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## **Prevalence and predictors of advance directives in Australia**

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## **Abstract**

**Background:** Advance care planning is regarded as integral to better patient outcomes yet little is known about the prevalence of advance directives in Australia.

**Aims:** To determine the prevalence of advance directives (ADs) in the Australian population.

**Methods:** A national telephone survey about estate and advance planning. Sample was stratified by age (18-45 and >45 years) and quota sampling occurred based on population size in each State and Territory.

**Results:** Fourteen percent of the Australian population has an AD. There is State variation with people from South Australia and Queensland more likely to have an AD than people from other states. Will making and particularly completion of a financial enduring power of attorney are associated with higher rates of AD completion. Standard demographic variables were of limited use in predicting whether a person would have an AD.

**Conclusions:** Despite efforts to improve uptake of advance care planning (including ADs), barriers remain. One likely trigger for completing an AD and advance care planning is undertaking a wider future planning process (e.g. making a will or financial enduring power of attorney). This presents opportunities to increase advance care planning but steps are needed to ensure that planning which occurs outside the health system is sufficiently informed and supported by health information so that it is useful in the clinical setting. Variations by State could also suggest that redesign of regulatory

frameworks (such as a user-friendly and well publicised form backed by statute) may help improve uptake of ADs.

## **Introduction**

Advance care planning (ACP) enhances patient participation in care and there is evidence that it leads to better outcomes for both patients and families<sup>1-3</sup> and assists health professionals in decision-making.<sup>1,2</sup> It is part of good medical practice<sup>4,5</sup> and governments have repeatedly stated their desire to promote its uptake by patients and acceptance by health professionals.<sup>6,7</sup> Yet ambitions to enhance implementation and uptake of ACP have not been realized.<sup>3,8</sup>

Designing policy responses to address this requires an understanding of foundational questions such as when and why people undertake ACP. Yet significant knowledge gaps remain. Little is known in Australia about the prevalence of advance directives (ADs). Debates about terminology in this area are noted<sup>6</sup> so we clarify that in this paper, ADs refer to what are sometimes called written instructional directives: documents completed by competent adults, which express views and wishes about future medical treatment that they would accept or refuse at a time when capacity is lost.<sup>9</sup> In Australia, six of the eight jurisdictions have recognised in statute the common law right to make ADs while New South Wales and Tasmania continue to rely on common law (the law made and interpreted by judges as opposed to Parliament) (Box 1).<sup>10</sup> ADs are only part of ACP, which is a wider process including, for example, ongoing conversations between the competent adult and their family and health professionals about goals of future care.

Because ADs are a tangible document, they provide a useful measure of one aspect of ACP. In this study, we examined statutory directives in the six jurisdictions that have them and

common law “advance care directives” in New South Wales and Tasmania. Another form of ACP is to appoint a substitute decision-maker such as an enduring guardian or power of attorney but there was not scope to include these appointments in this study.

There is no national data available about prevalence of AD completion in Australia. Data from South Australia suggests completion rates for “living wills” to be 11.8%.<sup>11</sup> By comparison, 2.7% of Tasmania’s population has lodged an enduring guardianship form with that State’s Guardianship and Administration Board.<sup>12</sup> Such forms allow binding directions about health to be given to enduring guardians so may be regarded as an AD, although less than half of the forms included a statement about end of life care.<sup>12</sup> Research has also been undertaken on prevalence of ADs in residential aged care facilities<sup>8,13,14</sup> and for older persons presenting to an emergency room<sup>15</sup> or attending rehabilitation services.<sup>16</sup> There is some national prevalence data overseas, for example it is estimated that 30% of Canadians have an AD,<sup>17</sup> but variation in populations, health systems and legal frameworks cautions generalisability of these results to Australia.

The aim of this paper, which draws on a recent national survey into estate and advance planning, is to (1) estimate the prevalence of ADs in Australia and (2) examine the likelihood that a person with particular demographic characteristics will have an AD or not.

## **Methods**

A survey was conducted on a range of future planning issues between August and September 2012 using the Computer Assisted Telephone Interview laboratory at The University of Queensland and with approval from The University of Queensland Ethics Committee (2011001264). Before survey commencement, trained interviewers described

what the study involved, obtained consent to undertake the survey and informed participants of their right to withdraw.

Participants throughout Australia were asked whether they had a “document where you make decisions about what sort of medical treatment you want or don’t want”. They were then prompted with: “In [insert State], this would be called [insert name of main document in their State]” (Box 1). Participants were also asked for demographic information (Table 2) and questions about future financial planning (time constraints meant that questions relating to enduring guardians or attorneys for health were not asked).

The survey was implemented with a national sample of the Australian adult population (aged 18 plus) representative of age and state. A national sample enabled exploration of state differences and generalisability. The sample drawn from most States and Territories reflected the proportion of the Australian population who reside in each location as estimated by the Australian Bureau of Statistics 2011 Census. The smaller jurisdictions – Australian Capital Territory (ACT), Tasmania and Northern Territory (NT) – were deliberately over-sampled to include at least 100 respondents, ensuring sufficient data from these populations for subsequent analysis. Approximately 2,400 completed surveys were needed to ensure adequate numbers from each state jurisdiction and age grouping for the proposed analysis. The sample was aged stratified to ensure at least 50% of respondents were aged 18-45 years. Participation of younger people in estate and ACP is under-researched but this is an important area as future planning for accidents and other unexpected illnesses is relevant across all ages. There was no gender quota but this was monitored to ensure roughly equal numbers of males and females. The large population

sample has error margins at 95% confidence level of 2% for analyses for the total population, 5.7% for state comparisons and 8% for age/state comparisons.

A total of 12,110 households were randomly contacted by telephone with 40% (4,846) of households falling outside the proposed sample (e.g., no one over 18 available, jurisdictional or age quotas already met), leaving a potential 7,264 respondents to be interviewed. Random fixed-line number generation, rather than reliance on a pre-existing list, ensured a greater coverage of telephone numbers. Forty percent of respondents were born overseas or had at least one overseas-born parent which is culturally comparable to the Australian population (46%).<sup>18</sup>

Statistical procedures were implemented using SPSS version 21 (IBM). Statistical significance was set at 5% ( $p \leq .05$ ). Descriptive statistics (proportions with odds ratios and 95% confidence intervals) were used to report prevalence of ADs, financial enduring powers of attorney (EPAs) and wills. Data were weighted for age for all analyses to compensate for over-representation of older (45+) respondents from Queensland, South Australia (SA) and Tasmania using the latest Australian Bureau of Statistics data.<sup>19</sup> Odds ratios (ORs) were used to compare the odds of respondents in some States/Territories having ADs relative to others. Logistic regressions were employed to determine the ability of standard demographic variables (e.g. age, gender, relationship status, estimated estate value, parenthood, education level and ethnic diversity), financial EPA preparation and will making behaviour entered simultaneously to classify respondents as having, or not having, an AD.

## **Results**

## **Prevalence of advance directives**

Of the 7,264 respondents within the inclusion criteria, 2,405 agreed to be interviewed, 50% of whom were female. Only 14% of these respondents had prepared an AD. This is significantly less than the proportion of respondents who had a financial EPA (30%) or a will (59%) (both differences significant at the  $p < 0.001$  level).

The proportion of respondents who had an AD was different in each State. Using New South Wales (NSW) as the reference group, being the Australia's most populous State, respondents from SA and Queensland were significantly more likely to have an AD (Table 1). Respondents from the ACT, Tasmania, Victoria and NT were no more or less likely than respondents from NSW to have completed an AD. Western Australia (WA) respondents were significantly less likely to have done so.

## **Who has advance directives?**

The strongest predictor of ADs was preparation of other planning documents (Table 2). Respondents with a financial EPA were almost 9 times more likely to have an AD than those without a financial EPA. Respondents with a will were 2.5 times more likely than non-will makers to have an AD.

Relationship status was the only demographic characteristic significantly associated with AD preparation. Respondents who were either single or not in a legally recognised relationship ("Other" in Table 2) were 1.7 times more likely than respondents who were married to have an AD. In contrast, respondents who were married were 1.6 times more likely than respondents who were either single or not in a legally recognised relationship to have a will (OR = 1.58, 95% CI = 1.18 – 2.14,  $p < .003$ , Wald = 21.83, unpublished data



from same survey but not shown in tables). Relationship status was not associated with the likelihood of having a financial EPA.

No other characteristics, including age, gender, estimated estate value, parenthood, education level or ethnic diversity, were associated with AD preparation.

## **Discussion**

The prevalence of AD completion in the Australian population is relatively low, particularly compared with other planning documents such as financial EPAs and wills. While establishing a national prevalence benchmark is useful, the question remains as to why this disparity exists. A possible explanation is that wills and financial EPAs, which involve planning for one's *financial* future, are of a different character from ADs. They do not require the same engagement with one's mortality and possible ill-health.<sup>3</sup> Also contributing to the low prevalence of ADs may be limited awareness by the public and health professionals of their existence and useful role in medical decision-making. Further, ADs are often conceptualised as documents only to make specific future health decisions (particularly refusals of treatment). This can limit their perceived utility as being relevant only to those who are older or are already unwell.<sup>3,12</sup> Our results may also reflect a preference for less formal means of ACP such as discussions with family and friends.

There was a clear association between those who might be described as “planners” (i.e. those with a will and/or financial EPA, and AD completion). This suggests that there may be opportunities to increase uptake of ADs (and other ACP documents such as appointing substitute decision-makers) within a wider future-planning process. This is particularly so for financial EPAs as there is a stronger association between the presence of an EPA and an

AD, than between making a will and ADs. This is unsurprising given that both documents guide decision-making while alive but with impaired capacity.

The only significant demographic collected in this study that correlated with completion of ADs was relationship status. Respondents who were single or not in a legally recognised relationship (“Other” in Table 2) were more likely than married respondents to have an AD. This is consistent with previous research that divorced people are more likely to seek information on ADs.<sup>20</sup> The absence of a partner to act as a substitute decision-maker may increase the significance of these documents as an option to exercise control over future medical decision-making. Demographic variables other than those collected in this study may need to be examined. For example, because the survey did not ask about the health status of respondents or their partner, this research was unable to determine whether ACP occurs in response to adverse health outcomes people have witnessed<sup>22</sup> or current health status. A small Australian qualitative study by Brown and Jarrard noted that diagnosis of a terminal illness or life-threatening or chronic disease, such as dementia, is an impetus for some patients to obtain information about ACP.<sup>23</sup> This suggests a more nuanced understanding of drivers for ACP is needed beyond abstract population level approaches. Certainly, this type of planning is different from financial EPAs and wills, which are more strongly predicted by certain demographic variables, and so more in-depth research is needed to understand why planning with ADs is different.

This study reveals significant State/Territory differences in prevalence of ADs. Reasons for this variation are likely to include differences in law and policy, useability of AD forms and education of community and health professionals. While more research is needed to understand the interaction of these factors, some observations can be made about the

possible impact of the varying regulatory frameworks. Taking NSW (13.3%) as the reference group, being Australia's most populous state, we see a significantly higher proportion of ADs in Queensland (19%) and SA (21%). Common to these two jurisdictions is the existence of a long-standing, reasonably well-publicised statutory AD form allowing a person to accept or refuse treatment.

The prevalence of ADs is not significantly different from NSW in the NT (9%), Victoria (13.4%), Tasmania (15.1%) and the ACT (18.5%). The ACT, Victoria and the NT share most of the features outlined above of the "higher prevalence" States but their statutory forms focus on *refusing* treatment, particularly Victoria with its "refusal of treatment certificate". The utility of Victoria's statutory AD is further limited in applying only to refusals of treatment for a patient's current medical condition. The NT's AD prevalence may also be due to poor public awareness: its AD at the time of survey was opaquely titled "Schedule" and located in the regulations to the legislation.

NSW and Tasmania both rely on the common law and the absence of legislative backing for an endorsed, standardised form may affect community awareness and acceptance of ADs. The prevalence of ADs in WA (7.5%), which is significantly lower than NSW, may be partly explained by limited public awareness of their new statutory AD which only came into force in 2010. While the regulatory framework is just one factor affecting uptake, these jurisdictional differences may well point to the value of ADs that are backed by statute, user-friendly, accessible, supportive of a wide range of decision-making and well publicised to health professionals and to the public.

A limitation of our study is a response rate of 33%. However, this is comparable to other large representative community telephone surveys examining end of life issues and perhaps

reflects community reluctance or disinterest in discussing such issues.<sup>24,25</sup> A further limitation is that we specifically named the main AD in each State: the statutory AD in six jurisdictions and term “advance care directive” as used by Health Departments where only the common law applies in NSW and Tasmania (Box 1). This was done to improve the accuracy of collected data by being specific and avoiding uncertainty associated with whether a document counts as an AD. But this means that other types of ADs are probably not captured, especially in those statutory jurisdictions where common law ADs also have force. This could mean that the prevalence of ADs generally may be higher than reported. The study also relies on participants knowing and accurately recalling the nature of the ACP they have undertaken.

More research is needed to understand why the prevalence of ADs is low in Australia, and how uptake can be improved. Key strategies include raising community awareness, developing a range of triggers for ACP conversations to occur and providing funding and training to support ACP becoming “core business” in clinical practice.<sup>3</sup> This research suggests that at least some ACP is occurring as part of wider future planning processes. This presents an opportunity to achieve the policy goal of increasing ACP and should be encouraged. Public education campaigns should be calibrated to take account of this and facilitate discussions occurring in these wider settings.

But this raises important health policy issues because it will be the health system and health professionals who are confronted with ADs when treatment decisions need to be made. A challenge is to ensure that ADs completed outside the health system have sufficient input from health professionals to optimise the quality of AD content, given that wider future planning processes typically involve legal and financial but not

medical or health advice. This may mean health professionals need to inquire about existing ADs and the circumstances of their completion so as to identify where further clinical input is needed. Legal professionals and financial advisors should also ensure that people are connected with an appropriate health professional for advice. Such approaches will help ensure that the focus of these additional opportunities to undertake ACP remains on the process of determining personal values, making informed decisions and communicating them in a way that achieves the goals of treatment that matter to patients rather than simply completing forms.<sup>6, 12</sup>

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## Tables

### Box 1: Main advance directives by State

Australian Capital Territory (ACT):	Health direction
New South Wales (NSW):	Advance care directive (not in legislation but terminology used by Ministry of Health)
Northern Territory (NT):	Direction (although legislation, passed since the survey, now changes this terminology)
Queensland:	Advance health directive
South Australia (SA):	Anticipatory direction (although legislation, passed since the survey, now changes this terminology)
Tasmania:	Advance care directive (not in legislation but terminology used by Department of Health and Human Services)
Victoria:	Refusal of treatment certificate
Western Australia (WA):	Advance health directive

**Table 1: Proportion of respondents who had an advance directive nationally and by State**

State	ACT	NSW <sup>†</sup>	NT	QLD	SA	TAS	VIC	WA	Aust
<b>% (no.) with AD</b>	18.5 (18)	13.3 (92)	9.0 (9)	19.0 (82)	21.0 (36)	15.1 (15)	13.4 (71)	7.5 (19)	14.4 (342)
<b>95% CI</b>	10.6 – 26.4	10.8 – 15.9	3.3 – 14.7	15.6 – 22.7	14.8 – 27.1	7.9 – 22.3	10.5 – 16.3	4.2 – 10.8	13.0 – 15.8
<b>OR (95% CI)</b>	1.50 (0.86 – 2.62)	1 <sup>†</sup>	0.64 (0.31 – 1.32)	1.52 (1.10 – 2.11) *	1.72 (1.12 – 2.64) *	1.17 (0.65 – 2.12)	1.01 (0.72 – 1.41)	0.54 (0.32 – 0.90) *	
<b>Weighted Sample Size</b>	96	689	100	432	172	98	528	249	2364

Percentage reflects the proportion of all respondents within each jurisdiction who had prepared an AD. The data shown is weighted to reflect the distribution of older (45+) and younger (18-44) populations within each jurisdiction as estimated by the Australian Bureau of Statistics. Note: \* =  $p < .05$ .

<sup>†</sup> Reference group. Those who refused or answered “don’t know” were excluded from the analysis (n=39, reflects the sample totals rather than weighted data).

**Table 2 Characteristics of respondents who have an advance directive**

Characteristic	Proportion with AD (95% CI)	OR (95% CI)	Wald <sup>‡</sup>	p-value
<b>Financial enduring power of attorney</b>				
• No EPA	4.4% (3.4% – 5.4%)	1 <sup>†</sup>		
• EPA	38.8% (35.1% – 42.4%)	8.87 (6.33 – 12.44)	160.32	<.001
<b>Will making behaviour</b>				
• Non-will maker	4.2% (2.9% – 5.4%)	1 <sup>†</sup>		
• Will maker	22.0% (19.8% – 24.2%)	2.50 (1.51 – 4.12)	12.82	<.001
<b>Relationship status at time of survey<sup>§</sup></b>				
• Married	14.9% (12.7% – 17.7%)	1 <sup>†</sup>		
• De-facto relationship	10.3% (6.1% – 14.5%)	1.08 (0.57 – 2.07)	0.06	.811
• Other	15.2% (13.0% – 16.8%)	1.70 (1.17 – 2.45)	7.85	.005
<b>Age</b>				
(continuous variable)	M = 47 yrs (Range: 18-98 yrs)	1.00 (0.99 – 1.02)	0.37	.542
<b>Gender</b>				
• Male	13.0% (11.1% – 14.9%)	1 <sup>†</sup>		
• Female	16.5% (14.4% – 18.6%)	1.23 (0.91 – 1.67)	1.79	.181
<b>Estimated value of estate</b>				
• <\$200,000	7.3% (5.3% – 9.2%)	1 <sup>†</sup>		
• \$200,000 - \$500,000	11.9% (9.2% – 14.6%)	0.81 (0.51 – 1.29)	0.81	.369
• >\$500,000	20.4% (17.5% – 23.3%)	1.24 (0.80 – 1.94)	0.93	.335
<b>Parenthood</b>				
• Non-parent	9.0% (6.7% – 11.3%)	1 <sup>†</sup>		
• Parent	16.6% (14.9% – 18.3%)	1.47 (0.86 – 2.50)	2.00	.158
<b>Ethnic diversity<sup>¶</sup></b>				
• Moderate / high ethnic diversity	8.8% (4.3% – 12.4%)	1 <sup>†</sup>		
• Little or no ethnic diversity	15.4% (13.9% – 17.0%)	1.05 (0.59 – 1.87)	0.02	.879
<b>Financial dependents at time of survey</b>				

• Yes	12.9% (10.9% - 14.8%)	1 <sup>†</sup>		
• No	16.4% (14.3% - 18.4%)	1.02 (0.68 – 1.52)	0.01	.938
<b>Highest level of education</b>				
• Primary	25.7% (10.5% - 40.9%)	2.19 (0.77 – 6.21)	2.16	.141
• Some secondary	15.7% (12.5% - 18.8%)	0.83 (0.55 – 1.27)	0.70	.402
• Completed secondary	12.2% (9.6% - 15.3%)	0.93 (0.61 – 1.42)	0.11	.740
• Post-secondary	14.2% (11.2% - 17.1%)	1.07 (0.71 – 1.59)	0.10	.755
• Tertiary	15.9% (13.3% - 18.5%)	1 <sup>†</sup>		

Note: <sup>†</sup> Across all comparisons, 1 denotes the reference group against which the remaining categories are compared.

<sup>‡</sup> The Wald statistic indicates the strength of the relationship between each unique predictor and ADs.

<sup>§</sup> De-facto relationship includes same-sex de-facto relationships. The “Other” category is comprised of respondents who reported they were currently single, separated, divorced, widowed or in a non-de facto relationship.

<sup>¶</sup> The survey collected a range of measures to assess ethnic diversity including: respondent’s birthplace, parent’s birthplace, and language spoken at home. Respondents reporting any combination of two or more indicators were categorised as having moderate/high ethnic diversity.