires clarification, to reconcile its definition across relevant disciplines and ensure consistency in different contexts. In a legal context, lack of legislative clarity perpetuates the confusion associated with this term, its assessment and the role of a legal practitioner. Indeed, there has been significant discussion regarding the appropriate professional to involve in the determination of capacity at different stages of the POA process.¹⁰⁰ The threshold of capacity at execution of an EPA is different to that at activation of the EPA. As a result, there was widespread support for a clinical capacity assessment at the point of activation, to safeguard the principal's autonomy and to ensure activation is in fact necessary.¹⁰¹ The approach taken in the assessment of capacity requires consistency and efficiency.

In contrast, the *ACD Act* incorporates a legislative definition of 'impaired decision-making capacity'.¹⁰² The *ACD Act* introduces four criteria to define capacity. These criteria are premised on understanding, retaining information, decision-making ability, and communication.¹⁰³ The definition provides much needed clarity and guidance for the SDM, medical professionals and the individual who created the ACD. A recurring theme in SALRI's consultation was support for the adoption and enumeration of this definition within the POA legislative framework. Medical consultation revealed widespread familiarity and ongoing use of this definition and its consistency with current clinical approaches to capacity assessment.¹⁰⁴ In addition, recognition of 'fluctuating capacity' within the *ACD Act* definition is of particular importance, as it acknowledges capacity can be regained. It signals an important advancement in understanding the nature of capacity and attempts to enforce a degree of consistency across end-of-life decision-making support.

B *The Assessment of Capacity*

The threshold of capacity required to create an ACD and EPA is distinct from capacity at the point at which it is activated. Therefore, capacity must be assessed at two specific time points and for two distinct purposes. First, at the time in which the ACD or EPA is executed, capacity is assessed and the key question is whether or not the principal understands the nature and effect of the instrument, in addition to the authority they are giving the SDM or attorney. The second point in time in which capacity is assessed is at the point of activation. This assessment determines whether capacity to make financial and medical decisions is temporarily or permanently lost. For the purposes of this article, capacity at the point of activation will be

¹⁰⁰ SALRI's Final Report (n 23) 161–8 [4.5.42]–[4.5.87].

¹⁰¹ See *ibid* 171–2 [4.5.110].

¹⁰² *ACD Act* (n 3) s 7.

¹⁰³ *Ibid* s 7(1)(a)(i)–(iv).

¹⁰⁴ SALRI's Final Report (n 23) 138.

explored. While capacity can be difficult to assess at the point of execution, a legal practitioner is usually capable of making this determination.¹⁰⁵

A clinical capacity assessment should be undertaken prior to the activation of the ACD or EPA, to avoid premature, unnecessary activation. A finding that an individual has lost capacity is significant, as the appointed decision-maker is conferred absolute authority to make decisions. It also represents the point at which an individual loses autonomy and agency. Our society views these as fundamental human rights, which cannot be limited or extinguished unless absolutely necessary. Whilst the nature of the powers conferred on the SDM and attorney differ, the outcome of the activation of an ACD or EPA is the same, serving to extinguish these fundamental rights. Consequently, activation must proceed with due care. The current lack of clarity around the definition of capacity in the context of an EPA fails to enable consistency, care or precision.

1 *Practical Barriers to Capacity Assessments*

The specific professional tasked with undertaking a clinical capacity assessment plays a critical role in preserving the individual's autonomy, ensuring capacity is retained for as long as possible. Further, as noted above, precision is more likely to be achieved through the use of clinical capacity assessments, undertaken by qualified medical professionals. Whilst many factions of the medical profession can assess capacity, there are four in this particular context — psychiatrists, geriatricians, general practitioners and neurologists.¹⁰⁶ The assessment of capacity can also be undertaken by a neuropsychologist (desirable)¹⁰⁷ or psychologist.¹⁰⁸ The issue concerning who should undertake a clinical capacity assessment raises practical barriers in relation to access. Therefore, the practical barriers with respect to the assessment of capacity

¹⁰⁵ This was reinforced in SALRI's consultation, by both legal and medical practitioners: see, eg, SALRI's Final Report (n 23) 161–8, 171–2. Assessment of capacity at execution is arguably less problematic, specifically in relation to its implications. Contrast this to assessment at activation, in which a finding of incapacity is of great magnitude, leading to the complete removal of the individual's autonomy and agency in decision-making.

¹⁰⁶ The Law Society of New South Wales, *When a Client's Mental Capacity is in Doubt: A Practical Guide for Solicitors* (Guide, 2016) 9; *NSW Capacity Toolkit* (n 86) 11–12; Simon Zuscak et al, 'The Marriage of Psychology and Law: Testamentary Capacity' (2019) 26(4) *Psychiatry, Psychology and Law* 614, 618.

¹⁰⁷ In SALRI's consultation, it was revealed that a neuropsychologist's specialised skillset is required for complex capacity assessments and they are often in the best position to determine prognosis of a condition: SALRI's Final Report (n 23) 165–6 [4.5.72], 167 [4.5.83], 172 [4.5.111]. See also Paul J Moberg and Jacqueline H Rick, 'Decision-Making Capacity and Competency in the Elderly: A Clinical and Neuropsychological Perspective' (2008) 23(5) *NeuroRehabilitation* 403; Karen Sullivan, 'Neuropsychological Assessment of Mental Capacity' (2004) 14(3) *Neuropsychology Review* 131.

¹⁰⁸ See also The Law Society of New South Wales (n 106) 9; *NSW Capacity Toolkit* (n 86) 11–12; Zuscak et al (n 106).

and appropriate activation of an ACD or EPA pertain to wait times, access, cost and the presence of fluctuating capacity. In the context of fluctuating capacity, part-orders will be further explored to determine whether they are a viable option to prevent unnecessary activation and initiate revocation when required.

First, while it is acknowledged that the cost and wait time of medical professionals is a significant barrier — access will also be contingent upon the individual's circumstances leading to a referral for a clinical capacity assessment. For example, if an individual is admitted to hospital, the treating care team can request a capacity assessment. Referral to a specific medical professional will be at the discretion of the treating team. Alternatively, if an individual visits their general practitioner, who believes a clinical capacity assessment is required, the general practitioner may wish to complete the assessment or refer to another medical professional. This is also the case if an individual visits a legal practitioner, who believes a clinical capacity assessment is necessary. Regardless of the pathway taken leading to a referral, it is within the concerned individual's right to refuse the assessment.

Second, out-of-pocket costs associated with a specialist or neuropsychologist/psychologist will be dependent on a number of factors. If a public patient presents to a public hospital, the patient will not be required to pay out-of-pocket costs for specialists, such as a psychiatrist, or a neuropsychologist/psychologist.¹⁰⁹ If a private patient, a person with private medical insurance, attends a public hospital, they may need to pay out-of-pocket costs.¹¹⁰ However, a private or public patient, who wishes to choose the specialist or neuropsychologist/psychologist they see, will incur costs in accordance with the overall fee and designated gap payment, if not covered by Medicare. It is at the discretion of the specialist or neuropsychologist/psychologist to bulk-bill the patient. The waiting lists for many specialists or neuropsychologists/psychologists are long, which is a significant impediment to access. As a result of the long wait time, patients may be inclined to see someone privately, thereby paying out-of-pocket costs.

In cases of urgency, relying on the public health system can be arduous and untenable. Further, the cost of visiting a specialist or neuropsychologist/psychologist privately is financially burdensome for many. While the need for clinical capacity assessments in the context of ACD and EPA activation is obvious, reforms must address and alleviate these barriers to access. This involves comprehensive training for general practitioners¹¹¹ to undertake capacity assessments, employment of more public service medical professionals to ease the backlog of referrals and decrease wait times, increased frequency of bulk-billing and reduced gap fees for patients.

¹⁰⁹ See 'Out of Pocket Costs', *Australian Government Department of Health* (Web Page, 18 August 2021) <<https://www.health.gov.au/health-topics/private-health-insurance/what-private-health-insurance-covers/out-of-pocket-costs#costs-for-services-outside-hospital>>.

¹¹⁰ *Ibid.*

¹¹¹ General practitioners are more accessible, with lower gap payments or use of bulk billing.

Finally, fluctuating capacity contributes significantly to the practical efficacy of ACD and EPA policy and practice. It refers to individuals who transition between periods of capacity and incapacity. In the event that an individual with a valid ACD and/or EPA has fluctuating capacity, these legal instruments are often lost in translation. The proper function and purpose of each instrument cannot be achieved, as the individual will not require ongoing substitute decision-making. In practice, once an EPA is activated, this is permanent — the process to revoke the legal instrument is scarcely undertaken.¹¹² This strengthens the argument to reform the definition of capacity to recognise fluctuating capacity within legislation, to ensure there are clear and accessible mechanisms to revoke the instrument if prematurely activated and greater access to clinical assessments of capacity. Whilst there is a strong argument to incorporate a legislative definition of capacity as observed in the *ACD Act*, its impact in practice must be examined. Specifically, it must be considered whether or not this legislative definition influences the activation or enforcement of an ACD. Further investigations will determine whether a legislative definition serves both a symbolic and practical function to promote autonomy.

A clinical assessment will identify cases of fluctuating capacity and advise on the most appropriate path forward. This may be a re-assessment of capacity in six or 12 months or recommendations to amend the ACD or EPA to incorporate express limitations on the SDM's or attorney's power.

Fluctuating capacity is a clinical diagnosis, manifested as a symptom of an underlying medical cause. It is nuanced, 'fraught with intricacies and ethical underpinnings'¹¹³ and must be viewed holistically, in light of existing co-morbidities.¹¹⁴ As a result, a clinical assessment of capacity undertaken by an appropriately 'skilled and trained clinician'¹¹⁵ is required, which relies on a high standard of 'clinical acumen that enhances clinical judgment'.¹¹⁶ The legal and policy approach to fluctuating capacity in the context of ACDs and EPAs must acknowledge this medical interface and facilitate access to clinical capacity assessments. The concerned

¹¹² This was reiterated in SALRI's consultation, in which consultees emphasised the importance of retaining decision-making capacity in light of this reality. For relevant revocation provisions, see *ACD Act* (n 3) s 29. In the context of EPAs

[p]resent law and practice is not always clear on the revocation of an EPA. This is an issue that would benefit from legislative clarity. SALRI's consultation brought to light the importance of introducing a clear and effective means for the revocation of EPAs. There were several examples provided to SALRI involving EPAs being abused where an old EPA has been revoked and a new one prepared, but the former attorney continued to use the old EPA.

SALRI's Final Report (n 23) 97 [3.7.53].

¹¹³ Arlin Pachet, Lauren Allan and Leslie Erskine, 'Assessment of Fluctuating Decision-Making Capacity in Individuals with Communication Barriers: A Case Study' (2012) 19(1) *Topics in Stroke Rehabilitation* 75, 81.

¹¹⁴ *Ibid* 83.

¹¹⁵ *Ibid*.

¹¹⁶ *Ibid*.

individual's autonomy and rights are best safeguarded through greater utilisation of clinical assessments, as the clinician is able to understand the cause and duration of fluctuating capacity. It is the clinician who assumes 'responsibility of revealing capacity and preserving patients' autonomy whenever possible'.¹¹⁷ Therefore, with greater reliance on clinical capacity assessments, medical professionals should be encouraged to develop and adopt efficient assessment processes and protocols.¹¹⁸

In a case study examining decision-making capacity, Arlin Pachet, Lauren Allan and Leslie Erskine proposed nine considerations when assessing patients with fluctuating capacity:

- Patient fatigue can lead to incorrect assumptions and inaccurate conclusions; whenever possible, assess the patient when he or she is well rested.
- Level of alertness and cognitive status are extremely vulnerable to extraneous factors such as illness or fatigue toward the end of the day. Is the patient's level of fluctuation profound enough to affect his or her decision-making abilities?
- Consider the influence of medications on capacity.
- Determine whether the patient's fluctuating capacity is related to delirium. Ensure that all potential factors causing the delirium have been ruled out.
- As a patient declines or improves, reassess decision-making capacity. Do not base the assessment on an inaccurate static view of the patient's cognitive status level.
- Determine the frequency of the patient's fluctuations. Determine whether a surrogate decision maker is necessary based on the dramatic nature of the fluctuations or the frequency of the fluctuations alone.
- Decision-making capacity is task-specific. Patients may need to be evaluated for capacity each time a decision is introduced.
- Patients may retain the capacity to identify a surrogate or proxy and should be encouraged to do so.
- Family and other caregivers should be encouraged to involve the patient in decision making whenever possible.¹¹⁹

¹¹⁷ Ibid 81.

¹¹⁸ Ibid 83.

¹¹⁹ Ibid 82.

The authors proceeded to conclude that

[k]nowledge of the patient’s medical status is necessary to ensure potential reversible conditions are addressed and aid in the assessment of cognitive and functional issues. The ability to provide clear, thorough, and concise documentation of the assessment results and the triggers necessitating the assessment is essential. The combination of such clinical skills and knowledge should place the professional in good position when faced with complex capacity evaluations that involve the assessment of patients with communication impairments and in patients who present with fluctuating capacity.¹²⁰

It is important to note the medical considerations necessary when assessing an individual with fluctuating capacity. Capacity, when assessed through a clinical lens, is treated as a ‘fluctuating rather than [a] static condition’.¹²¹ In addition, the assessment is administered in a way which safeguards the individual’s autonomy, ensuring capacity is retained for as long as possible. This raises an important question — how can clinical capacity assessments operate alongside an active ACD or EPA?

In the context of EPAs, the utility of part-orders was raised in SALRI’s Final Report.¹²² Using the existing infrastructure of the South Australian Civil and Administrative Tribunal (‘SACAT’) guardianship system, it was suggested that part-orders could be implemented as a means to address fluctuating capacity.¹²³ Part-orders arguably serve three purposes, all of which promote the vulnerable individual’s autonomy. First, part-orders could enforce limitations on the attorney’s power, by identifying the extent of the principal’s capacity and ability to make simple or complex financial decisions. Capacity is decision-specific — it may be that an individual is capable of making simple financial decisions, but requires support for more complex decisions. A part-order would clearly identify the types of financial decisions an individual can and cannot make. Second, part-orders attempt to circumvent premature activation of EPAs in cases where an individual’s fluctuating capacity is temporary. A part-order may significantly limit an attorney’s power until the individual permanently loses capacity. Third, part-orders encourage revocation of the EPA once capacity is regained. A re-assessment monitors fluctuating capacity and identifies cases of temporary incapacity. As a result, it facilitates a periodic review of part-orders to ensure activation is necessary and if not, initiate its revocation.

Despite the merit of its intent and purpose, it could be argued part-orders raise additional issues of practicality, such as time, costs and the need for periodic review. A number of factors were considered burdensome, leading to greater uncertainty

¹²⁰ Ibid 83.

¹²¹ Ruth Piers et al, ‘Advance Care Planning in Dementia: Recommendations for Healthcare Professionals’ (2018) 17(1) *BMC Palliative Care* 88:1–17, 9, table 3, recommendation 6.

¹²² SALRI’s Final Report (n 23) 174–5 [4.5.122]–[4.5.127].

¹²³ Ibid.

with respect to the operation and enforcement of part-orders. These included the frequency of SACAT hearings, physical/remote access issues to attend hearings, the payment of fees, dealing with matters or decisions of urgency and opportunities for recourse if a part-order contained an inaccurate condition or omitted a condition.¹²⁴

Part-orders also rely on an attorney or another interested party to raise any suspicions regarding impropriety on behalf of the attorney or changes to the vulnerable individual's condition to SACAT. Whilst periodic reviews of capacity are essential as an oversight measure, one would need to ensure the vulnerable individual attends the assessment. Further, following amendments to part-orders by SACAT, these must be corrected in the EPA and all relevant third parties, such as financial institutions, must be updated.¹²⁵ This is arguably administratively burdensome.

Part-orders are a familiar concept and well known in the context of guardianship. Although there are practical barriers, the underlying premise of a part-order is consistent with the policy objectives and basic principles governing ACDs and EPAs.

A clear legislative definition of capacity or impaired decision-making capacity, as observed in the *ACD Act*, is necessary to incorporate into the current POA legislative framework, to provide relevant parties with a straightforward test. In addition, the enumeration of guiding principles into legislation recognises fundamental human rights and informs the capacity assessment.

At the point of activation, the question of capacity will be prompted by a particular event or trigger. Therefore, access to a clinical capacity assessment is advisable to ensure activation is not premature or unnecessary. This is especially the case for individuals with fluctuating capacity. Further, the utility of part-orders represents one possible solution to address fluctuating capacity, by providing an oversight function.

V CONCLUSION

Both ACDs and EPAs are rights-based instruments, operating to protect and promote autonomy and self-determination in advance planning and decision-making. There is a significant lack of community understanding and knowledge of both instruments, which translates to practical issues relating to their application. This necessitates greater community education, which can be facilitated through the implementation of targeted communication strategies for vulnerable populations. For example, community education sessions, productive collaboration with vulnerable populations and the dissemination of educational written/audio/visual material¹²⁶ will aid in improving community understanding. Further, simplification of language

¹²⁴ Ibid 174 [4.5.123].

¹²⁵ For further discussion of part-orders, see *ibid* 174–5.

¹²⁶ *Ibid* 403–4, recommendations 113–14.

associated with ACDs and EPAs will increase accessibility and understanding. Adoption of these measures will lead to greater utilisation of these instruments, by increasing awareness and knowledge of the formal law and practice.

While the *ACD Act* has many challenges, legislative enumeration of ‘impaired decision-making capacity’ represents the exemplar. It is strongly recommended the *POA Act* be amended to adopt this legislative definition. This would provide clarity and consistency in the way in which capacity is defined and assessed. Further, the inclusion of guiding principles is necessary to codify fundamental human rights, which must always inform capacity assessment.

With respect to capacity assessments, current barriers to access may contribute to the improper activation of ACDs or EPAs. Mandatory professional development for general practitioners, to provide training on capacity and its assessment will help to prevent premature activation. This will ease the burden on medical professionals (specifically specialists) and neuropsychologists/psychologists to undertake assessments. These professionals can then be relied upon for complex cases, such as those involving fluctuating capacity.

It is time to consider reforms to legislation and practice to ensure ACDs and EPAs retain their proper purpose and function following activation.