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Public knowledge, preferences and experiences about medical substitute decision-making: a national cross-sectional survey

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ABSTRACT

Objective To describe the Australian adult public's knowledge and experiences regarding substitute decision-making for medical decisions and their preferences for obtaining information about the substitute decision-maker (SDM) role.

Methods This is a national cross-sectional online survey of the Australian adult public. The survey examined participants' advance care planning (ACP) awareness and experience, SDM experiences and preferences for obtaining more information about SDM, and participant knowledge about SDM.

Results Of 1586 people who opened the survey, 1120 (70.6%) were included in the final sample. 13% (n=142) of participants indicated they had acted as an SDM. A median score of two correct responses out of five showed low to moderate knowledge about the SDM role among all participants, with only 33% reporting awareness of SDM laws existing in Australia. While most (59%) participants ranked a health professional as their preferred source of obtaining information about supporting SDMs, few participants who had been an SDM (n=64, 45%) reported obtaining any support in making medical decisions. The median SDM knowledge scores for people who had discussed ACP (3.0 vs 2.0, U=1 45 222, z=6.910, p<0.001), documented their ACP preferences (3.0 vs 2.0, U=71 984, z=4.087, p<0.001) or acted in the SDM role (3.0 vs 2.0, U=56 353, z=-3.694, p<0.001) were significantly higher compared with those who had not.

Conclusions The Australian public may have low to moderate knowledge about the SDM role and access only minimal support when making challenging medical decisions.

Key messages

What was already known?

- A healthcare substitute decision-maker (SDM) is a person who has legal power to make medical decisions on another's behalf if they are unable to make these decisions for themselves.
- The role of SDMs for medical decisions is very significant as decisions about healthcare can include consenting to, withholding and/or withdrawing life-sustaining treatment.

What are the new findings?

- Few (13%) members of the Australian adult public had acted in the SDM role, and low to moderate knowledge about the SDM role was observed overall, with only 33% of participants reporting knowledge that SDM laws existed in Australia.
- Of those who had acted in the SDM role, challenges about knowing the best decision to make and making decisions about end of life were the most frequently reported, but only a minority of participants indicated they had obtained any support in the SDM role.

What is their significance?

- The Australian community's ability to appoint an SDM, and for the SDM to act appropriately, depends on awareness of the requirements of these roles, however, the low to moderate knowledge of the SDM role observed in this study suggests this may be problematic.
- The findings also indicate a potential need to develop resources addressing the types of challenges SDMs are likely to encounter, and for this content be delivered in ways that are preferable for potential SDMs.

INTRODUCTION

In high-income Western countries, there has been increasing recognition that

end-of-life care is suboptimal.^{1,2} Simultaneously, there has been greater emphasis on autonomy (the right to make one's own decisions)^{3–5} and informed consent in the ethical and legal discourse,⁶ representing a shift away from medical paternalism in healthcare delivery.⁷ One of the main issues identified is that preferences about end-of-life care for people (including those at high risk of dying) are often unknown. This often leaves substitute decision-makers (SDMs) to make difficult end-of-life decisions on the person's behalf⁸ and tends to result in more intensive treatments than the person would have otherwise wanted.⁹

In general, a healthcare SDM refers to a person who has legal power to make medical decisions on another's behalf if they are unable to make these decisions for themselves.¹⁰ Laws which facilitate medical decision-making by SDMs are common internationally, including, for example, in North America,¹¹ Europe¹² and the Asia Pacific region.¹³ However, the terminology and legal standing of SDMs vary depending on local legislation (eg, surrogate or proxy decision-maker). In Australia, SDMs can be nominated by the person within an advance care directive, appointed by a tribunal or assigned by laws that make provisions for a hierarchy of persons who would undertake this role when no one has been appointed.¹⁴ The role of SDMs in medical decisions is very significant as decisions about healthcare could include consenting to, withholding and/or withdrawing life-sustaining treatment.¹⁵

In addition to the existence of legislative frameworks relating to SDMs, interventions such as advance care planning (ACP)^{8,16} can educate and prepare SDMs and help to clarify the person's goals and values to inform future decision-making.¹⁷ Yet, despite potential benefits, uptake of ACP is low in Australia^{18–20} and internationally²¹ and the role of SDM remains a challenging experience.^{22–25} Difficulties can arise when the SDM's values do not align with the preferences of the person for whom they are making decisions,^{23,26,27} if there is disagreement between the SDM and health professionals,¹⁷ or other family members or supporters,²³ or when the SDM feels uncertain making decisions that best reflect the preferences and values of the person.²⁸ This uncertainty is further demonstrated in studies that show only modest rates of concordance between end-of-life decisions made by SDMs and the preferences of the person for whom they are making decisions.²⁹

Few studies have attempted to describe the general public's knowledge, preferences and experiences regarding the SDM role. A 2016 Australian study involving participants from the three most populous Australian states examined community awareness and knowledge of the laws relating to end-of-life care.³⁰ This showed that although 19% had experience of making end-of-life decisions for others and 12% had formally appointed an SDM, almost half of the sample lacked required knowledge regarding SDM legislation. In addition, a recent national survey of Canadians

examining preparedness to act as an SDM showed that while 25% of the sample had previous experience as an SDM and 71% believed they would have to act as an SDM in the future, 62% believed they understood the SDM role and only 53% felt prepared to be an SDM.³¹

The authors are not aware of additional similar studies exploring the general public's knowledge and preparedness for the SDM role. However, observational studies from the USA suggest being an SDM is associated with elevated levels of anxiety and depression in some people³² and that a person's confidence to be an SDM varies substantially, with people who have previous SDM experience or greater communication with the patient's doctor demonstrating increased confidence levels compared with those who do not.³³ Yet it may not be common for health professionals to provide guidance to SDMs in practice, such as counselling an SDM on how to perform the role or the principles underpinning it, suggesting a need to understand the specific challenges SDMs experience and their preferences for obtaining support in the role.³⁴

Little is known about the Australian public's knowledge about the SDM role (such as how to access information and support, and other legal rights) or how common it is to have acted in the SDM role, the types of medical decisions that SDMs make and the support SDMs access to make such decisions. This study aims to address this gap and to describe the Australian adult public's knowledge and experiences regarding substitute decision-making for medical decisions and their preferences for obtaining more information about the SDM role.

METHODS

Study reporting is based on the Strengthening the Reporting of Observational Studies in Epidemiology statement: guidelines for reporting observational studies.³⁵

In September 2018, a cross-sectional online survey was conducted nationally over 9 days.

Survey development

The survey was developed following a literature review and research team discussion, and then further refined following a pilot with 14 adult Australians to assess question comprehension. The survey comprised five sections (online supplemental file 1). Demographic information collected was adapted from the categories used by the Australian Bureau of Statistics.³⁶ To determine ACP awareness and experience, participants were asked if they knew about ways to plan for future medical care (yes/no), were then presented with a definition of ACP adapted from the international literature¹⁶ (see online supplemental file 1) and then asked if they had heard of ACP prior to the survey. Participants were asked if they knew about ways to plan for future medical care and what types of ACP

Table 1 Demographic characteristics (N=1120)

	n (%)	Population (%)	χ^2 *	P value
Gender				
Male	494 (44.1)†	49.3	10.8	0.001
Female	619 (55.3)†	50.7		
Other or not specified	7 (0.6)	–		
Age in brackets				
18–20	14 (1.2)	–	61.1	<0.001
20–29	124 (11.1)†	13.8		
30–39	243 (21.7)†	14.0		
40–49	208 (18.6)	13.6		
50–59	211 (18.8)†	12.7		
60–69	189 (16.9)†	10.7		
≥70	112 (10.0)	10.7		
Unspecified	19 (1.7)	–		
Born in Australia				
Yes	856 (76.4)†	66.7	47.7	<0.001
No	264 (23.6)†	33.3		
Location of residence				
Australian Capital Territory	20 (1.8)	1.7	3.5	0.836
New South Wales	351 (31.3)	32.0		
Northern Territory	12 (1.1)	0.9		
Queensland	224 (20.0)	20.1		
South Australia	95 (8.5)	7.2		
Tasmania	26 (2.3)	2.2		
Victoria	278 (24.8)	25.3		
Western Australia	114 (10.2)	10.6		
Relationship status				
Married/de facto	687 (61.0)	58.1	14.3	0.002
Separated	29 (2.6)	3.2		
Divorced	86 (7.6)	8.5		
Widowed	34 (3.0)†	5.2		
Single	248 (22.0)	–		
In a relationship	43 (3.8)	–		
Religion				
Catholic	237 (21.2)	22.6	1.33	0.249
Anglican	197 (17.6)	13.3	17.9	<0.001
Uniting Church	56 (5.0)	3.7	5.31	0.021
No religion	420 (37.5)	29.6	33.54	<0.001
None of the above/not stated	210 (18.8)	–		
Speak any languages other than English at home				
Yes	143 (12.8)†	22.2	79.6	<0.001
Education level				
Years 1–6	7 (0.6)	–		
Years 7–10	115 (10.3)	10.8	0.33	0.556
Years 11–12	239 (21.3)	20.6	0.00	0.974
Certificate III/IV	189 (16.9)	15.7	1.17	0.280
Diploma/advanced diploma	177 (15.8)	8.9	65.8	<0.001
Bachelor's degree (including honours)	249 (22.2)	22.0	0.04	0.851
Graduate diploma/graduate certificate	58 (5.2)	–		
Postgraduate degree (master's, PhD, doctorate)	86 (7.7)	–		
Have ever worked in the following professions				
Aged care	46 (4.1)	–		
Financial planning services	19 (1.7)	–		
Funeral services	3 (0.3)	–		
Healthcare	95 (8.5)	–		
Legal practice	13 (1.2)	–		
Social services	35 (3.1)	–		
None of the above/not stated	909 (81.2)	–		

*Variables with no population value (eg, gender, other or not specified) excluded from the analysis.

†Indicates large contribution to the overall test statistics.

experiences they had had (if any). Types of ACP experiences included any previous discussions with others about ACP, outcomes after ACP discussions (such as ACP documentation, including appointment of an SDM) and whether they had ever been involved in a discussion with their family, friends or other people about their preferences regarding ACP.

Participants were also presented with a definition of an SDM for medical decisions (see online supplemental file 1) and asked if they had ever made medical decisions on behalf of someone else after being appointed by them as an SDM (yes/no). They were then asked to rank their most to least preferred source of obtaining information about how to support SDMs make their decisions from six options (an event, discussion with a family member or friend, traditional media, new media, healthcare professional or other). If participants had previously been an SDM, they were asked what types of decisions they had made, the most challenging aspects about making those decisions and the type of support accessed that helped them with their decisions (if any). Participants' SDM knowledge was assessed using five questions (three about accessing information and support or consulting with others in the SDM role, one about SDM laws and one about resigning from an SDM appointment) to be answered 'True', 'False' or 'Don't know'.

Sampling

Adults who had voluntarily signed up to a recruitment agency register (Dynata; <https://www.dynata.com/>) were invited to complete the survey through invitations and advertisements on the company's website. At the time of the survey, the estimated number of registrants on the company's Australian panel was 1 000 000 and participants were reimbursed for the inconvenience (ie, time taken) to complete the survey, as set out and provided by the recruitment agency. Participants were eligible if they were aged 18 years or older and residing in Australia at the time of the study. Participation was voluntary and all responses were anonymous. Participants were informed that consent was implied by completing the survey.

In addition, with the aim of achieving a nationally representative sample, quotas were set for gender and state or territory based on the 2016 Australian census data.³⁶ This resulted in men and people from the Northern Territory being invited to participate in a second round of invitations, as responses were initially low in these groups. Given the use of non-probabilistic sampling (ie, opt-in), we were unable to estimate a response rate in accordance with standardised definitions.³⁷ Participants were included in the final sample if they had completed sufficient questions to address the research questions (up to question 27; having been appointed an SDM and made medical decisions in that role).³⁸ The survey took approximately 15–30 min to complete.

Data analysis

Incomplete responses (n=59) were excluded from the analysis. Variable recoding and data analyses were conducted in SPSS V.23.0. Initial descriptive analyses tabulated experience with ACP and substitute decision-making and preferences and knowledge about the SDM role. Sample representativeness was assessed by comparing demographics (age, gender, location of birth, location of residence, relationship status and speaks languages other than English) with population census data. Mann-Whitney U tests and Kruskal-Wallis H tests were run to determine whether there were any differences between the total number of SDM knowledge questions answered correctly and having had experience with ACP, substitute decision-making or working in a relevant profession ('aged care', 'financial planning services', 'funeral services', 'healthcare', 'legal practice', 'social services' or 'none of the above'). In addition, to determine whether there were differences between levels of working in a relevant profession and SDM knowledge, pairwise comparisons were performed using Dunn's³⁹ procedure with a Bonferroni correction for multiple comparisons (statistical significance accepted at the $p < 0.0023$ level). Alpha levels for statistical significance were set at $p < 0.05$ for all other analyses.

Content analysis⁴⁰ was undertaken to describe responses to questions about SDM experiences: types of decisions made, most challenging aspects about making those decisions and type of support accessed that helped them with their decisions (if any). Codes were initially drafted by MS inductively based on each free-text response and a coding framework was developed, which was revised through discussion and consensus within the research team. Coding was undertaken (each response dichotomously coded (yes/no) to confirm the presence of a code) by two independent coders trained in qualitative research (MS and JT). Following this and using SPSS V.23.0, intercoder reliability was assessed using Cohen's kappa, showing a substantial to almost perfect agreement for all codes (all kappas > 0.743). Discrepancies were resolved by discussion among coders.

RESULTS

In total, of 1586 people who opened the survey, 1000 completed all survey questions. Two were screened out because they did not meet the eligibility criteria and 409 were redirected from the survey because sampling quotas had been exceeded. Of the 175 partial completers, 120 were included in the final sample (N=1120; completion rate 70.6%).

The characteristics of the sample compared with the 2016 population census data are shown in table 1. Participant characteristics were comparable with population census statistics in terms of location of residence and most categories relating to relationship status, religion and education level. However, participants were

Table 2 Awareness and experience regarding ACP (N=1120)

	n (%)
Do you know about ways you can plan for your future medical care and what would happen if you could not make decisions or speak for yourself?	
Yes	611 (54.6)
No	509 (45.4)
Had heard about ACP prior to the survey	
Yes	431 (38.5)
No	689 (61.5)
Source of learning or hearing about ACP (n=431)	
Healthcare professional (eg, nurse, general practitioner)	173 (40.1)
Family or friends	262 (60.8)
Traditional media (television, radio, newspaper, magazines, flyers/brochures/booklets, signs/billboards)	128 (29.7)
New media (social media, eg, Facebook and Twitter, website, and smartphone apps)	74 (17.2)
Legal practitioner	70 (16.2)
Financial planner	31 (7.2)
An event	20 (4.6)
Other	94 (21.8)
If knew about ways to plan for future medical care, ever had a discussion about ACP (n=611)	
Yes	267 (43.7)
No	344 (56.3)
Discussed ACP with (n=267)	
Your family	211 (79.0)
Friends	64 (24.0)
Health professionals	75 (28.1)
Legal practitioner	42 (15.7)
Other/unclear (eg, financial advisor/planner)	6 (2.2)
Outcome(s) after the ACP discussion (n=267)	
Told my family, friends or doctor about medical treatments I would or would not want if I could no longer tell them	163 (61.0)
Completed a document outlining my future medical treatment and care preferences in writing	82 (30.7)
Completed a form appointing someone to make medical decisions on my behalf in case I could no longer tell them in the future	73 (27.3)
Completed at least one type of ACP documentation listed above (either to document their future treatment preferences or to appoint an SDM)	117 (43.8)
Decided not to complete advance care planning	31 (11.6)
Other	15 (5.6)
Ever been involved in a discussion with your family, friends or other people about their preferences regarding advance care planning (only asked if previously had a discussion about ACP, n=267)	
Yes	230 (85.9)
No	37 (14.1)

ACP, advance care planning; SDM, substitute decision-maker.

more commonly female (55% vs 51%), older (median age 48 years vs 38 years), born in Australia (76% vs 67%) and less commonly spoke a language other than English at home (13% vs 22%) than the broader Australian population.

Experiences with ACP are shown in [table 2](#). Most participants had never heard of ACP (62%) or discussed

ACP with others (76%). Only 10% (n=117) reported having completed ACP documentation (either to document their future treatment preferences or to appoint an SDM or both). Of those who had been involved in an ACP discussion with others (n=267), 61% (n=163) had told someone about their future treatment preferences, and of these 30% (n=50) had also documented their ACP preferences. Of the group who had discussed ACP, a larger proportion (86%, n=230) reported having discussed the ACP preferences of someone else as opposed to discussing their own ACP preferences.

SDM experience and preferences

Of the participants 13% (n=142) indicated they had acted in the role of SDM and made medical decisions on an adult's behalf after they were appointed by them. [Table 3](#) shows the final coding categories, the frequency of these and examples of participant quotations to illustrate. Decisions about routine treatment and end of life were most frequently reported (n=22, 16%), and 'knowing the best decision to make' and 'making decisions about end of life' were the most commonly reported challenges (n=25, 17%). Of the 142 who acted in an SDM role and made decisions for others, 64 (45%) reported accessing support, with help from doctors being the most commonly accessed (n=30, 21%).

Participants' preferred source(s) of obtaining more information to support SDMs to make their decisions were (from most to least preferred for six sources, n=1049) healthcare professionals (59%, n=621), discussion with a family member or friend (23%, n=236), traditional media (7%, n=69), new media (6%, n=61), an 'other source' (3%, n=35) followed by an event (3%, n=27).

Knowledge regarding SDMs

Participants had a median correct response score of 2.00 (out of a maximum of 5) ([table 4](#)). The question least frequently answered correctly was regarding laws about SDMs (33%, n=374), with most participants (58%) reporting they did not know if there were laws regarding SDMs where they live ([table 5](#)). Similarly, most participants (65%) incorrectly answered the question about SDMs being limited in their ability to consult others when making their decisions. The question most frequently answered correctly was regarding SDMs' ability to access information from healthcare providers about the person they are making decisions for (64%).

The median knowledge scores for people who had ever discussed ACP (3.0 vs 2.0, U=145 222, z=6.910, p<0.001), documented their ACP preferences (3.0 vs 2.0, U=71 984, z=4.087, p<0.001) or acted in the SDM role (3.0 vs 2.0, U=56 353, z=-3.694, p<0.001) were significantly higher compared with those who had not. In addition, a Kruskal-Wallis H test was conducted to determine if there were differences

Original research

Table 3 Content and example quotations for types of SDM decisions made, most challenging aspects of these decisions and support accessed to support them with their decision (n=142)

Content*	Quotations	n (%)
Type of medical decisions made		
Routine treatment and care (eg, dentist, diet, medications)	"If that person needs dental treatment or not." "Doctor, dentist."	22 (15.5)
End-of-life care decisions (eg, to withdraw or continue treatment, to administer resuscitation, chemotherapy, a feeding tube or antibiotics, to adopt a conservative pathway, follow ACP documentation)	"To make decisions regarding end of life care and treatment." "Life support." "The decision to allow (my husband) to pass away in the nursing home."	18 (12.7)
To continue with/decide course of treatment	"Continuation of treatment." "Course of treatment."	9 (6.3)
Surgery/operations	"Liver transplant." "About the surgery they need to undergo immediately."	8 (5.6)
Hospitalisation	"About hospitalizing a family member." "Deciding to take the person to hospital."	8 (5.6)
Future treatment and care in the event of a deterioration	"What to do if suffers heart attack." "d n r."	7 (4.9)
Transfer to aged care facility	"Dementia putting my father into a nursing home for care." "Moving into aged care facility."	4 (2.8)
Acute medical problem (eg, cancer, stroke)	"Treatment of a stroke." "Ongoing cancer treatment."	4 (2.8)
Choosing a healthcare provider or medical insurance	"Buy medical insurance." "Medical provider to choose one."	3 (2.1)
Medical tests and assessments	"My mother had dementia. Took her to the doctor to have her assessed."	2 (1.4)
Respite care	"Respite care."	2 (1.4)
Not specified or unclear		63 (44.4)
The most challenging aspects of making these decisions (if any)		
No challenges	"None." "No challenge quite straight forward."	31 (21.8)
Knowing what decision to make and making the best/most correct decision (eg, is what the person would have wanted, if preferences misaligned with person or others, not having medical knowledge)	"Just deciding which way to go." "Being certain that the person really agreed with DNR."	25 (17.6)
Decision about end of life	"Having a parent who chose no treatment and preferred to die in pain." "Knowing that she would die."	9 (6.3)
Family	"Waiting for the rest of family." "Siblings."	6 (4.2)
Impact on others, helping others	"Impact on others." "Helping people."	5 (3.5)
Emotions	"Grief." "The burden of guilt even though I was sure I was meeting their wishes."	4 (2.8)
Financial issues	"Money effect." "Financial crisis."	4 (2.8)
Government/paperwork	"Government." "Dealing with bureaucrats."	3 (2.1)
Own health	"My health."	3 (2.1)
Being responsible for someone else	"Taking responsibility for someone else."	2 (1.4)
Struggling to help the person	"Watching her getting more and more frustrated at being denied the right to a dignified death at a time of her own choosing." "Trying to keep my friend comfortable and pain free."	2 (1.4)
Not specified or unclear		44 (31.0)
Type of support (if any) accessed to help you with your decision		
None	"No help or support." "None."	33 (23.2)
Doctors (medical staff)	"Medical professionals." "Specialist doctor."	30 (21.1)
Family or friends	"Sibling." "Other family members."	22 (15.5)

Continued

Table 3 Continued

Content*	Quotations	n (%)
Other healthcare professionals and services (eg, hospitals, palliative care, aged care assessment team, social workers)	"Pharmacist, social worker." "Nursing staff."	16 (11.3)
Support not needed	"Luckily I didn't have to make that call because after 7 weeks he was allowed home thank goodness."	2 (1.4)
Counselling or support groups	"A support group."	3 (2.1)
Internet	"Internet."	2 (1.4)
Religion	"None other than prayer."	1 (0.7)
Not specified or unclear		43 (30.3)

*Multiple codes were permitted.

ACP, advance care planning; DNR, do-not-resuscitate order; SDM, substitute decision-maker.

Table 4 Associations between total knowledge questions answered correctly regarding substitute decision-making and SDM, ACP and professional experiences

Variable		Total correct responses, n (%)					M	Test statistics*	P value	
		0.00	1.00	2.00	3.00	4.00				5.00
Acted in SDM role	Yes (n=142)	10 (7.0)	21 (14.8)	28 (19.7)	38 (26.8)	31 (21.8)	14 (9.9)	3.0	56 353	<0.001
	No (n=978)	202 (20.7)	152 (15.5)	189 (19.3)	204 (20.9)	150 (15.3)	81 (8.3)	2.0		
Discussed ACP	Yes (n=269)	14 (5.2)	37 (13.9)	51 (19.1)	73 (27.3)	60 (22.5)	32 (12.0)	3.0	145 222	<0.001
	No (n=851)	198 (23.3)	136 (15.9)	166 (19.5)	169 (19.8)	121 (14.2)	63 (7.4)	2.0		
Completed ACP documentation	Yes (n=117)	5 (4.3)	19 (16.2)	20 (17.1)	33 (28.2)	29 (24.8)	11 (9.4)	3.0	71 984	<0.001
	No (n=1003)	207 (20.6)	154 (15.4)	197 (19.6)	209 (20.8)	152 (15.2)	84 (8.4)	2.0		
Worked in any of the following professions (yes)	Aged care (n=46)	4 (8.7)	6 (13.0)	10 (21.7)	12 (26.1)	11 (23.9)	3 (6.5)	3.0	32.0	<0.001
	Financial planning services (n=19)	2 (10.5)	1 (5.3)	4 (21.1)	7 (36.8)	4 (21.1)	1 (5.3)	3.0		
	Funeral services (n=3)	—	—	1 (33.3)	1 (33.3)	1 (33.3)	—	3.0		
	Healthcare (n=95)	10 (10.5)	10 (10.5)	23 (24.2)	25 (26.3)	20 (21.1)	7 (7.4)	3.0		
	Legal practice (n=13)	—	—	—	3 (23.1)	5 (38.5)	5 (38.5)	4.0		
	Social services (n=35)	4 (11.4)	8 (22.9)	4 (11.4)	10 (28.6)	5 (14.3)	4 (11.4)	3.0		
None of the above or not specified (n=909)	192 (21.1)	148 (16.3)	175 (19.3)	184 (20.2)	135 (14.9)	75 (8.3)	2.0			
Total (N=1120)		212 (18.9)	173 (15.4)	217 (19.4)	242 (21.6)	181 (16.2)	95 (8.5)	2.0		

*Kruskal-Wallis H test statistics for profession (independent groups); Mann-Whitney U test for other variables.

ACP, advance care planning; SDM, substitute decision-maker.

Table 5 Knowledge about substitute decision-makers (N=1120)

	Believes statement is true, n (%)	Believes statement is false, n (%)	Don't know if statement is true or false, n (%)	Answered correctly, n (%)
To help them to make their decisions, substitute decision-makers can access all information about the person they are making decisions for from healthcare provider(s)—True.	721 (64.4)	83 (7.4)	316 (28.2)	721 (64.4)
Substitute decision-makers cannot seek a second opinion from other healthcare providers to help inform them when making decisions on someone's behalf—False.	188 (16.8)	552 (49.3)	380 (33.9)	552 (49.3)
Where I live, there are no laws about substitute decision-makers—False.	97 (8.7)	374 (33.2)	649 (57.9)	374 (33.2)
Substitute decision-makers are limited in who they can consult in helping them make their decisions—False.	235 (21.0)	392 (35.0)	493 (44.0)	392 (35.0)
Once a person has been legally appointed as a substitute decision-maker, they cannot resign from that appointment—False.	152 (13.6)	493 (44.0)	475 (42.4)	493 (44.0)

in knowledge scores between people who differed in relevant professional experience: aged care (n=46), financial planning services (n=19), funeral services (n=3), healthcare (n=95), legal practice (n=13), social services (n=35) or none of the above (n=909). Distributions of knowledge scores were not similar for all groups, as assessed by visual inspection of a boxplot, with legal practices group appearing to have greater frequency of higher scores. The distributions of knowledge scores were statistically significantly different between participant groups with relevant professional experience ($\chi^2(6)=32.032$, $p<0.001$). A post-hoc analysis showed statistically significant differences in knowledge scores between people who had ever worked in legal practice (mean rank=939.27) and healthcare (mean rank=628.58) ($p=0.020$), legal practice and social services (mean rank=599.89) ($p=0.021$), and legal practice and people who had not worked in any of the professions or did not specify a response (mean rank=540.13) ($p<0.001$). Statistical significance was not identified in any other group combination.

DISCUSSION

This study describes the Australian adult public's knowledge and experiences regarding substitute decision-making for medical decisions and their preferences for obtaining more information about the SDM role. Less than four in ten participants reported that they had heard of, or discussed, ACP and only 11% reported having documented their ACP preferences. Similarly, few (13%) participants had acted in the SDM role and the median score of two correct responses out of five in all participants indicates low to moderate knowledge about the SDM role. It is striking that only 33% of participants reported knowing that SDM laws existed in Australia. Of those who had acted in the SDM role, challenges about knowing the best decision to make and making decisions about end of life were the most frequently reported. In addition, while most ranked a health professional as their preferred source of obtaining information about how to support SDMs in their role, few participants indicated they had obtained any support in the SDM role.

The Australian community's ability to appoint an SDM, and for the SDM to act appropriately, depends on awareness of the requirements of these roles. It is likely that SDMs would be more likely to advocate on behalf of the person regarding treatment preferences or use legal recourse (such as a tribunal) if they are aware of existing legislation that will support them in this process.⁴¹ However, this study found low awareness of ACP, limited engagement with ACP behaviours (such as discussing or documenting medical treatment preferences) and low to moderate SDM knowledge in the sample overall, suggesting these may be problematic. Nonetheless, participants in our study with ACP or SDM experience answered significantly more SDM

knowledge questions correctly than those without these experiences, which suggests participating in such activities may improve a person's knowledge regarding the SDM role and the laws that underpin it. This may be a result of experiences associated with acting in the SDM role, the professional support accessed by some who reported this, or alternatively they might have been selected into the role (or self-selected to some extent) due to greater health/legal literacy.

Past studies show SDMs can experience stress and uncertainty if they feel insufficient information has been provided to support them in their role.^{42 43} In our study, some people who had acted in the SDM role also encountered challenges in knowing the best decision to make and making decisions about end of life. However, few participants reported accessing support to help them make these decisions, which highlights a potential need to develop resources addressing the types of challenges SDMs are likely to encounter and for this content to be delivered in ways that are preferable for potential SDMs. Findings from a recent survey among the Canadian general population showed that most participants would support the introduction of a curriculum for senior high school students to learn about being an SDM,³¹ further highlighting the need to develop and evaluate interventions that address the problem of a lack of preparedness to be an SDM in the general public.⁴⁴

In our study, a majority of participants preferred to obtain information from a health professional. This is consistent with a recent Australian study which found most people preferred to learn about end-of-life law from health professionals.³⁰ This highlights the importance of doctors, nurses and others involved in a person's care being well informed about relevant legislation and confident to educate and counsel SDMs regarding their role.

One challenge, however, is that the law in this field is complex and past studies of Australian doctors show significant knowledge gaps in end-of-life law⁴⁵ and varying attitudes towards its helpfulness in clinical practice.⁴⁶ Accordingly, participants who had worked in healthcare showed no evidence of increased SDM knowledge compared with participants without such professional experience. The small sample of participants who had worked in legal practice were the only group who answered significantly more SDM knowledge questions correctly than those without relevant professional experience. This suggests that education for health professionals may improve their ability to support SDMs to make medical decisions.

Strengths and limitations

To our knowledge, this is the first national study to examine the Australian public's knowledge about SDM role or how common it is to have acted in the SDM role, the types of medical decisions that SDMs make and the support SDMs access to make such decisions.

All survey content was piloted for comprehensibility with people from the Australian population, and questions regarding SDMs and ACP were accompanied with definitions adapted from internationally accepted definitions where necessary. Unduly technical terms were avoided in the survey where possible. In addition, all Australian states and territories were represented, and participants' locations of residence were comparable with the broader Australian population. However, our study has some limitations that suggest caution. First, women more commonly responded to the survey than men and participants were older than the available estimates for the Australian public overall. In addition, given our opt-in sampling methodology, the generalisability of the findings to the Australian general public may be limited. However, this study was largely descriptive, and future research could employ other methodologies to achieve population representative samples values for Australian's SDM knowledge and experiences. Nonetheless, our findings regarding reported ACP documentation completion rate (10%) were broadly comparable with those identified in a past Australian national telephone survey study conducted in 2014,¹⁹ where only 14% of the sample had completed ACP documentation (advance directive).

One further challenge is the need to draft survey questions that are both legally precise across eight Australian jurisdictions and expressed in non-legal language appropriate for respondents. While legal questions were asked in accordance with Australian law, a study limitation is that, to ensure questions were understandable to the members of the community, questions were sometimes framed in terms of general principles that avoid undue legal complexity or detail that would impede comprehension. Further, the question about access to information was framed in overly broad terms as generally not all information can be obtained from healthcare providers but rather this is usually limited to that which is needed to undertake the SDM role.

CONCLUSION

This study surveyed the Australian adult public to describe their knowledge and experiences regarding substitute decision-making for medical decisions and their preferences for obtaining more information about the SDM role. The findings suggest the Australian public have low to moderate knowledge about the SDM role. In particular, there is a gap between the support required to act in the SDM role and the limited support currently available and used by SDMs. Given health professionals were identified as the preferred source of obtaining information about SDM, this suggests improved education and awareness of this cohort may indirectly support those acting as SDMs.

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Project title: *Making health decisions on behalf of others: A national survey of knowledge, attitudes and intentions of Australian adults on substitute decision-making*

SURVEY QUESTIONS

DEMOGRAPHICS

Below are some questions about you

- a) What is your gender?
 - Male
 - Female
 - Prefer not to say
 - Other: specify

- b) In what year were you born?

- c) Are you of Aboriginal or Torres Strait Islander origin?
 - Neither Aboriginal or Torres Strait Islander
 - Aboriginal
 - Torres Strait Islander
 - Aboriginal and Torres Strait Islander
 - Prefer not to say

- d) In what country were you born?
 - Australia
 - Other: please specify

- e) How many years have you lived in Australia? (If other is selected)

- f) In which state do you live?
 - Australian Capital Territory
 - New South Wales
 - Northern Territory
 - Queensland
 - South Australia
 - Tasmania
 - Victoria
 - Western Australia

- g) What is your postcode?

- h) What is your relationship status?
 - Married/de facto
 - Separated
 - Divorced
 - Widowed
 - Single

- In a relationship

i) Do you have any children?

- Yes – please complete the table (j)
- No

j) What is the age and gender of your child or children? Please indicate whether or not they have been adopted.

Child:	Age	Gender (Male, Female)	Adopted (Yes, No)
1			
2			
3			
4			
5			
6			

k) What is your religion?

- Anglican (Church of England)
- Baptist
- Buddhism
- Catholic
- Greek Orthodox
- Hinduism
- Islam
- Uniting Church
- No religion
- Other: specify

l) What is your highest of level of education?

- Years 1-6
- Years 7-10
- Years 11-12
- Certificate III/IV
- Diploma/Advanced Diploma
- Bachelor degree (including Honours)
- Graduate Diploma/Graduate certificate
- Postgraduate degree (Master, PhD, Doctorate)

m) What is current employment status?

- Full-time
- Part-time
- Not employed
- Retired

n) Have you worked in any of the following professions?

- Aged Care
- Financial planning services
- Funeral services
- Health care
- Legal practice
- Social services
- None of the above

o) Do you speak any languages other than English at home?

- Yes: please specify
- No

KNOWLEDGE: Advance Care Planning and Substitute Decision-Making

1. *Do you know about ways you can plan for your future medical care and what would happen if you could not make decisions or speak for yourself?*

- Yes -
- No – go to 1.11

1.1 Advance Care Planning description/definition (If Yes to Q1)

This is known as advance care planning. Advance care planning is a process which focuses on understanding your values and preferences regarding your future medical decisions. Your preferences then inform medical decisions if you are ever unable to decide or speak for yourself. You may choose to record your preferences in a legally binding document, which is called an advance care directive, also known as Advance Health Directive, Health Direction or Advance Personal Plan (depending on your state or territory).

1.1.1 Advance Care Planning description/definition (if No to Q1)

You can plan for your future medical care through advance care planning. Advance care planning is a process which focuses on understanding your values and preferences regarding your future medical decisions. Your preferences then inform medical decisions if you are ever unable to decide or speak for yourself. You may choose to record your preferences in a legally binding document, which is called an advance care directive, also known as Advance Health Directive, Health Direction or Advance Personal Plan (depending on your state or territory).

1.2 Prior to this survey, had you previously heard of advance care planning?

- Yes
- No (go to Q2)

1.3 From which of the following source(s) did you learn or hear about advance care planning? Please select all that apply (if Yes to Q1)

- An event: please specify
- Family or friends
- Traditional media (go to Q2.1) (TV, radio, newspaper, magazines, flyers/brochures/booklets, signs/billboards)
- New media (social media, e.g. Facebook, Twitter, website, smartphones)
- Health care professional (e.g. nurse, GP)
- Legal professional
- Financial planner
- Other: please specify

1.3.1 From which traditional media did you learn or hear about advance care planning? (if Traditional Media is selected in Q1.3)

- Television
- Radio
- Newspaper
- Magazines
- Flyers/brochures/booklets
- Signs/billboards

1.3.2 From which new media did you learn or hear about advance care planning? (if New Media is selected in Q1.3)

- Facebook
- Twitter
- Website (excluding social media websites Facebook, Twitter, etc.)
- Smartphone apps (excluding social media apps Facebook, Twitter, etc.)
- Other: please specify

1.4 Have you ever had a discussion about advance care planning?

- Yes
- No (go to Q2)

1.5 Who of the following did you have a discussion about **your own** advance care planning with? Please select all that apply.

- Your family
- Friends
- Health professional(s)
- Legal practitioner
- Other: please specify

1.6 After the discussion, what was the outcome? Please select all that apply.

- I told my family, friends or doctor about medical treatments I would or would not want if I could no longer tell them
- I completed a document outlining my future medical treatment and care preferences in writing
- I completed a form appointing someone to make medical decisions on my behalf in case I could no longer tell them in the future
- I decided not to complete advance care planning
- Other: please specify

1.7 Have you ever been involved in a discussion with your family, friends or other people about **their** preferences regarding advance care planning?

- Yes
- No

2. Do you know that a person can choose to legally appoint someone to make medical decisions on their behalf if they can no longer decide for themselves?

- Yes
- No

2.1 Substitute Decision-Maker description/definition

These people are known as substitute decision-makers. Depending on the state or territory you live in, they might be called an attorney, enduring guardian, or medical treatment decision-maker but they refer to a person who is legally appointed to make medical decisions on someone's behalf if they are ever unable to make these decisions for themselves due to illness or injury. We will refer to this role as 'Substitute Decision Maker' for the remainder of the survey.

3. Below are statements regarding substitute decision-makers. Please indicate whether you think these are true or false (or don't know where applicable).

	True	False	Don't Know
1 To help them to make their decisions, substitute decision-makers can access all information about the person they are making decisions for, from healthcare provider(s).	X		
2 Substitute decision-makers cannot seek a second opinion from other healthcare providers to help inform them when making decisions on someone's behalf		X	
3 Where I live, there are no laws about substitute decision-makers		X	
4 Substitute decision-makers are limited in who they can consult in helping them make their decisions		X	

5 Once a person has been legally appointed as a substitute decision-maker, they cannot resign from that appointment		X	
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***correct answers**

4. Have you ever made medical decisions on an adult's behalf after you were appointed by them as their substitute decision-maker?

Yes – go to 4.1

No – go to question 5A

4.1 What type of medical decisions did you have to make?

4.2 What were the most challenging aspects of making these decisions (if any)?

4.3 What type of support (if any) did you access to help you with your decisions?

ATTITUDES: Substitute Decision-Making

5A. Below are statements about appointing or being appointed a substitute decision-maker. Please indicate your level of agreement to each of the statements, with 1 being strongly agree and 5 being strongly disagree.

Statements	1 Strongly agree	2 Agree	3 Neither disagree or agree	4 Disagree	5 Strongly disagree
Appointing a substitute decision-maker is not a priority for me at the moment					
If I was appointed, I would feel confident in my role as a substitute decision maker (<u>only if No to Q4</u>)					
Making medical decisions on someone's behalf would be a difficult and stressful experience for me (<u>only if No for Q4</u>)					
Making medical decisions on someone's behalf can be a difficult and stressful experience for me (<u>only if Yes to Q4</u>)					

It is best if only family members are appointed as substitute decision makers.					
--	--	--	--	--	--

5B. Below are statements about how substitute decision-makers should make their decisions. Please indicate your level of agreement to each of the statements, with 1 being strongly agree and 5 being strongly disagree.

Statements	1	2	3	4	5
	Strongly agree	Agree	Neither disagree or agree	Disagree	Strongly disagree
It is important for substitute decision-makers to:					
consider a person's past values and preferences when making decisions on their behalf					
consistently follow the preferences outlined in advance care directives (a document outlining the person's preferences in writing)					
consider advice from health care providers when making decisions on someone's behalf					
consider a person's past values and preferences, as well as the advice of health care providers when making decisions on someone's behalf					
know where to seek support when needed					

NEEDS, CONCERNS AND INTENTIONS: Substitute Decision-Making

6. Please read the following scenario carefully and answer the following questions as honestly as you can. There are no right or wrong answers.

Scenario 1

Julia is 72 years old. She has advanced breast cancer, but she is still able to make plans regarding her future medical care. She is thinking about appointing a substitute decision maker to make medical decisions on her behalf in case she becomes too unwell and can no longer decide for

herself. She is married and lives with her husband. She has two children, a son and daughter. Julia plans to appoint her son, Ryan, the younger of the children to be her substitute decision-maker.

6.1 What do you think were Julia's main considerations when weighing up who to appoint as her substitute decision maker? Please rank in order of importance, with 1 being the most important.

- The person appointed is caring
- The person appointed will be able to cope with the substitute decision-maker role
- The person appointed is honest
- The person appointed is someone she trusts to make decisions that she would make herself
- The person appointed knows about her preferences for medical care
- The person appointed has a similar outlook to herself
- The person appointed will make the right decision
- The person appointed knows about health care and the decisions to be made
- Other: please specify

6.2 What do you think would be Julia's main concerns when deciding about who to appoint as her substitute decision maker? Please rank in order of importance, with 1 being the most important.

- The person appointed may not accept the role
- The person appointed might not be available when important decisions are needed to be made
- The person appointed might lack or misinterpret the information necessary to make an informed decision
- The person appointed might not be able to cope with the responsibilities
- The person appointed may not make the right decision
- If she chooses her youngest child she may upset her husband and / or her oldest child
- Other: please specify

6.3 What do you think Ryan was thinking or feeling about the possibility of becoming his mother's substitute decision maker?

6.4 What do you think would be Ryan's main considerations in accepting his appointment as a substitute decision maker? Please rank in order of importance, with 1 being the most important.

- He might not make the right decision for his mother
- He might feel uncertain about the outcomes of the decisions made
- He may not be able to cope with the stress that comes with the role
- The decisions he is expected to make might cause family conflict
- He is prepared to make important medical decisions when needed
- He is willing to act based on his mother's preferences
- He clearly understands his duties and responsibilities
- He knows where he can get help regarding his role if he needs it

- He feels he is the right person to be his mother's SDM
- He aims to be fair in his decisions so that family conflict is avoided
- Other: please specify

6.5 Based on the order of Ryan's considerations, do you think he should accept his appointment?

	<i>Strongly agree</i>	<i>Agree</i>	<i>Neither disagree or agree</i>	<i>Disagree</i>	<i>Strongly disagree</i>
<i>Ryan should accept his appointment</i>					

7. Please read the following scenario carefully and answer the following questions. There are no right or wrong answers.

Scenario 2

Mathew is 76 years old, and is in hospital after a stroke. His doctor has said that he requires minor surgery for tube feeding. He is currently unable to make his own decisions regarding his treatment. His daughter, Sarah, is his appointed substitute decision maker. Matthew has previously completed an Advance Care Directive and stated in this that he would not like to have life prolonging treatment, such as surgery, or tube feeding if he were to be in a situation such as this. Sarah is aware of the advance care directive and its contents. Mathew's son, Connor, has also been included in discussions with Sarah and Matthew's doctor. The preferences outlined in Mathew's advance care directive are new to Connor and he has not previously considered his father's treatment preferences.

7.1 What do you think Sarah was thinking or feeling about the possibility of following her father's preferences in his Advance Care Directive?

7.2 What do you think were some of the thoughts Sarah considered before making her decision? Please drag and drop to rank in order of importance.

- She should be actively involved to ensure that decisions are consistent with her father's preferences
- She should seek advice from another doctor
- She should let the doctor decide as she trusts his medical expertise
- She should talk to her brother about the decision
- She should resign as the substitute decision maker
- She should let Connor make the decision
- Other: please specify

7.3 What type of support could Connor/Sarah be offered after having made his/her decision?

RESOURCE DEVELOPMENT

8. If you wanted more information about how to support substitute decision-makers make their decisions, which of the following source(s) of information would you prefer?

- An event: please specify
- Discussion with a family member or friend
- Traditional media (go to Q8.1)
- New media (go to Q8.2)
- Health care professional (e.g. nurse, GP)
- Other: please specify

8.1 From which traditional media would you like to be informed about support for substitute-decision makers?

- Television
- Radio
- Newspaper
- Magazines
- Flyers/brochures/booklets
- Signs/billboards
- Other: please specify

8.1.1 Why did you rank this as the most preferred?

8.1.2 Please provide reasons for selecting this option

8.2 From which type of new media would like to be informed about support for substitute decision makers?

- Facebook
- Twitter
- Website (excluding social media websites Facebook, Twitter, etc.)
- Smartphone apps (excluding social media apps Facebook, Twitter, etc.)
- Other (e.g. USBs): please specify

8.2.1 Why did you rank this as the most preferred?

8.2.2 Please provide reasons for selecting this option

9. Which of the following information about substitute decision-makers would be most important to you? Please rank in order of importance, with 1 being the most important.

Themes	Rank
Traits and qualities of substitute decision-makers (e.g. over 18, trustworthy, willing and able, etc.)	
Rights and responsibilities of substitute decision-makers (e.g., follow instructions, right to access information about the person, right to resign, etc.)	

Limitations for substitute decision-makers (e.g. that medical substitute decision-makers cannot make legal or financial decisions unless authorised to do so)	
Benefits of being substitute decision-makers (e.g. knowing you are trusted, helping a person to have their preferences respected)	
Challenges of being substitute decision-makers (e.g. stress, family conflict, putting aside their own values)	
Needs and concerns of substitute decision-makers	
Support for substitute decision-makers (e.g. further information, advice, counselling)	

10. Why did you think X was the most important?

10.1 Please provide your reasons

11. Why did you think X was the least important?

11.1 Please provide your reasons

12. What other information do you think is important?