

**REPORT ON THE REVIEW OF
THE ADVANCE CARE
DIRECTIVES ACT 2013 (SA)**

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For the Minister for Health and Wellbeing

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TERMS OF REFERENCE

1. Achievement of objectives of the Act

To assess the extent to which the objects of the *Advance Care Directives Act 2013* are being achieved. This will involve public and other consultation. The objects are:

- (a) To enable competent adults to give directions about their future health care, residential and accommodation arrangements and personal affairs;
- (b) To enable competent adults to express their wishes and values in respect of health care, residential and accommodation arrangements and personal affairs, including by specifying outcomes or interventions that they wish to avoid;
- (c) To enable competent adults to allow decisions about their future health care, residential and accommodation arrangements and personal affairs to be made by another person on their behalf;
- (d) To ensure, as far as is reasonably practicable and appropriate, that health care that is provided to a person who has given an advance care directive (ACD) accords with the person's directions, wishes and values;
- (e) To ensure that the directions, wishes and values of a person who has given an advance care directive are considered in dealing with the person's residential and accommodation arrangements and personal affairs;
- (f) To protect health practitioners and others giving effect to the directions, wishes and values of a person who has given an advance care directive;
- (g) To provide mechanisms for the resolution of disputes relating to decisions made on behalf of those who have given an advance care directive.

2. The ACD Act - other issues

To recommend changes to the legislation, administration, policy or practice which would improve the extent to which the objects are achieved with particular reference to:

- (a) General understanding of ACDs in the community;
- (b) Uptake and understanding of the ACD form and non-statutory ACDs and ways to increase their uptake;
- (c) Understanding of ACDs amongst the clinical community including access to and adherence of signed ACDs;
- (d) The practicality of the process to complete an ACD, in particular:
 - (i) the requirement that a Substitute Decision Maker must sign their acceptance of the role prior to the person signing the ACD;
 - (ii) the appropriateness of the list of authorised witnesses, taking into consideration providing reasonable access to witnesses and ensuring the integrity of the witnessing process. Consideration should be given to the ability of witnesses to determine the decision making capacity of the person giving the ACD.
- (e) The different roles the Act assigns to the Public Advocate and the extent to which those roles are reconcilable.
- (f) The extent to which the distribution of functions between the Public Advocate and the South Australian Civil and Administrative Tribunal are appropriate;

- (g) The opportunities to enhance the support provided, including the provision of interpreting assistance;
- (h) Opportunities to enhance the ACD Form and the DIY Kit to enable the form to be easily understood and complied with by clinicians.

3. Other Opportunities for Reform

To consider whether further inquiries should be made (outside the scope of this review) into how the following issues may enhance future care and arrangements including:

- (a) A process by which adults who do not have decision making capacity can give directions, to the extent of their capacity, about their future health care, residential and accommodation arrangements and personal affairs;
- (b) Increase organ donation consents and compliance with those consents;
- (c) The interaction of ACDs with other related documents such as Medical Powers of Attorney and Legal Powers of Attorney.

EXECUTIVE SUMMARY

TERM OF REFERENCE 1

To assess the extent to which the objects of the *Advance Care Directives Act 2013* are being achieved.

FINDING 1

The objects of the Act are widely supported across the South Australian community, including among clinicians, health professionals, lawyers, health networks, advocacy groups, key statutory agencies and the general public. However, it is a commonly held view that the practical realisation of those objects is being hindered by a lack of support, in particular, to medical professionals and the public, especially around resources, education, awareness and training. This Review makes several recommendations that will improve the uptake of ACD's by the community, and their recognition by the health sector.

TERM OF REFERENCE 2(a)

To recommend changes to the legislation, administration, policy or practice which would improve the extent to which the objects are achieved with particular reference to:

- (a) General understanding of ACDs in the community.

FINDING 2

General understanding of ACDs within the community is low. Many people only learn of their importance and role through word of mouth or serendipitous meetings and conversations, for example, when a person sees their lawyer to update their will and/or appoint a power of attorney. Following the Act's enactment, the Department had 2 dedicated staff members who were responsible for education, training, oversight and promotion of ACDs. In retrospect, the decision to discontinue those roles is widely viewed as being short-sighted and retrograde in its effect.

FINDING 3

The current ACD Form and, in particular, the DIY Kit, are no longer fit for purpose. They are overly complicated, unduly long and act as a barrier to the adoption and execution of ACDs within the community.

RECOMMENDATION 1

The government should reinstate 1, but preferably 2, positions within the Department for Health and Wellbeing, with the dedicated role of promoting understanding and awareness of ACDs. This/these role(s) should work in collaboration with community and advocacy groups to promote the understanding and uptake of ACDs, as well as taking leadership of an ongoing

education and training program for clinicians and health practitioners in each of the Local Health Networks (LHNs).

RECOMMENDATION 2

Both the ACD Form and the DIY Kit need to be reviewed and the latter significantly updated. Each needs to be tailored for a lay-person and contain sufficient information for a person to complete an ACD without the necessity to consult either a lawyer or a doctor. However, both documents should make it clear that speaking with both (or either) a lawyer and a doctor may result in the completion of an ACD which more closely reflects the wishes and preferences of the person.

TERM OF REFERENCE 2(b)

To recommend changes to the legislation, administration, policy or practice which would improve the extent to which the objects are achieved with particular reference to:

...

- (b) uptake and understanding of the form and non-statutory ACDs and ways to increase their uptake ...

FINDING 4

Despite the desire to have only 1 document for future directions and preferences with regard to medical care, accommodation and personal issues, the Act needs to also accommodate non-statutory ACDs, recognising that it is unrealistic to expect that a statutory ACD will address all possible scenarios or situations, and highlighting the importance of non-statutory ACDs, particularly in clinical settings.

RECOMMENDATION 3

The Act should be amended to make it expressly clear that it is not intended to operate to the exclusion of the common law. Directives which meet the common law requirements must be treated as legally valid. In addition, non-statutory directives, irrespective of form or whether they appear in a statutory ACD, should be treated as relevant and highly persuasive, particularly when decisions are being made with regard to medical care and treatment, or personal preferences, at the end of life.

TERM OF REFERENCE 2(c)

To recommend changes to the legislation, administration, policy or practice which would improve the extent to which the objects are achieved with particular reference to:

...

- (c) Understanding of ACDs amongst the clinical community including access to and adherence of signed ACDs

FINDING 5

There appears to be a significant gap between the legal obligations of the Department and the practice regarding ACDs in acute health care settings. Significant change needs to take place in each health network and hospital to ensure that ACDs are treated as a priority in clinical settings. This must include ongoing training and education of clinicians, health practitioners and administrators within hospitals.

FINDING 6

The government should consider a trial voluntary register for all ACDs, including previous legal documents (EPGs, Medical Powers of Attorney and Anticipatory Directions).

RECOMMENDATION 4

Each Local Health Network and hospital should be required to report annually to the Minister on their practices and protocols for identifying, managing and implementing ACDs (in any form). Hospitals must adopt a ‘whole of hospital’ approach to identifying, flagging and managing ACDs. Each institution must also develop a system for recording conversations and treatment plans (including the 7 step pathway) which incorporate non-statutory directives in files related to ACDs. These files must be digitally retained by each hospital.

RECOMMENDATION 5

The use of digital copies of certified ACDs should be both permissible and promoted within South Australia’s hospitals. The Act should be amended to facilitate this process and provision should be made in the Act to ensure that medical practitioners and hospital staff are entitled to rely on the purported validity of an ACD contained on a patient’s My Health Record.

RECOMMENDATION 6

The South Australian Government should consider conducting a trial in relation to the development and use of a voluntary register for ACDs. Any register should be devised following consultation with relevant stakeholders and involve an independent evaluation following a sufficient length of time. One of the components for evaluation must be the improved level of compliance with ACDs in clinical settings.

FINDING 7

The Review did not reveal any inadequacy in the protections afforded to medical practitioners under the Act. However, there is a need for clearer guidance in relation to the presence of legally binding documents which are now deemed to be ACDs under the Act (Enduring Powers of Guardianship, Medical Powers of Attorney and Anticipatory Directions).

RECOMMENDATION 7

A clear protocol should be developed for use in South Australian hospitals which ensures that questions are not limited to the existence of ACDs, but extend to questions regarding a previous, valid instrument, including Enduring Powers of Guardianship, Medical Powers of Attorney and Anticipatory Directions.

TERM OF REFERENCE 2(d)(i)

To recommend changes to the legislation, administration, policy or practice which would improve the extent to which the objects are achieved with particular reference to:

...

- (d) The practicality of the process to complete an ACD, in particular:
 - (i) the requirement that a Substitute Decision Maker must sign their acceptance of the role prior to the person signing the ACD.

FINDING 8

There is no practical or legal basis for changing the order of signing with regard to ACDs.

FINDING 9

The decision to impose a cap on Substitute Decision Maker (SDM) appointments is inconsistent with the spirit and intent of the legislation, including the desire to empower people to exercise self-determination with regard to future care, accommodation and personal matters. Accordingly, both the ACD Form and the Act should be amended to make it absolutely clear that people can appoint as many SDMs as they desire.

RECOMMENDATION 8

The Act and the ACD form should be amended to make it absolutely clear that there is no limit on the number of SDMs that can be appointed.

FINDING 10

Both the Act and the ACD form should be amended to enable people making an ACD to establish a hierarchy of SDMs, with a preferred SDM or SDMs acting as the first substitutes (separately and together), followed by secondary substitutes acting separately and together.

RECOMMENDATION 9

The wording in section 22 of the Act should be changed from ‘jointly and severally’ to ‘separately and together’.

RECOMMENDATION 10

The Act and the ACD form should be amended to enable people to have a hierarchy of SDMs, with one or more preferred SDMs, as well as alternate SDMs (ie, appointing a spouse as the preferred SDM and children as alternate SDMs). All SDM appointments should be able to be exercised together and separately.

TERM OF REFERENCE 2(d)(ii)

To recommend changes to the legislation, administration, policy or practice which would improve the extent to which the objects are achieved with particular reference to:

...

(d) The practicality of the process to complete an ACD, in particular:

...

- (ii) the appropriateness of the list of authorised witnesses, taking into consideration providing reasonable access to witnesses and ensuring the integrity of the witnessing process. Consideration should be given to the ability of witnesses to determine the decision making capacity of the person giving the ACD.

FINDING 11

The current list of suitable witnesses should be significantly reduced through an amendment to Schedule 1 of the Regulations. Suitable witnesses should be limited to health practitioners, legal practitioners, judges and magistrates, Justices of the Peace (JPs) and social workers. Both JPs and social workers should be required to engage in professional training and/or refresher courses every 2 years. Training courses should be approved by the Department for Health and Wellbeing and must include training on ACDs and the legal requirements of witnessing, offences under the Act, as well as training on the Adult Safeguarding Unit (ASU), the categories of elder abuse, obligations to report elder abuse and when evidence or suspicion of abuse or exploitation may vitiate the validity of an ACD.

FINDING 12

The models used in both the Victor Harbor and Barossa regions need to be replicated in every council area within the state. Dedicated staff within the Department for Health and Wellbeing (Recommendation 1) should assume responsibility for the training of volunteers and the facilitation of networks between council areas, local hospitals and between volunteer groups and the Adult Safeguarding Unit.

RECOMMENDATION 11

Schedule 1 of the Regulations needs to be amended and the list of suitable witnesses limited to health practitioners, legal practitioners, judges and magistrates, social workers and Justices of the Peace.

RECOMMENDATION 12

Justices of the Peace and social workers should be required to complete a professional training course, approved by the Department for Health and Wellbeing, every 2 years. Such courses must address legal requirements under both the *Advance Care Directives Act 2013* (SA) and the legal effects of the *Office for the Ageing (Adult Safeguarding) Amendment Act 2018* (SA).

RECOMMENDATION 13

The government should give consideration to the inclusion of an additional offence where witnesses have failed to comply with the legal requirements for witnessing.

RECOMMENDATION 14

The Department for Health and Wellbeing should assume responsibility for the establishment of new volunteer ACD groups in each council area, drawing on the experiences of similar groups in Victor Harbor and the Barossa. The Department should also facilitate the establishment of networks between volunteers, local hospitals, the local council and Justices of the Peace.

FINDING 13

The Act could potentially be amended to ensure that it is an offence for any individual or corporation, including a residential aged care facility, to compel any person to complete and sign an ACD, particularly where the person lacks decision making capacity. However, the best approach would be to adequately resource an education program designed specifically for residential aged care providers.

RECOMMENDATION 15

The government should resource an ongoing and targeted education campaign for aged care providers around ACDs, delivered by the Department for Health and Wellbeing.

TERM OF REFERENCE 2(e)

To recommend changes to the legislation, administration, policy or practice which would improve the extent to which the objects are achieved with particular reference to:

...

- (e) The different roles the Act assigns to the Public Advocate and the extent to which those roles are reconcilable.

FINDING 14

The Review demonstrated that, despite OPA exercising a range of complex roles and functions under several Acts, the Office has managed the potential for conflicts with diligence and a strict compliance with internal protocols and policies. Accordingly, there is no obvious basis for reducing the number of roles currently fulfilled by OPA. Nonetheless, a reduction in resources

or funding of OPA would have a direct and adverse effect on the operation of the Act and, potentially, the caseload of SACAT.

FINDING 15

OPA requested that an amendment be made to s 45(4) of the Act to enable them to disclose material evidence 'said or done' in a mediation to SACAT in cases where there is a reasonable suspicion of elder abuse. However, an exception to s 45(4), and specifically to facilitate applications by OPA to SACAT under s 51(2), is not necessarily the most appropriate way of achieving this. A preferable legal mechanism would be to require OPA to discontinue dealing with the matter (whether at a preliminary or mediation stage) and refer the matter to SACAT for determination. OPA should be permitted to disclose general information in a written referral to SACAT, which would require a clear statement to that effect in s 45. This could be achieved through the insertion of additional sub-sections of s 45(3)(a) and 45(7).

FINDING 16

The declaratory powers of OPA contained in section 45(5)-(9) have never been used in the 5 years in which the Act has operated. While the intention was originally to facilitate a simple process for dispute resolution, it is clear that people are seeking to have matters resolved by SACAT where the matter is complex or urgent, or where a binding decision is required or desired. Those sections should, accordingly, be repealed.

RECOMMENDATION 16

There is no clear legal or other reason to reduce the powers or functions of OPA, other than those recommended under Recommendation 18.

RECOMMENDATION 17

Section 45 of the Act should be amended to require OPA to discontinue a matter where a reasonable suspicion of elder abuse exists and refer the matter to SACAT for determination. OPA should be entitled to disclose the general basis of that suspicion in a written referral to SACAT. Consideration should also be given to an amendment which requires OPA to publish on its website, as well as notify all parties accessing the DRS from the outset, that evidence of elder abuse will trigger a discontinuation of mediation and that a referral to SACAT will follow.

RECOMMENDATION 18

The declaratory powers of OPA under s 45(5)-(9) have never been used and should be repealed.

TERM OF REFERENCE 2(f)

To recommend changes to the legislation, administration, policy or practice which would improve the extent to which the objects are achieved with particular reference to:

...

- (f) The extent to which the distribution of functions between the Public Advocate and the South Australian Civil and Administrative Tribunal are appropriate.

FINDING 17

There are no publicly available statistics on the caseload of SACAT, including in its community stream and with respect to matters relating to ACDs. Either SACAT or the Attorney General's Department should be required to collate both statistics and analysis of SACAT's caseload on an annual basis for government.

FINDING 18

The government should fund and commission research into SACAT's jurisdiction over ACDs in order to obtain a better understanding of how frequently ACDs are invalidated or revoked and the reasons for invalidity or revocation, the number of applications received from hospitals regarding the validity, scope or effect of binding refusals of health care, the frequency of and reasons for revoking an appointment of a substitute decision maker, the reason why referrals to OPA have reduced, the number of applications for internal review of SACAT decisions, and any other matter related to the Act's operation and enforcement.

FINDING 19

Assuming that recommendations 17 and 18 are implemented, the government should review the adequacy of SACAT's resourcing and consider whether an increase in staff or resources are required in relation to ACDs.

RECOMMENDATION 19

In order to inform future policy and resourcing decisions of government, either SACAT or the Attorney General's Department should collate, on an annual basis, statistics and analysis on SACAT's jurisdiction, including its jurisdiction in ACD matters. The information should be made available to both the Attorney-General and the Minister for Health and Wellbeing.

RECOMMENDATION 20

The Minister should commission and fund a research project focussed on the decisions of SACAT related to ACDs to build understanding of how the *Advance Care Directives Act 2013* (SA) is being implemented. The research should investigate all aspects of the Act's effect and operation but should examine the extent to which ACDs are invalidated or revoked and the reasons for invalidity or revocation, the extent to which ACD appointments are revoked and the reasons for revocation, applications by hospitals or hospital staff for decisions regarding

binding refusals of health care, the nature of those applications and the outcomes of such cases, the frequency or rate of internal reviews of SACAT decisions, and any other relevant matter.

RECOMMENDATION 21

Assuming that recommendations 19 and 20 are implemented, the government should review the adequacy of SACAT's resourcing and staffing levels.

TERM OF REFERENCE 2(g)

To recommend changes to the legislation, administration, policy or practice which would improve the extent to which the objects are achieved with particular reference to:

...

- (g) The opportunities to enhance the support provided, including the provision of interpreting assistance.

FINDING 20

The use of interpreters under the Act is insufficiently regulated and is open to abuse and possible conflicts of interest, both of which undermine the integrity of the Act and the possible validity of ACDs.

RECOMMENDATION 22

A new section of the Act is required which imposes clear requirements on interpreters. In particular, interpreters must be duly qualified as interpreters of the relevant language, they should be adults with capacity and they should be subject to similar requirements as apply to witnesses under section 15.

TERM OF REFERENCE 2(h)

To recommend changes to the legislation, administration, policy or practice which would improve the extent to which the objects are achieved with particular reference to:

...

- (g) Opportunities to enhance the ACD Form and the DIY Kit to enable the form to be easily understood and complied with by clinicians.

RECOMMENDATION 23

The government needs to fund a comprehensive education and awareness raising campaign throughout the State, but only following the establishment of local, community owned programs which support the completion and adoption of ACDs.

RECOMMENDATION 24

The government should establish a new Advance Care Directives Advisory Board to advise the Minister on all matters dealing with ACDs. The Act should be amended to ensure that the Board reports directly to the Minister on an annual basis, and that LHNs are required to report annually to the Board with regard to their compliance with the Act. Membership of the Board needs to be diverse and include an appropriate mix of expertise in palliative care, gerontology, general practice, succession law/estate planning, human rights law, nursing and aged care.

TERM OF REFERENCE 3(a)

To consider whether further inquiries should be made (outside the scope of this review) into how the following issues may enhance future care and arrangements including:

- (a) A process by which adults who do not have decision making capacity can give directions, to the extent of their capacity, about their future health care, residential and accommodation arrangements and personal affairs.

FINDING 21

The government should engage in a public consultation process and/or commission a research project, designed to explore the most appropriate methods for enabling adults to engage in Advance Care Planning (ACP), beyond the adults covered by the ACD Act. This must, of necessity, involve the disability sector which, for various reasons, was beyond the scope of this Review beyond the relevance of ACDs.

RECOMMENDATION 25

The government should conduct a public consultation process and/or commission research for determining how persons with limited or impaired decision-making capacity can be facilitated to record and convey (including through supported decision making) their preferences for future medical care, accommodation and personal matters. The consultation must engage with the disability sector and be framed by a human rights based approach.

TERM OF REFERENCE 3(b)

To consider whether further inquiries should be made (outside the scope of this review) into how the following issues may enhance future care and arrangements including:

- (b) Increase organ donation consents and compliance with those consents.

FINDING 22

Assuming that Recommendations 1, 2 and 15 above are implemented, organ and tissue donation should be addressed in a new section of the ACD Form and be a core component of any future training and education campaigns, but must highlight the difficulties of facilitating donation and the clear conflict with the desire to die at home.

RECOMMENDATION 26

The government should ensure that organ and tissue donation is the subject of a separate section in the ACD Form (Recommendation 2), and that any education or training programs delivered through Recommendations 1, 2 and 15 include relevant information on such donations.

TERM OF REFERENCE 3(c)

To consider whether further inquiries should be made (outside the scope of this review) into how the following issues may enhance future care and arrangements including:

- (c) The interaction of ACDs with other related documents such as Medical Powers of Attorney and Legal Powers of Attorney.

This Term of Reference is addressed in Recommendation 7(above).

RECOMMENDATION 27

The Department should investigate how the use of digital signatures could be implemented under the Act, and make appropriate amendments to the Act if required.

RECOMMENDATION 28

Before any changes are made to the certification requirements surrounding ACDs, the Department should engage in a broader consultation with key stakeholders, taking into account the recommended changes to the list of authorised witnesses in this Report. Any consultation for this purpose should include the relevant bodies representing particular classes of witnesses, the Local Health Networks and the Law Society.

FINDING 23

The Act should be amended to ensure that an ACD cannot be used to deny life-saving treatment following an attempted suicide or act of self-harm. The remainder of an otherwise valid ACD must be preserved.

RECOMMENDATION 29

The Act must be amended to ensure that it is explicit, in the operative provisions of the Act, that an ACD cannot be used as the basis for refusing life-saving treatment following an attempt to suicide or cause self-harm. The remainder of an otherwise valid ACD must be preserved.

PART 1

BACKGROUND TO THE REVIEW

1.1 *The Advance Care Directives Act 2013 (SA)*

1.1.1 The *Advance Care Directives Act 2013 (SA)* (the Act) was passed by the South Australian Parliament in 2013 and entered into force on 1 July 2014. Section 62 of the Act provides as follows:

- (1) The Minister must cause a review of the operation of this Act to be conducted and a report on the results of the review to be submitted to him or her.
- (2) The review and the report must be completed before the fifth anniversary of the commencement of this Act.
- (3) The Minister must cause a copy of the report submitted under subsection (1) to be laid before both Houses of Parliament within 6 sitting days after receiving the report.

The review of the Act was conducted over a 10 week period from the 10th April 2019 until the end of June 2019.

1.2 Scope of the Review

1.2.1 The scope of the review was framed by the Terms of Reference and was conducted over a condensed timeframe of 10 weeks, including the scheduling of targeted consultations, the call for and receipt of written submission, and the carrying out of 2 surveys via Your SAy through the Department for Health and Wellbeing ('the Department') website. One survey was general in nature and directed towards community members with lived experience of Advance Care Directives (ACDs). The second survey was specifically directed at substitute decision-makers (SDMs). The 10 week timeframe also included the drafting of this Report. Despite the shortened timeframe for the Review, extensive consultation was completed and a significant amount of data and information generated.

1.3 Targeted consultations

1.3.1 Given the limited timeframe for the Review, targeted consultations were arranged with key stakeholders, community and advocacy groups, clinicians and health professionals representing the Local Health Networks (LHNs). These meetings were attended either in person or via conference call by members of the review team. The external consultant also had a number of one on one meetings either in person or over the phone where additional or follow-up meetings were requested by key health practitioners or leading researchers and advocates. These consultations were held between the 7th May and the 18th June, and included the following:

- Legal Services Commission
- Aged Rights Advocacy Service
- Office of the Public Advocate

- End of Life Care Board
- South Australian Civil and Administrative Tribunal (SACAT)
- Attorney General's Department
- Northern Adelaide Local Health Network (NAHLN)
- Southern Adelaide Local Health Network (SAHLN)
- Country Health SA
- Palliative Care SA
- Victor Harbor Health Service (Justices of the Peace and volunteers)
- Barossa ACD Volunteer Group

While efforts were made to meet with clinicians, administrators and allied health workers from the Central Adelaide Local Health Network (CALHN), a meeting was unable to be scheduled during the review period. The external consultant did, however, have email communication with senior clinicians from CALHN, as well as a conference call with a senior palliative care clinician from the RAH.

1.3.2 Meetings were scheduled with members of the Succession Law Committee and the Country Practitioners Committee, both standing committees of the Law Society of South Australia (LSSA). However, for unexpected reasons, these meetings did not take place. Rather, each Committee, along with the Law Society, were invited to make written submissions and to participate in the Your SAY surveys. The Law Society also made a written submission to the review.

1.3.4 In addition to the consultation meetings, the external consultant had one on one consultations with the following people:

- Dr John Brayley, Chief Psychiatrist
- Dr Chris Moy, Vice President, Australian Medical Association, South Australia
- Margaret Brown, Adjunct Research Fellow, University of South Australia, End of Life Care Board
- Dr Sandra Bradley, Flinders University
- Kathy Williams, Department for Health and Wellbeing
- Professor Greg Crawford, Senior Consultant in Palliative Medicine, Director of Research and Education, Northern Adelaide Palliative Service, and Professor of Palliative Medicine, University of Adelaide
- Dr Christine Drummond, Senior Palliative Care Consultant, RAH and Chair, Improving End of Life Care Working Group, CAHLN

In addition, invitations for one on one consultations were sent to a number of senior clinicians at both the Royal Adelaide Hospital (RAH) and Flinders Medical Centre (FMC), but appointments were unable to be scheduled during the review period.

1.3.5 A number of clinicians made written submissions and attempts were also made to arrange a meeting with the Royal Australian College of General Practitioners. In addition to these targeted meetings, the review team also facilitated one workshop with the Health Consumers Alliance of South Australia (HCASA) and two focus groups with members

of the Council of the Ageing (COTA) South Australia. A total of 11 people attended HCASA workshop and 28 people attended the two COTA focus groups.

1.4 Submissions received

1.4.1 Members of the community were invited to make written submissions during the review, and a total of 35 submissions were received. These included the following:

- 12 submissions from lawyers, including the Law Society of South Australia
- Office of the Public Advocate
- Commissioner for Affidavits
- 9 individual submissions from the general public
- Health Consumers Alliance of South Australia
- Advance Care Planning Australia
- MIGA
- Australian and New Zealand Society of Geriatric Medicine
- 2 from the Northern Adelaide Local Health Network – one general and one from NAHLN Social Workers
- Fleurieu Justices Group
- 2 academic submissions representing 3 universities
- 2 submissions from clinicians at the Royal Adelaide Hospital (RAH) and Flinders Medical Centre (FMC)

1.5 Survey results

1.5.1 In addition to the Department's two Your SAY surveys, HCASA also conducted its own survey of members, which formed the basis of their written submission. The HCASA survey results were separately generated through the Alliance's invitation to consumers to attend a focus group and/or complete an online survey which offered the opportunity to reflect on their experience in completing an ACD (either for themselves or another person), or in acting as an SDM.¹ The Your SAY surveys generated a total of 249 general survey responses and an additional 53 responses from SDMs.

1.5.2 Since the Act was implemented in 2014, the Department has enabled consumers to provide feedback on the ACD form and DIY Kit, and has received over 230 email responses during that time. Consumers are asked to respond to a brief survey, which generates an email sent to the Department. The survey asks the following questions:

- Did the Guide help you fill out the Advance Care Directive Form?
Comments:
- Do you think the information in the Guide is easy to understand?
Comments:
- Was the Advance Care Directive Form easy to fill out?
Comments:

¹ HCASA, *Submission 35*.

- Do you have any other feedback about the Advance Care Directive?
Comments:

Of the responses received between 2014 and 2019, an overwhelming majority have been positive (approximately 66%). A further 14% provided negative feedback and approximately 20% offered suggestions for improvement. Further analysis of the Department's feedback is examined elsewhere in the Report and a comprehensive analysis of all survey data is contained in Appendices A and B. When the trends in reporting are analysed over the last 5 years, it clearly emerges that the Department has taken on board any negative feedback or suggestions for improvement, developing their website and addressing technical issues as they were brought to light. Responses received in 2018 and 2019 show an even higher number of positive responses, along with a reduction in technical issues being reported. Those same responses demonstrate clearly, however, that this avenue for providing feedback is heavily skewed to people who have engaged with the online or electronic versions of the form, as opposed to the paper-based version available to purchase from Service SA or available to print from the website.

1.5.3 The Your SAy survey responses sought during the review period of April to June 2019, asked for more targeted responses than the questions asked in relation to the online form. The general survey, which received 249 responses, asked the following questions:

1. How easy or hard was it for you to get an ACD form?
2. Where did you get your ACD DIY Kit or form?
 - I bought a DIY Kit or form from Service SA
 - I downloaded a DIY Kit or form from the ACD website
 - I completed my ACD online on the ACD website
 - Other – Please tell us how you got your DIY Kit or form
3. How easy or hard was it for you to fill out the ACD form?
 - Easy
 - Fairly easy
 - Neither easy nor hard
 - Fairly hard
 - Hard
4. If you used as ACD DIY Kit did you find it was:
 - Helpful
 - Fairly helpful
 - Neither helpful nor unhelpful
 - Fairly unhelpful
 - Unhelpful
5. When you completed your ACD did you appoint one or more substitute decision makers?
 - Yes I appointed 1 substitute decision maker
 - Yes I appointed 2 substitute decision makers
 - Yes I appointed 3 substitute decision makers
 - No I did not appoint any substitute decision makers
6. In Part 3 of the ACD form 'what is important to me – my values and wishes' there are 6 areas the document suggests for you to consider when decisions are

being made for you. Which of these things did you consider and include in your ACD?

- When decisions are being made for me I want people to consider the following
 - Outcomes of care I wish to avoid (what I don't want to happen to me)
 - Health care I prefer
 - Where I wish to live
 - My dying wishes
 - Other personal arrangements
7. Part 4 of the ACD form allows you to fill out a section titled 'binding refusals of health care'. In this part you can state what health care you do not want and the circumstances in which your refusal will apply. Did you fill out this section?
- Yes
 - No
8. Once you have completed you ACD it must be signed and witnessed. How hard or easy was it for you to find a witness?
- Easy
 - Fairly easy
 - Neither easy nor hard
 - Fairly hard
 - Hard
9. Did you complete your ACD yourself, or did you have a lawyer or someone else complete it?
- I completed my ACD myself
 - A lawyer completed my ACD
 - Someone else completed my ACD for me
10. Thank you for taking the time to provide us with this information. If there is anything further you would like to say about Advance Care Directives, please use the textbox below.

1.5.4 The results of the general survey are provided in Appendix A and, where relevant, are presented alongside the results of the HCASA's consumer survey.

1.5.5 The YourSAy survey of SDMs asked the following questions:

1. When you were appointed as a substitute decision maker, how many other people, if any, were appointed?
 - I was the only substitute decision maker appointed
 - One other person was also appointed as a substitute decision maker
 - Two other people were also appointed as substitute decision makers
2. Did the person who appointed you as a substitute decision maker talk to you about how they wanted you to make decisions on their behalf?
 - Yes, they spoke to me about how they wanted me to make decisions
 - No, they didn't tell me how they wanted me to make decisions
3. When the person who gave the ACD could no longer make their own decisions, or could not make decisions at specific times, did you make decisions on their behalf about:
 - Where the person was to live

- Other personal arrangements
 - Dying wishes
 - Binding refusals of health care
4. In regard to decisions about living arrangements, how easy or hard was it to have your decisions about the person concerned put into action?
 - Easy
 - Fairly easy
 - Neither easy nor hard
 - Fairly hard
 - Hard
 5. In regard to other personal arrangements for the person, such as their grooming and clothing preferences, preferred daily routines etc, how easy or hard was it to have your decisions about the person concerned put into action?
 - Easy
 - Fairly easy
 - Neither easy nor hard
 - Fairly hard
 - Hard
 6. If the person had indicated what their dying wishes were, how easy or hard was it to have their wishes put into action?
 - Easy
 - Fairly easy
 - Neither easy nor hard
 - Fairly hard
 - Hard
 7. If the person had stated that there were certain types of health care that they did not want (a binding refusal of health care), and the circumstances in which they did not want the health care, how easy or hard was it for your refusal of this health care to be accepted by health practitioners?
 - Easy
 - Fairly easy
 - Neither easy nor hard
 - Fairly hard
 - Hard
 8. How important do you think it is that the person giving the ACD talks to the substitute decision maker about how they want decisions made and what is most important to them?
 - Very important
 - Fairly important
 - Neither important nor unimportant
 - Fairly unimportant
 - Unimportant

PART 2

ACHIEVEMENT OF THE ACT'S OBJECTIVES

2.1 Achievement of the Objectives of the Act

Term of Reference 1

To assess the extent to which the objects of the <i>Advance Care Directives Act 2013</i> are being achieved.

2.1.1 The Long Title of the *Advance Care Directives Act 2013* (SA) reads as follows:

An Act to enable a person to make decisions and give directions in relation to their future health care, residential and accommodation arrangements and personal affairs; to provide for the appointment of substitute decision-makers to make such decisions on behalf of the person; to ensure that health care is delivered to the person in a manner consistent with their wishes and instructions; to facilitate the resolution of disputes relating to advance care directives; to provide protections for health practitioners and other persons giving effect to an advance care directive; and for other purposes.

2.1.2 The 7 objects of the Act are set out in section 9 and include as follows:

- (a) To enable competent adults to give directions about their future health care, residential and accommodation arrangements and personal affairs;
- (b) To enable competent adults to express their wishes and values in respect of health care, residential and accommodation arrangements and personal affairs, including by specifying outcomes or interventions that they wish to avoid;
- (c) To enable competent adults to allow decisions about their future health care, residential and accommodation arrangements and personal affairs to be made by another person on their behalf;
- (d) To ensure, as far as is reasonably practicable and appropriate, that health care that is provided to a person who has given an advance care directive accords with the person's directions, wishes and values;
- (e) To ensure that the directions, wishes and values of a person who has given an advance care directive are considered in dealing with the person's residential and accommodation arrangements and personal affairs;
- (f) To protect health practitioners and others giving effect to the directions, wishes and values of a person who has given an advance care directive;
- (g) To provide mechanisms for the resolution of disputes relating to decisions made on behalf of those who have given an advance care directive.

2.1.3 The objects of the Act need to be read together with the Act's principles and operative provisions and the *Advance Care Directives Regulations 2014* (SA) (hereinafter the

‘Regulations’). In addition, the Gazetted ACD Form and DIY Kit also contain a number of elements that warrant consideration and are separately examined under other Terms of Reference below. The Act’s principles are contained in section 10 and provide as follows:

The following principles must be taken into account in connection with the administration, operation and enforcement of this Act (including, to avoid doubt, the resolution of disputes under Part 7):

- (a) An advance care directive enables a competent adult to make decisions about his or her future health care, residential and accommodation arrangements and personal affairs either by stating their own wishes and instructions or through 1 or more substitute decision-makers;
- (b) a competent adult can decide what constitutes quality of life for him or her and can express that in advance in an advance care directive;
- (c) a person is, in the absence of evidence or a law of the State to the contrary, to be presumed to have full decision-making capacity in respect of decisions about his or her health care, residential and accommodation arrangements and personal affairs;
- (d) a person must be allowed to make their own decisions about their health care, residential and accommodation arrangements and personal affairs to the extent that they are able, and be supported to enable them to make such decisions for as long as they can;
- (e) a person can exercise their autonomy by making self-determined decisions, delegating decision making to others, making collaborative decisions within a family or community, or a combination of any of these, according to a person's culture, background, history, spiritual or religious beliefs;
- (f) subject to this Act, an advance care directive, and each substitute decision-maker appointed under an advance care directive, has the same authority as the person who gave the advance care directive had when he or she had full decision-making capacity;
- (g) a decision made by a person on behalf of another in accordance with this Act —
 - (i) must, as far as is reasonably practicable, reflect the decision that the person would have made in the circumstances; and
 - (ii) must, in the absence of any specific instructions or expressed views of the person, be consistent with the proper care of the person and the protection of his or her interests; and
 - (iii) must not, as far as is reasonably practicable, restrict the basic rights and freedoms of the person;
- (h) in the event of a dispute arising in relation to an advance care directive, the wishes (whether expressed or implied) of the person who gave the advance care directive are of paramount importance and should, insofar as is reasonably practicable, be given effect;
- (i) subject to this Act, in determining the wishes of a person who gave an advance care directive in relation to a particular matter, consideration may be given to —
 - (i) any past wishes expressed by the person in relation to the matter; and
 - (ii) the person's values as displayed or expressed during the whole or any part of his or her life; and

- (iii) any other matter that is relevant in determining the wishes of the person in relation to the matter.

2.1.4 Throughout the consultation period, feedback was almost unanimously positive with regard to the Act's objects and principles and the original intent behind them. In the 5 years since the Act has been in force, that support has not waned; if anything, it has increased and been affirmed over time. That support was the same whether speaking with consumers or consumer advocacy groups, clinicians and health practitioners, or lawyers and Justices of the Peace (JPs). Below are a sample of the comments made throughout the consultation period:

On the whole, my impression of the *Advance Care Directives Act 2013* is that it is progressive and has brought about welcome change.

Dr Steven Galluccio, Senior Consultant,
Intensive and Critical Care Unit, Flinders Medical Centre

I think the ACD is a good idea and that every person over 18 regardless of age ought to be encouraged to do one.

Geraldine Gillen, Whyalla

The objectives of the Act are broadly consistent with the objectives identified in the relevant international agreements, and academic and policy literature on capacity and human rights.

Associate Professor Wendy Bonython, Bond University &
Associate Professor Bruce Arnold, University of Canberra

MIGA is generally supportive of the advance care directive regime in South Australia and sees the objectives of the *Advance Care Directives Act 2013* (SA) as being broadly achieved, but with more work to do ... In MIGA's experience, the most significant issue it encounters in advising, assisting and educating its members and clients around ACDs and end of life care issues more broadly is the comparatively limited use of ACDs in South Australia and across Australia. There is a need for concerted efforts by a wide range of stakeholders to try and increase ACD usage.

Timothy Bowen, Senior Solicitor, MIGA

2.1.5 Assessing the extent to which the Act's objects are being achieved, as opposed to the widespread support for them, is more complex. The take-up of ACDs is still relatively low and Australian research indicates that the uptake of ACDs is still relatively uncommon. As the Royal Commission into Aged Care recently observed,²

² Royal Commission into Aged Care, *Discussion Paper 5: Advance Care Planning in Australia* (2019), at 5-6, available at: <https://agedcare.royalcommission.gov.au/publications/Pages/default.aspx> (accessed 21 June 2019).

Research into the uptake, outcomes and utility of advance care planning in Australia is limited.³ The available research suggests that the practice of advance care planning in Australia is not common, particularly when compared with other planning documents such as wills.⁴

A 2017 Australian study assessed how many people aged 65 years or over had at least one advance directive on file. The study found a rate of 48% in residential care, 16% in hospitals and 3% in general practices.⁵ Most of the directives were non-statutory documents. Less than 3% had a statutory advance care directive outlining preferences for care, and only 11% had a statutory advance directive appointing a substitute decision-maker.⁶

These rates are significantly higher than those recorded in previous Australian studies.⁷ For example, a 2014 study found zero advance directives among 100 elderly patients in a tertiary referral hospital⁸ and a 2009 study found a 5% median uptake of advance directives in selected residential aged care facilities.⁹

2.1.6 As the Royal Commission’s Discussion Paper noted, prevalence studies conducted in recent years throughout Australia tend to indicate that the uptake of ACDs is improving, and that South Australians are more likely to have an ACD in place compared with the rest of Australia. However, at focus groups conducted as part of the Review, anecdotal feedback indicated that the uptake rate for ACDs among older South Australians could be as low as 10% among some groups.¹⁰ During the review period, a current SA based multi-disciplinary research project was revealed in consultations. While the research is yet to be published, and cannot be cited with any specificity in this Report, their datasets add further evidence of low ACD take-up rates in the State. The researchers surveyed all patients with decision-making capacity in 2 metropolitan hospitals over one weekend and found that only a very small number – less than 10 - had an existing ACD on file and only about one third of patients had heard of ACDs. Significantly more than a third had a 7 Step Pathway completed, however. The results, therefore, are mixed and while the Act’s enactment appears to have sparked an increase in ACD adoption, there is certainly more that could be done to promote awareness of ACDs in the broader community, as well as support for ACD completion.

³ Australian Government Department of Health and Ageing, *A National Framework for Advance Care Directives*, 2011, at 5.

⁴ B White, C Tilse, J Wilson, L Rosenman, T Strub, R Feeney and W Silvester, ‘Prevalence and predictors of advance directives in Australia’ (2014) 44(10) *Internal Medicine Journal*, at 975-980.

⁵ K Buck, K Detering, M Sellars, R Ruseckaite, H Kelly and L Nolte, *2017 Prevalence of advance care planning documentation in Australian health and residential aged care services*, Short Report, 2018, at 4.

⁶ Ibid.

⁷ The inclusion of both statutory and non-statutory advance directives may account for this: See K Detering, K Buck, R Ruseckaite, H Kelly, M Sellars, C Sinclair, J Clayton and L Nolte, ‘Prevalence and correlates of advance care directives among older Australians accessing health and residential aged care services: multicentre audit study’, (2019) 9 *BMJ Open*, 2019.

⁸ F Cheang, T Finnegan, C Stewart, A Hession and JM Clayton, ‘Single-centre cross-sectional analysis of advance care planning among elder inpatients’ (2014) 44(10) *Internal Medicine Journal* at 967–74.

⁹ AJ Bezzina, ‘Prevalence of advance care directives in aged care facilities of the Northern Illawarra’ (2009) 21(5) *Emergency Medicine Australasia* at 379–85.

¹⁰ Comment – COTA Policy Council ACD Public Consultation Forum, 24 May 2019.

- 2.1.7 To compare earlier Australian studies, a 2014 study found zero ACDs among 100 elderly patients in a tertiary referral hospital¹¹ and a 2009 study found a 5% median uptake of ACDs in selected residential aged care facilities.¹² Another study conducted over 2 months during 2018/19, however, found that 40% of older South Australians accessing health services had an ACD in place compared with 25.3% of the population Australia-wide.¹³ A similar study conducted over four months in 2017/18 found that 53% of older South Australians accessing health services had an ACD compared to 29.8% of the population Australia-wide.¹⁴ By way of contrast, rates in New South Wales and Tasmania, which have no statutory ACD regime, were 36.8% and 14% respectively.¹⁵
- 2.1.8 The 2017 Australian study referred to in the Royal Commission’s Paper (quoted above) was focussed on people over the age of 65 and showed that 30% of participants had an ACD.¹⁶ The majority of the directives were non-statutory documents, however. Less than 3% had a statutory ACD outlining preferences for care, and only 11% had a statutory ACD appointing an SDM.¹⁷ This study also found that an additional 20% of respondents had some form of Advanced Care Planning (ACP) documentation, although only 20% of that documentation was written by the person who made the plan.¹⁸ A 2016 study involving South Australians aged over 65, or 50 for Aboriginal and Torres Strait Islanders, showed that 35% of participants had an ACD in place.¹⁹
- 2.1.9 Assessing the impact of the legislation on improving the uptake rate for ACDs is somewhat difficult given the number of instruments that ACDs replaced, in addition to the absence of data around the existence of still valid Enduring Powers of Guardianship (EPGs), Medical Powers of Attorney (MPAs) and Anticipatory Directions (ADs). Yet, the Act seems to have triggered an increase in the rate of ACD adoption. A 2010 study based on the SA Health Omnibus found that 53% of people aged over 65 had an enduring power of attorney, 31% had an enduring power of guardianship, 26% had a medical power of attorney and 17% had an anticipatory direction.²⁰ The 2018 report

¹¹ F Cheang, T Finnegan, C Stewart, A Hession and JM Clayton, ‘Single-centre cross-sectional analysis of advance care planning among elder inpatients’ (2014) 44(10) *Internal Medicine Journal* at 967–74.

¹² AJ Bezzina, ‘Prevalence of advance care directives in aged care facilities of the Northern Illawarra’ (2009) 21(5) *Emergency Medicine Australasia* at 379–85.

¹³ Buck K, Detering K, Sellars M, Kelly H, and Nolte L. 2019. Prevalence of advance care directives in Australian health and residential aged care services: report for South Australian services. Advance Care Planning Australia, Austin Health, Melbourne at 18.

¹⁴ Detering, K Buck, R Ruseckaite, H Kelly, M Sellars, C Sinclair, J Clayton and L Nolte, ‘Prevalence and correlates of advance care directives among older Australians accessing health and residential aged care services: multicentre audit study’, (2019) 9 *BMJ Open*, 2019, at 6.

¹⁵ Ibid

¹⁶ K Buck, K Detering, M Sellars, R Ruseckaite, H Kelly and L Nolte, *2017 Prevalence of advance care planning documentation in Australian health and residential aged care services*, Short Report, 2018, at 4.

¹⁷ Ibid.

¹⁸ Buck et al, above n 6.

¹⁹ W Lacey and H Middleton ‘Planning Ahead’ (Presentation at Ageing in South Australia: The attitudes and preferences of consumers, University of South Australia, 2 September 2016)

²⁰ S Bradley, R Woodman, J Tiernan and P Phillips ‘Use of advance directives by South Australians: results from Health Omnibus Survey Spring 2012’ (2014) 201(8) *Medical Journal of Australia* Appendix 3

published by Advance Care Planning Australia found that 40% of South Australians had ACDs in place, compared with 25.3% Australia-wide.²¹

- 2.1.10 As the Legal Services Commission stated during the consultation, the number of downloads of the electronic ACD form surpassed 20,000 in 2018. Website data showed significant spikes in enquiries regarding ACDs following the introduction of ACDs in 2014 and an advertising campaign in 2018.²² A further 17,702 ACD DIY Kits have been purchased through Service SA centres since the Act came into force, up until the end of May 2019. In the absence of a register for executed ACD forms, it is difficult to determine the proportion of the adult population who have completed ACDs. For example, while one lawyer in a submission to the review stated that he finalised between 250 and 300 ACDs each year,²³ many law firms use their own precedent software to develop ACDs based on the Gazetted template. In addition, many people choose to use the electronic version of the ACD form, which makes it easier for people to revoke, amend and execute different ACDs over time. As the Law Society of South Australia reported during the review,²⁴ one of their members had appeared in a matter before the South Australian Civil and Administrative Tribunal (SACAT) involving 5 successive ACDs.²⁵ The person who had completed them was a resident of an aged care facility and had completed each at the behest of her individual children. Thus, there are a number of practical barriers to determining the prevalence of ACD take-up throughout South Australia. There is, therefore, a need for further and more systematic research in South Australia. Recommendations 4-6 below, if adopted, will go a significant way to improving our understanding of the prevalence of ACDs within the State.
- 2.1.11 Nonetheless, the available studies suggest that somewhere around a third of the population have an ACD or some form of advance care planning (ACP) document in place, but there is little research that captures the uptake rates across different age groups. Studies also show that South Australia has a higher prevalence of ACDs compared to the whole of Australia and significantly higher than those jurisdictions without a statutory regime. Interest in ACDs in South Australia was shown to be highest at the time of introduction of the statutory ACD scheme and following media campaigns, suggesting that the promotion of ACDs through future education and awareness raising campaigns would improve their uptake.
- 2.1.12 In addition to having an ACD in place, the documentation needs to be available at the time it is needed, particularly in hospital settings. A 2018 study conducted Australia-wide revealed that 54% of participants self-reported having advance care planning documentation in place, however, only 48% of those had that documentation in their health care record. It is important to note that this study included informal planning documentation written by the person as well as ACDs.²⁶

²¹ Advance Care Planning Australia, Prevalence of Advance Care Directives in Australian Health and Residential Aged Care Services,

²² Legal Services Commission website analytics, provided to this Review on 11 June 2019.

²³ G Edwards, Mobile Wills Service, *Submission 15*.

²⁴ Law Society of South Australia, *Submission 27*.

²⁵ Ibid.

²⁶ K Buck, A Pollard, R Ruseckaite, B White and L Nolte, 'Concordance between self-reported completion of advance care planning documentation and availability of documentation in Australian health and

- 2.1.13 Levels of community awareness and understanding of ACDs are also difficult to determine in the absence of reliable data.²⁷ Despite this, a number of themes emerged throughout the Review concerning key, common or persistent challenges around the level of understanding of ACDs and their implementation. These emerged through oral consultations, written submissions and surveys conducted by the review team and the Health Consumers Alliance of South Australia (HCASA). Concerns and challenges were not limited to specific groups but extended across many of the diverse sectors and population groups represented in the Review. Given that these surveys captured the consumer perspective, they provide insight into the extent to which the objects of the Act are being realised. And, given that the first 3 objects of the Act pertain directly to consumers, it is beneficial to use the survey results as the point of departure for examining the extent to which those objectives are being realised in practice. The following sections do, however, also engage with written and oral submissions where relevant.
- 2.1.14 The second 3 objects of the Act (s 9(d)-(f)) relate directly to the activation or implementation of an ACD when a person loses the capacity to make decisions on their own, or the ability to communicate their wishes. In assessing the extent to which these objects are being realised, they relate more specifically to clinicians, health practitioners and substitute decision-makers (SDMs) as opposed to consumers. SDMs, however, raise issues of both form and substance: form, with regard to appointment and acceptance of the role as SDM; and substance, with regard to how clinicians and SDMs carry out their role when the ACD is activated. SDMs are frequently the conduit between the consumer and clinicians in a health or aged care setting. For this reason, different aspects of the SDM role and function are considered in several sections below.
- 2.1.15 The final object of the Act relates to the resolution of disputes and is addressed in much greater detail under Term of Reference 2(e) and (f), addressed at 3.4 and 3.5 below.
- 2.1.16 Due to the overwhelming support for the Act's objects conveyed throughout the review period, and extending across the clinical, legal and community sectors, no recommendations have been made to amend s 9 of the Act. However, the review itself revealed a number of concerns regarding the Act's implementation, including the adherence to directions within an ACD in clinical settings. These issues are discussed and incorporated into the recommendations contained in Part 3 of this Report. Because the second term of reference asks whether changes should be made to 'legislation, administration, policy or practice' in promoting the realisation of the Act's objects, analysis of feedback received through consultations, written submissions, focus groups, workshops and surveys are discussed in those sections below. The Act is widely supported across the community, but aspects of its practical operation and implementation can and should be improved. Accordingly, a finding from the Review to the first Term of Reference is that the Act's objects are clear, unambiguous and widely supported across the community. However, there was also a consistent theme that the

residential aged care services', (2019) *Journal of Pain and Symptom Management*, at 5-6. <<https://doi.org.access.library.unisa.edu.au/10.1016/j.jpainsymman.2019.04.026>>

²⁷ Legal Services Commission, *Consultation*, 7 May 2019.

Act's implementation is being undermined in a practical sense through a lack of resources, education, awareness and training to support the realisation of its objects. In this sense, the objects contained in s 9 of the Act must be construed and given effect by way of further reference to the 9 articulated principles of the Act (s 10), in addition to its operative provisions. An example is s 11(5), which outlines the reasons why minor breaches of manner and form will not result in invalidity. Recommendations for change to 'legislation, administration, policy or protocol', discussed in relation to the sub-elements of Term of Reference 2, are informed by such an approach.

2.1.17 Barriers to the realisation of the Act's core goals have less to do with issues with the Act itself and more to do with the levels of understanding and awareness of ACDs and their operation. Confusion around ACDs, their effect and operation was also not limited to particular groups but, extended across all professional sectors consulted, as well as members of the public. The Act is, in a number of respects, a complex one. The changes brought by its enactment had a number of ambitious intents: to empower individuals to make directions and express their personal wishes, values and preferences without the necessity to seek specialist advice, including from either medical or legal specialists; to appoint SDMs to make decisions by 'standing in their shoes' at times when decision making capacity is lost; to make binding directions related to the refusal of particular health care; to bind SDMs and health practitioners (subject to certain legal qualifications); to develop a template and toolkit for community members to use in creating an ACD; and, to replace previous legal instruments, including EPGs, with a single document.²⁸ However, as Margaret Brown observed,²⁹

The implementation of the Advance Directives Act includes educating health and legal professionals and the general public. In order to create the required cultural change the relevant professionals need to understand the legal effect of the ACD documents and the principles which underpin them including the social purpose which led Parliament to change the law and people to complete the ACD Document. The person providing the treatment or care needs to share a common understanding with the patient/consumer, their SDM and their family.

A change in the law was an essential precondition for this cultural change to occur but ongoing education is critical to ensure that the philosophy which motivated the Parliament to change the law is carried over into every hospital, GP clinic and aged care facility, and to all members of the community (including all rural regions) so that everyone understands the change in the law and can exercise their rights and duties under the law ...

There has not been an adequate commitment to the implementation or in co-ordinating education and policies for health care professionals and for the public in how to prepare and execute the documents and what their rights and duties are under the legislation.

²⁸ South Australia, Parliamentary Debates, House of Assembly, 17 October 2012.

²⁹ M Brown, *Submission 36*.

2.1.18 A constant observation made during the Review was that there had been inadequate resources for education and training and for building awareness and understanding of the Act. Without dedicated staff within the Department responsible for ACDs, there has been a lack of leadership in relation to the Act's implementation. These issues are addressed further in the following section.

FINDING 1

2.1.19 The objects of the Act are widely supported across the South Australian community, including among clinicians, health professionals, lawyers, health networks, advocacy groups, key statutory agencies and the general public. However, it is a commonly held view that the practical realisation of those objects is being hindered by a lack of support, in particular, to medical professionals and the public, especially around resources, education, awareness and training. This Review makes several recommendations that will improve the uptake of ACD's by the community, and their recognition by the health sector.

PART 3

OTHER ISSUES RELATED TO THE ACT

3.1 Community Understanding of Advance Care Directives

Term of Reference 2(a)

To recommend changes to the legislation, administration, policy or practice which would improve the extent to which the objects are achieved with particular reference to:

- (a) General understanding of ACDs in the community ...**

3.1.1 It became evident during the review that many South Australians are unaware of Advance Care Directives and, of those that are, there continue to be significant barriers to the adoption and completion of ACDs. This lack of understanding can be reduced to 3 issues:

- Many people are simply not aware of the importance or role of ACDs until they meet with a lawyer as part of estate planning, a doctor following a critical diagnosis or as a precursor to surgery, or in the event that they hear of (and attend) a community forum on ACDs, or via word of mouth;
- The ACD Form, but particularly the DIY Kit, are both confusing and overly complicated and, while many people print off both, a significant number do not complete the document because they find the process overwhelming;
- The discontinuation of 2 dedicated roles with the Department following the Act's enactment, as well as a targeted public education campaign, had a direct and detrimental effect on levels of understanding of ACDs within the community.

3.1.2 In its submission to the Review, Advance Care Planning Australia made the following comments:

Advance care planning is an essential enabler of person-centred care and is particularly important for ageing Australians and those accessing aged care services. The prevalence of documentation in Australia is low and there are current issues with the quality, timing, accessibility and implementation of advance care planning ...

ACPA believes there is evidence of low prevalence, accessibility, quality and risk issues associated with current advance care directive documentation in Australian aged care services. These issues place aged Australians at significant physical harm,

for example, poor quality directive documentation may result in life-sustaining treatment being unlawfully withheld or unlawfully provided to a person.

3.1.3 Other comments received during the Review included the following anonymous survey responses:

The DIY kit is too messy and tries to please everyone but fails because it is like reading a book.

There should be proforma models because a lot of people think the same such as "let me go" if I get terminally ill.

I got a lawyer because it was difficult to fill in, and then lawyer had copies, not sure what to do with them now, do I give copy to my GP? My mother completed one earlier at age of 80; she found it very difficult to get a form and to fill in. It shouldn't be this hard.

The ACD is too generalised and throws up many issues relating to its enforceability subject to how it is completed.

Way too long and involved. Easy to lose interest. Thank heavens I had a medical power of attorney in place before ACD. Was the ACD designed with the end users or by a bureaucrat who assumed they knew what users need and want?

The template is really bad.

The form is difficult to complete as there are sometimes more than one place to put a response. For example, what is to occur in the final stages of life.

3.1.4 The review heard from many groups in relation to the ACD Form and the DIY Kit. A constant theme was that neither is fit for purpose and presents a barrier to the broader adoption of ACDs within the community. Below is a selection of comments provided to the Review:

I have a number of clients who contact me to do just the ACD. They have found the booklet too confusing and too long.

I give a number of talks to community groups and at retirement villages and when I explain that the part they need to fill in is only the 6 pages in the middle, you can see audience members think, ok maybe I can do it.

Some of the examples in the book are not practical. I advise my clients that when completing the document to keep their instructions to the big picture issues such as DNR and organ donation. Where substitute decision maker/s have been appointed, they generally know the person they are acting for and can make decisions re personal grooming etc. without it having to be written down in an ACD. My

concern is that having things written down may leave other things not specifically mentioned open to debate - that is if some things are mentioned and not others.

Catherine Moyses

My feedback is that while I am well educated, a member of a health profession and reasonably literate I still have not completed the form. While I have had a couple of goes, I found it too difficult to decide what to put in without the opportunity to talk it through with someone who could provide some guidance.

Elaine Ashworth

I purchased an Advance Care Directive (ACD) kit three years before I completed it. Over the first two years I read it through a couple of times, left it on my desk for attention and watched as it was covered up with more urgent things. After two years I realised I needed help to complete it or it would sit on my desk forever. It seemed a big writing task but most importantly, it was a big psychological task. I was avoiding thinking about my end of life, thinking about not being able to make decisions for myself. I have always been a believer in mutual aid groups and I thought that was what I needed - the collaborative support of others. And perhaps other people needed it too.

Fiona Johnston

Anecdotally, the overwhelming majority of people find the forms complex and confusing and seek legal assistance with completion. This assistance is slower and therefore more costly as the form cannot be adapted to the firm's own systems.

Julie Van der Velde

I find the Kit difficult to navigate. Overall I find the pages too busy, with not enough white space, and consider the font could be smaller and still appropriate for the readership. The forms could be a different colour to the other content.

Dr Sue Jarrad, Mitcham

The 74 pages are too long for our elderly patients to read. As we deal with the frailer end of the spectrum, perhaps with people with dementia, often it is family members who help guide the process. It is good to have someone to help our population understand the document and that it is there to help respect their wishes, best done in the community, rather than when there is a crisis.

Australian Society of Geriatric Medicine, SA Division Committee

The ACD DIY-KIT ... in our opinion, goes far-beyond the literacy and comprehension levels of a good proportion of the persons to whom it is directed. In fact, we believe the very people who will require the most explanation of the intent and meaning of the legislation, together with procedural requirements for completing an advance care directive, will be the persons least likely to be able to interpret and absorb that quantum of information. We note that a high proportion of clients presenting at the Justices Signing Room to have their ACD document witnessed have their ACD Form only with them. They don't bring or present with the 'Information Statement' document which is a requirement of the witnessing process. When questioned, many confirm that they are not aware of the requirement

to do this or tell us that they have never read or know of the full contents of the ACD DIY KIT.

Fleurieu Justices Group

The ACD form is NOT printer friendly for home users as it has too many areas that are shaded, but serve no purpose.

Stephen Merrett

I work as a solicitor and worked throughout the transition period from Powers of Guardianship to ACDs ... I have found that clients find the ACD form to be 'busy', poorly laid out, overly wordy, somewhat esoteric and confusing. Client's feedback is that while certain decisions are important to them, e.g. what care they may receive while incapacitated, refusal of life support, etc. the amount of information that the ACD allows/asks for is overwhelming.

Tom Sheridan, Ezra Legal

3.1.5 Responses to the Health Consumers Alliance South Australia survey resulted in the following observations from HCASA:³⁰

Respondents identified a number of key suggestions and recommendations to improve the information resources in the Kit so that consumers understanding of specific terminology used and the context of when to 'use' an ACD was clearer. Many consumers felt the ACD and Kit were, though not specified, focused on planning for end of life for older people. Consumers commented there is a lack of targeted information for a wide range of circumstances and situations, including young people. Providing examples of when it might be opportune for people to complete an ACD would be very helpful and better inform the broader community.

FINDING 2

3.1.5 General understanding of ACDs within the community is low. Many people only learn of their importance and role through word of mouth or serendipitous meetings and conversations, for example, when a person sees their lawyer to update their will and/or appoint a power of attorney. Following the Act's enactment, the Department had 2 dedicated staff members who were responsible for education, training, oversight and promotion of ACDs. In retrospect, the decision to discontinue those roles is widely viewed as being short-sighted and retrograde in its effect.

3.1.6 The DIY Kit is extremely long at 74 pages for the online version. Page numbers are not chronological and each section is separately numbered. Formatting could also be significantly improved. The online version of the ACD Form is 6 pages long, however, the paper based (or printed version) does not permit sufficient room for a person to write detailed directives in each section. Email feedback received by the Department since 2014 demonstrates that there were a number of technical issues with the online form in the early years, but that the Department was very responsive to poor feedback from

³⁰ Health Consumers Alliance South Australia, *Submission 35*.

members of the public. Ultimately, the uptake of ACDs has been adversely affected by the complex and often overwhelming nature of the form and DIY Kit. The Review received many comments from the community to the effect that people will often print both documents out but fail to complete them.

3.1.7 The Your SAy general survey, which received a total of 249 responses, posed the question, ‘[h]ow easy or hard was it for you to get an ACD Form?’ A total of almost 68% of respondents commented that it was either easy or fairly easy to access the ACD form, with only 12.85% finding it either hard or fairly hard (see further Appendix A). However, when asked how they sourced a copy of the ACD Form and DIY Kit, the responses confirmed the view of the Legal Services Commission that around 20% of people complete their ACDs online,³¹ with the large majority (81.88%) choosing to download a paper-based version from the website or purchase a copy from Service SA. Of the 91 respondents who skipped the question but wrote in the textbox under ‘other’, the large majority sourced the form through either their lawyer or the Law Society of South Australia (58 of a total of 91 people, but 23.10% of total respondents). The next most common alternative source of accessing the ACD form (other than through the website or Service SA) was through medical and health practitioners (doctors, nurses, hospitals, GP clinics, employers within the health sector). Others were given forms through training or community groups, financial advisers, Palliative Care SA, a nursing home, a friend or family member.

3.1.8 Overall, the largest number of respondents accessed their ACD forms independently using the website to either print the paper-based form, complete the online version or purchase the Kit from Service SA (63.74%). The second largest group (23.10%) accessed the form through either their lawyer or the Law Society, and a much smaller number accessed it through health practitioners, community based organisations, advocacy groups, or other advisors. Clearly the largest and most important sources for accessing the ACD forms is to download the paper-based version from the website (41.83%), or to seek the assistance of the legal profession (23.10%). Given the proportion of people who use the paper-based version, and the number of comments received in submissions describing the lack of space to include all of their desired preferences in each section, the ACD form itself needs to be expanded. As one consumer explained, ‘I bought a booklet from Service SA some years ago. I found it did not allow me enough space to detail what I would like to happen as I age.’³² A principal objective of the Act is to facilitate a person’s right to express their preferences, wishes and values with respect to future medical care, accommodation and personal affairs through the completion of an ACD. That so many South Australians are unable to do so using paper based versions of the ACD Form means that this objective is not being realised for this group of people. While, future generations are likely to feel more comfortable in using an electronic version of the form, which is able to expand certain sections, South Australia will continue to have significant numbers of people who do not, and that is likely to remain the case for several decades.

³¹ Legal Services Commission, *Consultation*, 7 May 2019.

³² G Gillen, *Submission 2*.

3.1.9 Respondents were also asked to rate how easy or hard they found it was to complete the Form. A total of 41.91% stated that the ACD form was easy or fairly easy to complete, whereas 19.05% were neutral and 38.59% found it a hard or fairly hard process. This means that almost as many people found completing the form hard as those who said it was easy. These results were not reflected in the results of the HCASA survey results, however, where a total of 69% of respondents rated their experience of using the ACD form as ‘extremely good’. Nonetheless, it is very difficult to separate out responses to questions regarding the ACD form from those related to the Kit, given the tendency of both respondents, those engaged in oral consultations, and those who made written submissions to frequently conflate the experience of using both the form and the Kit.

3.1.10 When asked how helpful or unhelpful the DIY Kit to be, a total of 95 from 210 responses, or 44.24%, found the DIY Kit to be either helpful or fairly helpful in completing their ACD. However, far fewer respondents found it to be unhelpful or fairly unhelpful (23.34%), leaving 31.43% in the neutral category. The number of neutral responses given in the Department’s Your SAY survey was the highest for this particular question, but the results tend to indicate strongly the need for further work on the Kit in particular. This point was only reinforced in qualitative feedback received throughout the review. The HCASA written submission captures this point:

Consumers responded that they found the ACD generally easy to read however the Kit was far too wordy and was not an easy read given the pages were very text heavy. Consumers indicated that they felt most people would not read through the Kit and may find it difficult to navigate to relevant sections, particularly for people with low health literacy.

Respondents felt that the Form and Kit alone was not adequate for people considering completing an ACD and more education and information needed to be available to consumers and the community including:

- Community information forums;
- Information/resources made more readily available in community settings such as libraries, councils and community centres;
- Health practitioners, particularly GPs, should be better educated to take a more proactive approach to openly initiating and facilitating discussions with consumers/patients about the roles of ACDs, and how to complete them – including assisting them to complete key sections.

Respondents felt that the draft example of the ACD was helpful but suggested that a number of examples be provided that addressed the different circumstances people may be in when they decide to complete an ACD, including taking into account the environments people may choose (including their own home).

3.1.11 Similar sentiments were expressed in many other submissions received.³³ Interestingly, the HCASA results indicated that 75% of respondents were happy that the current form enabled them to initiate discussions around their preferences, and 74% felt that they were provided with sufficient information to prepare an ACD, with some specific reservations (discussed below). Despite these positive responses, overall a strong theme emerged

³³ Legal Services Commission, *Consultation*, 7 May 2019; S Jarrad, *Submission 32*; Fleurieu Justices Group, *Submission 29*; Health Consumers Alliance South Australia, *Submission 35*; W Bonython & B Arnold, *Submission 17*.

throughout the Review for the need to revise and update the Kit, to reduce its length and its complexity. As one anonymous consumer noted, in a view that was shared by many consumers,

I believe that such a directive is essential but that it should be as simple as possible to prepare. The Advance Care Directive system in its present form, while carefully thought through to cover many possibilities, has become unduly complicated.

3.1.12 This sentiment was echoed by many other consumers or groups who work with consumers, including professionals with expertise in ACDs. Margaret Brown, a member of the End of Life Care Board and a long-standing advocate and researcher in the field, stated that, in her view, the Act is not well understood at all and there is considerable confusion in relation to the Kit, including among health professionals.³⁴ Often, people do not know where to start; the Kit needs a ‘very good edit’ with attention to both content and formatting.³⁵ This view was mirrored in many submissions and was reinforced by experts who had facilitated community workshops on preparing an ACD, as well as consumers who had attended them.³⁶ The review also met with volunteers from both the Barossa and Victor Harbor groups, who have separately coordinated community-based programs in their respective communities.

3.1.13 The present Kit contains a number of example (or sample) completed ACDs and, for many people, these have been very helpful. The Legal Services Commission stated that the sample contained within the Kit can be very helpful in educating people about the sort of statements to include in an ACD. Others raised some concerns about their usefulness and/or accuracy.³⁷ Many clinicians also expressed their concern about the inclusion of generic statements in an ACD that are often not properly understood unless a person has sufficient medical and health literacy, or has consulted with a medically trained person.³⁸

3.1.14 The Review also generated a significant number of written submissions from lawyers, both individually and through the Law Society, with the majority of submissions tending to raise the same concerns (some of which are addressed more specifically under other Terms of Reference). In a letter from the Law Society, the following points were made in relation to the Kit:³⁹

Members who practice in this area are frequently approached by clients seeking assistance to complete these documents because they find them confusing and too lengthy. For example, the Society is informed by its Members who practice in this area that many people are confused as to what should be contained in a will as opposed to an ACD with respect to dying wishes. This could result in testamentary wishes not being carried out as they are not contained in the will.

³⁴ End of Life Care Board, *Consultation*, 13 May 2019; M Brown, *Consultation*, 12 June 2019.

³⁵ Ibid.

³⁶ F Johnston, *Submission 16*; Sandra Bradley, *Consultation*, 10 May 2019; Victor Harbor Volunteers and Justices of the Peace, *Consultation*, 13 May 2019; Barossa ACD Service, *Consultation*, 20 May 2019.

³⁷ S Jarrad, *Submission 32*, W Bonython & B Arnold, *Submission 17*.

³⁸ Dr J Morton, *Submission 20*.

³⁹ Law Society of South Australia, *Submission 27*.

The Society remains of the view that the kit is over-engineered, and that a more practical approach is required.

- 3.1.15 Another lawyer wrote that his experience with clients has been that ‘the process is far more overwhelming now than it used to be with Powers of Guardianship. I have found that clients find the ACD form to be ‘busy’, poorly laid out, overly wordy, somewhat esoteric and confusing.’⁴⁰

FINDING 3

- 3.1.16 The current ACD Form and, in particular, the DIY Kit, are no longer fit for purpose. They are overly complicated, unduly long and act as a barrier to the adoption and execution of ACDs within the community.**

- 3.1.17 Throughout the review, it became clear that one of the biggest impediments to the implementation of the Act was the lack of dedicated staff within the Department responsible for leading education, training and public awareness of ACDs. Trends with regard to the accessing and downloading of the form and DIY Kit clearly demonstrate the impact of the withdrawal of resources within the Department. To re-establish 1-2 roles within the Department for these purposes would be a relatively small investment that will ultimately benefit South Australians, as well as provide clearer guidance to clinicians working with the hospital system with greater clarity around medical treatment and end of life care. While many people working in Local Health Networks (LHNs) reported positive experiences in seeking support and guidance from the Office of the Public Advocate (OPA), the provision of support and expertise within the Department would further strengthen compliance with ACDs in clinical settings.

- 3.1.18 The Review also highlighted the importance of pro-bono and volunteer work within the community in relation to ACDs. A number of academics, former lawyers, nurses and medical professionals, as well as JPs, are engaged in unpaid training and education programs designed to support people to develop ACDs. Some academics have secured funding support, but this has been limited and the large majority operate on the goodwill of experienced volunteers. Two prominent examples include the voluntary programs coordinated in the Barossa and in Victor Harbor. Each represents best practice within the State, involving people with different professional backgrounds and experience, and each is supported by their local hospitals and councils. Programs provide a supportive environment for learning about and completing ACDs, involve multiple sessions with experts, and access to photocopying and witnessing services in order to facilitate the completion and proper execution of ACDs. Each program, including the resources used and developed by the volunteers, could easily be adapted to other areas across both metropolitan Adelaide and regional South Australia. By appointing dedicated staff within the Department to work on the promotion and understanding of ACDs would also enhance the roll out of similar programs to that which operate in both the Barossa and Victor Harbour and, ultimately, result in a higher uptake of ACDs across the state.

⁴⁰ T Sheridan, Ezra Lawyers, *Submission 19*.

Recommendation 1

The government should reinstate 1, but preferably 2, positions within the Department for Health and Wellbeing, with the dedicated role of promoting understanding and awareness of ACDs. This/these role(s) should work in collaboration with community and advocacy groups to promote the understanding and uptake of ACDs, as well as taking leadership of an ongoing education and training program for clinicians and health practitioners in each of the Local Health Networks (LHNs).

Recommendation 2

Both the ACD Form and the DIY Kit need to be reviewed and the latter significantly updated. Each needs to be tailored for a lay-person and contain sufficient information for a person to complete an ACD without the necessity to consult either a lawyer or a doctor. However, both documents should make it clear that speaking with both (or either) a lawyer and a doctor may result in the completion of an ACD which more closely reflects the wishes and preferences of the person.

3.2 Uptake and Understanding of Statutory and Non-Statutory Advance Care Directives

Term of Reference 2(b)

To recommend changes to the legislation, administration, policy or practice which would improve the extent to which the objects are achieved with particular reference to:

...

- (b) uptake and understanding of the form and non-statutory ACDs and ways to increase their uptake ...

3.2.1 This Term of Reference has been largely addressed under 3.1 above. However, it also emerged during the review that few people are aware of the difference between statutory and non-statutory ACDs. This can be largely explained by the fact that the Act never addressed the continued operation of the common law, despite the then Minister's references to the common law during his Second Reading Speech. In hindsight, the Act should have made such reference. While it was laudable that the Act desired to create one instrument to deal with all advance directives, thus replacing EPGs, MPAs and ADs, the potential for non-statutory directives should have been expressly retained.

3.2.2 According to the common law, a person's right to self-determination outweighs the right of the State to preserve life. As Justice McDougall stated in *Hunter and New England Area Health Service v A*,⁴¹

[i]t is in general clear that, whenever there is a conflict between a capable adult's exercise of the right of self-determination and the State's interest in preserving life, the right of the individual must prevail. (I note, but leave to one side, because it does not arise in this case, the situation where the State takes drastic action to deal with a widespread and dangerous threat to the health of its citizens at large.)

His Honour also cited, with approval, the decision of Lord Keith of Kinkel in the United Kingdom case of *Airedale NHS Trust v Bland* [1992] AC 789 at 859:

[I]t is established that the principle of self-determination requires that respect must be given to the wishes of the patient, so that if an adult of sound mind refuses, however unreasonably, to consent to treatment or care by which his life would or might be prolonged, the doctors responsible for his care must give effect to his wishes, even though they do not consider it to be in his best interests to do so ... To this extent, the principle of the sanctity of human life must yield to the principle of self-determination.

⁴¹ [2009] NSWSC 761 (6 August 2009), at [17].

3.2.3 The common law has several requirements, the first of which is capacity. As McDougall J noted in *Hunter*, ‘there is a presumption of capacity, whereby an adult “is presumed to have the capacity to consent to or to refuse medical treatment unless and until that presumption is rebutted”’.⁴² While his Honour held that there is no ‘sharp dichotomy’ between having capacity and a want of capacity, there is a sliding scale and capacity must be determined by considering the importance of the decision in question.⁴³ According to McDougall J,⁴⁴

the ultimate question is whether that person suffers from some impairment or disturbance of mental functioning so as to render him or her incapable of making the decision. That will occur if the person:

- (1) is unable to comprehend and retain the information which is material to the decision, in particular as to the consequences of the decision; or
- (2) is unable to use and weigh the information as part of the process of making the decision.

3.2.4 Consent, or the refusal of consent, may be vitiated in a range of cases: (1) where the individual in question is not legally competent to give or refuse consent; (2) where the individual is competent at law but has been the victim of undue influence (or other vitiating factor) in reaching the decision; (3) where consent or refusal of consent does not extend to the current situation; and (4) where the terms of the consent or refusal of consent is ambiguous or uncertain.⁴⁵ Consent will also be vitiated if the patient has been provided with inadequate information about the treatment or procedure and its benefits and dangers.⁴⁶ On this, his Honour added the following:⁴⁷

A consent that is based on misleading information is clearly of no value; and a consent based on insufficient information is not much better. But once it is accepted that religious, social or moral convictions may be of themselves an adequate basis for a decision to refuse consent to medical treatment, it is clear that there is no reason that a decision made on the basis of such values must have taken into account the risks that may follow if a medical practitioner respects and acts upon that decision. This is so a fortiori where there is no discernible rational basis for the decision. No question arises of justifying what would otherwise be unlawful, and factors to be taken into account in determining whether something is or is not unlawful do not have application by analogy.

3.2.5 Consent will not be necessary where the situation is an emergency or of necessity, for example, where the patient is unconscious and cannot give consent. In such

⁴² [2009] NSWSC 761, at [23], citing *Re MB* [1997] 2 FCR 514, per Butler-Sloss LJ at 553.

⁴³ *Ibid*, at [24].

⁴⁴ *Ibid*, at [25].

⁴⁵ *Ibid*, at [26].

⁴⁶ *Ibid*, at [29], citing the High Court in *Rogers v Whitaker* (1992) 175 CLR 479, per Mason CJ, Brennan, Dawson, Toohey and McHugh JJ at 489.

⁴⁷ *Ibid*, at [30].

circumstances, ‘the practitioner can lawfully treat the patient in accordance with his clinical judgment of what is in the patient’s best interests’.⁴⁸ This rule, however, has 2 requirements: there must be a necessity to act when it is not possible to communicate with the patient or another person entitled to act on the patient’s behalf, and the action must be such as a reasonable person would in all the circumstance take, acting in the patient’s best interests.⁴⁹ His Honour described the court’s approach to determining the validity of an advance care directive in the following terms:⁵⁰

It is proper, and not inconsistent with an individual’s right of self-determination, that if there is any real doubt as to the sufficiency of an advance refusal of medical treatment, the court should undertake a careful analysis. But the analysis should start by respecting the proposition that a competent individual’s right to self-determination prevails over the State’s interest in the preservation of life even though the individual’s exercise of that right may result in his or her death. An over-careful scrutiny of the material may well have the effect of undermining or even negating the exercise of that right.

It is necessary to bear in mind that not all those who execute advance care directives are legally trained. Their words should not be scrutinized with the care given to a particularly obscure legislative expression of the will of Parliament. On the other hand, particularly bearing in mind the likely consequences of upholding an apparent exercise of the right of self-determination, the court must feel a sense of actual persuasion that the individual acted freely and voluntarily, and intended his or her decision to apply to the situation at hand. As Robins JA pointed out in *Malette* at 337, if a medical practitioner is to act on doubts as to the validity of an advance refusal of medical treatment, those doubts must be rationally founded. The same applies to a court asked to determine the validity of an advance refusal of medical treatment. It cannot be correct to recognise, on the one hand, an individual’s right of self determination; but, on the other, effectively to undermine or take away that right by over-nice or merely speculative analysis.

3.2.6 It emerged throughout the review that clinicians and other health practitioners in hospital settings are very adept at and comfortable with dealing with non-statutory directives. People express their wishes and preferences in myriad ways, including in letters, conversations and reflections, often in discussions with their SDMs or treating doctors. Particularly at or towards the end of life, treating medical practitioners are often faced with situations that are not strictly or literally dealt with in an ACD. At that point, these antecedent, often informal, discussions between family members become extremely important in determining the appropriate type of medical care and treatment. The Act, while promoting the use of the standard ACD form, should not limit or underplay the importance of such informal conversations. If anything, an ACD should act as a stimulus for ongoing conversations between people and their SDMs and doctors. In addition, medical practitioners should be encouraged to ask questions of SDMs and a person’s

⁴⁸ Ibid, at [31]-[32].

⁴⁹ Ibid, at [32].

⁵⁰ Ibid, at [36]-[37].

next of kin with regard to these matters. The Act should make it expressly clear that non-statutory ACDs may be particularly significant, especially near or at the end of life.

3.2.7 The MIGA submission also highlighted the absence of any reference to the common law as a shortcoming of the Act:⁵¹

Although MIGA acknowledges the potential benefits of prescribed ACD forms as used in South Australia, it is concerned to ensure that deficiencies in ACD form should not prevent it being followed if it complies with common law requirements.

...

MIGA sees common law advance care directives as being valid under South Australian law, but is concerned that this is unclear to the medical and other healthcare professions. It could potentially lead to valid ACDs not being followed by doctors or other health practitioners where they believe in good faith they are not valid.

It would be fair to say that this issue was not a major concern raised in other submissions. However, clinicians regularly discussed the importance of informal comments and conversations, not otherwise covered in the ACD form, and their relevance to treatment decisions. For this reason, the provision of clarity around non-statutory ACDs would assist both SDMs and medical professionals, without the risk of undermining the integrity of the statutory form.

FINDING 4

3.2.8 **Despite the desire to have only 1 document for future directions and preferences with regard to medical care, accommodation and personal issues, the Act needs to also accommodate non-statutory ACDs, recognising that it is unrealistic to expect that a statutory ACD will address all possible scenarios or situations, and highlighting the importance of non-statutory ACDs, particularly in clinical settings.**

Recommendation 3

The Act should be amended to make it expressly clear that it is not intended to operate to the exclusion of the common law. Directives which meet the common law requirements must be treated as legally valid. In addition, non-statutory directives, irrespective of form or whether they appear in a statutory ACD, should be treated as relevant and highly persuasive, particularly when decisions are being made with regard to medical care and treatment, or personal preferences, at the end of life.

⁵¹ MIGA, *Submission 25*, at paragraphs 40 and 42.

3.3 Understanding of and Adherence to ACDs in Clinical Settings

Term of Reference 2(c)

To recommend changes to the legislation, administration, policy or practice which would improve the extent to which the objects are achieved with particular reference to:

...

- (c) Understanding of ACDs amongst the clinical community including access to and adherence of signed ACDs;**

3.3.1 Perhaps one of the most concerning issues raised by the Review, is the extent to which ACDs are managed and implemented in clinical settings. There is not only variation between LHNs, but there appears to be significant differences between departments within certain hospitals. Some of this can be attributed to the absence of dedicated staff within the Department responsible for ongoing training and development of hospital staff (discussed above). However, much of it is attributable to the fact that hospitals are required to operate in accordance with an overall budget, within which the legal obligations with respect to ACDs appears to be undermined by virtue of more (perceived) pressing needs around meeting budgets within specific departments. Not only does this potentially impede patient care, it also presents a significant legal risk to the Department. Internal concerns about costs and responsibility need to give way to the legal obligation to implement valid ACDs.

3.3.2 A striking example was provided during the consultation with the Southern Adelaide Local Health Network (SALHN). Apparently it is the practice at Flinders Medical Centre (FMC) for patient files to be kept together and with important documents like an ACD in a plastic sleeve at the beginning of the file. However, when a patient is transferred between departments, all documents are removed from the plastic sleeve, which is then retained by the first department. As a consequence, ACDs and other important forms can be lost, misplaced or located in a separate part of the patient file. This is a clear example of how budgetary controls can lead to absurd outcomes, potentially compromising patient care and opening up the possibility that a hospital may fail to give effect to a legally binding document such as an ACD. To avoid such outcomes, each LHN should review its practices around ACDs and beyond admission protocols. Obviously, the transition to electronic records will address many of the current problems. And, assuming that the Department reinstates dedicated roles for the promotion of ACDs, those staff should be utilised and engaged by LHNs to conduct regular training around ACD implementation in clinical settings. Ideally, such training should also include the input and involvement of specialist clinicians and doctors who are experienced in working with ACDs.

3.3.3 It also became evident throughout the Review that the implementation of ACDs in clinical settings is being impaired by confusion and divergence in practice around the use of certified copies of an ACD, and a reluctance to rely on digital copies of a certified ACD. In this respect, hospitals, doctors and other staff should be permitted to rely on a digital copy of a certified ACD, including one that has been uploaded to My Health Record. The result would be a greater level of compliance with ACDs in South Australian hospitals. Permitting members of the public to use digital signatures is separately discussed below. While people can upload a copy of their ACD to My Health Record, there is obvious confusion among the public about what to do with their certified copies of an ACD. Some members of the public reported trying to leave a copy with their local hospital, but were told that there was no capacity to store them locally. While it appears that both the Ambulance Service of South Australia and emergency departments have appropriate procedures for asking about ACDs, it was not apparent that such procedures extend to all adults who present at a hospital, when they should. Nor was it apparent that questions are asked about pre-existing valid documents (such as an EPG) if a valid ACD has not been completed. It needs to be re-emphasised to all health practitioners that every adult with decision making capacity can complete an ACD and every adult person who presents at a hospital must be subjected to the same protocol as older South Australians. It also needs to be emphasised that previous legal documents, which are also treated as ACDs under the Act, may bind health practitioners in the same way as an ACD.⁵²

3.3.4 Finally, one further way of enhancing compliance with ACDs in clinical settings, would be to have a system for the registration of such documents. Different hospitals use different electronic health records and many Australians have opted out of My Health Record for privacy, personal or other reasons. One submission received during the review recommended that South Australia consider the trial of a voluntary register for ACDs and other related documents, including orders of a court or tribunal.⁵³ The Australian and New Zealand Society for Geriatric Medicine submitted that, '[i]f there could be a central registry for quick access especially in the emergency department, and to ensure the latest or older documents are available, so that ACPs are transparent for families, health and the community, should they be required.⁵⁴ Bonython and Arnold also discussed their preference for a register:⁵⁵

Australian regimes regarding advanced care are not uniform. They embody a significant but readily resolvable information deficit. That deficit is not in the interests of people making or dealing with advanced care directives. Currently there appears to be no formal requirement for Advance Care Directives (ACD) to be registered or stored anywhere. This is a significant limitation on what is potentially a good system of ensuring that people's wishes are respected once they are no longer able to communicate those wishes on their own behalf.

⁵² Pursuant to Schedule 1 of the Act.

⁵³ MIGA, *Submission 25*, at paragraph 31.

⁵⁴ Australian and New Zealand Society of Geriatric Medicine, *Submission 30*.

⁵⁵ W Bonython and B Arnold, *Submission 17*.

Registration has a number of benefits ... [W]ithout a registration mechanism, it is impossible to determine the number of ACDs in existence, or assess how effective they are as a mechanism for ensuring people's wishes are respected.

Further, lack of registration means that the effectiveness of an ACD depends entirely on the honesty or ability of the substitute decision-maker, or any others who know of the existence of the ACD, to alert healthcare providers to its existence and terms. That in turn requires that those decision-makers or others have retained a copy of the ACD and can make it available to health practitioners when required.

A trial of this nature, as suggested by MIGA, following consultation with key stakeholders, would provide a mechanism for identifying particular issues associated with the implementation of ACDs in clinical settings.

FINDING 5

3.3.5 There appears to be a significant gap between the legal obligations of the Department and the practice regarding ACDs in acute health care settings. Significant change needs to take place in each health network and hospital to ensure that ACDs are treated as a priority in clinical settings. This must include ongoing training and education of clinicians, health practitioners and administrators within hospitals.

FINDING 6

3.3.6 The government should consider a trial voluntary register for all ACDs, including previous legal documents (EPGs, Medical Powers of Attorney and Anticipatory Directions).

Recommendation 4

Each Local Health Network and hospital should be required to report annually to the Minister on their practices and protocols for identifying, managing and implementing ACDs (in any form). Hospitals must adopt a ‘whole of hospital’ approach to identifying, flagging and managing ACDs. Each institution must also develop a system for recording conversations and treatment plans (including the 7 step pathway) which incorporate non-statutory directives in files related to ACDs. These files must be digitally retained by each hospital.

Recommendation 5

The use of digital copies of a certified ACDs should be both permissible and promoted within South Australia’s hospitals. The Act should be amended to facilitate this process and provision should be made in the Act to ensure that medical practitioners and hospital staff are entitled to rely on the purported validity of an ACD contained on a patient’s My Health Record.

Recommendation 6

The South Australian Government should consider conducting a trial in relation to the development and use of a voluntary register for ACDs. Any register should be devised following consultation with relevant stakeholders and involve an independent evaluation following a sufficient length of time. One of the components for evaluation must be the improved level of compliance with ACDs in clinical settings.

- 3.3.7 One matter that was raised in the written submission of MIGA concerned section 9(f) of the Act, which lists as an object, ‘[t]o protect health practitioners and others giving effect to the directions, wishes and values of a person who has given an advance care directive’.⁵⁶
- 3.3.8 MIGA was satisfied with s 37 of the Act in its present form (conscientious objection of clinicians and health practitioners).⁵⁷ However, they did express concerns with the wording of s 40, which allows medical practitioners to presume an apparently genuine ACD is valid and in force unless they knew of ought reasonably to have known that it was not valid. MIGA’s concern lay with the words ‘apparently genuine’ and ‘ought reasonably have known’ in s 40, suggesting that ‘consensus professional guidance’ be

⁵⁶ MIGA describes itself as a ‘medical defence organisation and medical/professional indemnity insurer advising, assisting, educating and advocating for medical practitioners, medical students, healthcare organisations and privately practising midwives throughout Australia’: MIGA, *Submission* 25.

⁵⁷ *Ibid.*, at paragraph 22.

developed to guide clinicians in determining whether an ACD is ‘apparently genuine’.⁵⁸ Considering this issue from the viewpoint of clinicians and practitioners across the LHNs who were consulted during the review, it would appear that doctors and hospital staff are quite comfortable with treating an ACD as, on its face, being valid and effective. Thus, the Review did not reveal a strong argument or basis for strengthening the current provisions of the Act which afford legal protections to medical professionals. However, challenges were acknowledged, as feedback from NAHLN demonstrated:

During the initial psychosocial assessment and during ongoing social work intervention, the social worker identifies concerns relating to family dynamics, family conflict and questions around capacity. The social worker will then seek advice from the medical teams regarding capacity. Where capacity is questioned and issues around the validity of the ACD, advice from the OPA/SACAT is sought. If no issues/concerns are identified at time of admission and assessment it is assumed that the ACD was completed when the patient had capacity. If it has been signed, dated and witnessed, this implies the person was assessed to have been of sound mind when it was made.⁵⁹

3.3.9 NAHLN also reported a need for clearer guidance and protocols around ACDs and previous legal documents, including Enduring Powers of Guardianship (EPGs) which, while remaining valid under the new legislative framework, are now treated as ACDs under Schedule 1, Part 8 of the Act.⁶⁰ When asked how hospitals deal with cases where an ACD has not been completed or is potentially invalid, but where a pre-existing EPG has been validly executed, NAHLN responded as follows:⁶¹

It would be extremely difficult to follow up the validity of an ACD for a patient arriving in ED in a critical state where lack of immediate emergency care would affect [the] outcome.

If practicable, the social worker would explore this with the patient (if appropriate) and family or next of kin. If this is unknown, advice/orders may be required via SACAT.

A protocol for determining the existence of previous documents would be useful.

3.3.10 While each of the LHNs has procedures in place for presentation or admission to hospital regarding ACDs, it is clear that those procedures could be improved. As MIGA commented, ‘[d]octors and other health practitioners should not be put in the role of ‘pseudo-lawyers’ in assessing the validity of an ACD form by reference to manner and form requirements. Their focus should be on its validity on its face, and its directives.’⁶² As a result, MIGA questioned whether the non-invalidity of provisions in s 11(5) were sufficient to ensure that deficiencies in ACD manner and form did not result in them being followed.⁶³ Manner and form deficiencies should not be the focus or concern of clinicians and other health professionals working in hospitals, but of lawyers, tribunal

⁵⁸ Ibid, at paragraph 53.

⁵⁹ R Horgan, NAHLN, *Submission 34*.

⁶⁰ Ibid.

⁶¹ Ibid.

⁶² MIGA, *Submission 25*, at paragraph 37.

⁶³ Ibid, at paragraph 55.

members in SACAT and OPA when exercising functions under the Act. In this respect, the Act currently provides adequate legal protection for clinicians acting in good faith and upon a purportedly valid ACD.

FINDING 7

3.3.11 The Review did not reveal any inadequacy in the protections afforded to medical practitioners under the Act. However, there is a need for clearer guidance in relation to the presence of legally binding documents which are now deemed to be ACDs under the Act (Enduring Powers of Guardianship, Medical Powers of Attorney and Anticipatory Directions).

Recommendation 7

A clear protocol should be developed for use in South Australian hospitals which ensures that questions are not limited to the existence of ACDs, but extend to questions regarding a previous, valid instrument, including Enduring Powers of Guardianship, Medical Powers of Attorney and Anticipatory Directions.

3.4 Completing an ACD: Substitute Decision Makers and the Signing Process

Term of Reference 2(d)(i)

To recommend changes to the legislation, administration, policy or practice which would improve the extent to which the objects are achieved with particular reference to:

...

(d) The practicality of the process to complete an ACD, in particular:

(i) the requirement that a Substitute Decision Maker must sign their acceptance of the role prior to the person signing the ACD;

3.4.1 By far the most common criticism levelled against the Act and its operation by legal practitioners related to the order of signing of ACDs. In particular, lawyers were very concerned about the fact that SDMs are required to sign an ACD prior to the person making the ACD signing and executing the ACD (frequently referred to as the ‘donor’ or ‘principal’) before a suitably qualified witness. There are a number of reasons behind this concern:

- The ‘donor/principal’ should be required to sign the ACD prior to an SDM being required to sign and accept the appointment (this point was often made by asking how a person could ‘donate’ a power that has not even been finalised or articulated in full by the donor first);
- There is unnecessary and undue expense for clients of legal practitioners who are required to attend another appointment with their lawyer because of the signing order. The order is quite different to the order of signing a Power of Attorney (PoA).
- SDMs are frequently living interstate or overseas and the inevitable delay in the return of signed ACDs can leave clients vulnerable in the intervening period;
- There is a high likelihood that people will not properly execute an ACD due to the additional complexities and cost.

3.4.2 The submission of the Law Society of South Australia (LSSA) is apposite here and worth citing in full:⁶⁴

1. Where the person making the appointment is extremely ill or becoming increasingly forgetful, the delays that can eventuate whilst all SDM signatures are collected, particularly when a person wishes to appoint someone who is

⁶⁴ Law Society of South Australia, *Submission 27*.

currently overseas or lives interstate, could render useless all attempts to have the document signed whilst the person still has capacity or is capable of making an appointment. This may lead to inappropriate people being appointed as a SDM for the sole reason that it is urgent that the person making the appointment sign as soon as possible. Under the previous legislation, the person making the appointment was the first to sign. Frequently clients wish to discuss with their solicitor the appropriateness or otherwise of the persons they wish to appoint. So long as that person is competent at the time they give instructions and sign the document, there is then no immediate pressure to obtain all other required signatures.

2. Country clients appear to be more prejudiced than most as a result of this requirement. Country practitioners have cited instances where a client receives late notice that necessary surgery has been scheduled for the following week or two in Adelaide. This often, understandably, precipitates a desire to ensure that they have all necessary estate planning documents in place and up to date before surgery, and frequently in undertaking the review, a solicitor will advise them to execute an ACD, and just as frequently, their children will live interstate. There is rarely time for the SDMs to sign their acceptance and for the client to then execute the document. Although it is possible to execute an ACD expressing one's wishes without actually appointing an SDM, in some instances this can be an inadequate interim measure. If the client has a stroke or some other medical emergency during surgery which renders them permanently incapacitated, they have lost the ability to appoint an SDM to make ongoing lifestyle and medical decisions for them during what may be a lengthy incapacity. The client's family may then be faced with an emotionally upsetting application under the *Guardianship and Administration Act*.
3. Members of the Society have reported many instances where clients have gathered all necessary signatures of their SDMs, and then requested their solicitor to assist them to complete the wording in the ACD as they found the volume and content of the kit overwhelming. In one case, a member of the Society's Succession Law Committee has reported that only about one out of every ten clients attend at the second appointment with directives in their ACDs completed. The remainder failed to do so, not for lack of trying, but because they found the whole exercise difficult and stressful. In these instances, the SDMs have accepted an appointment, the details of which they have no knowledge because they have in effect signed a blank form. This is far worse than accepting an appointment where the directives are already documented and can be read and understood by the SDM and the donor questioned about their wishes if there is any ambiguity.
4. Many clients wish to discuss the appropriateness of an appointee with their solicitor before making a decision. If the person making the ACD obtains independent advice and then decides that they do not wish to appoint one or more SDMs who have already signed their acceptance, this would create not only practical problems but also potential family disruption.

5. ACDs are frequently prepared at the same time as other estate planning documentation, including enduring powers of attorney. An enduring power of attorney requires the donor to sign first and the donee to accept after the appointment has been made. Practitioners have cited many incidences of annoyance on the part of clients who are required to have family members first sign their acceptance on the ACD, and then need to go back to the same people to have acceptances on their enduring power of attorney signed after all documents have been witnessed by their solicitor. The need for people preparing these documents (often at the same time, and not always by solicitors) to undertake differing procedures in the execution and acceptance of them creates a more complex and confusing situation, which directly increases the likelihood that documents may be incorrectly signed.

3.4.3 From both a logical and legal perspective, the lawyers who made submissions (including the Law Society) are completely right. It is anathema that someone would assign another person to fulfil a legal role without first clearly setting out their preferences, wishes and values, so that SDMs understand the role they are accepting prior to their signing of the document. In another respect, it seems contrary to reason that SDMs would ‘accept’ an appointment prior to it being ‘assigned’ or ‘conferred’ by a donor/principal. Inconvenience or irritation alone is insufficient to warrant a change to the order of signing. However, the more substantive concerns raised by legal practitioners concern the perceived disadvantage to people living in rural and regional areas, the claim that some clients are appointing SDMs for convenience rather than based on sound and considered judgement, and that some clients are forced to execute an ACD in urgent situations (ie, when facing pending surgery) without appointing SDMs but where there is the possibility that they may lose decision-making capacity permanently during a medical procedure. In such cases, the person making the ACD may lose the right to appoint SDMs entirely.

3.4.4 The perception that residents of country areas of South Australia are disadvantaged by virtue of the signing order is, however, misplaced. Delays in SDMs signing an ACD apply equally to all residents and surgery is frequently scheduled with a short notice period. Were the order of signing reversed there would be no guarantee that all SDMs would duly sign the document prior to the scheduled surgery and any possible period where a person lacked decision making capacity. The execution of the ACD in accordance with the person’s wishes is, therefore, not guaranteed irrespective of either order of signing. In addition, if the recommendations made in this Report are adopted, the process of completing an ACD should be simpler and local support for validly completing an ACD would be strengthened.

3.4.5 This criticism of the signing order also ignores the operation and effect of Part 2A of the *Consent to Medical Treatment and Palliative Care Act 1995 (SA)* (‘the *Consent Act*’). In the majority of cases – at least based on the submissions received during this review – SDMs are most likely to be close family members of the person. Those same people are very likely to also be a ‘person responsible’ within the meaning of s 14 of the *Consent Act*, which is defined as follows:

- (1) ...

"person responsible" for a patient means—

- (a) if a guardian has been appointed in respect of the patient, and his or her powers as guardian have not been limited so as to exclude the giving of a consent contemplated by this Part and he or she is available and willing to make a decision as to such consent — that guardian; or
- (b) if paragraph (a) does not apply, but a prescribed relative of the patient who has a close and continuing relationship with the patient is available and willing to make a decision as to a consent contemplated by this Part — that prescribed relative; or
- (c) if paragraphs (a) or (b) do not apply, but an adult friend of the patient who has a close and continuing relationship with the patient is available and willing to make a decision as to a consent contemplated by this Part — that friend; or
- (d) if paragraphs (a), (b) or (c) do not apply, but an adult who is charged with overseeing the ongoing day-to-day supervision, care and well-being of the patient is available and willing to make a decision as to a consent contemplated by this Part—that person; or
- (e) if none of the preceding paragraphs apply, or otherwise with the permission of the Tribunal — the Tribunal on the application of —
 - (i) a prescribed relative of the patient; or
 - (ii) the medical practitioner proposing to give the treatment; or
 - (iii) any other person who the Tribunal is satisfied has a proper interest in the matter;

"prescribed relative" — the following persons are prescribed relatives of a patient:

- (a) a person who is legally married to the patient;
 - (b) an adult domestic partner of the patient (within the meaning of the *Family Relationships Act 1975* and whether declared as such under that Act or not);
 - (c) an adult related to the patient by blood or marriage;
 - (d) an adult related to the patient by reason of adoption;
 - (e) an adult of Aboriginal or Torres Strait Islander descent who is related to the patient according to Aboriginal kinship rules or Torres Strait Islander kinship rules (as the case requires).
- (2) If a man and woman are married according to Aboriginal tradition, they will be regarded as legally married for the purposes of this Part.

3.4.6 Section 14A of the *Consent Act* expressly states that s 14 is not to apply if a patient has given an ACD, has appointed an SDM and the ACD covers the relevant medical treatment. Section 14B provides for a 'person responsible' to give consent to medical treatment and s 14C imposes a clear obligation on 'persons responsible' to act in a manner that is akin to a substitute decision maker:

A decision of a person responsible for a patient to give, or refuse to give, consent under this Part must, as far as is reasonably practicable, reflect the decision that the patient would have made in the circumstances had his or her decision-making capacity not been impaired.

Note —

In cases where the patient has given an advance care directive under which no substitute decision-maker is appointed, but the patient's wishes or instructions in relation to treatment of the relevant kind is recorded, it may nevertheless be necessary to give effect to those wishes or instructions – see Part 5 of the *Advance Care Directives Act 2013*.

- 3.4.7 Clearly, the *Consent Act* adequately addresses the concern of legal practitioners in relation to medical treatment, while recognising that persons responsible are statutorily prescribed whereas an ACD enables a person to appoint their preferred SDMs. While the *Consent Act* does not extend to accommodation or personal decisions – only medical treatment – by ensuring the preservation of the common law and the relevance of non-statutory ACDs (assuming that Recommendation 3 of this report is adopted), the ACD Act can effectively ensure that previously expressed wishes will be followed with respect to accommodation and personal matters. While pressing or emergency situations will prevent a person from appointing SDMs through ACDs, persons responsible as defined under the *Consent Act* will capture the most common and obvious people, relatives and friends that would commonly be appointed as SDMs under ACDs. If there are additional categories of people that should be captured under s 14, then that is a matter which pertains to a proposed amendment of the *Consent Act* and not the *Advance Care Directives Act 2013* (SA). This matter lies beyond the scope of the present Review.
- 3.4.8 The final concern conveyed by the LSSA and a number of other legal practitioners relates to the question of the appointment of SDMs. In particular, this covers both the assertion that clients of lawyers often seek their lawyer's advice regarding the appropriateness of SDM appointments and, secondly, the claim that clients occasionally appoint possibly the wrong people as SDMs by virtue of urgency and/or convenience. Both claims do not stand up to interrogation. Previous discussion of the *Consent Act* outlines clearly why close relatives and friends are still legally entitled to exercise the same (or virtually similar) powers of an SDM, at least in relation to medical treatment. By also recognising the continued operation of the common law, preferences and wishes related to accommodation and personal matters (Recommendation 3) are also addressed. The order of signing should have no bearing whatsoever on the decision over who to appoint as an SDM. Indeed, lawyers have every opportunity to discuss this subject at their first appointment with clients. In the event that a client presents to a lawyer having already appointed SDMs, the lawyer is still able to discuss the suitability of those appointments, recognising that the ACD is not legally binding until duly signed, witnessed and certified. Of course, a change in decision regarding the appointment of individual SDMs may result in a difficult conversation between family members, but it is the very nature of ACDs that they require difficult conversations. For most people, advance care planning (ACP) can be difficult, uncomfortable and confronting, but a process that facilitates a smooth, non-contentious or easy process for SDMs would completely undermine the Act and its intention to empower individuals with decision making capacity to determine, for themselves, what their preferences are when they are at their most vulnerable. It would also undermine the intention that principals must initiate a conversation with their SDMs prior to seeking their acceptance and signature.

3.4.9 An ACD is also very distinct to the appointment of a PoA or other form of estate planning. Indeed, it is unique among such documents and was always designed to be so. It does not apply to decisions after one's death, nor to financial decisions or medical decisions prior to losing capacity. It also enables individuals completing an ACD far greater scope to set out one's wishes, preferences and values, beyond future medical treatment. However, as one submission to the Review stated, there remain limits on a person's capacity to predict the future:⁶⁵

[T]o what extent can we all – and in equal measure – know and grasp the future? Do we all want or have the capacity to make rational, independent and calculative care decisions? Can we plan for the final stages of our lives? As Mol (2008) makes clear in her monograph on care and choice in a diabetes clinic, we never have all the facts on the table before decisions are made. Following analyses on choice and decision-making (Mol, 2008; Borgstrom and Walter, 2015), this paper calls into question the temporal orientation to the future and detached reasoning inscribed in ACDs, and attends to the uncertainty and relationality that characterises anticipatory decision-making. Drawing on Derrida's deconstructive approach to death and decisions, it outlines migrant responses to ACDs in the face of an unknown and uncertain future. The instant of a decision, for Derrida (1995), is beyond reason or fact because we cannot advance beyond the present moment in time ... The irrevocable termination of one's cognitive and sensory capacities precludes one's personal experience of death. Death, as such, can never be an event in one's life.

3.4.10 It should be noted that lawyers were not unanimous in their opposition to the signing order for ACDs and that some lawyers outlined ways of ensuring that the process was complied with without leaving a client vulnerable or without an executed ACD – one of the more substantive of the concerns expressed by many lawyers. In order to effect such ACDs in urgent situations, one firm conveyed their own approach, which was to complete 2 ACDs – one that conveyed a person's wishes without appointing ACDs (applicable in the short-term) and a second, later ACD (replacing the first) which contained both a person's future wishes as well as the appointment of SDMs.⁶⁶ Such an approach, in conjunction with the *Consent Act*, is a clear option for lawyers that would help to protect potentially vulnerable people who are facing surgery or the potential loss of capacity in the short-term. It does not, however, prevent a situation where the person making the ACD loses capacity prior to executing the second ACD. In such cases, nothing can be done. However, when considering the validity of the first ACD, coupled with the operation of the *Consent Act* and the recommendations regarding additional resources and education around ACDs, one could safely assume that individuals would not be disadvantaged.

3.4.11 The Legal Services Commission also described the signing order as being 'fundamental' to the Act, a point that was also endorsed by the Office of the Public Advocate.⁶⁷ The Act was originally designed to empower individuals without the need to consult with lawyers

⁶⁵ T Zivkovic, *Submission 26*, citing T Zivkovic, 'Forecasting and Foreclosing Futures: The Temporal Dissonance of Advance Care Directives' (2018) 215 *Social Science and Medicine* 16-22 at 17.

⁶⁶ K Harris, Wearing Law, *Submission 10*.

⁶⁷ Legal Services Commission, *Consultation*, 7 May 2019; Office of the Public Advocate, *Consultation*, 10 May 2019.

or doctors. As the then Minister for Health, the Hon John Hill MP, explained in the Act's Second Reading Speech, 'an Advance Care Directive does not have to be legally or medically informed to be valid, merely that they understand the implications of their direction.'⁶⁸ A number of people who made submissions to the review, or were engaged in consultations, described many cases prior to the Act's implementation where the preferences or wishes of a person had been ignored by family members and/or doctors.⁶⁹ The order of signing ACDs, as contained in clause 8 of the Regulations, was deliberately intended to ensure that a person making an ACD discussed their preferences, wishes and values with their SDM, and prior to the SDM accepting the appointment. As OPA stated in its written submission to the Review,⁷⁰

[p]rior to the introduction of the ACD Act, people could express their wishes for future health care, accommodation and lifestyle issues and appoint substitute decision makers using an Enduring Power of Guardianship. These documents were executed firstly by the donor of the power before authorised witnesses. The donor would then ask the donee substitute decision makers to sign the document to indicate that they accepted their roles.

OPA has identified several issues arising from this practice, including:

- donee substitute decision makers failing or refusing to execute the document, rendering their appointment invalid;
- the donor has appointed joint donee substitute decision makers but not all have accepted their appointment;
- donee substitute decision makers, who were not aware of the extent of their role and responsibilities, deciding - after the donor becomes legally incapacitated - they do not want to make the necessary substitute decisions.

Any of these situations leave the donor of the power without a substitute decision maker and often necessitate an application to the South Australian Civil and Administrative Tribunal (SACAT) for the appointment of a guardian. In the ACD context, the current requirement for substitute decision makers to accept the appointment prior to execution by the person giving the ACD avoids this outcome.

A significant number of disputes handled by OPA's Dispute Resolution Service arise out of claims that a particular ACD is invalid. Clients may claim that:

- the person who gave the ACD lacked the capacity to understand the document;
- the person was coerced into creating the document;

⁶⁸ South Australia, Parliamentary Debates, House of Assembly, 17 October 2012.

⁶⁹ This included the Legal Services Commission and the Office of the Public Advocate: Legal Services Commission, *Consultation*, 7 May 2019; Office of the Public Advocate, *Consultation*, 10 May 2019.

⁷⁰ Office of the Public Advocate, *Submission 33*.

- the person who witnessed the execution of the ACD spoke to the person giving it in the presence of others (rather than with the person on their own as instructed in the Information for Witnesses guide);
- the person who witnessed the execution is personally known to family members of the person who gave the ACD.

3.4.12 The implications of these concerns for witnessing are considered below. However, the comments of OPA and the Legal Services Commission highlighted to the Review that the previous use of EPGs, including the order of signing, had a number of significant problems in itself. While the Act, the accompanying Regulations, ACD Form and DIY Kit were deliberately designed to enable people to express their wishes and preferences without the necessity to seek specialist legal or medical advice, there are advantages to seeking such advice when preparing to complete an ACD. As Advance Care Planning Australia noted in its submission to the Review, consulting with family members, carers, doctors and lawyers will result in clearer and more specific ACDs:⁷¹

Quality advance care planning involves a coordinated communication and medical planning process between a person, their family, carers and/or treating healthcare team that aims to clarify the person's values and preferences for medical treatment and personal care, should the person lose their capacity to make or communicate decisions in future. It may also facilitate the identification and appointment of a substitute decision-maker who is required to make a substituted judgement, that is the decision the person themselves would make if they were able to.

The goal of advance care planning is to align the care the person actually receives with their documented values and instructional preferences. Ideally, values and preferences for medical treatment decision-making should be documented in an advance care directive. Medical practitioners and the treating team have obligations to implement the directive and/or consult with the appointed substitute decision-maker [footnotes excluded].

For the above reasons, there are sound reasons for retaining the current order of signing.

FINDING 8

3.4.13 There is no practical or legal basis for changing the order of signing with regard to ACDs.

3.4.14 Numerous lawyers were also highly critical of the limitation placed on the number of SDMs able to be appointed under an ACD. Indeed, neither the Act nor the Regulations imposes a limit on the maximum number of SDMs able to be appointed, whereas the Gazetted ACD Form imposes a maximum limit of 3 SDMs. Section 21(1) of the Act allows a person to appoint '1 or more adults to be substitute decision-makers', and section 22 of the Act enables SDMs to exercise their powers 'jointly and severally'. The

⁷¹ L Nolte, Advance Care Planning Australia, *Submission 11*.

phrase ‘jointly and severally’ is a legal term that is not consistent with the intention to use plain English in the Act and should be replaced with ‘separately and together’ making it clear to all that one SDM can exercise their powers alone, if needed. As the LSSA explained in their written submission,⁷²

The Society notes that the ACD Form only allows the appointment of three SDMs. Many couples preparing these documents wish to appoint each other to make decisions first, and if they are unable to make decisions for each other, their children. Many families comprise three or more children. The parents are then faced with the problem of who to leave out. The Society suggests that the limitation of three SDM’s be reconsidered.

3.4.15 It is not entirely clear why the ACD Form imposed a maximum limit of 3 SDMs when it was never included in either the Act or the Regulations. Many individuals described the problems and difficulties associated with only appointing 3 SDMs where their family is larger than 4 people or where the total number of children is greater than 3. One JP who participated in the consultation process – a JP from the Victor Harbor region - described how she had completed her ACD but had not had it properly executed because she did not want to upset 1 of her 4 children. Her decision not to sign or execute the document was entirely to avoid conflict within her family. Such situations are not consistent with the Act’s intent and need to be avoided.

FINDING 9

3.4.16 **The decision to impose a cap on SDM appointments is inconsistent with the spirit and intent of the legislation, including the desire to empower people to exercise self-determination with regard to future care, accommodation and personal matters. Accordingly, both the ACD Form and the Act should be amended to make it absolutely clear that people can appoint as many SDMs as they desire.**

Recommendation 8

The Act and the ACD form should be amended to make it absolutely clear that there is no limit on the number of SDMs that can be appointed.

3.4.17 Finally, with respect to SDMs, the Act and the ACD form should enable people to determine a hierarchy of SDMs, consistent with the desire to empower individuals making an ACD. The review frequently heard from individuals and lawyers of a preference to appoint their spouse as their preferred SDM, with their children appointed equally as alternate SDMs. Currently, the Act and the form do not permit this.

⁷² Similar comments were made in other submissions: A Michaels MP, *Submission 18*, J Van der Velde, VdV Legal, *Submission 9*.

FINDING 10

- 3.4.18** Both the Act and the ACD form should be amended to enable people making an ACD to establish a hierarchy of SDMs, with a preferred SDM or SDMs acting as the first substitutes (separately and together), followed by secondary substitutes acting separately and together.

Recommendation 9

The wording in section 22 of the Act should be changed from ‘jointly and severally’ to ‘separately and together’.

Recommendation 10

The Act and the ACD form should be amended to enable people to have a hierarchy of SDMs, with one or more preferred SDMs, as well as alternate SDMs (ie, appointing a spouse as the preferred SDM and children as alternate SDMs). All SDM appointments should be able to be exercised together and separately.

3.5 Completing an ACD: Authorised Witnesses

Term of Reference 2(d)(ii)

To recommend changes to the legislation, administration, policy or practice which would improve the extent to which the objects are achieved with particular reference to:

...

(d) The practicality of the process to complete an ACD, in particular:

...

(ii) the appropriateness of the list of authorised witnesses, taking into consideration providing reasonable access to witnesses and ensuring the integrity of the witnessing process. Consideration should be given to the ability of witnesses to determine the decision making capacity of the person giving the ACD.

3.5.1 The current approach to the witnessing of ACDs is governed by s 15 of the Act and clause 7 and Schedule 1 of the Regulations. Section 15 provides as follows:

- (1) An advance care directive will only be taken to have been witnessed in accordance with this Act if —
 - (a) the advance care directive form is witnessed by a suitable witness in accordance with the regulations; and
 - (b) the suitable witness completes the appropriate parts of the advance care directive form certifying that —
 - (i) he or she gave to the person giving the advance care directive any information required by the regulations for the purposes of this section; and
 - (ii) he or she explained to the person giving the advance care directive the legal effects of giving an advance care directive of the kind proposed; and
 - (iii) in his or her opinion, the person giving the advance care directive appeared to understand the information and explanation given to him or her by the suitable witness under this paragraph; and
 - (iv) in his or her opinion, the person giving the advance care directive did not appear to be acting under any form of duress or coercion; and
 - (c) any other requirements set out in the regulations in relation to the witnessing of advance care directives have been complied with.

- (2) However, a person cannot be a suitable witness in relation to a particular advance care directive —
 - (a) if he or she is appointed under the advance care directive as a substitute decision-maker; or
 - (b) if he or she has a direct or indirect interest in the estate of the person giving the advance care directive (whether as a beneficiary of the person's will or otherwise); or
 - (c) if he or she is a health practitioner who is responsible (whether solely or with others) for the health care of the person giving the advance care directive; or
 - (d) if he or she occupies a position of authority in a hospital, hospice, nursing home or other facility at which the person giving the advance care directive resides; or
 - (e) in any other circumstances set out in the regulations in which a person cannot be a suitable witness in relation to a particular advance care directive.
- (3) For the purposes of this section, a reference to duress or coercion in relation to a person giving an advance care directive includes a reference to duress or coercion due solely to a perception or mistake on the part of the person.
- (4) In this section —

suitable witness means a person, or a class of persons, who satisfies any requirements prescribed by the regulations for the purposes of this definition.

3.5.2 In accordance with the Regulations, witnessing an ACD cannot take place until all SDMs have first signed the ACD (where SDMs are appointed), and all ACDs must be signed in the presence of a suitable witness who must be a competent adult. The witness must provide the person making the ACD with the ACD Information Statement included in the DIY Kit, which will be deemed to constitute an explanation of the legal effects of an ACD (Regulation 7(2)). Schedule 1 of the Regulations contains a long list of suitable witnesses which includes, among others, bank officers with 5 years of continuous service, clerks of courts, commissioners for taking affidavits, commissioners for declarations, fellows of the National Tax and Accountants' Association, health practitioners (which includes paramedics and employees of an ambulance service), Judges and Magistrates, Justices of the Peace (JPs), marriage celebrants, members of the Governance Institute of Australia, non-student members of Engineers Australia, members of the Australasian Institute of Mining and Metallurgy, certain classes of officer within the Australian Defence Force, members of Parliament (federal and state) and elected members of local government, ministers of religion, a notary public, legal practitioners admitted to a Supreme Court or the High Court, police officers, teachers employed full-time and veterinarians. The list is, therefore, extremely broad, but was designed to optimise access and facilitate the execution of ACDs. However, witnessing of ACDs – if done correctly - is quite onerous. The following comments were received in the submission of the Fleurieu Justices Group:⁷³

⁷³ Fleurieu Justices Group, *Submission 29*.

Justices of the Peace currently set aside at least 30 to 45 minutes for the witnessing of advanced care directive documents or longer if necessary, according to each circumstance. It does not seem probable that this same amount of time will be available to persons on the expanded list. Take for example, a bank officer, building society officer, finance company officer or school teacher, or a police officer attending a public counter in a busy police station. It seems highly improbable that the necessary time to give due diligence to the process will be provided by the witness, or, disturbingly, an opportunity to speak with the donor privately if accompanied by a third party, and hence the importance of the independent witnessing process might very well be compromised ...

Our concern rests with protecting the rights of the individual donor and ensuring the validity of the witnessing process. What is difficult to grasp from a legal point of view is why critical legislation such as this Advance Care Directive Act has been compromised by a lowering of the witnessing standard as addressed above.

3.5.3 During the review, many comments were received to the effect that the list of suitable witnesses in the Regulations is too long. With the exception of health practitioners, legal practitioners, judges and magistrates, and JPs, many of the professions listed have had no training in either ACDs or how to assess decision making capacity. The assumption that many government employees who have served 5 years of continuous service, irrespective of the nature of their role, is another flawed premise underpinning the list. The majority of people spoken with during the Review felt strongly that the list needed to be sharpened and reduced. One common concern was the lack of professional training and, despite the reference to training courses offered to JPs and through Tafe SA in the DIY Kit, a search of the latter's website did not uncover any short courses on ACDs, and only members of the Royal Association of Justices South Australia (RAJSA) can access the courses from the former's website. The Law Society's written submission contains a number of points that were echoed by others:⁷⁴

Another key concern previously expressed by the Society is the wide class of persons who can witness a person's signature on an ACD, and the potential for abuse that could arise. This is pertinent to the Review, given that one of the Terms of Reference is whether greater protections should be included within the Act against elder abuse.

To witness a document such as an ACD, requires the witness to assess the capacity of the person signing the document. Solicitors and justices of the peace have experience in determining capacity and most regularly attend lectures and read papers on this topic. The Society is informed by its Succession Law Committee of many instances of inappropriate witnessing of ACDs, particularly within aged care facilities. These include staff arranging for residents to complete ACDs, regardless of their mental capacity and without regard to existing documents already in place. A Member of the Succession Law Committee was involved in a matter before the South Australian Civil and Administrative Tribunal (SACAT), where five successive ACDs were executed by a resident of a nursing home at the behest of each of her children, with each new document executed revoking the previous document. These examples demonstrate the need for the witnessing requirements to

⁷⁴ Law Society of South Australia, *Submission 27*.

be investigated with a review to possible reform. The Society further considers that the guidelines given in the ACD DIY Kit to witnesses to assess a donor's capacity are inadequate and require significant improvement.

The submission of academics, Bonython and Arnold, also conveyed a similar concern with the current list of witnesses:⁷⁵

Our position is that the list is too broad, to the extent that it is open to abuse, is inconsistent with practice elsewhere and will be regarded by key stakeholders as lacking legitimacy. It demonstrates a failure to understand the historical context in which the professions were identified as appropriate members of society to certify documents of legal significance, and the role those witnesses play in doing so.

3.5.4 Given the importance of the witnessing process to the overall operation of the Act, the potential for witnessing to reveal a lack of decision making capacity of the person making the ACD, and the potential for witnesses to uncover signs of elder abuse and/or undue influence by third parties, the Regulations warrant amendment. While this may make it more difficult to find a suitable witness, the witnessing process cannot operate as a safeguard against abuse and exploitation, nor can a witness properly attest to the decision making capacity of the person if they have had no formal training. For medical and legal practitioners, their formal training equips them to identify possible abuse and to know what type of questions to ask in determining a person's capacity. The same can be said for judges and magistrates. However, while most JPs consulted throughout the review demonstrated high levels of diligence in the fulfilment of their role, not every JP has completed professional training on ACDs. Accordingly, JPs should be required to do training on ACDs every 2 years to ensure that their understanding of the Act and the Regulations are maintained. Furthermore, social workers who are currently not included in the list of health practitioners under statute, should be entitled to witness an ACD, given their professional training, but subject to undertaking an approved training program every 2 years. Training for JPs and social workers should also include training on the operation of the Adult Safeguarding Unit (ASU), the classes of elder abuse recognised under South Australian law, legal obligations to report suspected abuse to the ASU and when evidence of abuse or exploitation may make witnessing an ACD unlawful.

3.5.5 The review also facilitated separate sessions with volunteers involved in the Victor Harbor and Barossa regions, both of which demonstrated best practice within the State of assisting people to complete an ACD. Staffed by volunteers with previous experience as lawyers, health practitioners and JPs, these programs have developed with the support of local hospitals and councils, providing people with substantial guidance around what can and cannot be included in an ACD, as well as providing access to witnesses and photocopiers. The Barossa group has also developed their own documents, using examples of the type of wording that may be used in drafting directives in an ACD. Both regional examples provide an excellent illustration of how communities can support individuals who desire to complete the ACD form. The Department for Health and Wellbeing should be responsible for developing similar programs in each council area

⁷⁵ W Bonython & B Arnold, *Submission 17*.

throughout the State, as well as the training of key volunteers. Assuming that the Department appoints 1-2 new staff responsible for ACDs (Recommendation 1), these staff can assume responsibility for the necessary training.

FINDING 11

- 3.5.6** The current list of suitable witnesses should be significantly reduced through an amendment to Schedule 1 of the Regulations. Suitable witnesses should be limited to health practitioners, legal practitioners, judges and magistrates, JPs and social workers. Both JPs and social workers should be required to engage in professional training and/or refresher courses every 2 years. Training courses should be approved by the Department for Health and Wellbeing and must include training on ACDs and the legal requirements of witnessing, offences under the Act, as well as training on the Adult Safeguarding Unit (ASU), the categories of elder abuse, obligations to report elder abuse and when evidence or suspicion of abuse or exploitation may vitiate the validity of an ACD.

FINDING 12

- 3.5.7** The models used in both the Victor Harbor and Barossa regions need to be replicated in every council area within the state. Dedicated staff within the Department for Health and Wellbeing (Recommendation 1) should assume responsibility for the training of volunteers and the facilitation of networks between council areas, local hospitals and between volunteer groups and the Adult Safeguarding Unit.

Recommendation 11

Schedule 1 of the Regulations needs to be amended and the list of suitable witnesses limited to health practitioners, legal practitioners, judges and magistrates, social workers and Justices of the Peace.

Recommendation 12

Justices of the Peace and social workers should be required to complete a professional training course, approved by the Department for Health and Wellbeing, every 2 years. Such courses must address legal requirements under both the *Advance Care Directives Act 2013 (SA)* and the legal effects of the *Office for the Ageing (Adult Safeguarding) Amendment Act 2018 (SA)*.

Recommendation 13

The government should give consideration to the inclusion of an additional offence where witnesses have failed to comply with the legal requirements for witnessing.

Recommendation 14

The Department for Health and Wellbeing should assume responsibility for the establishment of new volunteer ACD groups in each council area, drawing on the experiences of similar groups in Victor Harbor and the Barossa. The Department should also facilitate the establishment of networks between volunteers, local hospitals, the local council and Justices of the Peace.

- 3.5.8 An additional matter raised throughout the Review related to the practice of many residential aged care facilities (RACFs). It would appear that, following the Act's introduction, many RACFs have forced residents to complete an ACD, often despite the resident's lack of decision making capacity, and frequently using Forms that were not the Gazetted ACD Form. Both practices are not supported by the Act. While such documents could potentially be treated as informal or common law ACDs, the concern is that residents of RACFs are being compelled to complete an advance care plan (ACP), and often when a resident lacks decision-making capacity. OPA described their experience of such practices as stemming from confusion among aged care providers about the role of informal aged care plans and formal ACDs based on the template.⁷⁶ Of concern to OPA was the added fact that ACP is being required of people living in RACFs who lacked the capacity to engage in it. During the consultation with OPA, the Public Advocate

⁷⁶ Office of the Public Advocate, *Submission 33*.

described how she had written to all of the South Australian CEOs of RACFs in 2018, outlining her concerns about these practices, but failed to receive a single response.⁷⁷

3.5.9 The following submission was received by a concerned daughter of a resident:

My father moved into residential care a year ago. According to staff of the facility, he signed Enduring Power of Attorney and Advanced Care Directive documents on the day he moved there. Not since that day has he had copies of these documents. He doesn't have even the little card for his wallet that's meant to have his donee's names listed on it.

My father does not have memory impairment of any significance, yet he doesn't believe that he's signed these documents. Instead, he believes he's signed to formally *preserve* his rights to determine his health care and financial affairs. Perversely, however, he's just as convinced that he has to get permission from my siblings before he can have any medical advice or intervention. Threats and verbal abuse have reportedly been employed to convince him of this.

The evidence available suggests that my father was duped into signing an ACD (and EPoA). The witness apparently failed to fulfil the required duties in checking that he understood what he was signing.

When my father was first admitted to an aged care facility, I found him distressed and complaining of having to sign myriad forms all at once, 'In just a couple of minutes!', 'I only had a couple of minutes to sign all these documents!' he said. He was unable to describe what any of them were about and it was clear that he had no documentation.

On the same occasion, my father reported that his other children had aggressively barred him from consenting to hip-replacement surgery whilst they were away on an overseas holiday, should it be offered during that time.

All my father's health and financial affairs have been aggressively and minutely controlled by his two other children since the day he signed the ACD and EPoA documents, regardless of his expressed wishes. My father has been extremely upset by this on occasion, but doesn't believe that he can do anything about it.

This sort of outcome is clearly at odds with the intent of the Acts that underpin Advance Care Directive and Enduring Powers of Attorney.

3.5.10 The Review heard of similar stories of RACFs using forms other than the Gazetted Form and of residents being forced to complete such forms on admission. The Legal Service Commission and the Office of the Public Advocate were very familiar with such stories. This is particularly concerning, especially as many people who move into residential aged care have advanced or developing cognitive dysfunction, and many feel overwhelmed with the relevant paperwork. That RACFs are forcing residents to sign documents without any support of family, without legal advice, or without providing residents with relevant paperwork, is a significant concern. While such ACDs are unlikely to be upheld as validly completed by either the courts or SACAT, the external consultant was unable to find any evidence of cases where this was raised in argument. This, in itself, reiterates that residents of RACFs are often among the most silenced, vulnerable and marginalised people within our community.

⁷⁷ Office of the Public Advocate, *Consultation*, 10 May 2019.

3.5.11 The concerning nature of such practices could be addressed through an amendment to the legislation which made it an offence for either natural persons or corporations (recognising that all federally funded RACFs are required to be incorporated) to compel a resident of a RACF to complete any documents, including ACDs. Section 57 creates an offence of inducing another person to complete an ACD through fraud or dishonesty. However, there is no suggestion that facilities are using either fraud or dishonesty to induce residents to complete an ACP. And, in some circumstances, ACP can enable and empower residents to capture their preferences and wishes to the extent of their capacity. Recognising that the Act adopts a rights-based approach to ACDs, the encouragement of ACP and even less formal ACDs remain particularly important in clinical settings, especially at end of life. Thus, while the practices of RACFs that were reported during the Review are of particular concern, the problem is best addressed through targeted education programs.

FINDING 13

3.5.12 **The Act could potentially be amended to ensure that it is an offence for any individual or corporation, including a residential aged care facility, to compel any person to complete and sign an ACD, particularly where the person lacks decision making capacity. However, the best approach would be to adequately resource an education program designed specifically for residential aged care providers.**

Recommendation 15

The government should resource an ongoing and targeted education campaign for aged care providers around ACDs, delivered by the Department for Health and Wellbeing.

3.6 Dispute Resolution: The Various Roles of the Public Advocate

Term of Reference 2(e)

To recommend changes to the legislation, administration, policy or practice which would improve the extent to which the objects are achieved with particular reference to:

...

- (e) The different roles the Act assigns to the Public Advocate and the extent to which those roles are reconcilable.

3.6.1 OPA's functions under the Act are contained in Part 7, Division 2. Part 7 also deals with the resolution of disputes by SACAT and sections 43 and 44 deal with interpretation and application of the Part in relation to OPA and SACAT respectively. In accordance with s 44, the resolution of disputes may relate to the making or revocation of an ACD, a decision or proposed decision under an ACD, the provision or proposed provision of health care in relation to the person who made the ACD, and any other matter specified in the Regulations. Under clause 13 of the Regulations, a dispute may also be resolved by both OPA and SACAT if it pertains to 'a matter related to the residential and accommodation arrangements and personal affairs' of the person who made the ACD.

3.6.2 In his Second Reading Speech, the then Minister for Health, the Hon John Hill MP, described the various roles of OPA under the Act as conferring both 'advisory and mediation functions' and as providing 'a less formal way of resolving a dispute'.⁷⁸ OPA exercises a range of functions under the Act, as well as additional roles conferred under separate legislation (*Mental Health Act 2009* (SA), *Guardianship and Administration Act 1993* (SA)). On one level, these functions create the potential for conflict and, perhaps even more so, the potential for significant pressure on the resources of OPA.

3.6.3 Legislation confers upon OPA the role of:

- investigator (s 28 of the *Guardianship and Administration Act 1993* (SA), s 49 of the *Advance Care Directives Act 2013* (SA));
- advocate (s 54B(1)(a));
- guardian (under the *Guardianship and Administration Act 1993* (SA) and by virtue of an order of SACAT under s 48 of the *Advance Care Directives Act 2013* (SA));
- referrer of disputes to SACAT (s 46 *Advance Care Directives Act 2013* (SA)) and the Supreme Court (s 46A *Advance Care Directives Act 2013* (SA));

⁷⁸

South Australia, Parliamentary Debates, House of Assembly, 17 October 2012.

- mediator (ss 45 and 49 *Advance Care Directives Act 2013* (SA)); and
- decision-maker (s 45(5)(a)(iii) *Advance Care Directives Act 2013* (SA)).

Under s 23 of the *Guardianship and Administration Act 1993* (SA), the Public Advocate may delegate his or her functions, subject to certain requirements. However, under clause 14(1) of the *Advance Care Directive Regulations 2014* (SA), the delegation of powers or functions for the purposes of s 45 of the ACD Act can only be delegated where the Public Advocate ‘is satisfied that the person has suitable qualifications and expertise in mediation’. In the previous 5 years, a very experienced and senior employee of OPA with qualifications in social work and mediation, has coordinated the Dispute Resolution Service (DRS). However, she will retire at the end of 2019. While the Review demonstrated clearly that OPA have well established procedures, protocols and policies in place to manage a transition in personnel, any change to the funding or resources of OPA would significantly undermine OPA’s capacity to perform their roles under the Act, as well as potentially increase the caseload of SACAT.

3.6.4 In its submission to the Review, OPA described the list of its various roles in the following manner:⁷⁹

- providing the public with information and advice about the operation of the ACD Act, both in person and via telephone, through the OPA Information Service;
- presenting to health professionals, service providers and community members about the ACD Act and its practical application;
- providing preliminary assistance and a dispute resolution service (including mediation) in order to resolve disputes arising under an advance care directive and uphold the rights of people to preserve their Advance Care Directive wherever possible and appropriate, thus negating the need for SACAT to make a guardianship order;
- Identifying disputes that require referral to SACAT;
- assist in the prevention and response to elder abuse by offering information and early intervention through the dispute resolution service.

3.6.5 OPA’s power to resolve disputes is governed by s 45 of the Act. This section enables OPA to exercise a range of preliminary functions where an eligible person in relation to an ACD or on his or her own initiative seeks to have a matter resolved by OPA. ‘Eligible person’ is defined in s 43 as the person who made the ACD, an SDM, a health practitioner involved in providing, or proposing to provide, health care to the person who made the ACD, or any other person with a ‘proper interest’ in the matter, as determined by OPA. In accordance with s 45(1) of the Act, the preliminary assistance that OPA is able to perform in relation to a matter may include:

- (a) ensuring that the parties to the matter are fully aware of their rights and obligations; and
- (b) identifying the issues (if any) that are in dispute between the parties; and

⁷⁹ Office of the Public Advocate, *Submission 33*.

- (c) canvassing options that may obviate the need for further proceedings; and
- (d) where appropriate, facilitating full and open communication between the parties.

3.6.6 Mediation may be brought to an end if OPA determines that the matter is best resolved by SACAT or at the request of one of the parties (s 45(3)). Evidence of anything said or done in mediation is, however, inadmissible in subsequent proceedings including before SACAT, unless all parties have consented (s 45(4)). Section 45(5) lists the powers of OPA in relation to the mediation of a matter:

- (a) make such of the following declarations in respect of a matter to which this Part applies as the Public Advocate thinks necessary or desirable in the circumstances of the case:
 - (i) a declaration as to the nature and scope of a person's powers or responsibilities under an advance care directive;
 - (ii) a declaration as to the nature and scope of a person's powers or responsibilities under the advance care directive;
 - (iii) a declaration as to whether or not the person who gave the advance care directive has impaired decision making capacity in relation to the specified decision;
 - (iv) any other declaration prescribed by the regulations; and
- (b) give any advice that the Public Advocate considers necessary or desirable in the circumstances of the case.

3.6.7 Declarations can be varied or revoked (s 45(6)), and OPA may decline to mediate a matter entirely if it is considered more appropriate that the matter be dealt with by SACAT (s 45(7)). OPA also has a range of powers to determine the processes and form of mediation (s 45(8)-(13)). Section 46 permits OPA to refer a matter to SACAT for determination and s 46A enables OPA to refer a question of law to the Supreme Court. SACAT can also refer matters to OPA under s 49 of the Act. The powers of OPA to mediate and provide preliminary support on matters related to ACDs were a significant development under the Act and mediation through the Dispute Resolution Service (DRS) has been very successful. As OPA outlined in its submission to the Review, the Office has also engaged in extensive education work through its work with health practitioners and its information service. In numerous consultations and several written submissions, the Review received many positive comments from health practitioners and the LHNs regarding OPA's assistance in answering enquiries related to ACDs. Indeed, OPA reported that, in the 2018-2019 financial year, OPA had met with 680 community members and that there remains considerable confusion regarding ACDs and their operation. It is clear that OPA performs an extremely important function in educating both health professionals and members of the public. The importance of such education has been addressed above, but is also addressed under Term of Reference 3 below.

3.6.8 OPA provided the Review with statistics regarding the DRS.⁸⁰ Since the Act came into operation, OPA has received between 98-100 matters each financial year, although OPA reported a decline in that number in the current financial year (down to 61). This OPA

⁸⁰ Ibid.

attributed to a 2017 amendment to s 51(1)(ca). That amendment extended SACAT's powers to revoke the appointment of an SDM without the need for an application by OPA, as occurs under s 51(2). Using data from the previous financial year, OPA provided the following information outlining the nature of matters dealt with through the DRS:

The table below indicates the outcome of applications received by the OPA DRS during the last financial year. While there were 98 applications for Dispute Resolution made to the OPA DRS a number of matters were not able to proceed to mediation for the variety of reasons listed in the table. Of the 44 matters that were suitable for mediation, only one did not result in an agreement being reached and resulted in a Section 51 (2) application for the revocation of the ACD being made to SACAT. This indicates a success rate of mediated matters of 97.72 %.

NUMBER OF DISPUTES (APPLICATIONS RECEIVED) IN 2017-18	98
Number of disputes resolved by DRS	44
Client deceased prior to conclusion of matter	3
Number of applications for dispute resolution withdrawn	9
<input type="checkbox"/> Applicant did not want to continue following pre-mediation	6
<input type="checkbox"/> Matter being heard by Supreme Court	1
<input type="checkbox"/> No current advance care directive	2
Number of matter closed by DRS	24
<input type="checkbox"/> Client has decision making capacity and can state own views	3
<input type="checkbox"/> Parties not willing to mediate – applicant did not wish referral to be made	11
<input type="checkbox"/> No response from Interested parties	4
<input type="checkbox"/> Existing GO and AO in place, no jurisdiction for DRS	1
NUMBER OF DISPUTES (APPLICATIONS RECEIVED) IN 2017-18	98
<input type="checkbox"/> Issues relating to financial matters only	1
<input type="checkbox"/> Not suitable for mediation - IP wanted to record sessions	1
<input type="checkbox"/> No current ACD – DRS did not have authority to mediate	1
<input type="checkbox"/> Applicant passed away prior to conclusion of the matter	1
Number of matters referred to SACAT by DRS	25
Reasons for referrals to SACAT	
<input type="checkbox"/> Declaration re validity of documents	6
<input type="checkbox"/> Client wishes to revoke Advance Care Directive	2
<input type="checkbox"/> Elder Abuse	3

<input type="checkbox"/> Parties not willing to mediate and applicant wished to proceed to SACAT	6
<input type="checkbox"/> Interested Parties failed to respond and applicant wished to proceed to SACAT	1
<input type="checkbox"/> SDM wanted to renounce role (client does not have capacity)	2
<input type="checkbox"/> OPA made Section 51 (2) application (change of personal circumstances)	2
<input type="checkbox"/> Mediation unsuccessful	1
<input type="checkbox"/> Unsafe to mediate	1
<input type="checkbox"/> No Advance Care Directive – applicant made further application to SACAT for Guardianship Order	1
Matters ongoing at 30/6/18	7

3.6.9 The powers of OPA also extend to several roles in matters before SACAT. Section 48(1)(a) allows SACAT to deal with a matter previously handled by OPA under s 45. SACAT may confirm, cancel or reverse a decision of OPA, and may confirm, vary or revoke a declaration made by OPA (s 48(3)(a)(i) and (ii)). In any case, the Tribunal may make any declarations they consider necessary or desirable in the circumstances (s 48(3)(b)(i)). While SACAT may refer matters to OPA under s 49, the number has declined since the Act came into operation. Statistics provided by OPA showed that while 45 matters were referred in 2014-2015, only 5 matters were referred to OPA from SACAT in 2018-2019 (using figures up until the end of May 2019).⁸¹

3.6.10 Section 51 of the Act allows SACAT to revoke the appointment of an SDM and, in some circumstances, to appoint another SDM, vary the ACD or revoke the ACD. However, sub-section (i) enables SACAT to hear an application from an eligible person for revocation, or can revoke an appointment of its own motion, whereas sub-section (2) allows OPA to seek the revocation of an appointment following a change in the personal circumstances of either the person who made the ACD or the SDM. SACAT has determined that changes in personal circumstances may involve the following:⁸²

- the death or physical or mental illness of the substitute decision-maker
- the estrangement of a substitute decision maker from the donor
- a change in the nature of the personal relationship between the substitute decision-maker and the donor
- the inability to locate or make contact with a substitute decision-maker
- the particular medical or other care needs of the donor
- the impaired or reduced decision-making capacity of a substitute decision-maker (which may not be such as to amount to a lack of competence under s 21 (2)), and
- the actions of a substitute decision-maker relevant to the question of his or her suitability to exercise the decision making responsibilities as set out in s 10 (g) and s 35 (1) of the Act. Such actions might include apparent conflictual decision making, or an inability to make appropriate and objective decisions in the best interests of the donor, unimpeded by emotion or personal interests.

⁸¹ Ibid.

⁸² *AMT v COT & GSZ* [2017] SACAT 2 (17 February 2017), per Parker J at [101].

Such actions by a substitute may amount to negligence or incompetence or mere disregard of, or an inability to understand, the role of a decision-maker.

If SACAT is satisfied that it is no longer appropriate for the appointed SDM to continue in that role, s 51(2) allows SACAT to make the same orders as are permitted under s 51(1). Section 53(b)(iii) also lists OPA as one party who may seek internal review of a decision of SACAT. Section 54(i)(c) lists OPA as a party who must be notified of proceedings before SACAT and s 54B(1)(a) also provides that OPA may represent a person who is the subject of proceedings before SACAT.

3.6.11 It is clear, therefore, that OPA fulfils a range of significant roles under the Act, some of which could be perceived as creating a potential conflict for OPA. Factoring in the roles ascribed to OPA under the *Mental Health Act 2009* (SA) and the *Guardianship and Administration Act 1993* (SA), the situation looks even more complicated. However, during consultations, it was evident that OPA has adopted rigorous internal protocols and policies to prevent any conflict from arising between its various functions. Nor do OPA feel that they have too many roles under the legislation, although OPA readily acknowledged that it needed to work through those roles and establish clearly delineated systems for dealing with guardianship matters separately from ACD matters.⁸³ The OPA systems for maintaining confidentiality between the two systems (for DRS and guardianship) are actively ensured by staff at OPA. Indeed, they consider it to be a key strength at OPA:⁸⁴

OPA's Dispute Resolution Service (DRS) has been in operation since the ACD Act came into force on 1 July 2014. From that time to the present, DRS policies, procedures and guidelines have been continually reviewed and refined to ensure that the service complies with all aspects of the ACD Act ...

In addition to the various roles assigned by the ACD Act, the Public Advocate may also have the role of guardian) and/or investigator under sections 29 and 28 of the *Guardianship and Administration Act 1993*. When considering the extent to which the roles assigned by the ACD Act are reconcilable it is also necessary to consider how these roles are reconcilable with the Public Advocate's roles of guardian and investigator.

From time to time a person who has given an ACD that has been the subject of an application to the DRS will later come under the guardianship of the Public Advocate and/or be subject to an investigation ordered under the G&A Act. When this occurs, OPA is able to reconcile its roles by operating discrete services within the office, through the Public Advocate's Delegations and the promulgation of policy and procedure designed to uphold the integrity of the DRS on the one hand and guardianship services on the other.

⁸³ Office of the Public Advocate, *Consultation*, 10 May 2019.

⁸⁴ Office of the Public Advocate, *Submission 33*.

Information provided to the DRS concerning a dispute arising under an ACD is not accessed by staff responsible for investigation and guardianship services. This is achieved through:

- a policy preventing DRS from providing any submissions to SACAT regarding the appointment of particular persons as guardians of a person who has given an ACD;
- a procedure for the placement of alerts on OPA's database when applications to the DRS are received by the office. This serves to alert OPA staff to the fact that the matter is confidential to the DRS and should not be accessed by members of other OPA teams. As part of their induction, all staff members are required to sign an undertaking that they will honour this alert;
- the physical separation of the DRS from other services provided by OPA. DRS does not share its space within the office with other OPA teams.

3.6.12 During consultations, SACAT expressed concern with the breadth of the functions conferred on OPA under legislation and for the potential for conflict to arise.⁸⁵ Indeed, given the roles of OPA in conducting mediation, carrying out investigations referred to them by SACAT, as well as the potential for OPA to act as an advocate for a person appearing before SACAT, there is the need for a strict and clear demarcation between OPA's roles as an advocate, investigator and mediator. While internal processes within OPA have worked to ensure that demarcation, there remains a question surrounding the capacity of OPA to manage its complex set of statutory responsibilities in the event that its workload increases or its staffing and resources are reduced, or are simply placed under strain due to an increase in workload. OPA did, however acknowledge the potential for conflict to arise in relation to making declarations under s 45(5) and recommended that sub-sections (5)-(9) be repealed.⁸⁶

With respect to the declaratory role assigned by section 45(5) of the ACD Act, OPA takes the view that it is incompatible to serve as an impartial mediator/dispute resolution practitioner while also assuming the role of decision maker in the context of making a declaration about a matter. OPA has not made any declarations under section 45(5) in the five years of the Act's operation. This is due to:

- the incompatibility of serving as an impartial mediator/dispute resolution practitioner with the role of decision maker in the context of making a declaration about a matter that is in dispute;
- any declaration made by OPA can be cancelled or reversed by SACAT in any case. Were this to occur, it would likely have a negative impact on the confidence of potential applicants in the value of an OPA declaration;
- the DRS has never received an application seeking a declaration, which suggests that applicants are searching for advice or dispute resolution when they approach OPA rather than 'rulings' that might be expected to be made by a court or tribunal;

⁸⁵ South Australian Civil and Administrative Tribunal and Attorney Generals Department, *Consultation*, 10 May 2019.

⁸⁶ Office of the Public Advocate, *Submission 33*.

- general advice about the nature and scope of powers and responsibilities under the ACD is in any case given informally during the provision of preliminary assistance as is general advice as to whether a particular act or omission is within the powers, or discharges the responsibilities, of a substitute decision maker.

OPA does not see that there is any inconsistency between its roles as the provider of preliminary advice and dispute resolution services on the one hand, and the referral of appropriate disputes to SACAT upon ending a mediation. On the contrary, it is within the skill set of a dispute resolution practitioner to recognise when mediation is no longer appropriate. When this occurs, if full effect is to be given to the wishes of the person giving the ACD, it is important for the dispute to be promptly referred to SACAT rather than leaving it to the disputing parties to take action to resolve their dispute.

OPA takes the view that it is important that it retains its power to apply to SACAT under section 51(2) of the ACD Act for the revocation of the appointment of a substitute decision maker. This is particularly important where, during the provision of advice and/or mediation, the DRS has identified the likely instance of elder abuse. In these circumstances it is unlikely that a substitute decision maker will make such an application.

3.6.13 OPA also directly acknowledged the potential for conflict to arise between its power under s 51(2) of the Act (involving an application to SACAT for the revocation of an SDM appointment) and the fact that s 45(4) of the Act prevents anything done or said at a mediation from being admitted in subsequent proceedings (unless all parties to a matter otherwise consent).⁸⁷ OPA suggested that an exception could be made to s 45(4) where OPA reasonably suspects the commission of elder abuse against the giver of the ACD. Such an amendment could have significant implications for both the DRS and subsequent proceedings, as the mediation service could be undermined if things said or done at a mediation are later disclosed to SACAT or in other subsequent proceedings. An exception based on a reasonable suspicion of elder abuse held by the OPA staff working in the DRS could be prejudicial to parties in subsequent proceedings, whether before SACAT, in criminal proceedings, or under new adult safeguarding laws. Section 45(4) has been raised in one reported decision of SACAT – *AMT v COT & GSZ*.⁸⁸ In that case, it was submitted on an internal review that the Tribunal had erred in admitting a report from OPA which contained information from a previous mediation conducted by the OPA officer, and without the consent of all parties as required under s 45(4). A lawyer from the Crown Solicitor’s Office refuted the claim, arguing that OPA had not reported on what was said or done at the mediation but had simply reported the facts established prior to the mediation and summarised the general outcome of the mediation. Justice Parker, deciding the case, agreed with this argument and offered the following comments:

In any event, that information was clearly established by other evidence before the Tribunal. Moreover, there had been no objection to the receipt of that evidence.

⁸⁷ Ibid.

⁸⁸ [2017] SACAT 2 (17 February 2017), per Parker J at [34].

Even if the Tribunal had erred in receiving that evidence, it did not affect the outcome of the proceedings.

- 3.6.14 Justice Parker’s comments make an important, yet implicit, observation in relation to the scope and effect of s 45(4). There is a clear distinction between matters which are determined prior to the commencement of a mediation and matters which are ‘said or done’ in the mediation proper. In addition, OPA’s preliminary functions under s 45 are legally distinct from its functions with respect to mediation. Thirdly, SACAT is satisfied that a general summary of the outcome of a mediation does not breach s 45(4). These are important factors when considering the suggested amendment to s 45(4).
- 3.6.15 Rather than creating a statutory exception to s 45(4) in elder abuse cases, it would arguably be preferable for OPA to discontinue any mediation where evidence provides a reasonable basis for suspecting elder abuse and, instead, refer the matter to SACAT. This is already facilitated by s 45(3)(a) and (7). Coupled with the decision of Parker J in *AMT v COT & GSZ*, there is also a recognised way for OPA to craft a referral to SACAT that does not fall foul of s 45(4). Notwithstanding this, there may still be very sound reasons why OPA should be entitled to disclose some evidence of elder abuse in a referral to SACAT, but an exception to s 45(4) that would facilitate the disclosure of everything ‘said or done’ in a mediation related to the reasonable suspicion of elder abuse – and for the purposes of seeking a SACAT order under s 51(2) - is not necessarily the most appropriate way of achieving that. The potential in that scenario is that the integrity of the legal process used by both OPA and SACAT (and possibly other subsequent proceedings) may be compromised. An amendment to s 45 which made it clear that OPA must discontinue any proceedings (whether preliminary in nature or involving mediation) where there is a reasonable suspicion of elder abuse by OPA staff involved in the DRS, would arguably be preferable. An amendment of this kind would permit OPA to disclose that a staff member had formed a reasonable suspicion of elder abuse, without disclosing detailed information from a mediation, but in a way that facilitated SACAT hearing and deciding the matter. There are also considerations of OPA’s legal obligations under new adult safeguarding laws that need to be taken into account. Indeed, there is the real likelihood that OPA could be legally required to refer a matter to SACAT at the same time as reporting the suspicion of abuse to the new Adult Safeguarding Unit (ASU) in the Office for Ageing Well. Accordingly, this issue needs further examination by the Department for Health and Wellbeing, in consultation with OPA, SACAT and the ASU.
- 3.6.16 Another matter raised in reported decisions of SACAT concerned the absence of formal delegations of the Public Advocate’s office in accordance with the Act and s 23 of the *Guardianship and Administration Act 1993* (SA). The absence of formal delegation instruments was noted by Parker J in *AMT v COT & GSZ*.⁸⁹ His Honour noted the relevance of the *Carltona* principle, recognising that Parliament would not have intended that a statutory office holder (such as the Public Advocate) could be expected to exercise every specific role conferred upon him or her under legislation and that an officer of the body could exercise such powers without a formal instrument of delegation. However, his Honour was quite critical of the failure to issue formal delegations under the Act.⁹⁰

⁸⁹ [2017] SACAT 2 (17 February 2017), per Parker J at [34].

⁹⁰ [2017] SACAT 2 (17 February 2017), per Parker J at [85]-[87].

In the present circumstances those persons who comprise the dispute resolution service in the Office of the Public Advocate are clearly authorised by the Public Advocate to act on her behalf to attempt to resolve disputes about advance care directives under Division 2 of Part 7 of the ACD Act. Given the nature of their role and the fact that the personnel involved hold social work or other appropriate professional qualifications, if in fact no relevant delegation had been made, I am satisfied that the *Carltona* principle operated so that the satisfaction of the dispute resolution service staff can be taken to be the satisfaction of the Public Advocate or the purposes of determining whether a person should be regarded as an “eligible person”.

While I am satisfied that the inference drawn by Ms Rugless is correct, it would have been far preferable if the issue of Ms Rai’s status as an eligible person had been specifically considered by the Public Advocate or her staff. I understand that this practice has now been adopted.

If it has not already occurred, it is also highly desirable that the Public Advocate specifically delegate to the relevant members of her staff the function of forming an opinion about status as an eligible person. That can be done by way of an instrument in writing made under s 23 of the G&A Act. This provision empowers the Public Advocate to delegate her powers or functions under that Act or under any other Act. Use of a formal delegation is far preferable to reliance upon the *Carltona* principle in important matters that may be subject to review or litigation.

The Review received no complaints or concerns expressed in relation to delegations by the Public Advocate, so it is assumed that this matter has been appropriately addressed by the Public Advocate since the decision.

FINDING 14

3.6.17 The Review demonstrated that, despite OPA exercising a range of complex roles and functions under several Acts, the Office has managed the potential for conflicts with diligence and a strict compliance with internal protocols and policies. Accordingly, there is no obvious basis for reducing the number of roles currently fulfilled by OPA. Nonetheless, a reduction in resources or funding of OPA would have a direct and adverse effect on the operation of the Act and, potentially, the caseload of SACAT.

FINDING 15

3.6.18 OPA requested that an amendment be made to s 45(4) of the Act to enable them to disclose material evidence ‘said or done’ in a mediation to SACAT in cases where there is a reasonable suspicion of elder abuse. However, an exception to s 45(4), and specifically to facilitate applications by OPA to SACAT under s 51(2), is not necessarily the most appropriate way of achieving this. A preferable legal mechanism would be to require OPA to discontinue dealing with the matter (whether at a preliminary or mediation stage) and refer the matter to SACAT for determination. OPA should be permitted to disclose general information in a written referral to SACAT, which would require a clear statement to that effect in s

45. This could be achieved through the insertion of additional sub-sections of s 45(3)(a) and 45(7).

FINDING 16

3.6.19 The declaratory powers of OPA contained in section 45(5)-(9) have never been used in the 5 years in which the Act has operated. While the intention was originally to facilitate a simple process for dispute resolution, it is clear that people are seeking to have matters resolved by SACAT where the matter is complex or urgent, or where a binding decision is required or desired. Those sections should, accordingly, be repealed.

Recommendation 16

There is no clear legal or other reason to reduce the powers or functions of OPA, other than those recommended under Recommendation 18.

Recommendation 17

Section 45 of the Act should be amended to require OPA to discontinue a matter where a reasonable suspicion of elder abuse exists and refer the matter to SACAT for determination. OPA should be entitled to disclose the general basis of that suspicion in a written referral to SACAT. Consideration should also be given to an amendment which requires OPA to publish on its website, as well as notify all parties accessing the DRS from the outset, that evidence of elder abuse will trigger a discontinuation of mediation and that a referral to SACAT will follow.

Recommendation 18

The declaratory powers of OPA under s 45(5)-(9) have never been used and should be repealed.

3.7 Dispute Resolution: Distribution of Functions between the Office of the Public Advocate and the South Australian Civil and Administrative Tribunal

Term of Reference 2(f)

To recommend changes to the legislation, administration, policy or practice which would improve the extent to which the objects are achieved with particular reference to:

...

- (f) The extent to which the distribution of functions between the Public Advocate and the South Australian Civil and Administrative Tribunal are appropriate;**

- 3.7.1 In the then Minister’s Second Reading Speech he described the Bill as setting out a ‘simple resolution process for application in situations of uncertainty or if there is a dispute’.⁹¹ Much of that process has been outlined in the previous section. However, there are several matters which pertain directly to SACAT that have not been previously covered, but which warrant consideration in this section.
- 3.7.2 While the current distribution of functions between OPA and SACAT appears to be appropriate, excluding the suggested amendments in Recommendations 19 and 20, a number of improvements would enhance the operation of both bodies. However, neither changes relate to the separation of functions between the two. What came through during the Review is that OPA has particular expertise that has resulted in a very successful DRS, but, that the DRS is not able or appropriate to deal with cases involving elder abuse or significant conflict. In such cases, OPA refers, as a matter of course, those cases to SACAT, and this approach should be continued. Elder abuse is often accompanied with conflict and dysfunction within families, and mediation is rarely an appropriate method for the resolution of such disputes. In addition, SACAT has the advantage of being an independent tribunal with the authority to make binding decisions in such matters.
- 3.7.3 Notwithstanding this, it emerged during the Review that the conferral of jurisdiction in ACD matters had placed significant pressure on the Tribunal and that there are inevitable resource implications from managing what is a complex and resource intensive jurisdiction. The fact that SACAT is necessarily required to hold directions hearings in ACD matters followed by the substantive hearing, where people are not legally represented but which invariably involve complex legal disputes, significantly increases the workload of SACAT. According to SACAT, the majority of disputes over ACDs

⁹¹ South Australia, Parliamentary Debates, House of Assembly, 17 October 2012.

involve elder abuse and/or the validity of an ACD.⁹² This, in turn, raises questions regarding the operation of the new Adult Safeguarding Unit (ASU) and whether cases involving elder abuse could be referred from SACAT to the ASU, as well as the impact of Recommendations (outlined above) that are designed to enhance the completion, witnessing and execution of ACDs.

3.7.4 It would be hoped that developments in relation to both adult safeguarding and the improvement of ACD adoption and execution will ease the burden on SACAT, but there will inevitably remain cases where an ACD's validity and effect needs to be determined by SACAT. The Law Society, in its submission, pointed to the caseload of SACAT as evidence that the Act was not operating effectively.⁹³ While it was evident during the Review that SACAT's caseload is extensive, the Review also revealed the many positive stories of individuals who felt empowered by completing an ACD and health practitioners described the many benefits of having a patient's preferences, wishes and values recorded. If anything, ACD uptake needs to be encouraged and promoted. But the pursuit of that objective will invariably increase the workload of SACAT, not simply because disputes may increase as a result, but because hospitals and health practitioners will occasionally need SACAT to determine whether an ACD prevents a specific medical treatment or intervention. The reality is that, with greater uptake of ACDs, the Tribunal will be more likely to be asked to determine the validity, effect and scope of ACDs, including binding refusals of health care.

3.7.5 A review of SACAT decisions publicly available on AustLII (the Australian Legal Information Institute) reveals that a total of 172 cases are reported and publicly available. The SACAT website states that the Tribunal chooses which cases are reported and made publicly available. However, of the 172 decisions on AustLII, those cases cover all of SACAT's streams, and not just the community stream where ACDs are dealt with. A search of SACAT's publicly available decisions only returns 9 cases when 'advance care directive' is searched on AustLII's SACAT database. When the same search is done with the addition of 'and Public Advocate' the search returns only 5 cases. This is certainly not to say that SACAT does not deal with many complex and serious cases under the Act each year; merely that few decisions are reported and made publicly available.

3.7.6 A review of AustLII, as well as the annual reports of the AGD, Health and Wellbeing and the Courts Administration Authority (CAA), shows that SACAT does not provide any publicly available annual statistics of their caseload in ACD matters. This is unfortunate, as it was difficult to contextualise and examine the claim made by SACAT that the ACD jurisdiction is overwhelming. There is also no statutory obligation on the part of either SACAT or OPA to provide annual statistics to the Department or the Minister for Health and Wellbeing, recognising that both OPA and SACAT sit within the Attorney-General's portfolio, whereas the ACD Act is within the portfolio of the Minister for Health and Wellbeing. OPA does, however, include detailed information and statistics in its Annual Reports, but is a statutory authority. SACAT, by way of contrast, is an independent Tribunal, presided over by a Supreme Court judge, and forms

⁹² South Australian Civil and Administrative Tribunal and Attorney Generals Department, Consultation, 10 May 2019.

⁹³ Law Society of South Australia, *Submission 27*.

part of the South Australian justice system. Irrespective of reporting lines, the government would be in a better position to direct policy and resources if it received annual information on the different caseloads in each of SACAT's streams. In addition, it would be particularly useful to know how many ACDs are revoked or declared invalid by SACAT, and the basis for such determinations. Ideally, further research needs to be conducted to fully understand how the jurisdiction is working at SACAT, in all its aspects.

3.7.7 In consultations with SACAT and the Attorney General's Department (AGD), it emerged that SACAT is clearly overwhelmed by the need to follow quite complex procedures, including the use of directions hearings in ACD matters, in order to ensure that parties are adequately supported and informed of the process and their legal rights and obligations, and are provided with procedural fairness. In particular, SACAT described the fact that their procedures have become very legalistic – despite the statute's original intent – in order to ensure that parties' legal rights are adequately conveyed and protected. As a consequence and, as already mentioned, SACAT are having to hold 2 separate hearings in every matter.

3.7.8 It was never expected that SACAT would be so heavily burdened by this jurisdiction, although the scope and volume of the jurisdiction was unknown when the Act was developed. The consequence, however, is that SACAT has become more legalistic over time, given the imperative to meet their varied statutory obligations and the requirements of administrative law. Furthermore, cases involving ACDs are often related to protracted family conflict and family dysfunction, and can also involve instances of elder abuse. As a result, the jurisdiction has become more complicated and lengthy in an area that was designed to protect some of our most vulnerable people. While in some respects the legal requirements associated with operating this type of jurisdiction cannot, or should not, be changed (for example, dealing with vulnerable parties and witnesses, ensuring that procedural fairness is afforded to all parties, maintaining the integrity of the tribunal's processes), the Review was unable to access sufficient information regarding SACAT's jurisdiction to formulate specific recommendations that would improve its operation. Ultimately, the absence of statistical data or analysis and the inability to access a comprehensive database of SACAT decisions in ACD matters prevented this. Nonetheless, there are several matters which would facilitate a deeper understanding of the jurisdiction, including the collation of data and analysis of SACAT decisions in ACD matters, further research into the Act's interpretation, implementation and enforcement through SACAT, followed by a review of SACAT's resourcing and staffing levels.

FINDING 17

3.7.9 There are no publicly available statistics on the caseload of SACAT, including in its community stream and with respect to matters relating to ACDs. Either SACAT or the Attorney General's Department should be required to collate both statistics and analysis of SACAT's caseload on an annual basis for government.

FINDING 18

- 3.7.10 The government should fund and commission research into SACAT's jurisdiction over ACDs in order to obtain a better understanding of how frequently ACDs are invalidated or revoked and the reasons for invalidity or revocation, the number of applications received from hospitals regarding the validity, scope or effect of binding refusals of health care, the frequency of and reasons for revoking an appointment of a substitute decision maker, the reason why referrals to OPA have reduced, the number of applications for internal review of SACAT decisions, and any other matter related to the Act's operation and enforcement.

FINDING 19

- 3.7.11 Assuming that recommendations 19 and 20 are implemented, the government should review the adequacy of SACAT's resourcing and consider whether an increase in staff or resources are required in relation to ACDs.

Recommendation 19

In order to inform future policy and resourcing decisions of government, either SACAT or the Attorney General's Department should collate, on an annual basis, statistics and analysis on SACAT's jurisdiction, including its jurisdiction in ACD matters. The information should be made available to both the Attorney-General and the Minister for Health and Wellbeing.

Recommendation 20

The Minister should commission and fund a research project focussed on the decisions of SACAT related to ACDs to build understanding of how the *Advance Care Directives Act 2013 (SA)* is being implemented. The research should investigate all aspects of the Act's effect and operation but should examine the extent to which ACDs are invalidated or revoked and the reasons for invalidity or revocation, the extent to which ACD appointments are revoked and the reasons for revocation, applications by hospitals or hospital staff for decisions regarding binding refusals of health care, the nature of those applications and the outcomes of such cases, the frequency or rate of internal reviews of SACAT decisions, and any other relevant matter.

Recommendation 21

Assuming that recommendations 19 and 20 are implemented, the government should review the adequacy of SACAT's resourcing and staffing levels.

- 3.7.12 Finally, the review received a submission to the effect that the Act should come within the purview of the Attorney-General, which could well be a means for enhancing the distribution and oversight of functions between OPA and SACAT – both bodies

reporting directly to the Attorney.⁹⁴ However, this submission was not endorsed by any person other than the Law Society. Indeed, when considered in the context of all consultations conducted and submissions received throughout the Review, there is simply no evidence of a pressing need to move ministerial responsibility from Health and Wellbeing to the Attorney-General's Department (AGD). If anything, the Review highlighted the absolute necessity of health practitioners and local health networks (LHNs) as major stakeholders in the implementation of the Act. Without effective buy-in of both health practitioners and hospitals, the Act's objectives are simply not likely to be realised – irrespective of how comprehensive or well drafted an ACD is. For these reasons, no recommendation has been made to move responsibility for the Act to AGD, although, of course, the Department for Health and Wellbeing should work, wherever possible, with AGD to promote the Act's adoption and implementation. This includes engaging, on a regular basis, with legal practitioners and the Law Society. .

⁹⁴ Law Society of South Australia, *Submission 33*.

3.8 Opportunities to Enhance Support: Interpreters and other matters

Term of Reference 2(g)

To recommend changes to the legislation, administration, policy or practice which would improve the extent to which the objects are achieved with particular reference to:

...

- (g) The opportunities to enhance the support provided, including the provision of interpreting assistance.**

3.8.1 At present, the use of interpreters under the Act is quite relaxed. Currently, the Act makes no mention of interpreter assistance, nor do the Regulations. Only the ACD form and DIY Kit addresses this subject. In accordance with the Form, an interpreter must complete a statement whereby they are required to write their name and attest to the fact that they have read and interpreted the ACD Information Statement to the person making the ACD. An interpreter must also attest to the fact that the person making the ACD appeared to understand the information provided and that the information recorded in the ACD was translated by the interpreter and accurately conveyed, in English, the directions provided by the person to the interpreter. There are no requirements that an interpreter be qualified as an interpreter, nor that they be an adult, or that they be independent of the person making the ACD. In accordance with section 15 of the Act, witnesses cannot also be SDMs, or have an interest in the estate of the person giving the ACD, be a health practitioner responsible for the care of the person, or occupy a position of authority by virtue of their employment in a hospital, aged care facility or other institution. However, there are no equivalent prohibitions regarding interpreters, despite there being a similar potential for conflicts of interest to arise. Accordingly, the Act should be amended to prevent similar conflicts from being permitted to emerge, as is the case with respect to SDMs.

3.8.2 Responses to this general survey question regarding access to witnesses were overwhelmingly positive with a total of 58.90% of respondents stating that the process of finding a witness was either easy or fairly easy (see further Appendix A). Just over 21% of respondents found it hard or fairly hard. As there were no comments permitted in relation to this question, it is difficult to determine whether the latter categories were in regional or remote areas of South Australia, or if mobility or physical issues acted as an impediment for those who found it hard to access a witness. However, access to witnesses was designed to be relatively easy when the schedule of authorised witnesses was first developed. Nonetheless, a constant theme during the Review was that the current list is far too broad and needs to be significantly reduced to ensure the integrity of the process.

FINDING 20

- 3.8.3** **The use of interpreters under the Act is insufficiently regulated and is open to abuse and possible conflicts of interest, both of which undermine the integrity of the Act and the possible validity of ACDs.**

Recommendation 22

A new section of the Act is required which imposes clear requirements on interpreters. In particular, interpreters must be duly qualified as interpreters of the relevant language, they should be adults with capacity and they should be subject to similar requirements as apply to witnesses under section 15.

3.9 Opportunities to Enhance Support: The ACD Form and DIY Kit

Term of Reference 2(h)

To recommend changes to the legislation, administration, policy or practice which would improve the extent to which the objects are achieved with particular reference to:

...

(h) Opportunities to enhance the ACD Form and the DIY Kit to enable the form to be easily understood and complied with by clinicians.

3.9.1 Recommendations with regard to the ACD Form and DIY Kit have already been addressed above. However, there are a number of issues which require further support to facilitate the effective realisation of the Act's objects:

- The Act needs a significant allocation of resources to support a widespread education and awareness campaign – digitally, electronically and in print media.
- The oversight of the Act is currently not the responsibility of any dedicated group, although it is within the remit of the Minister for Health and Wellbeing. Given the breadth of ACDs, it would be particularly helpful if the Minister and the government were advised by a specialist advisory body with broad expertise on ACDs and ACP generally. This body should not replicate other advisory bodies that already represent particular groups or stakeholders within health, but should be specifically designed to promote ACDs and their adoption. Membership should include an appropriate mix of the following expertise:
 - A geriatrician
 - A palliative care specialist
 - A GP with a particular interest and expertise in end of life matters
 - A nurse, or former nurse, with experience in end of life care
 - A representative/advocate from aged care
 - A lawyer with expertise in end of life and/or estate planning
 - A lawyer with expertise in human rights law
 - A representative from OPA
 - A social worker with relevant experience and expertise
 - A representative from SAPOL
 - A Justice of the Peace

- A representative from the Adult Safeguarding Unit.

Recommendation 23

The government needs to fund a comprehensive education and awareness raising campaign throughout the State, but only following the establishment of local, community owned programs which support the completion and adoption of ACDs.

Recommendation 24

The government should establish a new Advance Care Directives Advisory Board to advise the Minister on all matters dealing with ACDs. The Act should be amended to ensure that the Board reports directly to the Minister on an annual basis, and that LHNs are required to report annually to the Board with regard to their compliance with the Act. Membership of the Board needs to be diverse and include an appropriate mix of expertise in palliative care, gerontology, general practice, succession law/estate planning, human rights law, nursing and aged care.

Part 4

OTHER OPPORTUNITIES FOR REFORM

4.1 Advance Planning and Persons Lacking Capacity

Term of Reference 3(a)

A process by which adults who do not have decision making capacity can give direction to the extent of their capacity, about their future health care, residential and accommodation arrangements and personal affairs.

- 4.1.1 The overwhelming majority of organisations and individuals consulted during the Review were extremely supportive of enabling persons who may lack, or partially lack, decision making capacity, to express their preferences, values and wishes. This included people with disabilities and people in the early stages of cognitive decline. Indeed, in all of the consultations conducted, people conveyed their overwhelming support Victoria has recently included the use of supported decision making for people in relation to ACP and the Australian Law Reform Commission has found that supported decision making should be incorporated into all law and policies. As Margaret Brown wrote in her submission,⁹⁵

There is an urgent need for a document for people who do not have legal capacity to complete the SA Advance Care directive but have a right to have their wishes documented and respected. Currently this is not happening in SA. The number of people in the state who do not have the capacity to complete a legal document is increasing as a result of acquired brain injury, disability, mental illness, and the increasing number of elderly people with dementia and frailty at the end of life.

Although the Advance Care Directives Act provide the legal right for people with capacity to have their wishes documented and respected, it is an indictment on our health system (and society) that people who do not have capacity do not have this right, even though United Nations Convention on the Rights of Persons with Disabilities (Article 12) states there should equal recognition before the Law. This includes the right to make decisions with support. This convention was ratified by the Australian Government in July 2013.

- 4.1.2 A Ministerial Advisory Committee recommended in September 2015 to the then Minister for Health that government introduce a uniform non-legally binding document for people who do not have decision making capacity to replace the multitude of ‘advance care

⁹⁵ M Brown, *Submission 36*.

plans' in South Australia which currently cause significant confusion.⁹⁶ In relation to this issue, the Committee made the following comments:

Currently, there are many different documents called 'advance care plans' or words to that effect, used in residential aged care facilities and hospitals to record an expression of the wishes of a person who lacks decision making capacity. The plethora of forms in use and the lack of any legal effect of any of these forms, have created a confusing picture for health professionals and consumers.

While no form can be legally binding when made by or on behalf of a person who lacks legal capacity, there would be a significant benefit if the Minister were to provide a uniform document that offered an agreed formula that care facilities could use.

- 4.1.3 Considerable work has already been done through research, both recent and ongoing, between Margaret Brown and OPA, which is informed by the principles of the ACD Act and the articles contained in the UN Convention on the Rights of Persons with Disabilities.⁹⁷ There is a need for ongoing research and wide consultation on the subject.

FINDING 21

- 4.1.4 **The government should engage in a public consultation process and/or commission a research project, designed to explore the most appropriate methods for enabling adults to engage in ACP, beyond the adults covered by the ACD Act. This must, of necessity, involve the disability sector which, for various reasons, was beyond the scope of this Review beyond the relevance of ACDs.**

Recommendation 25

The government should conduct a public consultation process and/or commission research for determining how persons with limited or impaired decision-making capacity can be facilitated to record and convey (including through supported decision making) their preferences for future medical care, accommodation and personal matters. The consultation must engage with the disability sector and be framed by a human rights based approach.

⁹⁶ *The Highest Standard Care for all People Dying in South Australia: Recommendations from the Ministerial Advisory Committee on End of Life to the Minister for Health*, September 2015, Recommendation.

⁹⁷ M Brown and the Office of the Public Advocate, *Goals of Care Plan Trial*, The Office of the Public Advocate, 2018.

4.2 Increasing Organ Donation Consent and Compliance

Term of Reference 3(b)

Increase organ donation consents and compliance with those consents.

- 4.2.1 Based on the feedback of many people and organisations engaged during the Review, the majority of people are quite keen to include directions regarding organ and tissue donation in their ACDs. However, as the Barossa Volunteers' Group and Country Health SA commented, a preference to donate organs and tissue is often directly inconsistent with the preference to die at home – something which many people are keen to include in an ACD. Indeed, organ and tissue donation requires a patient to be in ICU on life support to be viable for transplantation. Furthermore, where a person lives in rural or regional SA, the ability to donate organs and tissue is simply not feasible, given the lack of specialist transplantation facilities in most regional hospitals.

FINDING 22

- 4.2.2 **Assuming that Recommendations 1, 2 and 15 above are implemented, organ and tissue donation should be addressed in a new section of the ACD Form and be a core component of any future training and education campaigns, but must highlight the difficulties of facilitating donation and the clear conflict with the desire to die at home.**

Recommendation 26

The government should ensure that organ and tissue donation is the subject of a separate section in the ACD Form (Recommendation 2), and that any education or training programs delivered through Recommendations 1, 2 and 15 include relevant information on such donations.

4.3 Interaction of ACDs with Other Related Documents

Term of Reference 3(c)

The interaction of ACDs with other related documents such as Medical Powers of Attorney and Legal Powers of Attorney.

- 4.3.1 The transitional provisions for dealing with previous instruments (Enduring Power of Guardianship, Medical Power of Attorney and Anticipatory Directions), are not well understood by anyone within the community. Indeed, there appears to be a significant gap in hospital protocol with regard to what are otherwise legally valid ACDs. While the majority of lawyers understand how these provisions of the Act operate, there is a clear need to improve education across the wider community and among health practitioners. Accordingly, protocols within hospitals and the LHNs need to be enhanced to ensure that such documents are complied with. This matter is addressed under Recommendation 7 (above).

4.4 Other Issues Raised During the Review

4.4.1 A number of submissions made to the review raised several issues not entirely captured within the Terms of Reference. These included the following:

- The ability to use digital signatures when signing an ACD;
- The requirement to have certified copies of an ACD;
- The applicability of ACDs when a patient presents to hospital following an attempt to suicide or self-harm.

4.4.2 Digital Signatures

4.4.2.1 There is no reason why the Act should not facilitate the use of digital signatures when completing and executing ACDs, especially for the makers of ACDs. There exist a number of reasons why a witness should still be required to personally sign an ACD, given the protective nature of witnessing requirements. The Review period did not permit for a wide consultation on this issue, nor the necessary consideration of the technology issues involved, particularly in relation to how the protective features of executing an ACD would be managed or affected by using digital signatures.

Recommendation 27

The Department should investigate how the use of digital signatures could be implemented under the Act, and make appropriate amendments to the Act if required.

4.4.3 Certified Copies of ACDs

4.4.3.1 Given the recommendation to significantly reduce the list of approved witnesses under the Act, the Department should consider the removal of the requirements for certified copies of an ACD. While many classes of witnesses already have extensive experience and training in certifying legal documents, some of those suggested to be retained in this Report may not. Anything which facilitates the adoption, execution and implementation of ACDs is to be welcomed, provided that the integrity of the process for completing ACDs is retained. While a small number of submissions to the Review raised this issue, an insufficient number were received to justify a recommendation on this matter. Accordingly, the Department should engage in more extensive consultation before any changes to the requirement for certification is made.

Recommendation 28

Before any changes are made to the certification requirements surrounding ACDs, the Department should engage in a broader consultation with key stakeholders, taking into account the recommended changes to the list of authorised witnesses in this Report. Any consultation for this purpose should include the relevant bodies representing particular classes of witnesses, the Local Health Networks and the Law Society.

4.4.4 ACDs, Suicide and Self-Harm

4.4.4.1 The Review unexpectedly followed 3 relatively recent cases involving the application of a valid ACD and its relevance and applicability following a suicide attempt or attempt to self-harm, and where the ACD contained a binding refusal of health care. This issue was not contained within the Terms of Reference and was not a subject of either consultations conducted during the Review, nor of any submissions received as a part of the Review. Indeed, it was only discussed with 2 people consulted during the review – the Chief Psychiatrist and a senior palliative care clinician. In neither case were the specifics of the 3 cases discussed, although the Chief Psychiatrist was familiar with at least one of those cases to the knowledge of the external consultant.

4.4.4.2 The Act itself was designed to prevent individuals from including a binding refusal of health care following a suicide attempt or attempt to self-harm. Section 12, as well as the Second Reading Speech, make this clear. Section 12(1) provides as follows:

- (1) Subject to this Act, an advance care directive cannot make provisions of the following kinds:
 - (a) a provision —
 - (i) that is unlawful; or
 - (ii) that would require an unlawful act to be performed; or
 - (iii) that would, if given effect, cause a health practitioner or other person to contravene a professional standard or code of conduct (however described) applying to the health practitioner or person;
 - (b) a provision that comprises a refusal of mandatory medical treatment;
 - (c) any other provision of a kind declared by the regulations to be within the ambit of this section.

Example —

An example of such a provision would be a request for euthanasia.

- (2) For the purposes of subsection (1), a reference to a professional standard or code of conduct does not include a reference to a standard or code of conduct prepared by or on behalf of a hospital, clinic, hospice, nursing home or any other place at which health care is provided to a person that regulates the provision of health care other services at that place.

- (3) A provision of an advance care directive that contravenes subsection (1) is, to the extent of the contravention, void and of no effect.
- (4) In this section —
 - "mandatory medical treatment" means —
 - (a) medical treatment ordered under a community treatment order or an inpatient treatment order under the *Mental Health Act 2009* ; or
 - (ab) medical treatment provided under section 56 of the *Mental Health Act 2009* ;
 - (c) or any other medical treatment of a kind prescribed by regulations for the purposes of this definition

4.4.4.3 The Second Reading Speech also reiterates that the use of an ACD to facilitate an act of suicide or self-harm was also intended to be prohibited.⁹⁸

The Bill provides that the following would be void and of no effect if contained in an Advance Care Directive:

- unlawful instructions or instructions which would require an unlawful act to be performed such as voluntary euthanasia or aiding a suicide
- refusals of mandatory treatment such as compulsory mental health treatment under the *Mental Health Act 2009*
- actions which would result in a breach of a professional code or standard, for example a Code or Standard issued by the Medical or Nursing and Midwifery Boards of Australia. It does not mean a hospital code or standard

4.4.4.4 Despite the above, it is evident from the 3 cases referred to that ACDs have been applied to prevent the delivery of life-saving medical treatment following an attempted suicide. Given that the Act was deliberately drafted to prevent such an occurrence, coupled with the fact that the Act would have almost certainly not have been passed if this were the case, the Act should be amended to clearly reflect this. By failing to recognise the original intent of the legislation, as well as the intention of Parliament when passing the Act, the Act would have a completely unintended operation and effect without such an amendment.

4.4.4.5 In reaching this conclusion, it must be emphasised that there are many complexities involved in the medical care of people who have attempted suicide or self-harm, and in the use or application of previously stated preferences or wishes, including in an ACD. The ethical dilemmas are immense. However, to enable the Act to operate in a way that facilitates the use of ACDs to prevent medical intervention following a suicide or attempt to self-harm, is completely inconsistent with the original intent of the Act. Furthermore, to enable this to occur without a full and open exploration of the subject by the community, including clinicians, lawyers and members of parliament, would be inappropriate and a perverse outcome of the Act. This is especially so considering the clear statements made by the then Minister during his Second Reading Speech.

4.4.4.6 Any amendments to address cases of attempted suicide and self-harm need to ensure that the remainder of an otherwise valid ACD can remain valid and effective, including the

⁹⁸ South Australia, Parliamentary Debates, House of Assembly, 17 October 2012

appointment of SDMs. Thus includes the appointment of SDMs, any other permitted directives in an ACD, the interaction of valid ACDs with the *Consent Act* and the hierarchy of ‘persons responsible’ across the LHNs.

FINDING 23

4.4.4.7 The Act should be amended to ensure that an ACD cannot be used to deny life-saving treatment following an attempted suicide or act of self-harm. The remainder of an otherwise valid ACD must be preserved.

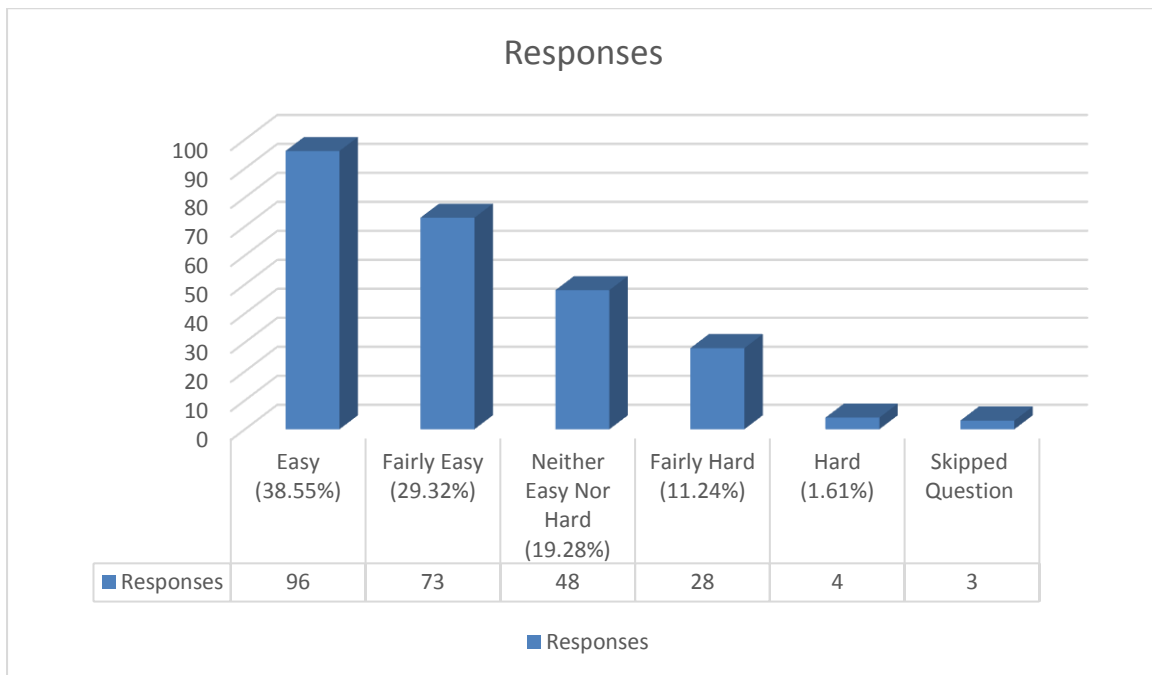
Recommendation 29

The Act must be amended to ensure that it is explicit, in the operative provisions of the Act, that an ACD cannot be used as the basis for refusing life-saving treatment following an attempt to suicide or cause self-harm. The remainder of an otherwise valid ACD must be preserved.

APPENDIX A

General Survey Responses

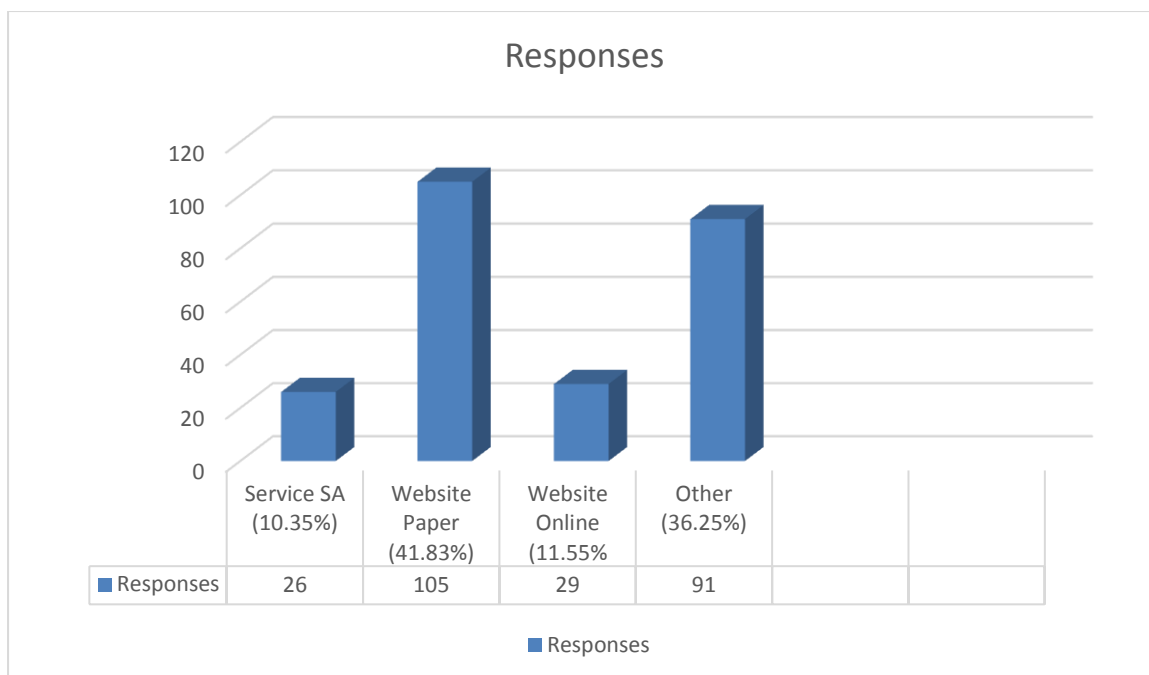
Question 1: How easy or hard was it for you to get an ACD form?



A total of almost 68% of respondents to the Department’s Your SAy survey responded that it was either easy or fairly easy to access the ACD form, with only 12.85% finding it either hard or fairly hard.

Question 2: Where did you get your ACD DIY Kit or form?

- I bought a DIY Kit or form from Service SA
- I downloaded a DIY Kit or form from the ACD website
- I completed my ACD online on the ACD website
- Other – Please tell us how you got your DIY Kit or form



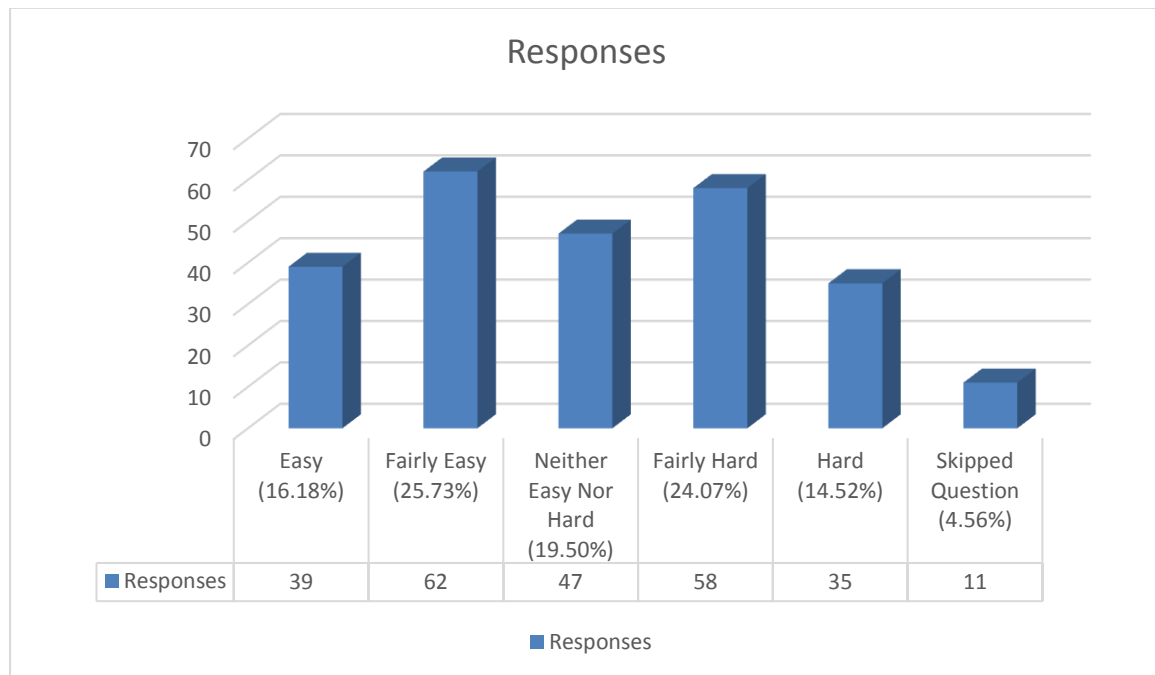
Responses to this question confirms the view of the Legal Services Commission that around 20% of people complete their ACDs online,⁹⁹ with the large majority (81.88%) choosing to download a paper-based version from the website or purchase a copy from Service SA. Of the 91 respondents who skipped the question but wrote in the textbox under 'other', the large majority sourced the form through either their lawyer or the Law Society of South Australia (58 of a total of 91 people, but 23.10% of total respondents). The next most common alternative source of accessing the ACD form (other than through the website of Service SA) was through medical and health practitioners (doctors, nurses, hospitals, GP clinics, employers within the health sector). Others were given forms through training or community groups, financial advisers, Palliative Care SA, a nursing home, a friend or family member. Overall, the largest number of respondents accessed their ACD forms independently using the website to either print the paper-based form, complete the online version or purchase the Kit from Service SA (63.74%). The second largest group (23.10%) accessed the form through either their lawyer or the Law Society, and a much smaller number accessed it through health practitioners, community based organisations, advocacy groups, or other advisors. Clearly the largest and most important sources for accessing the ACD forms is to download the paper-based version from the website (41.83%), or to seek the assistance of the legal profession (23.10%). Given the proportion of people who use the paper-based version, and the number of comments received in submissions describing the lack of space to include all of their desired preferences in each section, the ACD form itself needs to be expanded. As one consumer explained, 'I bought a booklet from Service SA some years ago. I found it did not allow me enough space to detail what I would like to happen as I age.'¹⁰⁰ A principal objective of the Act is to facilitate a person's right to express their preferences, wishes and values with respect to future medical care, accommodation and personal affairs through the completion of an ACD. That so many South Australians are unable to do so using paper based versions of the ACD form means that this objective is not being realised for this group of people. While, future generations are likely to feel more comfortable in using an electronic

⁹⁹ Legal Services Commission, *Consultation*, 7 May 2019.

¹⁰⁰ G Gillen, *Submission 2*.

version of the form, which is able to expand certain sections, South Australia will continue to have significant numbers of people who do not, and that is likely to remain the case for several decades. A recommendation to amend the paper based version of the form is incorporated into the recommendations attached to Term of Reference 2(b).

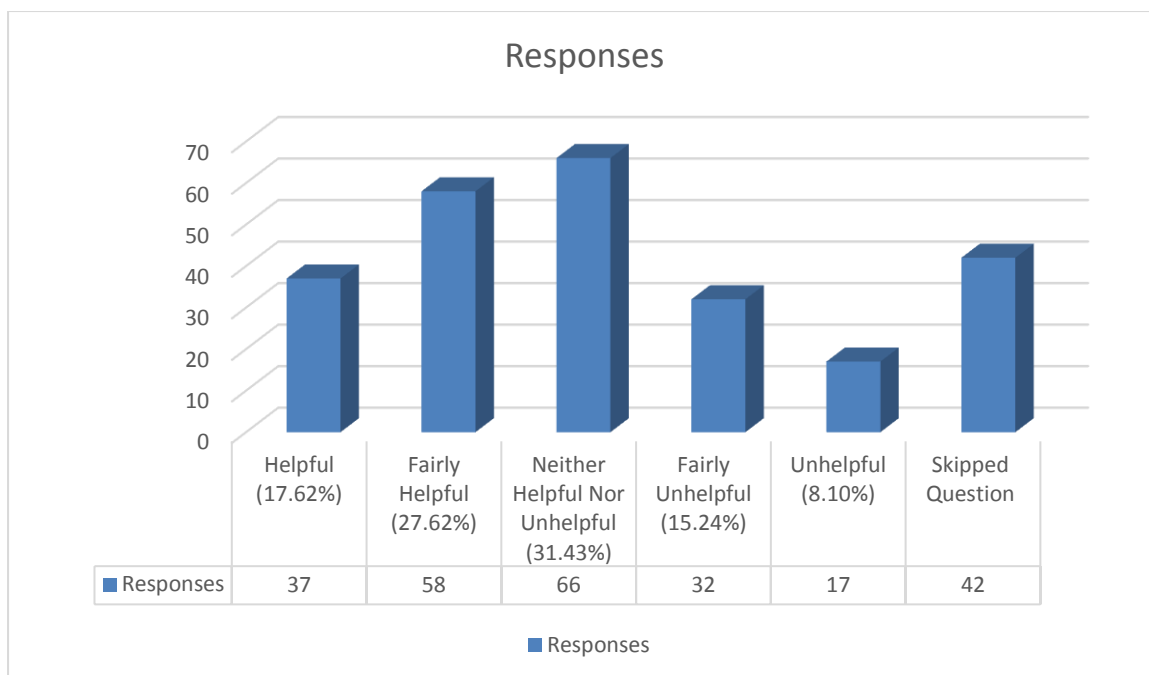
Question 3: How easy or hard was it for you to fill out the ACD form?



A total of 41.91% stated that the ACD form was easy or fairly easy to complete, whereas 19.05% were neutral and 38.59% found it a hard or fairly hard process. This means that almost as many people found completing the form hard as those who said it was easy. These results were not reflected in the results of the HCASA survey results, however, where a total of 69% of respondents rated their experience of using the ACD form as 'extremely good'. Nonetheless, it is very difficult to separate out responses to questions regarding the ACD form, from those related to the Kit, given the tendency of both respondents, those engaged in oral consultations, and those who made written submissions to frequently conflate the experience of using both the form and the Kit.

Question 4: If you used as ACD DIY Kit did you find it was:

- Helpful
- Fairly helpful
- Neither helpful nor unhelpful
- Fairly unhelpful
- Unhelpful



A total of 95 from 210 responses, or 44.24%, found the DIY Kit to be either helpful or fairly helpful in completing their ACD. However, far fewer respondents found it to be unhelpful or fairly unhelpful (23.34%), leaving 31.43% in the neutral category. The number of neutral responses given in the Department’s survey was the highest for this particular question, but the results tend to indicate strongly the need for further work on the Kit in particular. This point was only reinforced in qualitative feedback received throughout the review. The HCASA written submission captures this point:

Consumers responded that they found the ACD generally easy to read however the Kit was far too wordy and was not an easy read given the pages were very text heavy. Consumers indicated that they felt most people would not read through the Kit and may find it difficult to navigate to relevant sections, particularly for people with low health literacy.

Respondents felt that the Form and Kit alone was not adequate for people considering completing an ACD and more education and information needed to be available to consumers and the community including:

- Community information forums;
- Information/resources made more readily available in community settings such as libraries, councils and community centres;
- Health practitioners, particularly GPs, should be better educated to take a more proactive approach to openly initiating and facilitating discussions with consumers/patients about the roles of ACDs, and how to complete them – including assisting them to complete key sections.

Respondents felt that the draft example of the ACD was helpful but suggested that a number of examples be provided that addressed the different circumstances people may be in when they decide to complete an ACD, including taking into account the environments people may choose (including their own home).

Similar sentiments were expressed in many other submissions received.¹⁰¹ Interestingly, the HCASA results indicated that 75% of respondents were happy that the current form enabled them to initiate discussions around their preferences, and 74% felt that they were provided with sufficient information to prepare an ACD, with some specific reservations (discussed below).

Despite these positive responses, overall a strong theme emerged throughout the Review for the need to revise and update the Kit, to reduce its length (which currently exceeds 70 pages) and its complexity. As one anonymous consumer noted, in a view that was shared by many consumers:

I believe that such a directive is essential but that it should be as simple as possible to prepare. The Advance Care Directive system in its present form, while carefully thought through to cover many possibilities, has become unduly complicated.

This sentiment was echoed by many other consumers or groups who work with consumers, including professionals with expertise in ACDs. Margaret Brown, a member of the End of Life Care Board and a long-standing advocate and researcher in the field, stated that, in her view, the Act is not well understood at all and there is considerable confusion in relation to the Kit, including among health professionals.¹⁰² Often, people do not know where to start; the Kit needs a 'very good edit' with attention to both content and formatting.¹⁰³ This view was mirrored in many submissions and was reinforced by experts who had facilitated community workshops on preparing an ACD, as well as consumers who had attended them.¹⁰⁴

The present Kit contains a number of example (or sample) fictitious completed ACDs and, for many people, these have been very helpful. The Legal Services Commission stated that the sample contained within the Kit can be very helpful in educating people about the sort of statements to include in an ACD. Others raised some concerns about the usefulness and/or accuracy.¹⁰⁵ Many clinicians also expressed their concern about the inclusion of generic statements in an ACD that are often not properly understood unless a person has sufficient medical and health literacy, or has consulted with a medically trained person.¹⁰⁶ This issue is considered in greater detail below.

The review also generated a significant number of written submissions from lawyers, both individually and through the Law Society, with the majority of submissions tending to raise the same concerns (some of which are addressed more specifically under other Terms of Reference). In a letter from the Society, the following points were made in relation to the Kit:¹⁰⁷

Members who practice in this area are frequently approached by clients seeking assistance to complete these documents because they find them confusing and too lengthy. For example, the Society is informed by its Members who practice in this area that many people are confused as to what should be contained in a will as opposed to an ACD with respect to dying

¹⁰¹ Legal Services Commission, *Consultation*, 7 May 2019; S Jarrad, *Submission 32*; Fleurieu Volunteers and Justices of the Peace, *Consultation*, 13 May, Health Consumers Alliance South Australia, *Submission 35*; W Bonython & B Arnold, *Submission 17*.

¹⁰² End of Life Care Board, *Consultation*, 13 May 2019; M Brown, *Consultation*, 12 June 2019.

¹⁰³ Ibid.

¹⁰⁴ F Johnston, *Submission 16*; S Bradley, *Consultation*, 10 May 2019; Victor Harbor Volunteers and Justices of the Peace, *Consultation*, 13 May 2019; Barossa ACD Service, *Consultation*, 20 May 2019.

¹⁰⁵ S Jarrad, *Submission 32*; W Bonython and B Arnold, *Submission 17*.

¹⁰⁶ Dr J Morton, *Submission 20*.

¹⁰⁷ Law Society of South Australia, *Submission 27*.

wishes. This could result in testamentary wishes not being carried out as they are not contained in the will.

The Society remains of the view that the kit is over-engineered, and that a more practical approach is required.

Another lawyer wrote that his experience with clients is that ‘the process is far more overwhelming now than it used to be with Powers of Guardianship. I have found that clients find the ACD form to be ‘busy’, poorly laid out, overly wordy, somewhat esoteric and confusing.’¹⁰⁸

In contrast, many submissions highlighted the variability in the quality and clarity contained within ACDs prepared by lawyers.¹⁰⁹ In many comments received during the review, there were (and, in some case, still are) practices where an ACD form appoints SDMs but contains little if any directions regarding medical treatment, accommodation or personal matters. Clinicians and other health practitioners repeatedly emphasised the futility of such ACDs, including the inability of SDMs to have any sense of the preferences or wishes of the person concerned. Indeed, such ACDs are not only ineffective for the people creating them, they directly go against the intent of the legislation itself. In this respect, the Act was designed to prevent situations where the wishes of a person became drowned out by disputes between family members or between SDMs and clinicians at critical times. The Act was instead designed to empower individuals to outline their own wishes, preferences and values in advance of losing decision making capacity, to force SDMs to ‘stand in the shoes’ of the donor as opposed to having family members make decisions that were arguable in ‘the best interest’ of the donor, but not necessarily consistently with the preferences of the person concerned. It was also an intention of the Act to enable people to refuse medical treatment or intervention that would not enhance the quality of life for someone, and to enable clinicians to legally cease medical intervention – consistent with a patient’s legally binding wishes – even where it may hasten a person’s death. Underpinning these fundamental premises of the Act is both the empowerment of people prior to losing capacity, together with an unreserved desire to avoid the necessity for people to seek the advice of either doctors or lawyers in expressing personal preferences in a legally binding document. While there are unquestionably practical issues involved with giving effect to these premises – both legal and medical – the Review unearthed no appetite for interfering with, or removing, the capacity for individuals to complete an ACD without needing to seek advice from either doctors or lawyers.

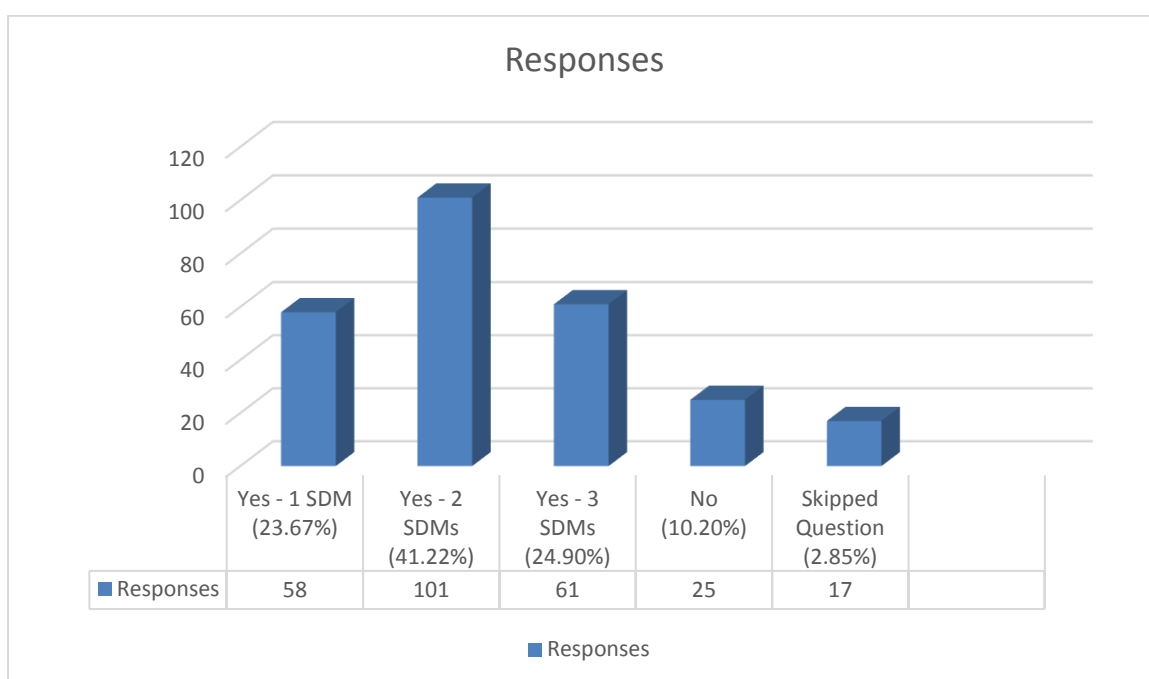
Notwithstanding this, while the Act’s objectives are seen as extremely important by consumers and others, there are barriers which remain that have the effect of reducing the take-up rates of ACDs within the community. While the forms are accessible both electronically and in paper form, the Kit itself is overly long, complex and difficult for consumers to engage with. Finally, while the examples provided in the Kit are treated as very helpful to many, a range of additional examples would offer further assistance in this regard. In particular, sample wording for commonly included statements could draw from the list developed by the Barossa’s ACD Volunteer Group, as well as other key stakeholders and expert groups.

¹⁰⁸ T Sheridan, Ezra Legal, *Submission 19*.

¹⁰⁹ Office of the Public Advocate, *Consultation*, 10 May 2019; Victor Harbor Volunteers and Justices of the Peace, *Consultation*, 13 May 2019; Barossa ACD Service, *Consultation*, 20 May; Office of the Public Advocate, *Submission 33*.

Question 5: When you completed your ACD did you appoint one or more substitute decision makers:

- Yes I appointed 1 supported decision maker
- Yes I appointed 2 supported decision makers
- Yes I appointed 3 decision makers
- No I did not appoint any substitute decision makers



By far, the largest group of respondents appointed 2 SDMs (41.22%), followed by the appointment of either 3 or 1. Only 10.50% of respondents did not appoint any SDMs and a very small number failed to answer the question. Qualitative feedback through oral consultations and written submissions – particularly from lawyers – highlighted the limiting nature of the form in reducing the number of SDMs to a maximum of 3.¹¹⁰ This was also a point raised by some consumers and Justices of the Peace. The most common reason for this related to clients who had more than 3 children and the parent did not want to exclude one of their children. Another related to circumstances where a person wished to appoint their spouse followed by their children as alternatives, but where the immediate family included more than 3 people. One JP, who was also a member of the Victor Harbor ACD Advisory Group had completed her ACD and discussed its contents with her children but, having 4 children she refused to execute the document as she was extremely reluctant to exclude one of her children over the other three.

¹¹⁰ Law Society of South Australia, *Submission 27*; A Michaels MP, *Submission 18*.

A further issue raised by several lawyers around the appointment of SDMs related to the issue of whether SDMs could be appointed either jointly and severally, and whether individuals could have a tiered approach to appointing SDMs:

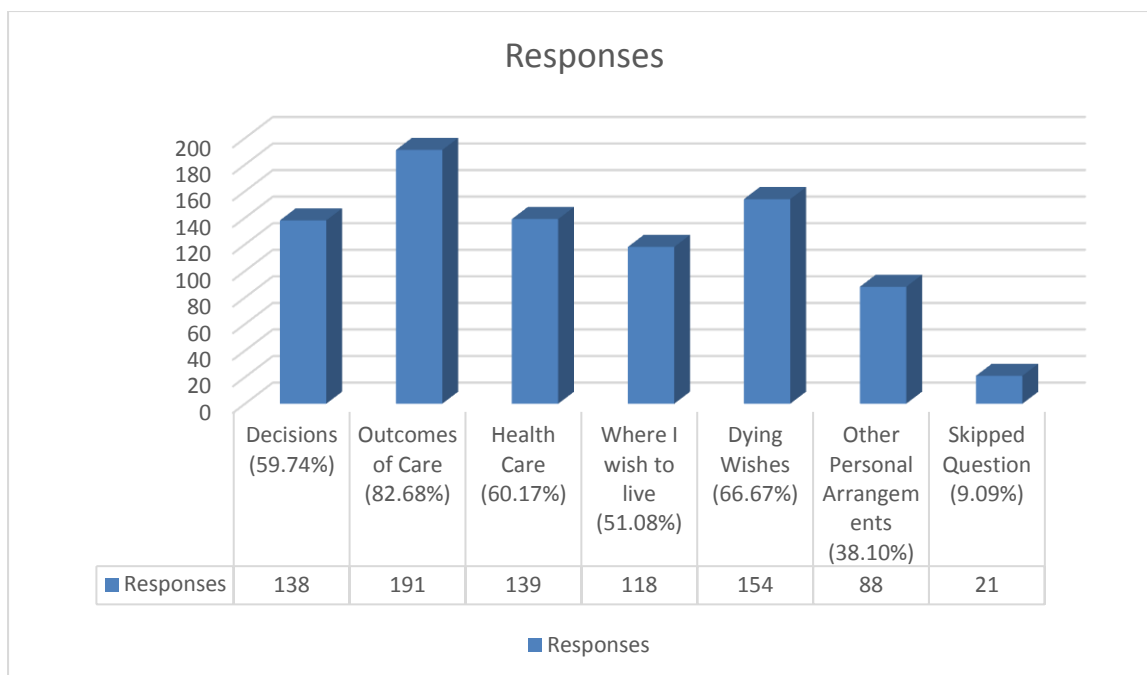
From a solicitor's point of view, the suggested options of appointing SDMs either together or separately, with there being no option to appoint one or more SDM first and then others in substitution, is impractical and often does not accord with the client's wishes. As a result, we have to draft the client's wishes in the Conditions of Appointment panel, which I assume will ultimately be more confusing for a medical practitioner than clearly laid out conditions.

Tom Sheridan, Ezra Legal.

If one of the core objects of the Act is to enable competent adults to allow decisions about their future health care, accommodation arrangements and personal affairs to be made by an SDM on their behalf, then limiting appointments to only 3 SDMs directly undermines that. Accordingly, change is necessary to the gazetted Form. While this is recognised here as a barrier to meeting the objects of the Act, it is one of several recommendations to the form and is thus incorporated into the discussion relevant to Terms of Reference 2(b) and 2(d)(i) below.

Question 6: In Part 3 of the ACD form - 'what is important to me – my values and wishes' - there are 6 areas the document suggests for you to consider when decisions are being made for you. Which of these things did you consider and include in your ACD?

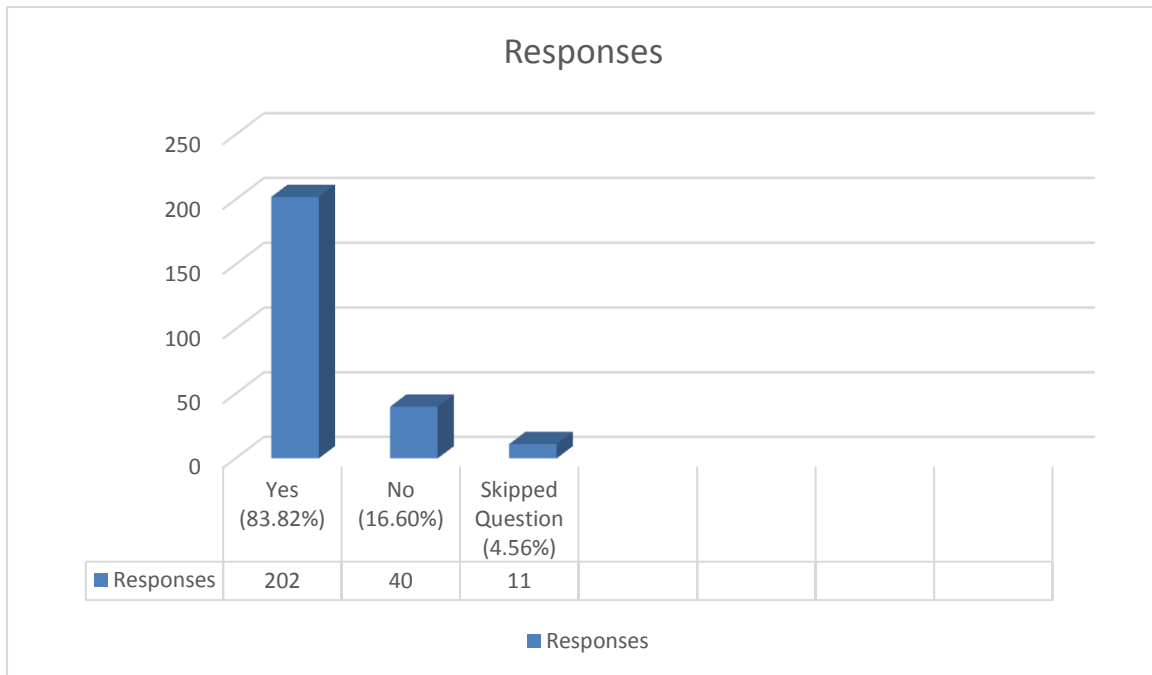
- **When decisions are being made for me I want people to consider the following**
- **Outcomes of care I wish to avoid (what I don't want to happen to me)**
- **Health care I prefer**
- **Where I wish to live**
- **My dying wishes**
- **Other personal arrangements**



The most common instructions provided by respondent related to preferences regarding the outcomes of care (82.68%), followed by dying wishes (66.67%), health care (60.17%) and when decisions are being made by an SDM (59.74%). The least common instructions related to other personal arrangements but, even here, respondents completed this section in 38.10% of cases which reflects a relatively high proportion of ACDs completed. Throughout both oral consultations and in written submissions we repeatedly heard comments from a variety of stakeholders that ACDs prepared by lawyers would often include the appointment of SDMs, but would give little if any guidance on a person’s preferences, values or wishes with respect to medical treatment, end of life, accommodation or personal preferences. For clinicians and other health practitioners, such ACDs offer little meaningful assistance to either doctors or SDMs. An additional comment that was repeatedly raised throughout the consultation was the use of vague or indeterminate words and phrases in ACDs. These issues raise the challenges of preparing ACDs without the expertise or support of either lawyers or medical experts – neither of which is required to complete a valid ACD and goes directly against the objectives of the Act. However, both are important factors which can significantly impact the efficacy of an ACD at the point of activation when a person loses capacity to make their own decisions. Consequently, both are examined in further detail below, but, not in the context of realising the objects of the Act; they relate more to practicals changes which may facilitate a higher adoption rate of ACDs, as well as the improved implementation of them by clinicians at the critical stage where an ACD is activated.

Question 7: Part 4 of the ACD form allows you to fill out a section titled ‘binding refusals of health care’. In this part you can state what health care you do not want and the circumstances in which your refusal will apply. Did you fill out this section?

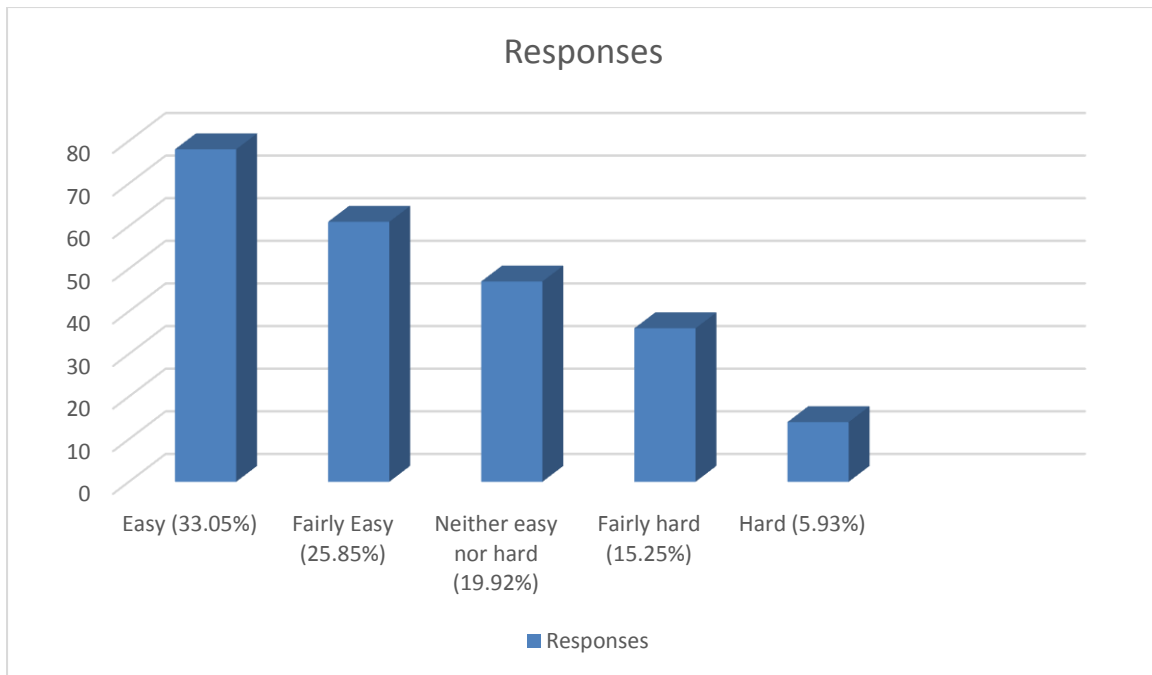
- Yes
- No



Based on the 242 responses to this question, the significant majority of people (83.82%) choose to include a binding refusal of health care in their ACD. However, it is difficult to assess the level of clarity offered in such sections as well as the level of assistance provided to clinicians through the inclusion of these instructions. Feedback at oral consultations with each of the Local Health Networks (LHNs) tended to show that the quality of guidance provided to clinicians is quite variable between ACDs, and generic statements such as ‘not for resuscitation’ can be decidedly unhelpful for both SDMs and medical practitioners.

Question 8: Once you have completed you ACD it must be signed and witnessed. How hard or easy was it for you to find a witness?

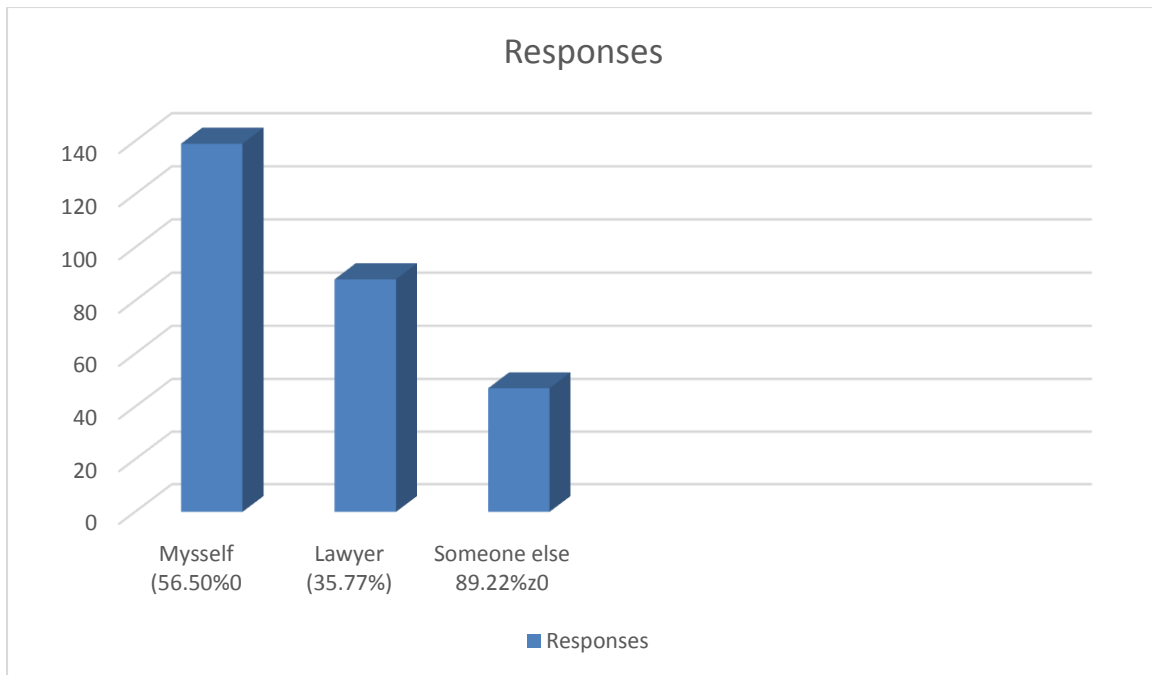
- Easy
- Fairly easy
- Neither easy nor hard
- Fairly hard
- Hard



Responses to this question were overwhelmingly positive with a total of 58.90% of respondents stating that the process of finding a witness was either easy or fairly easy. Just over 21% of respondents found it hard or fairly hard. As there were no comments permitted in relation to this question, it is difficult to determine whether the latter categories were in regional or remote areas of South Australia, or if mobility or physical issues acted as an impediment for those who found it hard to access a witness.

Question 9: Did you complete your ACD yourself, or did you have a lawyer or someone else complete it?

- I completed my ACD myself
- A lawyer completed my ACD
- Someone else completed my ACD for me



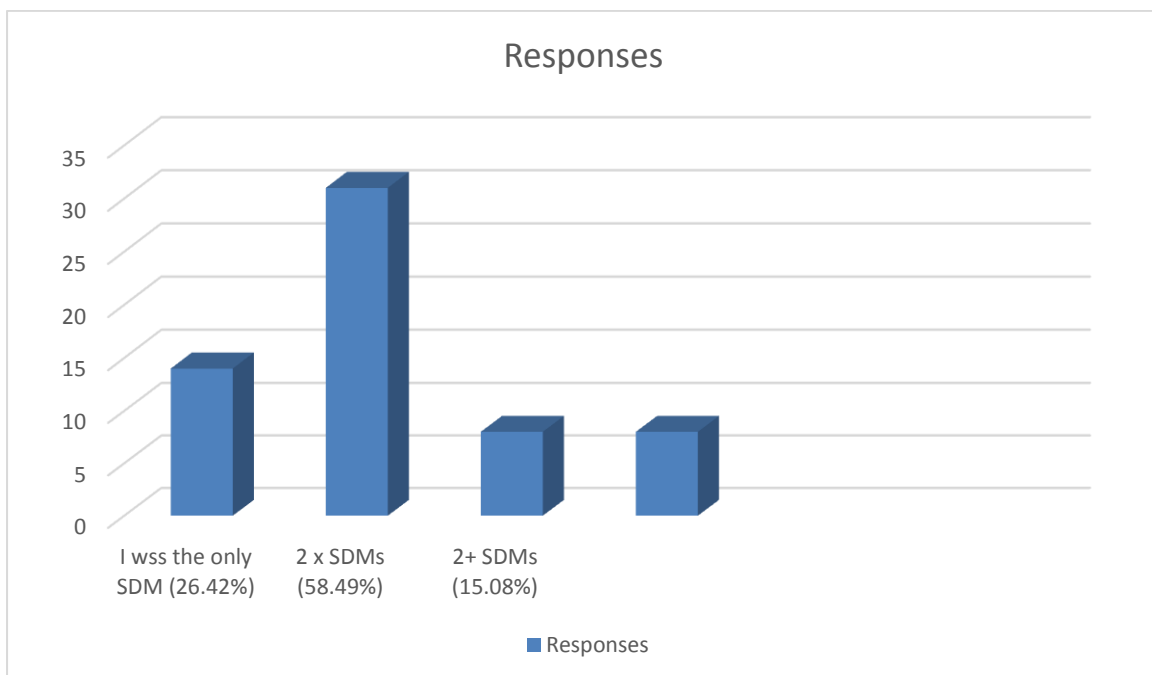
Clearly, the largest number of people are completing ACDs on their own but, with a significant proportion using lawyers to finalise their ACDs. There are a range of reasons why this would be the case: lawyers are responsible for doing estate planning (wills and PoAs, which invariably includes ACDs, where appropriate); and lawyers are often the first professional (other than medical specialists) that a person speaks with following a terminal diagnosis or where surgery is pending.

APPENDIX B

Supported Decision Maker Survey Responses

Question 1: When you were appointed as a substitute decision maker, how many other people, if any, were also appointed?

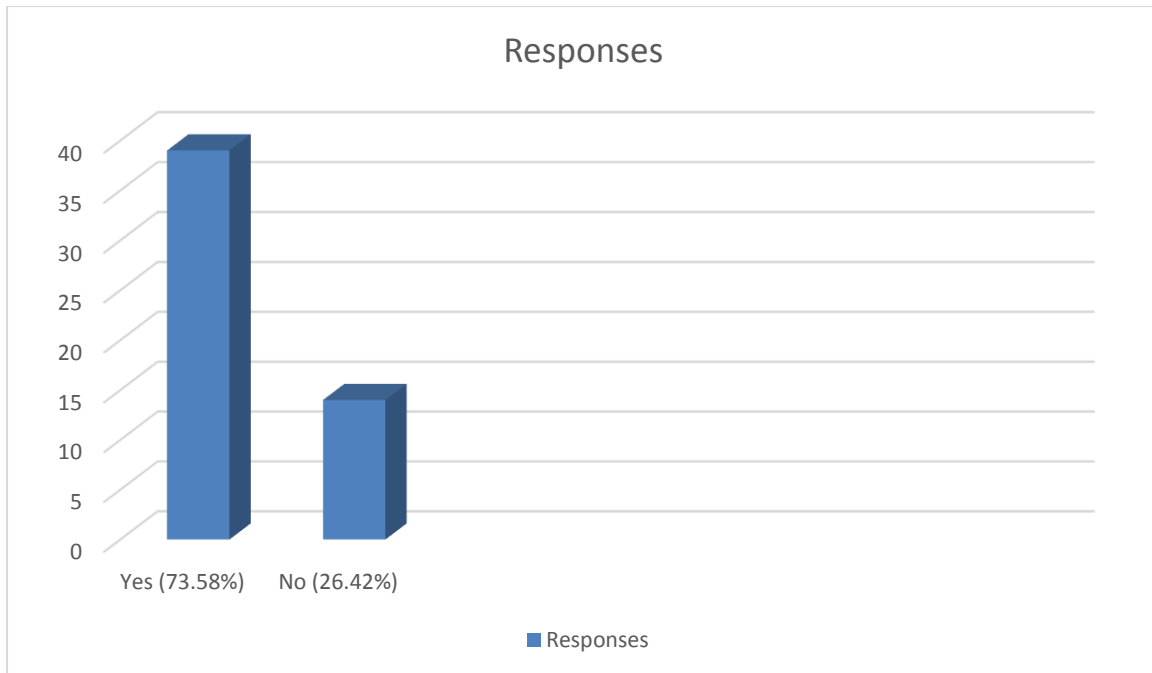
- I was the only SDM appointed
- One other person was appointed as a SDM
- Two other people were appointed as SDMs



Clearly the majority of individuals appoint 2 SDMs (58.49%), followed by 1 SDM (26.42%). While just over 15% appoint 3 SDMs, the Review revealed that some people are not properly executing their ACDs by virtue of the form not permitting more than 3 appointments.

Question 2: Did the person who appointed you as a substitute decision maker talk to you about how they wanted you to make decisions on their behalf?

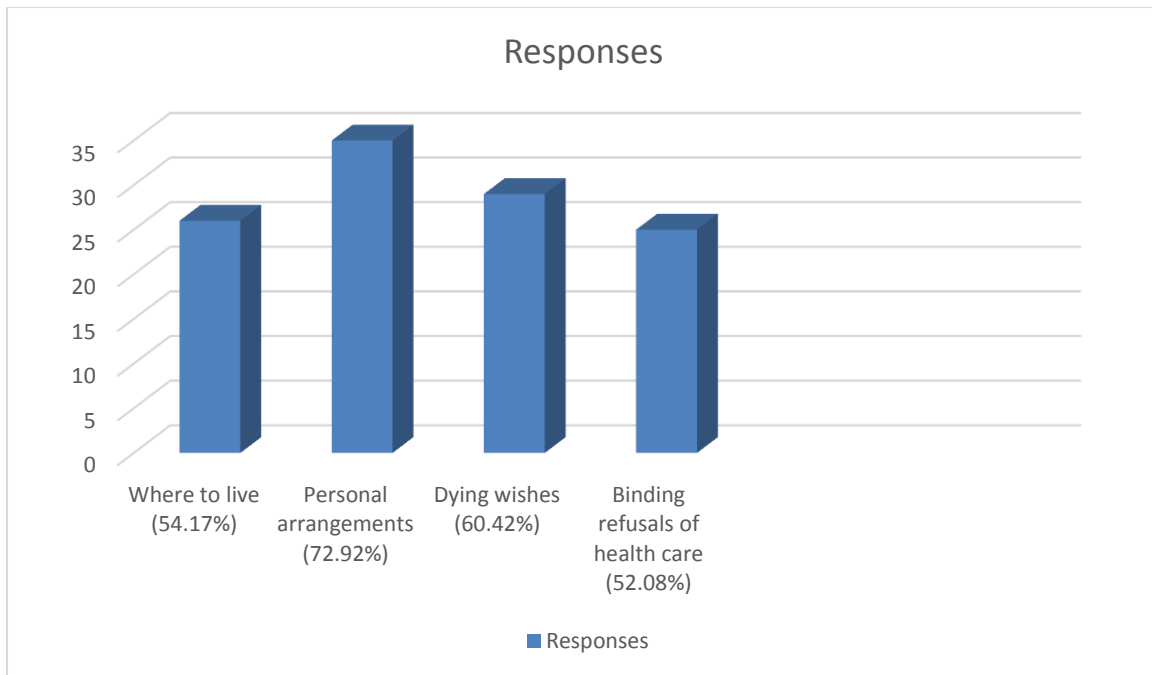
- Yes, they spoke to me about how they wanted me to make decision
- No, they didn't tell me how they wanted me to make decisions



The high percentage of people who speak with their SDMs regarding their preferences, wishes and values with regard to medical treatment, accommodation and personal matters is high at 73.58%. However, the fact that more than one quarter do not have a conversation regarding how they wish their SDMs to make decisions on their behalf is a concern. Responses to this question show the need for increased education and awareness raising within the community. It is also another reason why the order of signing an ACD should not be changed, as people are encouraged to have a conversation with their SDMs prior to finalising the document.

Question 3: When the person who gave the ACD could no longer make their own decisions, or could not make decisions at specific times, did you make decisions on their behalf about:

- Where the person was to live
- Other personal arrangements
- Dying wishes
- Binding refusals of health care



Responses to this question show that the most common decisions required to be made by SDMs relate to personal arrangements (72.92%), where a person would prefer to live (54.17%), dying wishes (60.42%), with binding refusals of health care decisions the least common at 52.08%.

Question 4: In regard to decisions about living arrangements, how easy or hard was it to have your decisions about the person concerned put into action?

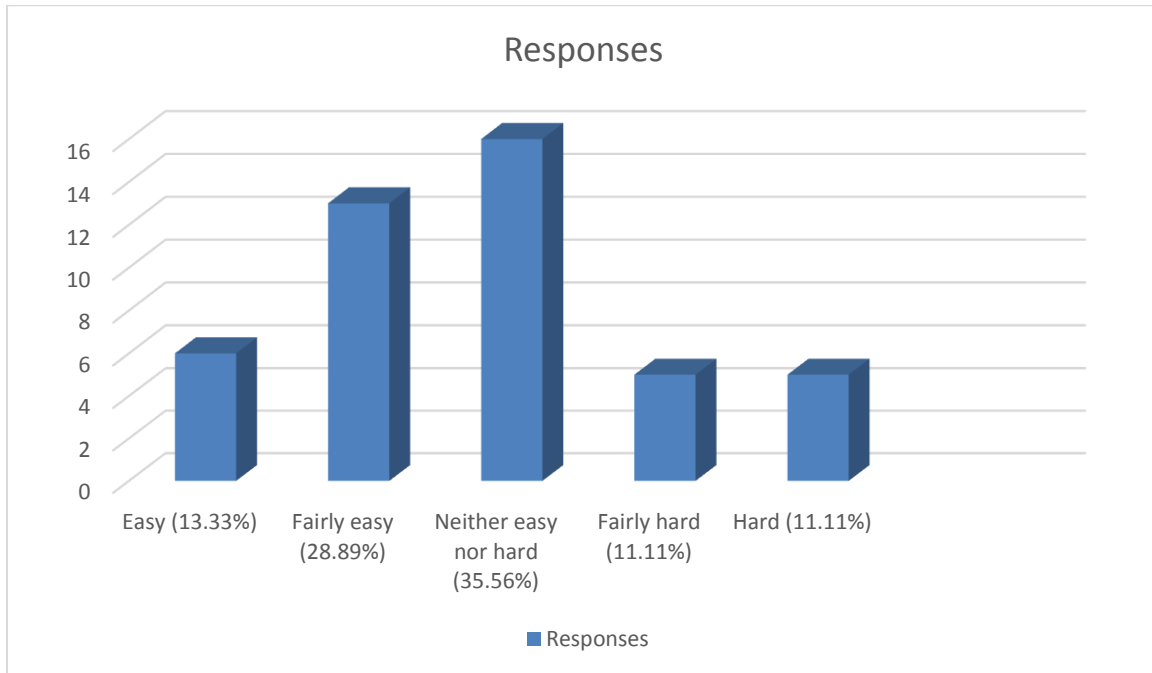
- Easy
- Fairly easy
- Neither easy nor hard
- Fairly hard
- Hard



The results for this question show that giving effect to a person's preferences about where they would prefer to live can be quite mixed. While approximately 1/3 of SDMs found it fairly easy to do so, slightly more than 1/3 were neutral and almost another third found it to be fairly hard or hard. The almost equal split in responses may well indicate that future survey questions should permit open comments so that SDMs are able to provide reasons as to why something was hard or easy. For example, the person who completed the ACD may have medical or other reasons why their preferences are not able to be accommodated with respect to where they would prefer to live, or there could well be other intervening circumstances which may make their preferred living arrangements no longer suitable.

Question 5: In regard to other personal arrangements for the person, such as their grooming and clothing preferences, preferred daily routines etc, how easy or hard was it to have your decisions about the person concerned put into action?

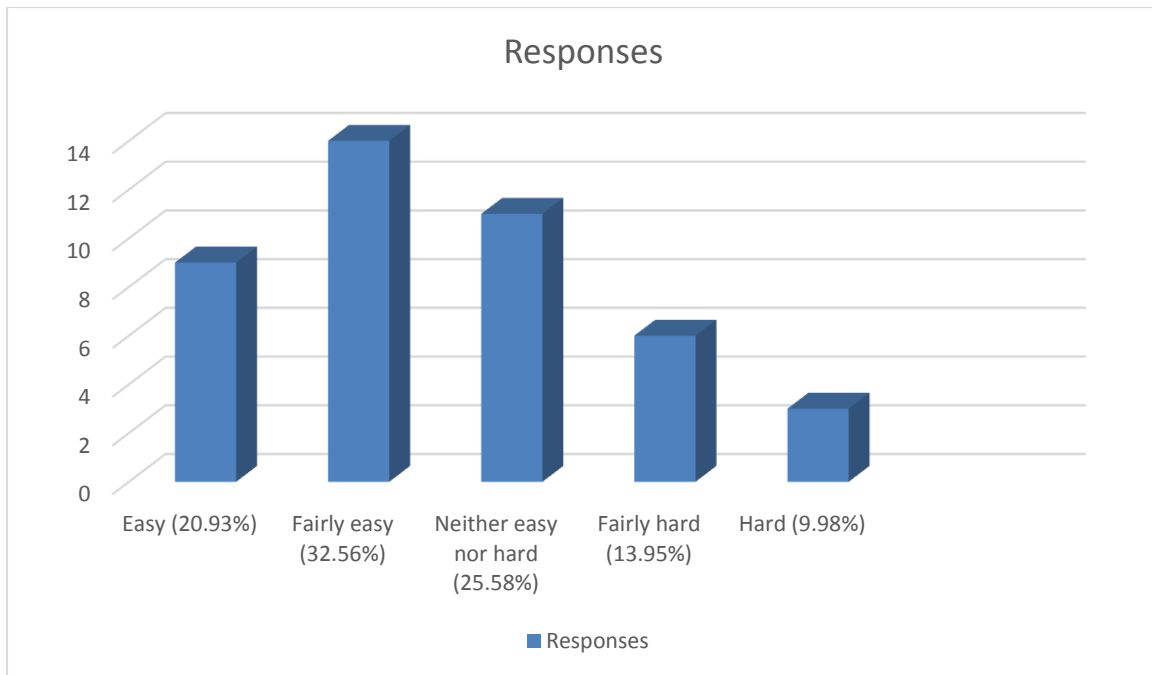
- Easy
- Fairly easy
- Neither easy nor hard
- Fairly hard
- Hard



The responses to this question indicate that few SDMs experience difficulty in ensuring that a person's preferences with respect to personal matters are followed.

Question 6: If the person had indicated what their dying wishes were, how easy or hard was it to have their wishes put into action?

- Easy
- Fairly easy
- Neither easy nor hard
- Fairly hard
- Hard



Responses to this questions were very similar to those for personal matters, indicating that less than a quarter of SDMs found it hard or fairly hard to give effect to someone’s dying wishes. Again, however, as no comments were permitted, it is impossible to determine why SDMs found it hard to follow a person’s dying wishes.

Question 7: If the person had stated that there were certain types of health care that they did not want (a binding refusal of health care), and the circumstances in which they did not want the health care, how easy or hard was it for your refusal of this health care to be accepted by health practitioners?

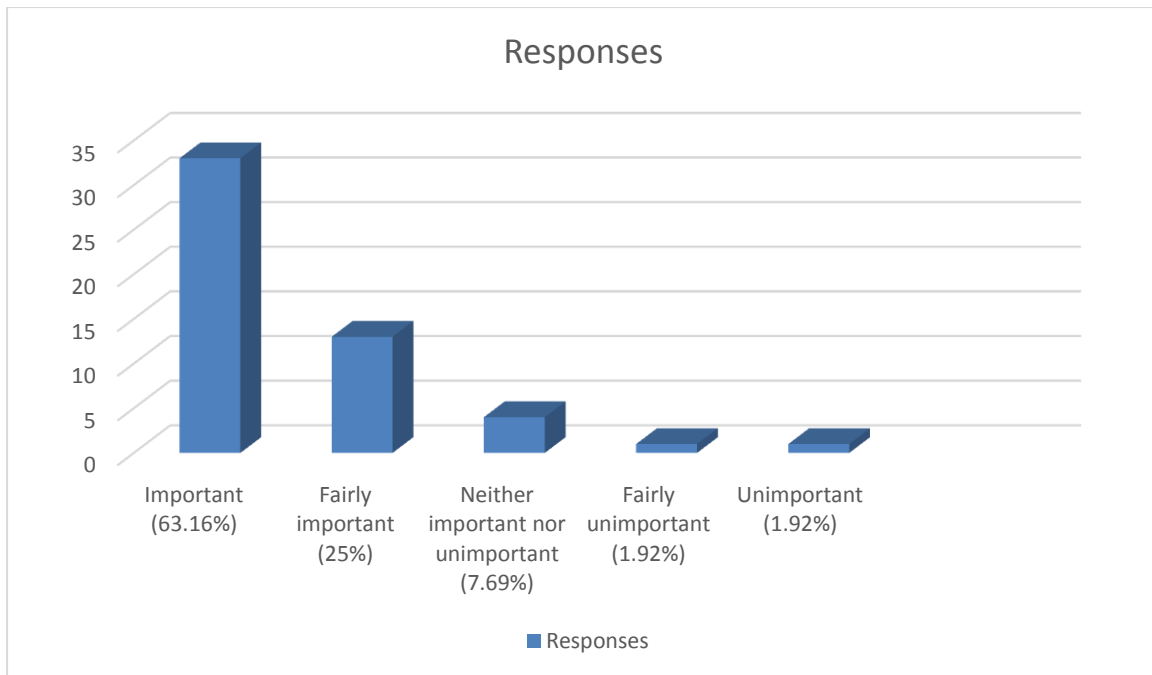
- Easy
- Fairly easy
- Neither easy nor hard
- Fairly hard
- Hard



Binding refusals of health care can be among the more difficult decisions for SDMs, but it is pleasing to see that approximately 45% of respondents found it either easy or fairly easy to implement a person’s preferences. That more than one quarter found such decisions hard or fairly hard is a concern. However, without qualitative data, it can be difficult to extrapolate from that figure. Future survey questions with regard to binding refusals of health should enable respondents to provide additional information when answering such questions.

Question 8: How important do you think it is that the person giving the ACD talks to the substitute decision maker about how they want decisions made and what is most important to them?

- Very important
- Fairly important
- Neither important nor unimportant
- Fairly unimportant
- Unimportant



Responses to this question showed overwhelmingly (over 88%) that SDMs feel it to be important that the person making the ACD discusses with their SDMs how they want decisions made on their behalf and what is most important to the person. This also emphasises the need for conversations to take place prior to an SDM accepting their appointment.

These results were also reinforced in the HCASA survey results where 75% of respondents agreed that the ACD form enabled them to discuss their preferences with SDMs. HCASA emphasised the importance of using the process of initiating discussions and conversations, and being able to specify a ‘ceiling or care’. One person stated, however, that the current form does not encourage younger persons to complete an ACD, when every adult is entitled to complete an ACD.

Email Feedback Received by the Department between 2014 and 2019

Among the most common negative comments were references to the point that neither the Guide nor the Form were helpful or easy to complete. Other concerns related to the lack of a Form in a particular language (ie, Polish), the lack of access to a word based version of the Form (as opposed to a PDF) and the fact that the automated time out of the website made it difficult for people who were not very computer literate. A sample of some of the more substantive comments are below:

I understand that if I want to change my ACD I have to cancel my existing one. Firstly, there is no provision in the form for including the version of the ACD that I want to cancel. How would anyone know which version I was cancelling, they may think it is the current one. Secondly, who do I give the form to? Is there a repository where copies of ACDs and the forms cancelling them are stored for future reference? If that is not the case then what is the point? ... Generally I find the ACD form is repetitive which makes it difficult to complete ... Apart from all the stuff about the medical treatment I will and won't accept I have some other very specific needs which are hard to articulate in this format. I have chemical sensitivity my biggest dread is being placed in an environment that is making me unwell but my carers are oblivious to this as I am unable to communicate.

Female, 2018.

I found some of the examples lacked strength – Section 4. I was looking for more specific statements which I eventually found in the superseded form 'Anticipatory Direction'.

Female, 2016.

The on line form needs to be improved. The time out period is far too short and puts unnecessary pressure on the person filling out the form. We should be concentrating on our needs not on you electronic system.

Male, 2016.

I found the online form impossible. It kept trying to 'time out', you cannot save and close partway through and then return to the form. The form in general has no flexibility in the space allocated to each section and there is a lot of potential for overlap of information eg 'outcomes I wish to avoid' and 'my dying wished' etc. Basically your wishes have to fit into the headings provided and the space provided!! Also nowhere in the information provided is there a clear statement of how incapacity to make decisions will be decided. Much messier approach than the old pre July 2014 system of Medical Power of Attorney and Enduring Power of Guardianship.

Female, 2016.

I have moved from Queensland to SA and found that the Qld form is much clearer, more legally precise and logical ... I understand that SA was the first state to introduce such a form and Qld was the last state. This meant that they had the advantage of correcting loose errors of the forms than other states. Nevertheless, I finally managed to include the important items of the Qld form in yours.

Male, 2016.

Having seen the NSW very comprehensive equivalent I thought the suggestions in the booklet were totally inadequate. I don't think they were much use for thinking comprehensively around such an important topic. I drafted out my own directive based slightly on the booklet but mostly on the experience of friends and the NSW form and lateral thinking. Had I used the booklet rather than doing it online (I tried) I found that there was far too little space in the 2nd and 3rd sections for anything other than a few instructions.

Female, 2016.

In relation to survey responses containing suggestions for improvement, many related to increasing the window boxes for the completion of each section and the difficulties encountered when trying to print out drafts or being able to review the contents of each sections. Other respondents wanted additional examples for possible wording that what was available in the DIY kit. A sample of suggestions for improvement are provided below:

The need to respond to the box about 'continuing' is somewhat distracting when you are trying to think of the words you want to use and the box pops up. A little more time on this would be useful ... Having downloaded and completed the form and sent it to print, it was rather disconcerting to see that the content prints larger than an A4 page can accommodate. The bottom of each page is cut off half way through the witness box and the page numbers do not show. I understand that this invalidates the form as the document is incomplete.

Male, 2019.

There are too many pages. It needs condensing.

Female, 2018.

There was almost too much information on content. More information is needed at the start of the online form about how the website works. I found myself losing the plot as the page kept refreshing before I had finished. Eventually I made a text file, then copied onto the form section by section. The fact that the form is converted to PDF when completed should be available at the start also, the limit on characters, and number of characters on each line. It took me a while to work it all out.

Female, 2017.

It should be made more explicit in a few locations that the ACD intention is to focus on 3 areas being – recording the wishes/values of a person for medical, residential and lifestyle (not just medical).

Female, 2016.

According to the Legal Services Commission, only about 20% of people complete their ACD using the online Form and, in 2018, the number of downloads exceeded 20,000. Given that the Department has received overwhelmingly positive feedback and less than 250 survey responses in total, one can safely deduce that some of the early teething problems experienced by consumers with the online Form were addressed. A review of responses received in 2018 and 2019 were almost universally positive, with the majority of respondents commenting that the form was 'easy' to use and complete.

APPENDIX C

Written Submissions Received

NUMBER	STAKEHOLDER GROUP	NAME
1	Evans Tester Barristers and Solicitors	Phil Testa
2	Individual	Geraldine Gillen
3	Wills on Wheels	Catherine Moyse
4	White and White Lawyers	W. Paul White
5	Baggiolegal	Andrew Baggio
6	Teusner & Company (Lawyers)	Brenton Miegel
7	Commissioner for Affidavits	Jo Mercer
8	Belperio Clark Lawyers	Charlie Belperio
9	VdVLegal	Julie Van der Velde
10	Wearing Law	Karin Harris
11	Advance care Planning Australia	Linda Nolte
12	Individual	Kylie Hvalica
13	Individual	Elaine Ashworth
14	Individual	Macy Sweet
15	Mobile Wills Service	Grant Edwards
16	Individual	Fiona Johnston
17	School of Law Bond University and University of Canberra	Wendy Bonython and Bruce Arnold
18	Electorate Office	Andrea Michaels MP
19	Ezra Legal	Tom Sheridan
20	Respiratory Physician SA Health	Dr Judith Morton
21	Individual	RV Scarborough
22	Individual/COTA	Peter Mussared
23	SA Health-FMC	Steven Galluccio
24	White & White Lawyers	Paul White
25	Miga	Timothy Bowen
26	University of Adelaide	Tanya Zivcovic
27	The Law Society of South Australia	Dr Anna Finizio
28	Individual	Diana Waters
29	Fleurieu Justices Group	Chris McRae
30	Australia and New Zealand Society of Geriatric Medicine	Ayesha Mohamed
31	NALHN Social Work	Marion Champion
32	Individual	Sue Jarrad
33	Office of the Public Advocate	Elly Nitschke
34	NAHLN	Rebecca Horgan
35	Health Consumers Alliance of SA	Julia Overton
36	Individual	Margaret Brown
37	Torrens University	Heather Allanson

1. y one of the sons, noting the shift in Australian law towards enabling persons with