



**Advance Care
Planning Australia**

An Australian Government initiative

Advance Care Planning Prevalence in Australia 2025

Suggested citation: Advance Care Planning Australia (2025). Advance care planning prevalence in Australia 2025. Available at: <https://www.advancecareplanning.org.au/>

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Disclaimer: This document was prepared by Quantum Market Research on behalf of Advance Care Planning Australia, an Australian Government initiative administered by Metro South Health (MSH) ABN 86 834 016 8616, via the Brisbane South Palliative Care Collaborative.

The purpose of this report is to present the findings of the national prevalence study of advance care planning in the Australian community. This report should not be relied upon for any other purpose. The views expressed in this publication are those of the authors and do not necessarily represent those of the Australian Government or MSH. MSH accepts no liability for any loss, damage or injury resulting from the use of, or reliance on, the information provided in this report.



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Executive summary



Top level findings

- 1 | Only 33% of Australian adults have undertaken any form of advance care planning (ACP).
- 2 | Only one in five Australians (19%) have discussed their future health care with someone else; even fewer have completed formal documents, including 13% who have formally appointed a substitute decision-maker and 6% who have completed an advance care directive.
- 3 | Discussions usually occurred with the person's own social network: partner/spouse (60%), adult children, parents, close friends, and siblings. Discussions with health care professionals (12%) were uncommon.
- 4 | Australians can see the benefits of advance care planning, particularly for loved ones, and 73% are open to talking about it.
- 5 | More awareness is needed: Awareness of advance care planning is low – only 35% were familiar with it.
- 6 | More support is needed: Barriers include not knowing where to start, being unsure how to do it, perceived cost and difficulty.

Executive summary



Are Australians prepared?

Most Australians are not fully prepared for future health care decisions. Only one-third have engaged in some form of advance care planning (ACP), with just 6% having completed a formal Advance Care Directive (ACD) and 13% having formally appointed a Substitute Decision Maker (SDM). While conversations are more common than documentation, there is still a large proportion of Australians who have neither discussed nor recorded their future care preferences. Older adults, people with long-term health conditions, and residents of Queensland and South Australia are more likely to be prepared, but overall, preparedness was low.



How do Australians view ACP?

ACP was not broadly understood by most Australians. While 80% had heard of ACP-related concepts, only 35% reported being familiar with ACP. Many Australians, particularly those aged 25 to 54, had thought about their care preferences but have not acted. This suggests potential to prompt people to take action through better education and engagement strategies. Younger individuals tended to see ACP as something for older people, contributing to delays in planning.



Why aren't more Australians preparing?

Key barriers to ACP included lack of knowledge, perceived irrelevance, and practical hurdles. The top reasons cited were not knowing where to start (29%), trusting family or friends to know what they want (27%), believing they are too young (27%), and uncertainty about future health (24%). The requirements of the process being complex, time constraints, and cost were also identified as barriers, especially for women, single people, and people with disabilities. The combination of reluctance to confront emotions associated with sickness and end of life and system-level complexity also contributes to low uptake.

Executive summary

ACP is a team effort



ACP works best when supported by a team of trusted people such as family and loved ones, health care professionals, and legal advisors. Yet, formal appointment of substitute decision makers (SDM) was low, even though nearly one in four Australians had been asked to take on this role for someone else. While most ACP conversations happen with partners, children, or close friends, few involved health care providers, legal advisors, or aged care professionals. Additionally, digital tools like My Health Record were not commonly used for storing ACP documents. Strengthening the roles of professionals (such as health care professionals and legal advisors) and integrating ACP into routine care could help improve uptake and effectiveness.



Why it matters to Australians

Australians value ACP for personal and interpersonal reasons. The leading motivations were peace of mind (51%), easing the burden on family and friends (44%), and ensuring everything is taken care of (40%). These motivations highlight the emotional and practical importance of ACP in helping people feel secure and in control of their future care. Carers, older adults, and those in poor health were especially driven by the desire to reduce stress for others and to formalise their preferences.

Background and methodology



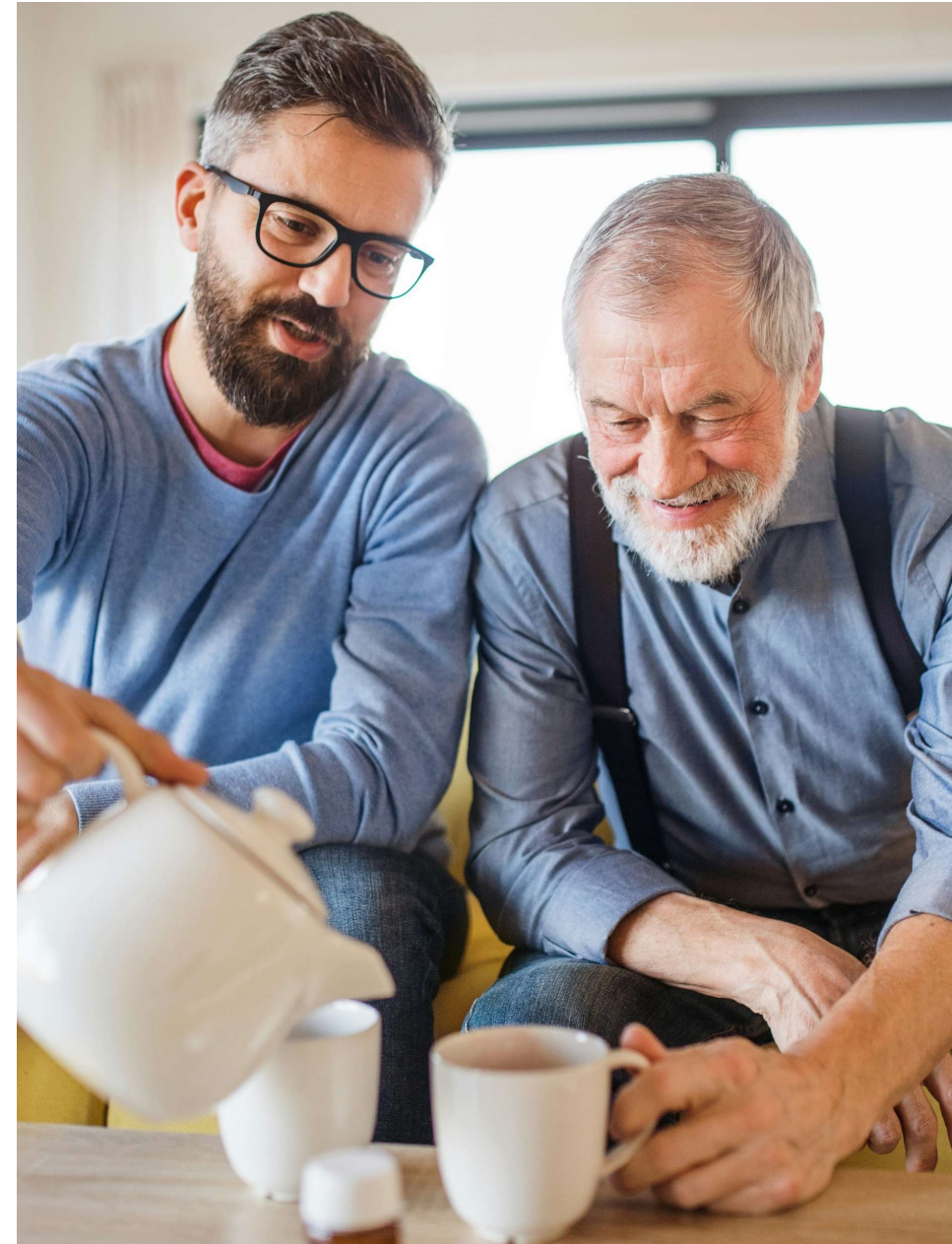
Project background

Advance care planning (ACP) involves making decisions about future health care preferences in case an individual becomes unable to make or communicate these decisions themselves. It is an ongoing process of reflection and discussion with health care professionals and loved ones to identify and communicate personal goals, values, and care. ACP may include completing legally binding documents, such as an Advance Care Directive, and/or appointing a substitute decision-maker, like an enduring power of attorney (health care matters) or enduring guardian.

An **Advance care directive** (ACD) is a statutory document that can include specific instructions about refusing medical treatments (or refusing and / or accepting medical treatments in some jurisdictions). It is also known as an Advance Health Directive in some Australian states.

A **substitute decision-maker** (SDM) is a person legally appointed or identified by the law to make health care decisions on behalf of a person that has impaired decision-making capacity. A substitute decision-maker may be chosen and formally appointed by the person, appointed for (on behalf of) the person by the courts, or identified as the default decision-maker within legislation.

Research presented in this report was commissioned by Advance Care Planning Australia (ACPA) and conducted by Quantum Market Research. ACPA is a national program funded by the Australian Government Department of Health and Aged Care and administered by Metro South Health. Its primary goals are to inform, educate, and promote awareness and national uptake of ACP.



Objectives

There is limited evidence on the prevalence of ACP at a national level in Australia. Existing research indicates that ACP uptake is low in the Australian community. However, this research has mainly focused on formal ACP documents and has concentrated on older populations.

To address these gaps, the objectives of this research were to:

1. Explore engagement with ACP among all Australian adults.
2. Develop robust measures of national ACP prevalence using several indicators of ACP engagement, including conversations and completion of formal documents.
3. Identify the barriers and enablers that influence the process across different age, demographic, and cultural groups.
4. Gain an improved understanding of factors associated with ACP engagement, including demographic and attitudinal factors.



Study design overview



Survey with Australians (18+) sourced from an online research panel



The study was approved by the Metro South Health Research Ethics Committee



Survey results were weighted to be representative of the Australian adult population by age, gender and location



Fieldwork was conducted between 17th February and 17th March 2025

Total sample size n=3,390

n=	Male						Female						State
	Age						Age						total
	18-24	25-34	35-54	55-64	65+	Total	18-24	25-34	35-54	55-64	65+	Total	
NSW	52	85	158	71	100	466	49	87	164	74	117	491	957
VIC	43	73	129	54	76	375	42	75	134	58	94	403	778
QLD	32	50	100	46	63	291	33	54	106	50	71	314	605
SA	21	33	63	31	46	194	20	33	65	33	55	206	400
WA	23	40	79	36	44	222	23	41	80	35	51	230	452
TAS	4	8	13	7	11	43	4	8	14	8	13	47	90
NT	1	3	5	2	2	13	2	3	5	2	2	14	27
ACT	5	9	14	5	7	40	5	9	14	5	8	41	81
Total	181	301	561	252	349	1644	178	310	582	265	411	1746	3390

The maximum margin of error (at the 95% confidence interval) on the total sample size is $\pm 1.8\%$

The project was carried out in line with the Market Research International Standard, AS ISO 20252.

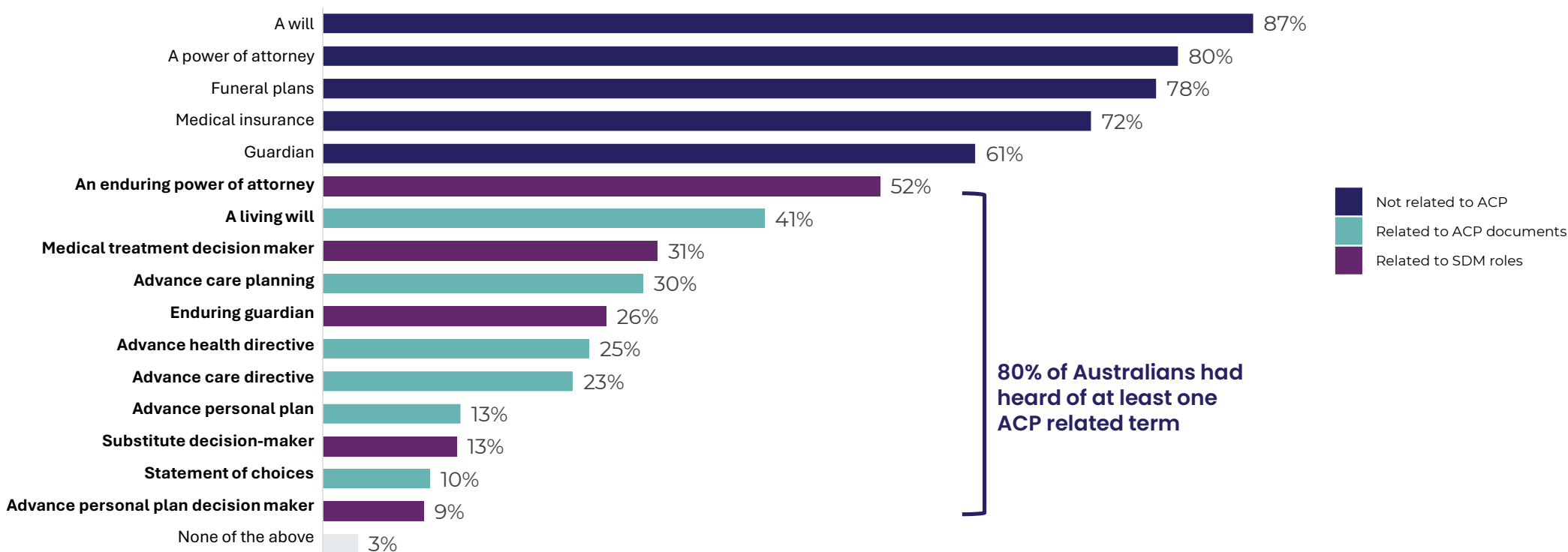
Further information can be found in the Detailed Methodology section of this report.

Detailed findings



Whilst awareness of specific ACP terms was low, most Australians had heard of something to do with it

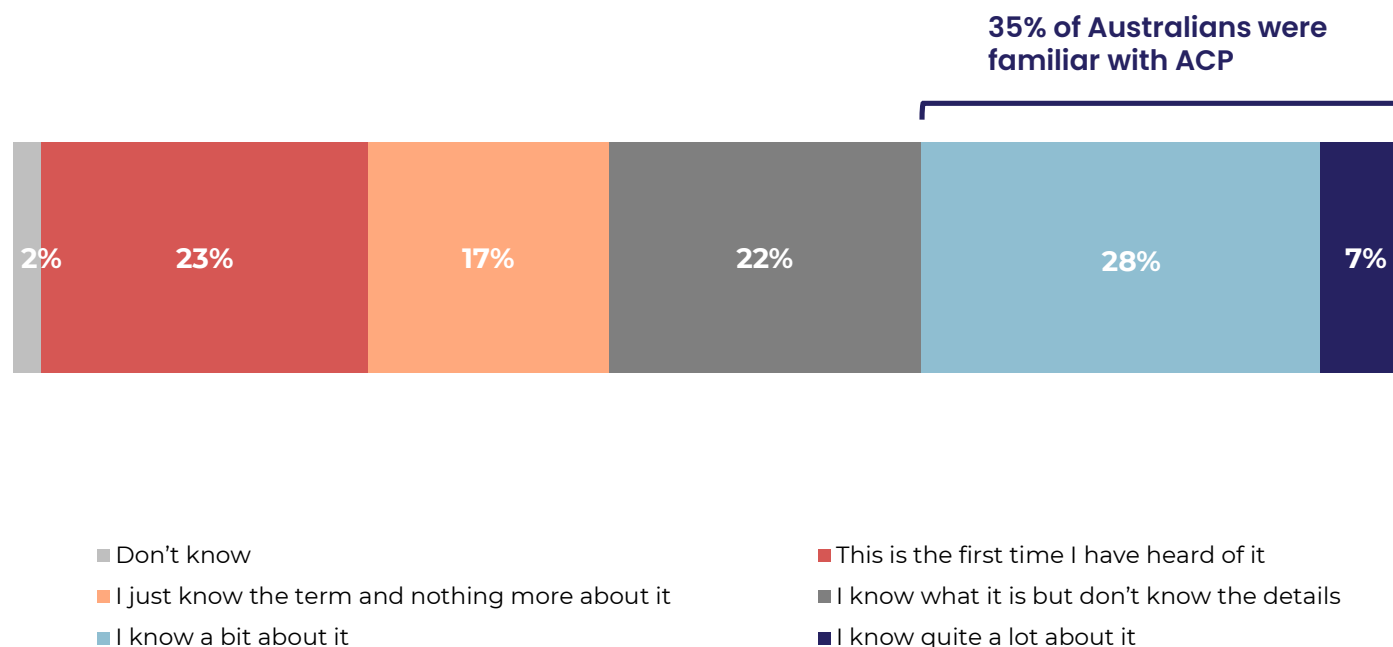
Awareness of ACP and related concepts



Q5 - Before today, which of the following have you heard of?
Base: All respondents (n=3,390)

Despite having heard of some terms, only a third felt they were familiar with ACP

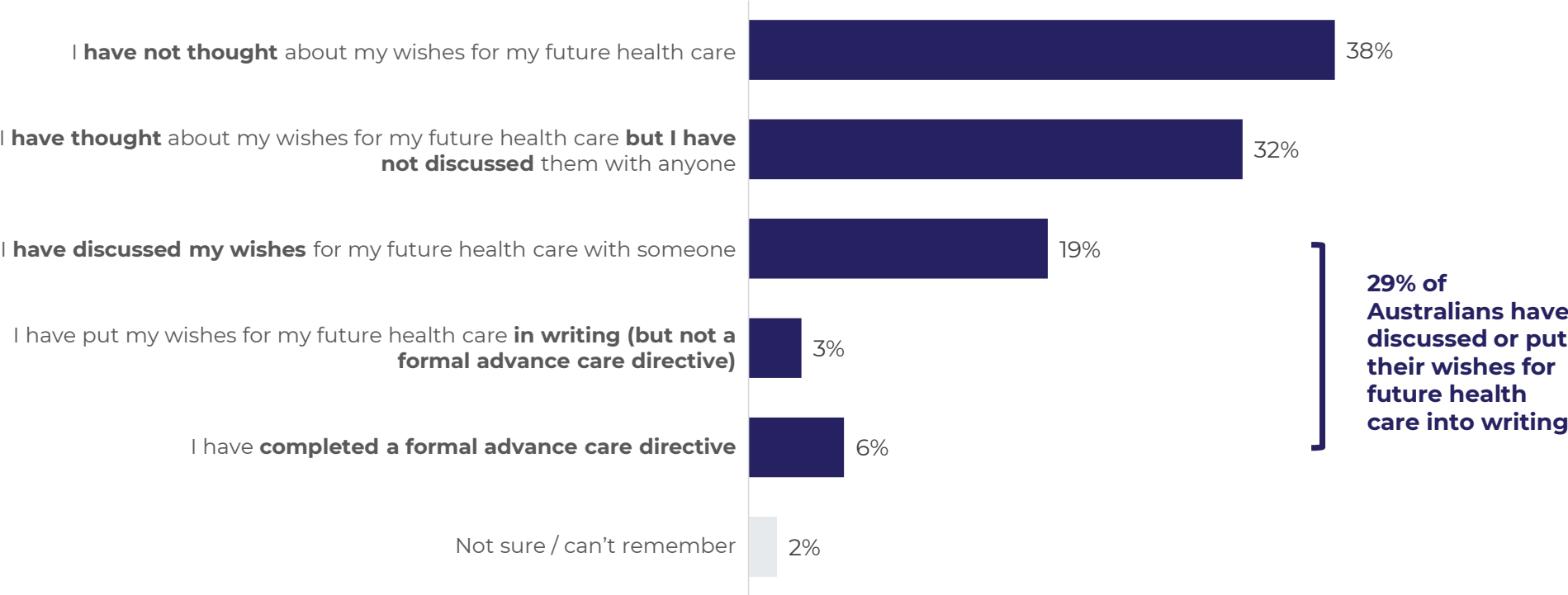
Familiarity with ACP



Q4 - How much would you say you know about advance care planning?
Base: All respondents (n=3,390)

Nearly four in ten Australians have not thought about their wishes for future health care

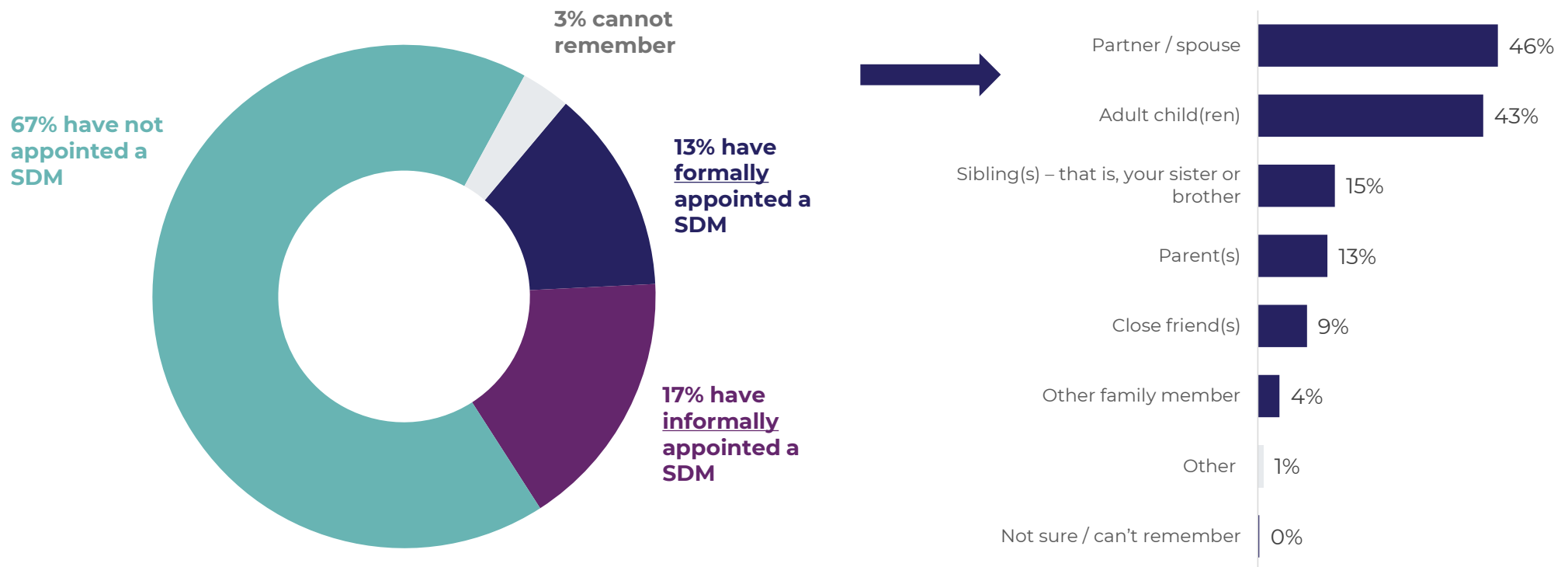
Percentage of Australians who have discussed or put their future wishes into writing



Q7 - Which of the following statements applies to you?
Base: All respondents (n=3,390)

The majority of Australians have not appointed a Substitute Decision Maker, either formally or informally

Percentage of Australians who have appointed a SDM and who they chose to be a SDM



Q13 - Have you appointed a Substitute Decision Maker for health care decisions?

Q14 - Who did you appoint as your Substitute Decision Maker?

Base: All respondents (n=3,390) and those who have formally nominated and SDM (n=429) 16

Australians were most likely to pick a SDM who they trust and they know would act on their wishes

Reasons for nominating a SDM – top 4



54% They would respect and act on my wishes



54% I trust their judgement



50% They know me best



49% They understand what I want and value

On average, SDMs were chosen for 4 different reasons showing that multiple factors influence who people nominate.

A third of Australians have undertaken some form of advance care planning

Prevalence of advance care planning among Australians



19% of Australians have discussed their wishes for future care with someone



6% of Australians have completed an advance care directive



3% of Australians have put their wishes for future care into writing (but not a formal advance care directive)



13% of Australians have formally appointed a substitute decision maker

=

33% of Australians have engaged in advance care planning to some extent

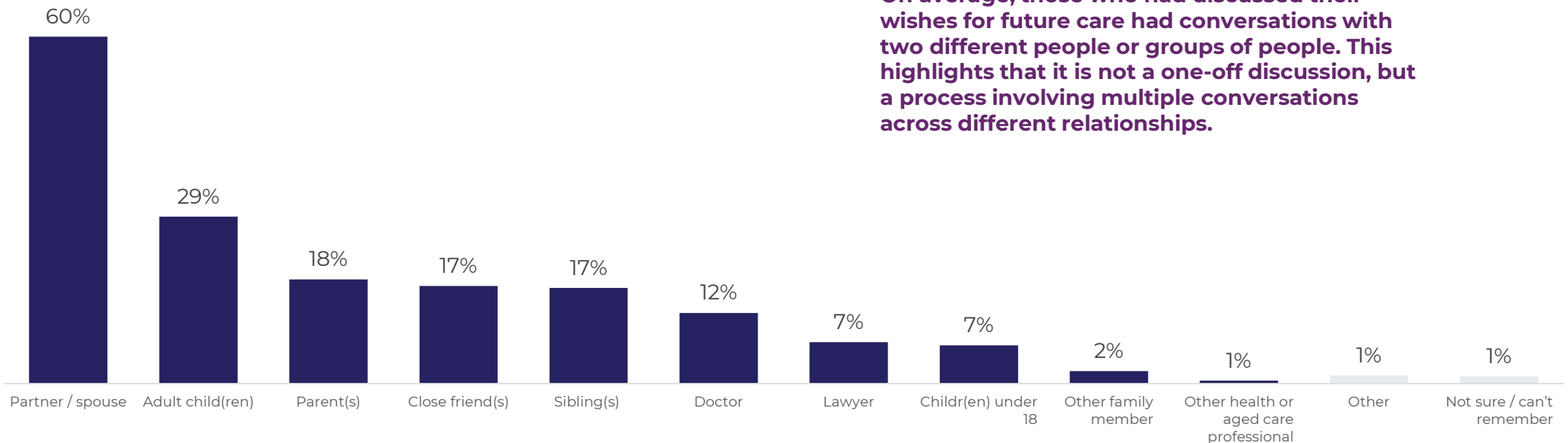
Combined metric: Q7 - Which of the following statements applies to you?
Q13 - Have you appointed a Substitute Decision Maker for health care decisions?
Base: All respondents (n=3,390)

Australians primarily turned to their partners / spouses when discussing their wishes for future care

Who wishes for future care were discussed with



19% of Australians have discussed their wishes for future care with someone



On average, those who had discussed their wishes for future care had conversations with two different people or groups of people. This highlights that it is not a one-off discussion, but a process involving multiple conversations across different relationships.

Q8 - Who did you discuss your wishes for your future health care with?
Base: Those who have discussed their wishes for future care with someone (n=652)

Discussions around future care largely consisted of medical treatments and health care

What was discussed when talking about wishes for future care – top 5



Q9 - When you discussed your future health care with someone, what did you talk about?

Base: Those who have discussed their wishes for future care with someone (n=652)

Although few people discussed ACP with a health care professional, those who did found them to be respectful, knowledgeable, confident and comfortable

Experience discussing with health care professionals



12% of those who had discussed their future health did so with a health care professional

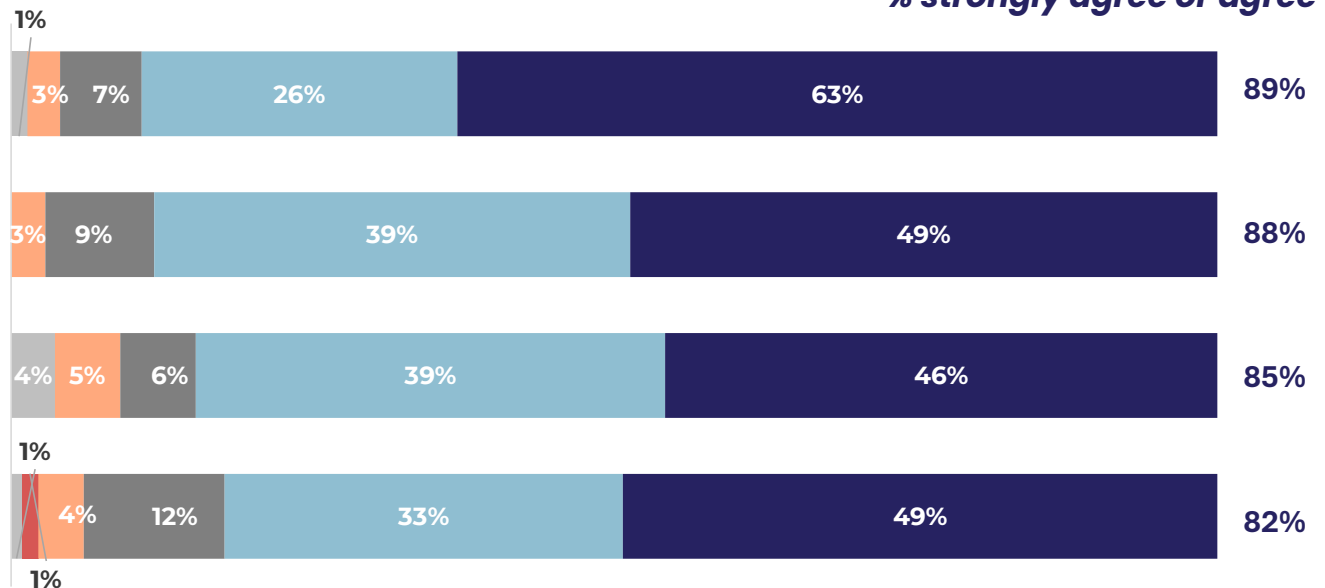
They were respectful

They were knowledgeable

They were confident talking about my values and wishes

They were comfortable with the topic

% strongly agree or agree



■ Not sure ■ Strongly disagree ■ Mildly disagree ■ Neither agree nor disagree ■ Mildly agree ■ Strongly agree

Q11 - When you discussed your wishes with your doctor or other health professional to what extent do you agree with the following?

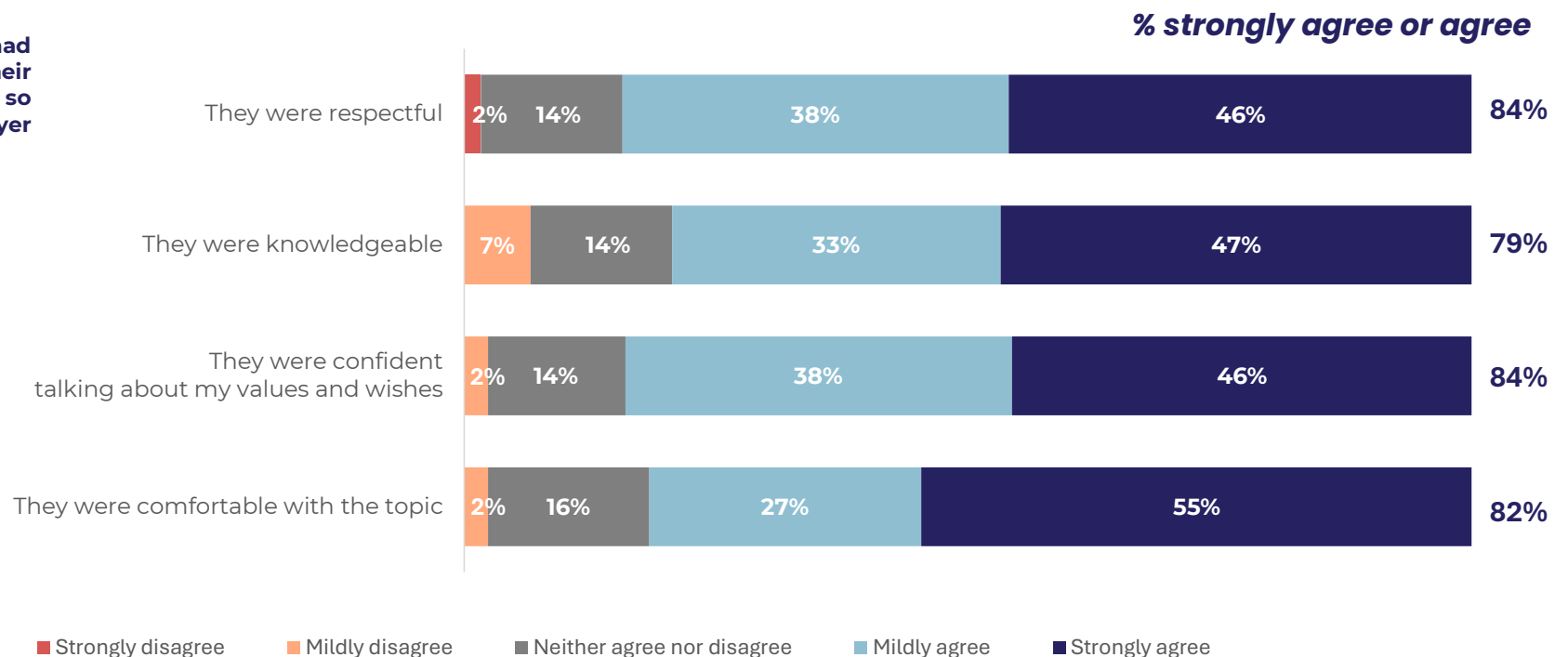
Base: Those who have discussed their wishes for future care with a health care professional (n=82)

Engaging a lawyer in ACP was less common, but those who did also found them to be respectful, knowledgeable, confident and comfortable

Experience discussing with lawyers



7% of those who had discussed their future health did so with a lawyer

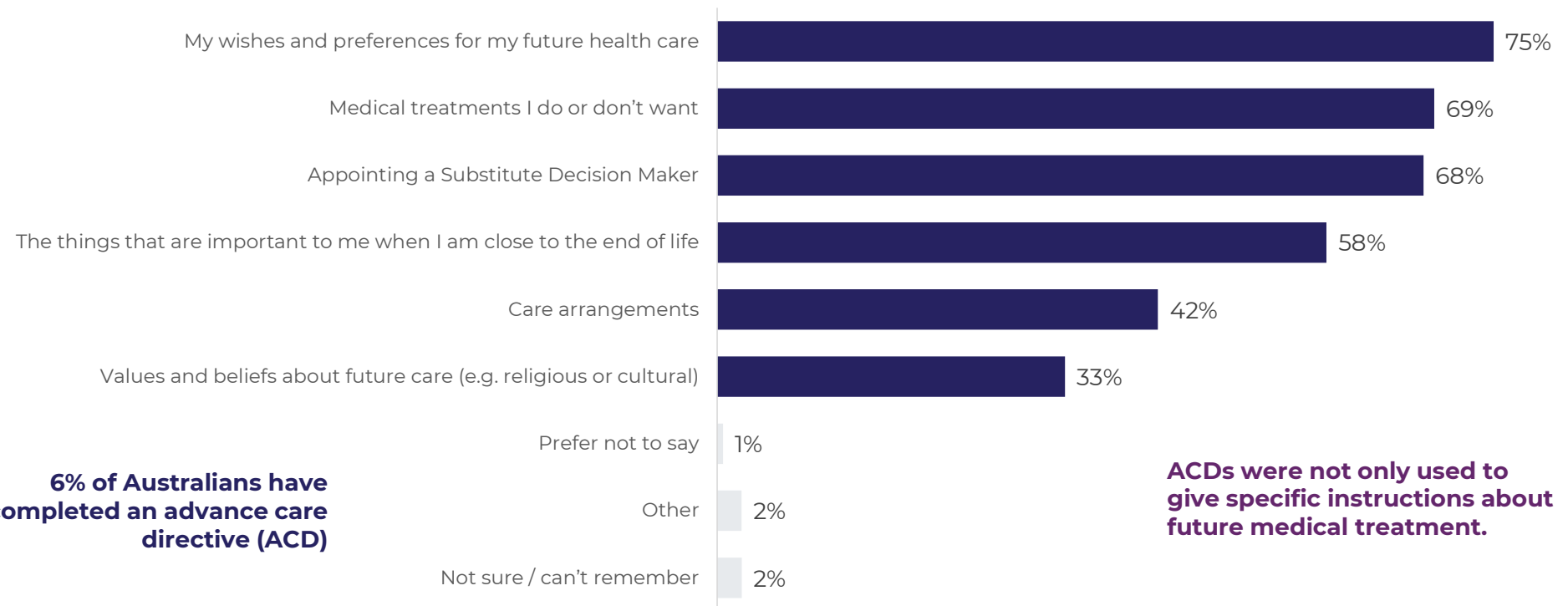


Q11a - When you discussed your wishes with your lawyer to what extent do you agree with the following?

Base: Those who have discussed their wishes for future care with a lawyer (n=46)

ACD most commonly contained wishes and preferences for future health care

Contents of ACD



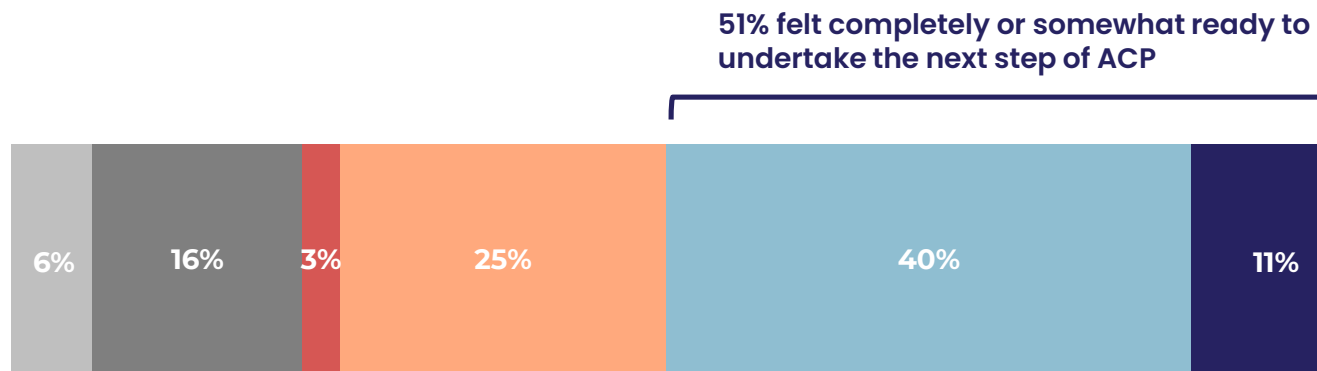
6% of Australians have completed an advance care directive (ACD)

ACDs were not only used to give specific instructions about future medical treatment.

Q12 - What does your advance care directive contain?
Base: Those who have completed a formal ACD (n=208)

Australians were split on being ready to take the next step

Readiness to undertake next step in the ACP process

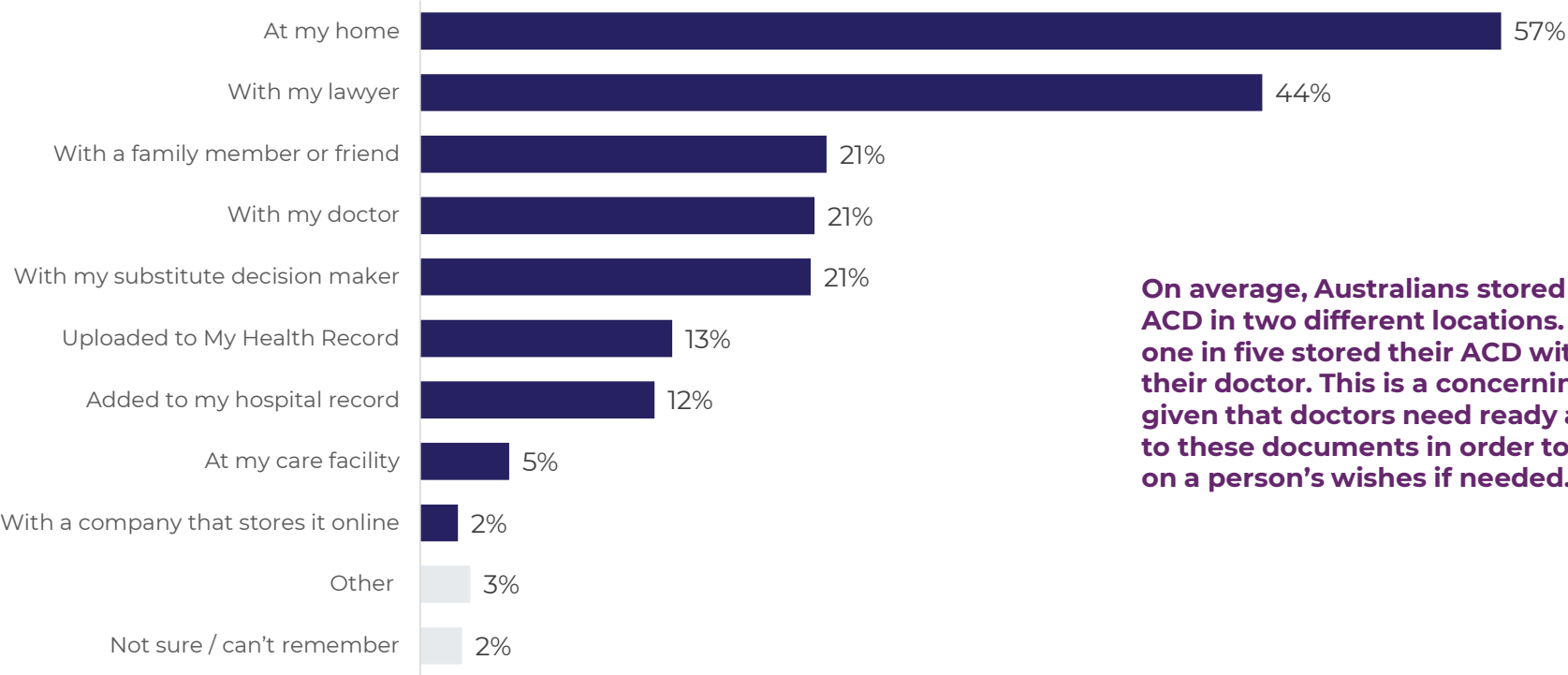


■ Not sure ■ I haven't decided either way ■ I have decided I do not want to ■ Not ready at all ■ Somewhat ready ■ Completely ready

Q22 - How ready do you feel to sign / complete formal documents / put your wishes for your future health care in writing / discuss your wishes for your future health care with someone? Base: Those who have not completed a formal ACD excluding those who preferred not to say (n=3,101)

Over half of Australians stored their ACD at home

ACD storage

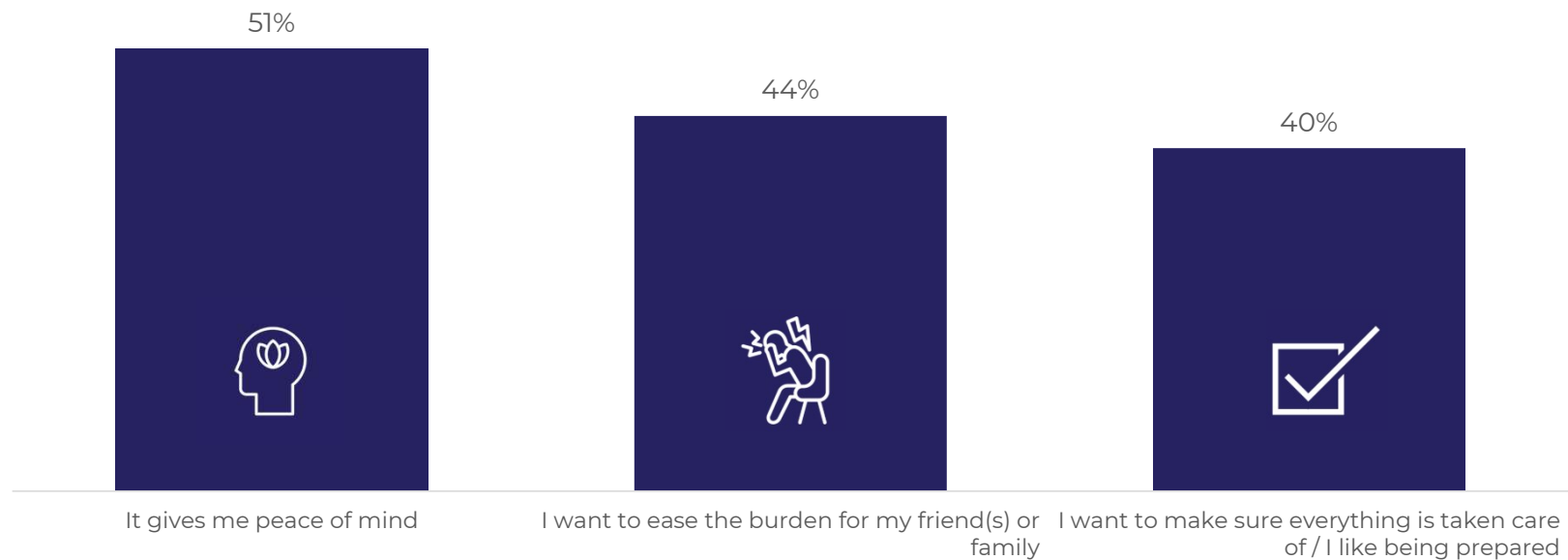


On average, Australians stored their ACD in two different locations. Only one in five stored their ACD with their doctor. This is a concerning gap given that doctors need ready access to these documents in order to act on a person's wishes if needed.

Q19 - Where is your advance care directive stored?
Base: Those who have completed a formal ACD (n=208)

Reasons for discussing or writing down wishes were focused on providing security for themselves or others

Most common reasons for discussing or putting wishes for future health care into writing or discussing – top 3

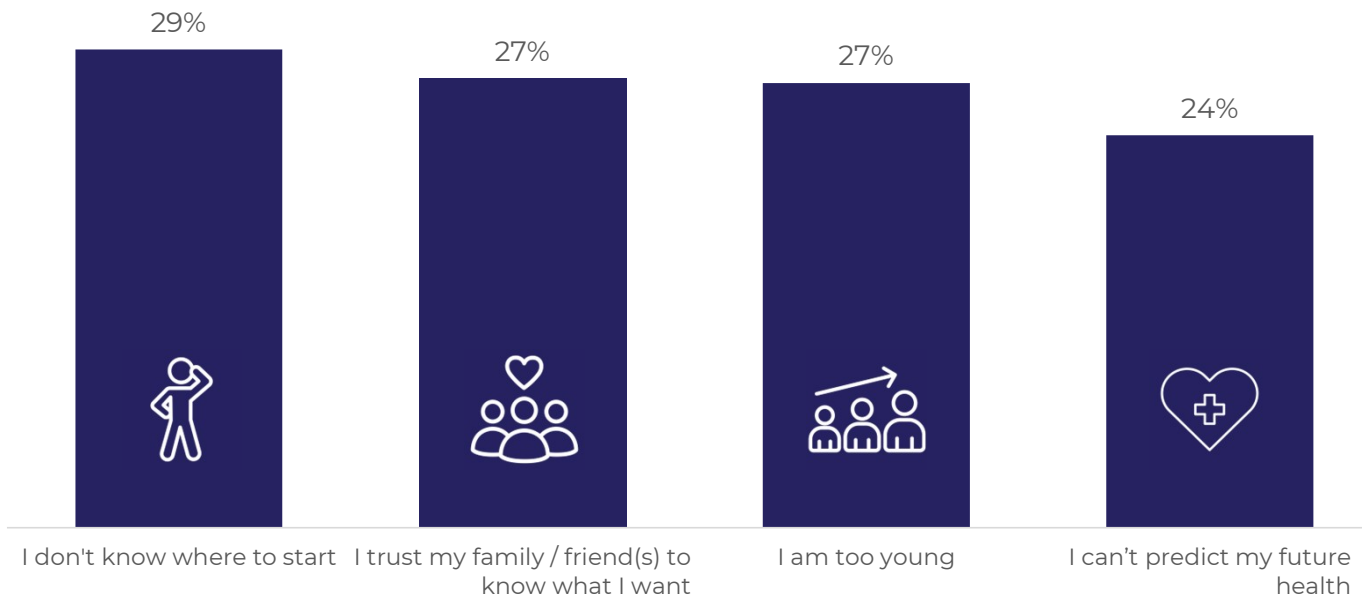


Q23 - Here are some reasons others have told us for completing an advance care directive / discussing their wishes about their future health care with others . Which apply to you?

Base: Those who have discussed or put their wishes into writing (n=975)

Reasons for not doing any kind of ACP were focused on trust, lack of need and uncertainty about future health and the process

Most common barriers for not undertaking any sort of ACP – top 4



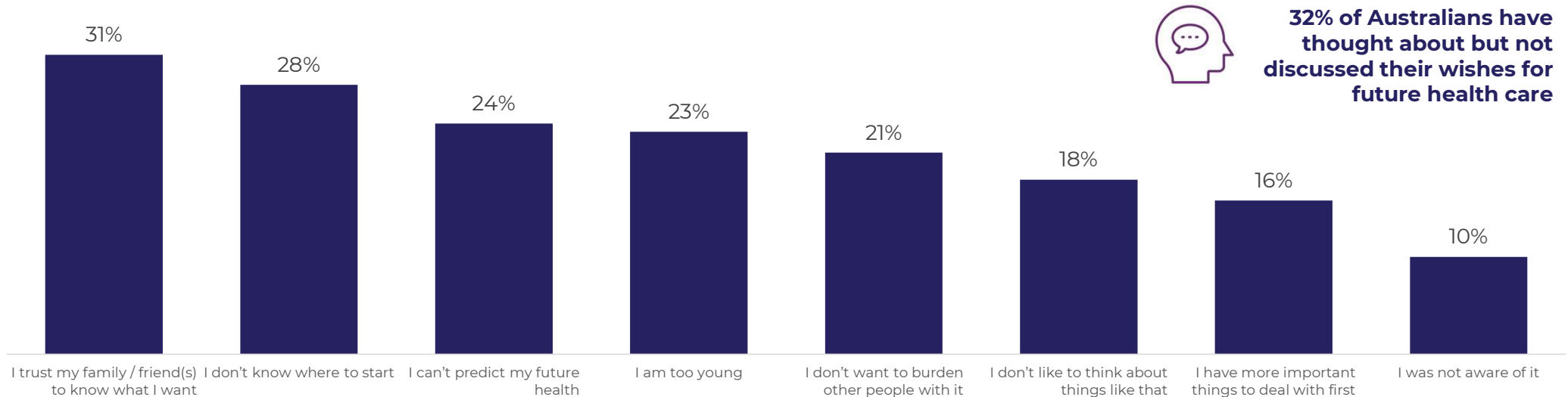
67% of Australians have not undertaken any form of advance care planning

Q20 - Here are some reasons others have told us they haven't discussed their future health care. Which apply to you?

Base: Those who have not done any form of advance care planning (n=2,221)

A third did not discuss their wishes as they trusted family / friends would already know what they wanted

Reasons for not discussing wishes for future health care after thinking about them*



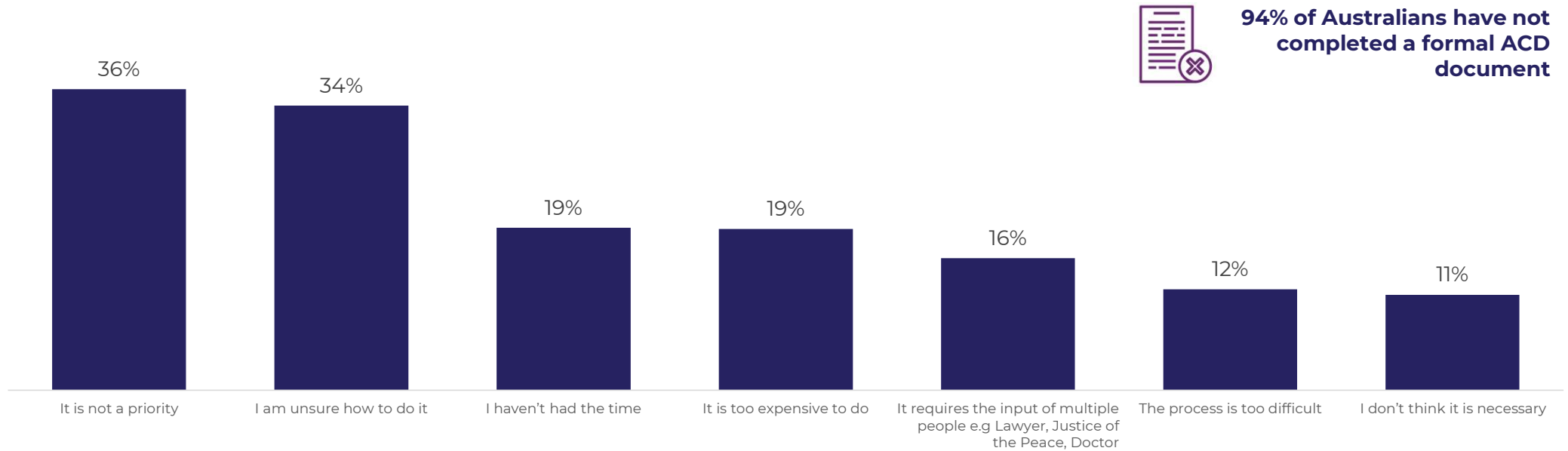
On average, Australians identified two different barriers that prevented them from discussing their wishes for future care with someone else, highlighting that it is rarely a single factor that holds people back.

Q20 - Here are some reasons others have told us they haven't discussed their future health care. Which apply to you?

Base: Those have thought about future health care but not discussed with someone (n=1,076) *results above 10% shown

A third did not complete a formal ACD as it was not a priority, or they were unsure how to do it

Reasons for not completing a formal ACD*

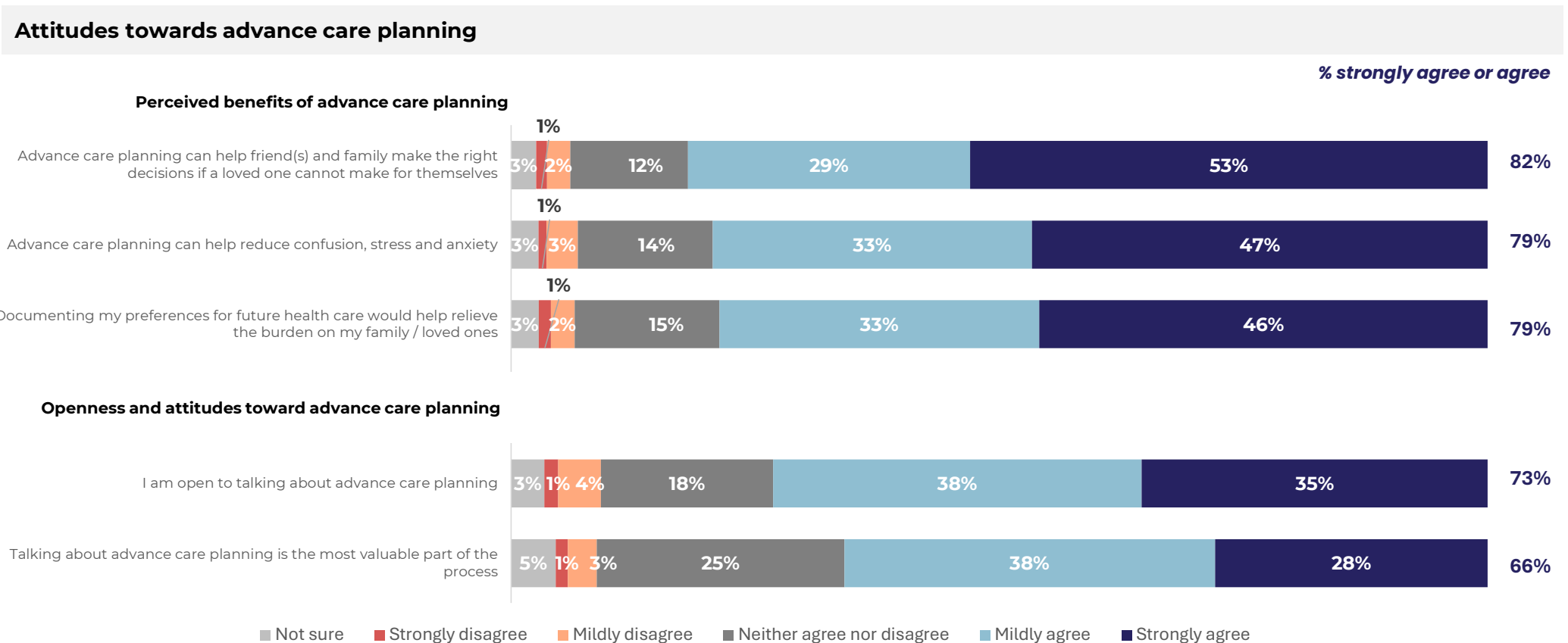


Q24 - The following are some reasons people have not put their wishes into writing or completed a

formal advance care directive, which apply to you?

Base: Those who have not completed a formal ACD (n=2,700) *responses above 10% shown

Australians showed strong support for ACP and the potential benefits...



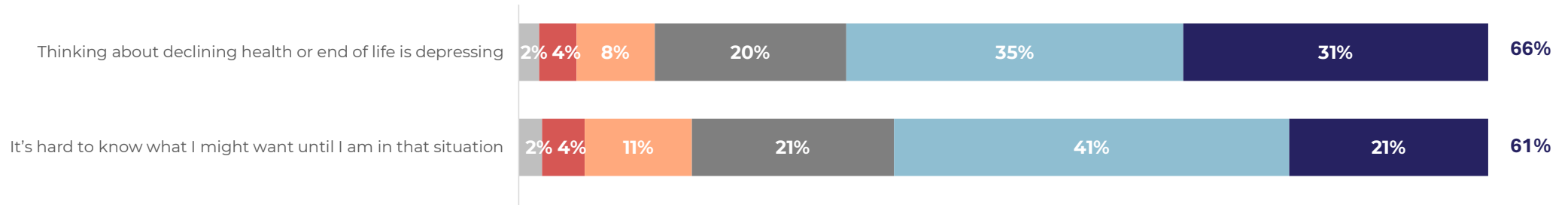
Q32 - How strongly do you personally disagree or agree with the following statements about advance care planning?
 Base: All respondents (n=3,390)

...but were less certain about the timing and need

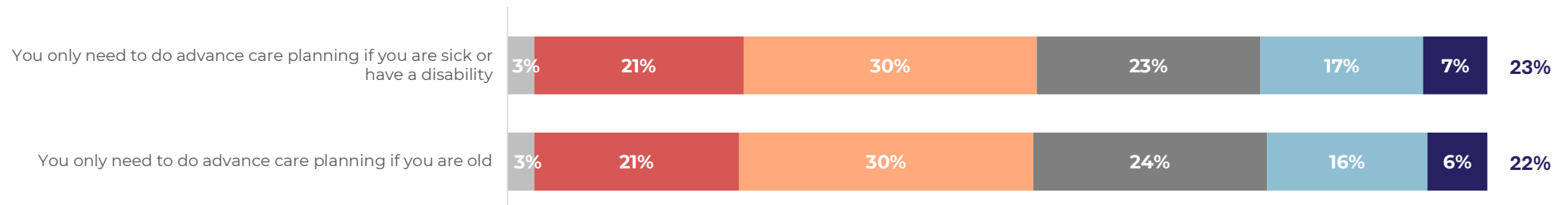
Attitudes towards advance care planning

% strongly agree or agree

Emotional Discomfort or Psychological Barriers



Misconceptions or Conditional Beliefs



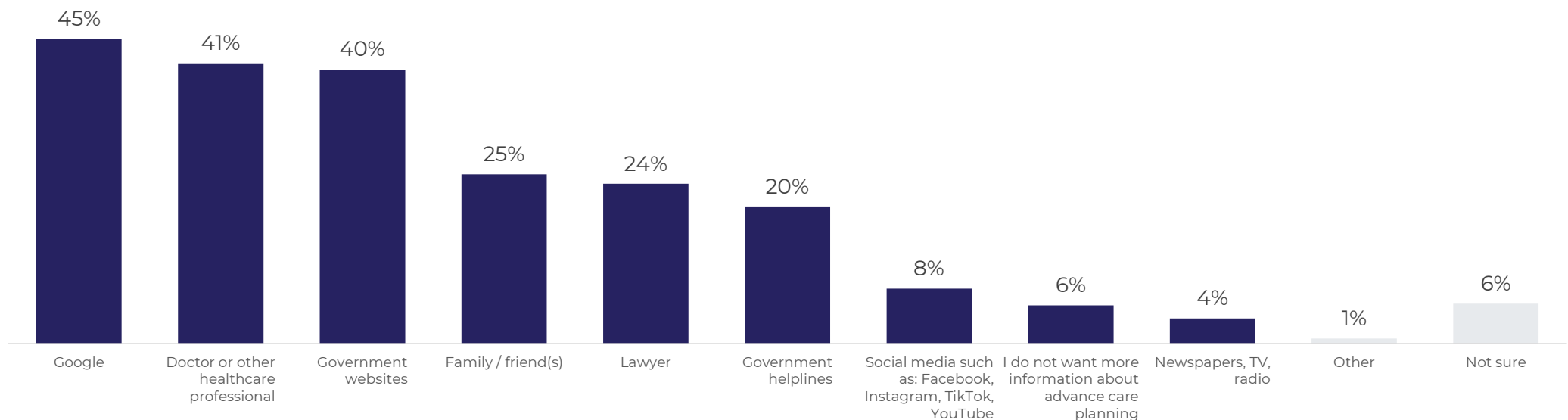
■ Not sure ■ Strongly disagree ■ Mildly disagree ■ Neither agree nor disagree ■ Mildly agree ■ Strongly agree

Q32 - How strongly do you personally disagree or agree with the following statements about advance care planning?

Base: All respondents (n=3,390)

After Google, Australians were most likely to turn to health care professionals or government sources to learn more about ACP

Sources for more information about ACP

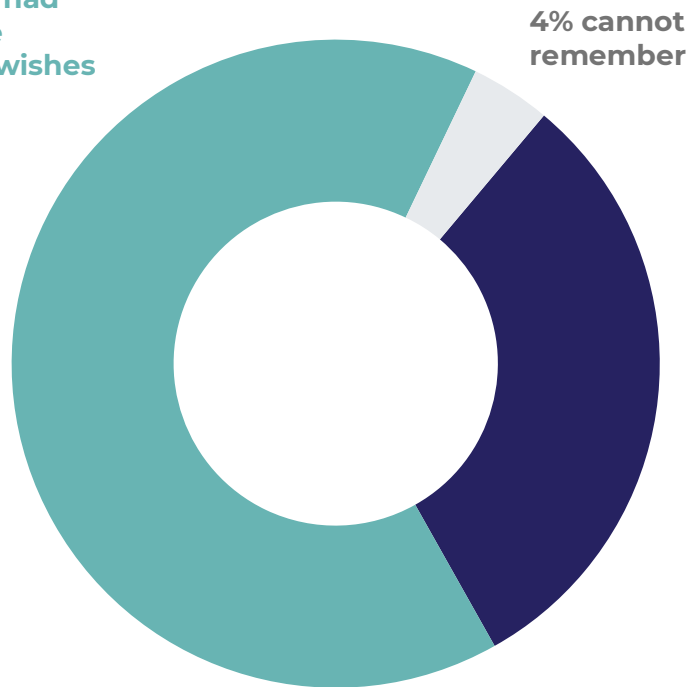


Q25 - Where would you look for more information about advance care planning?
Base: All respondents (n=3,390)

A third of Australians have had someone else discuss their wishes for future health care with them

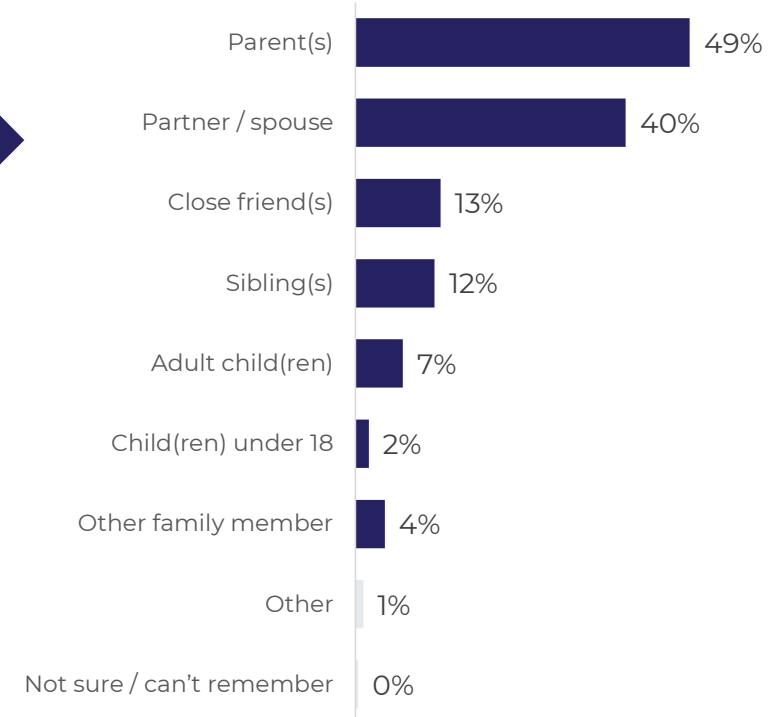
Percentage of Australians who have had someone else discuss their wishes for future care with them and who it was

65% have not had someone else discuss their wishes with them



4% cannot remember

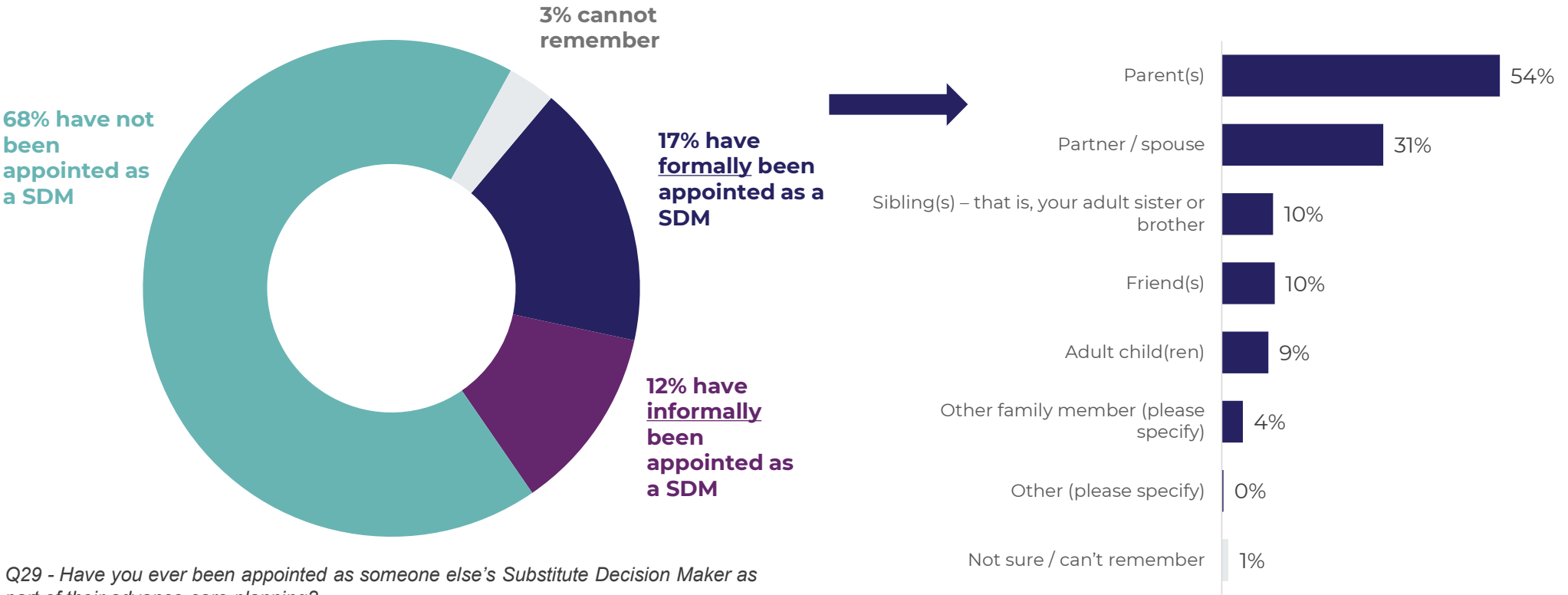
31% have had someone else discuss their wishes with them



Q26 - Has anyone discussed their wishes for their future health care with you ?
Base: All respondents (n=3,390), Those who had someone else discuss with them (n=1,040)

Nearly one in four Australians have been appointed as someone else's SDM

Percentage of Australians who have been appointed as someone else's SDM and who for (formally)



Q29 - Have you ever been appointed as someone else's Substitute Decision Maker as part of their advance care planning?
Q30 - Who are / were you the appointed Substitute Decision Maker for?
Base: All respondents (n=3,390) and those formally appointed as someone else's Substitute Decision Maker (n=585)

Socio-demographic characteristics influencing advance care planning:

Age



Older age correlated strongly with ACP engagement, whereas younger people perceived ACP as unnecessary. Older ages, particularly those aged 65+, were significantly more likely to have engaged in ACP, compared with lower rates in younger age groups. This older age group was more likely to have completed ACDs, be appointed formally as a SDM, and discussed preferences for future health care. Younger individuals (18–34) were more likely to have believed they were 'too young' for ACP, were less familiar with it, and cited barriers such as not knowing where to start. **As age increased, so did readiness to engage in ACP, familiarity with the concept, and the likelihood of document completion.**

Gender



There were no significant differences in ACP engagement by gender, however, women were more active in discussions. Women were more likely to have talked to adult children about ACP, been formally appointed as a SDM, and included detailed preferences in their ACDs. They also identified more reasons for engaging in ACP, such as peace of mind and reducing burden. **While both genders engaged with ACP at similar rates, women were more likely to have driven ACP conversations, particularly with family.**

State / Territory



ACP engagement varied considerably by location. Tasmanians were the least likely to have engaged in ACP in anyway, were less aware of ACP, and had lower rates of formal SDM appointments. Residents of Queensland and South Australia had the highest rates of engagement, were more likely to have been appointed as a SDM and to have discussed preferences for future health care. Residents from these states also had the highest ACD completion rates. **Overall Queensland and South Australia appeared most prepared, while Tasmania was less prepared in terms of readiness and engagement.**

Metropolitan / Regional



Regional residents were more likely to have had ACP discussions with family members, such as adult children, and to have been appointed as a SDM. However, metropolitan residents were more likely to have uploaded ACDs to My Health Record. Regional residents were also more likely to have cited trusting family as a top reason for not having completed ACP. **Both groups demonstrated strengths with regional residents being more likely to initiate conversations, while metropolitan residents were more likely to store documents digitally as part of their health record for easy access.**

Continued:

Relationship status



Widowed and married people were more active in advance care planning, while single people were less engaged, and often reported limited personal support and lack of access to information. Widowed people were the most likely to have engaged in ACP and to have appointed a SDM. Married people also showed higher engagement than single people. Single people were less likely to have felt they had someone to talk to, were less familiar with ACP, and were more likely to have said it was not a priority. Differences by relationship status could be associated with different age profiles of each group.

Parental status



Parents were significantly more likely to have engaged in ACP and documented their wishes, often citing the desire to reduce the burden on family as a key motivator. They were more engaged in ACP across all metrics, more likely to have completed ACDs, appointed a SDM, discussed future care with adult children and spouses, and stored ACDs with professionals. Those without children were more likely to have reported feeling too young or unsure how to start the process. **Along with relationship status, this suggests that going through major life changes increases the likelihood of engaging with ACP.** Like relationship status, differences between parents and those without children could be associated with parents (as a group) being older.

Health



Health challenges drove ACP engagement, though they also increased barriers. Individuals with a long-term health impairment were much more likely to have engaged in ACP, stored documents with doctors and hospitals, and discussed specific treatments. However, they also faced more barriers, including difficulty navigating the process and not having someone to talk to. This could be because older people are more likely to have long term health conditions.

Cultural background



People from culturally and linguistically diverse (CALD) backgrounds were less likely to have engaged in ACP or to have been appointed as a SDM. They were more likely to have stored ACDs with their SDM and discussed who to contact but showed lower overall familiarity and awareness. CALD individuals were less engaged overall in ACP.

Continued:

Religious affiliation



Religious affiliation supported higher ACP engagement, particularly in terms of motivation. Those with a religious affiliation were slightly more likely to have engaged in ACP and to have been appointed as a SDM. They more often cited peace of mind and preparation as reasons for undertaking ACP. No major differences in document content or barriers were observed. These differences could be because older people are more likely to have a religious affiliation.

Sexual identity



There were no major differences in ACP engagement based on sexual identity. However, non-heterosexual individuals were more likely to have cited cost and procedural complexity as barriers and were more likely to have discussed ACP with their parents. This could be due to those who identified as non-heterosexual being younger and more likely to be single compared with the total population.

Disability carer



Caring responsibilities significantly increased ACP engagement, including readiness, frequency of conversations, and document management. Carers for someone with a disability were more likely to have been appointed as a SDM, to have been familiar with ACP, and to have felt ready to take the next steps. They stored ACDs in more locations and cited reducing the burden on family as a key motivator.

Conclusion and recommendations



Opportunities for improving ACP engagement

The findings from this research highlight a clear disconnect between Australians' consideration of future care and the formal steps involved in ACP. While many have thought about their preferences, only a small proportion have documented their wishes or appointed a substitute decision-maker. ACP is typically approached informally, with most conversations occurring between close family or friends, and with limited engagement of health care professionals, legal advisors, or formal systems such as My Health Record. Similarly, around one in eight people (13%) have formally appointed a substitute decision maker, while 17% reported "informally appointing" one. This may include people who have spoken with someone about taking on this role. It may also include people who are simply assuming who this would be, such as their partner or spouse. This indicates opportunities to increase awareness of the importance and the benefits of formal appointments.

Barriers to participation are consistent across the population and include uncertainty about how to start, assumptions that ACP is only necessary later in life, reluctance to talk or think about death or decline, and perceptions that ACP involves complex processes.

Subgroup comparisons suggest significant differences by age and between states and territories. The factors contributing to higher uptake in Queensland and South Australia should be further explored to inform national practices. Further analyses which adjust for multiple factors will provide a more detailed and nuanced understanding of subgroup differences. Many people, including single individuals, people without children, and those from culturally and linguistically diverse backgrounds, lack confidence and support to navigate ACP processes. Notably, interactions with professionals (such as health care professionals and legal advisors), though rare, were described as positive as they were seen to be respectful, knowledgeable, confident and comfortable in the topic. Health professionals are seen as a trusted source of information about ACP. This indicates that there is an opportunity to encourage these touchpoints.

Overall, the data points to unmet needs in awareness of, and support for ACP. The following recommendations are designed to help bridge these gaps.



Recommendations for driving ACP engagement



Improve Awareness

Investment is needed to increase awareness of ACP across all sectors of the population.

Include tailored messaging for different groups

Launch a population-based campaign with broad reach and include tailored messaging for specific groups, for example, culturally and linguistically diverse people, carers, younger Australians.

Use multiple channels

As well as using different channels and platforms to engage different groups, building ACP into routine checks in health and aged care can also normalise ACP and build awareness and engagement.

Building ACP into routine legal practices such as wills and estate planning is another opportunity to normalise and build awareness of ACP.

Address identified gaps and misconceptions

Explain the importance of sharing ACP documents with SDMs, health professionals, and health services.

Encourage formal SDM appointments through highlighting the benefits.

Recommendations for driving ACP engagement



Increase Support

Many people would benefit from assistance to navigate the processes. ACP can be complex, especially if legal documents are involved.

Increase investment in personalised support services

Improve dedicated support services to build on free government resources and advice, to help increase uptake.

Train health and aged care professionals

Improve health and aged care professionals' confidence and skills to support people with ACP, and to recognise opportunities to raise ACP.

Improve digital document storage

Improve digital storage systems so that more people know about them, and they are easier for people, their SDMs, and health professionals to use.

Promote death literacy

Work in collaboration with other groups that are working to increase our comfort as a society in talking about death and the end of life.

Detailed Methodology



Questionnaire design

The research comprised a developmental cognitive testing phase and a quantitative survey phase. The methodology used in each phase is summarised below.

Quantitative survey

In close collaboration with Advance Care Planning Australia, Quantum Market Research designed a bespoke quantitative survey. A review of existing internationally validated ACP tools and key published academic studies was conducted, with the aim of capturing essential factors on ACP engagement and informing the design of a robust survey questionnaire. To minimise the possibility of respondent fatigue, thus ensuring high quality data, the survey was designed to take no longer than 15 minutes to complete; the average survey completion time was 11 minutes. A copy of this survey can be found in the appendix.

Cognitive testing

Before the full survey implementation, cognitive interviews and pilot testing of the questionnaire were conducted to ensure question appropriateness and alignment with the research study's aims and objectives. This ensured that questions were likely to be universally understood and interpreted, minimising subjectivity. Cognitive testing involved conducting the survey individually with a small group of target participants (n=24). A research consultant shadowed each participant, asking them to explain their understanding of each question, whether they could respond as intended (e.g., were the response options for closed-ended questions complete?), and to identify any unclear or ambiguous wording. The process aimed to highlight any aspects of the survey that could cause confusion and was typically conducted via video conference or in person.

To ensure the dynamics and complexity of ACP were adequately addressed, testing was conducted with participants from the following groups:

Location	Male	Female	Total
NSW	2	2	4
VIC	2	2	4
QLD	2	2	4
SA	2	2	4
WA	2	2	4
TAS / NT / ACT	2	2	4
Total	12	12	24



Fieldwork and sample design

Pilot testing

Following survey iterations from cognitive interviews, a pilot testing (n=30) was conducted to test the functionality of the survey tool, and ensure there were no unexpected terminations or skips, the survey ran to the stated duration, and no other issues were identified.

Survey sample design

Quantum recruited a nationally representative sample of n=3,390 Australians aged 18+, with a booster sample for smaller states. This robust sample size enabled sub-group analysis and produced a maximum margin of error of +/- 1.8% at the 95% confidence interval.

Respondents were recruited through an online panel, allowing close monitoring of who completed the survey by age, gender, and location to ensure a representative mix. The information provided was primarily for social research purposes, rather than statistical power, as this study did not involve a traditional experiment with fixed hypotheses.

Subgroup analysis

The analysis was largely exploratory to identify differences by sub-groups, with statistical power (and margin of error) for each comparison depending on the sample size, which varied by sub-group (e.g., gender, age, state) and the questions asked (some were filtered for specific sub-samples). This resulted in different group sizes and varying power analysis for each question.

While quotas were applied to ensure representativeness, it was not always possible to enforce them precisely, as multiple respondents could enter the survey simultaneously and were not recorded until they completed the survey. As a result, quotas may have slightly over- or under-represented certain groups. The data was weighted back to ensure representativeness and consistency in future studies to detect any shifts over time.



Weighting

As smaller states were boosted with a larger sample to get more robust estimates, the sample was weighted back to state representativeness to ensure all overall results reflected the Australian adult population.

Results were weighted to be representative of the Australian population by age, gender and location. Results were weighted according to:

%	Male					Female					Total
	18-24	25-34	35-54	55-64	65+	18-24	25-34	35-54	55-64	65+	
NSW	1.7%	2.8%	5.2%	2.4%	3.3%	1.6%	2.9%	5.4%	2.5%	3.8%	31.8%
VIC	1.4%	2.4%	4.3%	1.8%	2.5%	1.4%	2.5%	4.5%	1.9%	3.0%	25.7%
QLD	1.1%	1.7%	3.3%	1.5%	2.1%	1.1%	1.8%	3.5%	1.6%	2.3%	20.1%
SA	0.4%	0.6%	1.1%	0.6%	0.8%	0.4%	0.6%	1.1%	0.6%	1.0%	7.1%
WA	0.6%	0.9%	1.8%	0.8%	1.0%	0.5%	0.9%	1.8%	0.8%	1.1%	10.4%
TAS	0.1%	0.2%	0.3%	0.2%	0.3%	0.1%	0.2%	0.4%	0.2%	0.3%	2.2%
NT	0.1%	0.1%	0.2%	0.1%	0.1%	0.1%	0.1%	0.2%	0.1%	0.1%	0.9%
ACT	0.1%	0.2%	0.3%	0.1%	0.1%	0.1%	0.2%	0.3%	0.1%	0.2%	1.8%
Total	5.5%	9.0%	16.6%	7.4%	10.3%	5.3%	9.2%	17.2%	7.8%	11.7%	100.0%



Statistical analysis

Triple interlocking quotas were used to ensure that the respondent profile appropriately represented Australians by age, gender, and state. The sampling frame was developed as follows: Nationally representative of adults (18+ years of age) by age, gender, and state, based on 2021 ABS census data.

The sample size for the ACT, SA, WA and Tas was increased to match maximum feasibility the online panel could achieve, aligning with state representation for adults (18+ years) in each state, resulting in a total sample size of n=3,390.

Throughout this report, the key findings have been analysed by a range of demographic and other variables to highlight where results on the key measures are significantly higher or lower for the identified sample sub-groups in comparison to the rest of the sample. Analysis of statistically significant differences between sub-groups in the sample was conducted in Q Software using bivariate methods. Q looks at the data types and structures to determine the most suitable form of significance testing for each table and also takes into account the design factor introduced when using weighted data (as was the case in this instance). For many tables, significance testing was conducted using a Second Order Rao-Scott Test of Independence of a Contingency Table. Statistical testing was set at a threshold of $p \leq .05$, indicating a 95% confidence level in the results (i.e. 95% confidence there is a real difference between groups in the population rather than simply being due to sampling error).

Statistical notes

Where sub-group differences are mentioned in the report (e.g. differences in results between age cohorts), they are statistically significant at the 95% level of confidence, meaning there is only a 5% chance that there is no real difference in the comparison. Further analyses using multivariate methods to adjust for multiple factors will be undertaken in the future, to provide greater understanding of subgroup differences.

Note: Some reported figures may not add to 100% due to rounding, or due to multi-response question items.



Appendix – Questionnaire



Final 4/02/2025

Advance care planning survey

Job #: 0261

Advance Care Planning Australia

Survey type: Online

Methodology

Summary of research objectives:

- To explore engagement with advance care planning by adults in the Australian population and investigate barriers and enablers that facilitate this process across different age, demographic and cultural groups.
- Robust measures of national advance care planning prevalence rates for several indicators of engagement in ACP, including conversations and completion of formal documents.
- An improved understanding of factors that are associated with engagement in ACP, including demographic and attitudinal factors.

Project specifications:

Project consultants:	Mary Harvey-Collins
Programmer(s):	TBD
Tracker:	No
Total number of interviews to be completed for each wave specified above:	3,376 general population (nationally representative)
Questionnaire length for each wave specified above:	15 minutes
Definition of target audience:	Australian General Population
Panel Provider (panel sample only):	PureProfile
Fieldwork dates:	14/02/2025 – 17/03/2025
Data to be merged with a previous datafile?	N
Questionnaire has been reviewed by Sharon	Yes
Questionnaire approved by client	Yes
Any quotas on the sample? If yes, specify below	Y (see below)

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Quotas to be applied:

STATE	Male					Female					Total	TOTAL	
	18-24	25-34	35-54	55-64	65+	18-24	25-34	35-54	55-64	65+			
NSW	52	85	157	71	100	465	49	87	163	74	115	488	953
VIC	43	73	129	54	76	375	41	74	134	58	89	396	771
QLD	34	52	100	45	63	294	33	54	105	48	70	310	604
SA	22	33	63	31	46	195	20	33	65	33	54	205	400
WA	24	40	79	34	44	221	23	41	80	35	50	229	450
TAS	4	8	13	7	11	43	4	8	14	8	13	47	90
NT	2	3	5	2	2	14	2	3	5	2	2	14	28
ACT	5	9	14	5	6	39	5	9	14	5	8	41	80
TOTAL	186	303	560	249	348	1646	177	309	580	263	401	1730	3376

Weights to be applied:

The data will be weighted to ensure that is representative of the Australian adult population by age, gender and state. The breakdown of the weighting is presented in the table below:

LOCATION	Male					Female					Total
	18-24	25-34	35-54	55-64	65+	18-24	25-34	35-54	55-64	65+	
NSW	1.7%	2.8%	5.2%	2.4%	3.3%	1.6%	2.9%	5.4%	2.5%	3.8%	31.8%
VIC	1.4%	2.4%	4.3%	1.8%	2.5%	1.4%	2.5%	4.5%	1.9%	3.0%	25.7%
QLD	1.1%	1.7%	3.3%	1.5%	2.1%	1.1%	1.8%	3.5%	1.6%	2.3%	20.1%
SA	0.4%	0.6%	1.1%	0.6%	0.8%	0.4%	0.6%	1.1%	0.6%	1.0%	7.1%
WA	0.6%	0.9%	1.8%	0.8%	1.0%	0.5%	0.9%	1.8%	0.8%	1.1%	10.4%
TAS	0.1%	0.2%	0.3%	0.2%	0.3%	0.1%	0.2%	0.4%	0.2%	0.3%	2.2%
NT	0.1%	0.1%	0.2%	0.1%	0.1%	0.1%	0.1%	0.2%	0.1%	0.1%	0.9%
ACT	0.1%	0.2%	0.3%	0.1%	0.1%	0.1%	0.2%	0.3%	0.1%	0.2%	1.8%
Total	5.5%	9.0%	16.6%	7.4%	10.3%	5.3%	9.2%	17.2%	7.8%	11.7%	100.0%

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Introduction

Thank you for taking part in this survey.

This survey aims to explore Australian's awareness of and attitudes about advance care planning. The survey should take no more than 15 minutes to complete.

Please be reassured that this survey is anonymous. Quantum is an independent market research company and complies with the Australian Privacy Act 1988 and The Research Society's Code of Professional Behaviour. Our privacy policy can be found [here](#).

Quantum
Market
Research

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Participation information sheet and consent form					
Title	National prevalence study of advance care planning in the Australian Community				
Short Title	Advance care planning in the Australian community study				
Project Number	113941				
Principal Investigator	Dr Catherine Joyce (Advance Care Planning Australia)				
Co-investigator(s)	Mila Obucina (Advance Care Planning Australia); Dr Greg Parker (Advance Care Planning Australia and Metro South Health, Queensland); Kylie Ash (Advance Care Planning Australia)				
<p>1 Introduction</p> <p>Researchers from Advance Care Planning Australia are inviting you to take part in an online survey to find out what Australians think about advance care planning.</p> <p>Please take the time to read this information carefully. You may ask questions about anything you don't understand or want to know more about. Your participation is voluntary. If you don't wish to take part, you don't have to. If you begin participating, you can also stop at any time.</p> <p>Before deciding whether or not to take part, you might want to talk about it with someone you trust, like a family member or friend. You can take some time to make up your mind. You get to decide whether this project is right for you.</p>					
<p>2 What is this research about?</p> <p>The study is about community attitudes and awareness of advance care planning. We would like to explore your attitudes and opinions around future health planning, appointment of substitute decision makers (enduring power of attorney) and any plans or specific conversations you may have had on this topic with others. We would also like to hear about your experiences if you were required to provide support to family or loved ones to navigate the advance care planning process.</p> <p>We will also be asking to answer some questions about yourself, including your age, gender and health status, income and residence location.</p>					
<p>3 What will this research involve?</p> <p>We are asking about 3,000 people living in Australia to complete an online survey for this project.</p>					
<p>4 What do I have to do?</p>					
<p>Should you agree to participate, you will be asked to complete an online survey about advance care planning. This survey is expected to take up to 15 minutes, and there are no right or wrong answers.</p> <p>As members of Pure Profile research panel, participants who complete the survey will accrue incentive payment from in the form of points, that can be traded for direct deposit to your bank account, Gift Vouchers or movie vouchers. Alternatively, you can choose to be rewarded with entries into a monthly prize draw.</p>					
<p>5 Do I have to take part in this research?</p> <p>Participation is completely voluntary. You are under no obligation to consent to participation. If you do decide to participate in the survey or closing the browser button. Your decision whether to take part, will not affect any relationships between you and the institutions involved in the study.</p>					
<p>6 What are the possible benefits?</p> <p>Benefits to you: you will receive a small incentive payment in form of points with PureProfile, as a token of appreciation for your time.</p> <p>Benefit to others: By taking part, your responses will help us better understand views and knowledge about advance care planning in Australia. This in turn may help us improve awareness and uptake of advance care planning nationally.</p>					
<p>7 What are the possible risks?</p> <p>The risks of taking part in this research are low. The questions cover a range of topics about health, aging and death. You can choose not to answer any particular question and move on to the next question in the survey. In the unlikely event that you do experience discomfort, support services are available, as listed below.</p> <p>Support services:</p> <table border="0"> <tr> <td> <p>Beyond Blue Mental health support service. Phone 24/7: 1300 224 636 Website & online chat: www.beyondblue.org.au</p> </td> <td> <p>13YARN Crisis support for mob who are feeling overwhelmed or having difficulty coping. Phone 24/7: 13 92 76 Website: www.13yarn.org.au</p> </td> </tr> <tr> <td> <p>Headspace Support for young people aged 12 to 25. Phone 9am to 1am daily: 1800 650 890 Website & online chat: headspace.org.au</p> </td> <td></td> </tr> </table>		<p>Beyond Blue Mental health support service. Phone 24/7: 1300 224 636 Website & online chat: www.beyondblue.org.au</p>	<p>13YARN Crisis support for mob who are feeling overwhelmed or having difficulty coping. Phone 24/7: 13 92 76 Website: www.13yarn.org.au</p>	<p>Headspace Support for young people aged 12 to 25. Phone 9am to 1am daily: 1800 650 890 Website & online chat: headspace.org.au</p>	
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<p>Headspace Support for young people aged 12 to 25. Phone 9am to 1am daily: 1800 650 890 Website & online chat: headspace.org.au</p>					
<p>8 Can I withdraw from this research?</p> <p>Participants can withdraw from the survey at any time. To leave, click the 'X' at the top corner of your screen or close the browser application you are using. Your survey answers will not be kept and during the analysis, any responses you had before withdrawing will be ignored by the researchers. It will not be possible to withdraw once survey has been submitted.</p>					
<p>9 What will happen to information about me?</p>					
<p>The protection of your privacy is very important. To protect your identity, we are not asking you to provide your name, address, birth date, or any other information that may identify you, other than IP address. This will be stripped from the final data when survey is completed.</p> <p>We have no way of identifying you from the survey. All of your responses will be confidential and will be used for research purposes only. However, to protect your identity, please do not provide any specific details about you or someone else in the free-text sections of the survey. This includes things like names, dates of birth, or details of where someone you or someone else has been in hospital or received care.</p>					
<p>10 How will my information be used?</p> <p>The information you give us will be analysed by the research team. You will not be identified in any reports about this study. The collective findings and outcomes from the research project may published in journal articles or presented at research conferences.</p> <p>We may as part of any research reports or other products include direct quotes taken from the survey. However, these quotes will not include any identifying information, and will not be attributed to any specific individual.</p>					
<p>11 Who is organising and funding the research?</p> <p>This research project has been commissioned and funded by Advance Care Planning Australia; a commonwealth funded national program. The survey is administered by Quantum Market Research.</p>					
<p>12 Who has reviewed the research project?</p> <p>This project will be carried out according to the <i>National Statement on Ethical Conduct in Human Research (2023)</i> and The Research Society's <i>Code of Professional Behaviour</i>. The ethical aspects of this research project have been reviewed and approved by the Metro South Health Human Research Ethics Committee, Queensland [HREC/2024/QMS/113941]</p>					
<p>13 Further information and who to contact</p> <p>The person you may need to contact will depend on the nature of your query. If you want any further information concerning this project, you can contact any of the following people:</p> <p>Dr Sharon Morris, Quantum Market Research sharonm@qmr.com.au or 0416 198 517</p> <p>Mila Obucina, Advance Care Planning Australia mila.obucina@health.qld.gov.au or 0459 423 260</p> <p>If you have any concerns or complaints about any aspect of the project, the way it is being conducted or any questions about being a research participant in general, please contact:</p> <p>Human Research Ethics Committee Metro South Health, Queensland</p> <table border="1"> <tr> <td>Position</td> <td>Human Research Ethics Manager</td> </tr> <tr> <td>Telephone</td> <td>07 3443 8049</td> </tr> </table>		Position	Human Research Ethics Manager	Telephone	07 3443 8049
Position	Human Research Ethics Manager				
Telephone	07 3443 8049				

Document last modified: 18 March

Quantum Market Research

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Email msh-ethics@health.qld.gov.au

Please quote the following number: 113941

Consent Agreement

- I am 18 years of age or over
- I have read the Participant Information Sheet.
- I understand the purposes, processes and risks of the research described in the project.
- I have had an opportunity to ask questions and I am satisfied with the answers I have received.
- I freely agree to participate in this research project as described and understand that I am free to withdraw at any time until I have submitted the survey.
- I understand that I will be given the opportunity to download copy of this document to keep.

Do you give your consent to participate in this survey?

Yes 1
No 2 **TERMINATE**

If you would like to, you can click this [link](#) to download a copy of the Participant Information and Consent Agreement.

Screener

The first few questions are to check if this survey is relevant to you.

ASK ALL

Q1. How old are you?

OPEN NUMERIC [Help](#) IF UNDER 18 TERMINATE [UPPER LIMIT = 105]

ASK ALL

Q2. What gender do you identify with?

SINGLE RESPONSE	Code
Male	1
Female	2
Non-binary	3
Another gender (please specify)	99

ASK ALL

Q3. Where do you live?

SINGLE RESPONSE	Code
New South Wales	1
Victoria	2
Queensland	3
Western Australia	4
South Australia	5
Tasmania	6
Australian Capital Territory	7
Northern Territory	8
Other [Terminate]	99

Awareness and understanding of Advance care planning

ASK ALL

Q4. How much would you say you know about advance care planning?

SINGLE RESPONSE	Code
I know quite a lot about it	1
I know a bit about it	2
I know what it is but don't know the details	3
I just know the term and nothing more about it	4
This is the first time I have heard of it	5
Don't know	99

ASK ALL

Q5. Before today, which of the following have you heard of?

MULTIPLE RESPONSE, RANDOMISE	Code
Advance care planning	1
A will	2
Advance care directive	3
Advance health directive	4
Advance personal plan	5
Medical treatment decision maker	6
An enduring power of attorney	7
A power of attorney	8
Guardian	9
Enduring guardian	10
Medical insurance	11
Funeral plans	12
Statement of choices	13
Substitute decision-maker	14
Advance personal plan decision maker	15
A living will	16
None of the above [SR]	99

ASK THOSE WHO ARE FAMILIAR WITH ADVANCE CARE PLANNING (Q4=1,2,3)

Q6. Which of the following statements about advance care planning are true?

If you are not [sure](#) please select 'don't know.'

SINGLE RESPONSE PER STATEMENT, RANDOMISE, GRID	TRUE	FALSE	DON'T KNOW
A Advance care planning involves planning for your future health care	1	2	99
B Advance care planning documents differ by state	1	2	99

C	Advance care planning involves communicating your treatment preferences	1	2	99
D	Advance care planning can involve appointing your chosen substitute decision maker	1	2	99

SHOW AFTER ALL Q6 ANSWERED

All statements about advance care planning are true.

Advance care planning status

[PAGE 1: PUT 15 SECOND DELAY ON PAGE]

This survey is about advance care planning. Below is some information about what advance care planning involves.

Advance care planning:

Advance care planning is a process that allows you to express your wishes and preferences for future medical and health care, in case there comes a time when you are not able to make or communicate decisions for yourself. This can include your preferences and wishes about health care at the end of life. It can also include choices and preferences about health care if you are not able to make your own decisions. It may involve appointing someone who can make decisions on your behalf if you are not able to do so due to sickness or injury.

Overall, advance care planning aims to empower you to make informed choices about your health care and ensure that your wishes are honoured, enhancing quality of life and dignity in health care settings. It is a voluntary process which may involve formal or informal documents, or may consist of discussions with others who would be making decisions for you.

You will be able to move onto the next page after 15 seconds.

[PAGE 2: PUT 15 SECOND DELAY ON PAGE]

Advance care directives:

An advance care directive is a formal document that involves writing down the preferences you have for your future health care. This can include your values and beliefs, goals and preferred outcomes, and specific directions about future health care and treatments.

Substitute decision maker/s:

A person/s legally able to make decisions about your health care when you can't make decisions for yourself. You can choose to appoint a person to do this role. In some states and territories, a substitute decision maker can be appointed in an advance care directive.

The process of creating an advance care directive and the names of the documents varies between states and territories but they generally cover similar things. The different terms used by state and territory are:

State	Advance care directive	Appointed substitute decision maker
NSW	Advance care directive	Enduring guardian
VIC	Advance care directive	Medical treatment decision maker
QLD	Advance health directive	Attorney (Enduring Power of Attorney)
SA	Advance care directive	Substitute decision maker
WA	Advance health directive	Enduring guardian
TAS	Advance care directive	Enduring guardian
NT	Advance personal plan	Advance Personal Plan decision maker
ACT	Health Direction	Attorney (Enduring Power of Attorney)

For the rest of the survey the terms "advance care planning", "advance care directive" and "substitute decision maker" will be used.

You will be able to move onto the next page after 15 seconds.

ASK ALL

Q7. Which of the following statements applies to you?

SINGLE RESPONSE	Code
I have not thought about my wishes for my future health care	1
I have thought about my wishes for my future health care but I have not discussed them with anyone	2
I have discussed my wishes for my future health care with someone	3
I have put my wishes for my future health care in writing (but not a formal advance care directive)	4
I have completed a formal advance care directive	5
Not sure / can't remember	98

ASK IF Q7=2,3

Q7b. Which of the following have you done?

SINGLE RESPONSE	Code
I have started a formal advance care directive but not finished it	1
Done research about advance care planning	2
Other (please specify) _____	95
None of the above	99
Not sure / can't remember	98

Those who have discussed their wishes:

THOSE WHO HAVE DISCUSSED THEIR FUTURE WISHES WITH SOMEONE (Q7=3)

Q8. Who did you discuss your wishes for your future health care with?

MULTIPLE RESPONSE, RANDOMISE WITHIN GROUPS 1-5	Code
Partner / spouse	1
Child(ren) under 18	2
Adult child(ren)	3
Parent(s)	4
Sibling(s) – that is, your sister or brother	5
Other family member (please specify) _____	6
Close friend(s)	7
Lawyer	8
Doctor	9
Other health or aged care professional (please specify) _____	10
Other (please specify) _____	95
Not sure / can't remember	98

THOSE WHO HAVE DISCUSSED THEIR FUTURE WISHES WITH SOMEONE (Q7=3)

Q9. When you discussed your future health care with someone, what did you talk about?

MULTIPLE RESPONSE, RANDOMISE	Code
Medical treatments I do or don't want	1
My wishes and preferences for my future health care	2
Living arrangements	3
Care arrangements	4
Financial arrangements	5
Funeral arrangements	6
Appointing a substitute decision maker	7
The things that are important for me when I am close to the end of life	8
Values and beliefs about health care (e.g. religious or cultural)	9
Who to contact (e.g. doctor / lawyer)	10
Important documents	11
Not sure / can't remember [SR]	98
Prefer not to say [SR]	96

THOSE WHO HAVE DISCUSSED THEIR FUTURE WISHES WITH SOMEONE (Q7=3)

Q10. And how detailed was that conversation?

SINGLE RESPONSE	Code
I only mentioned it to them	1
We had a brief conversation	2
We had a somewhat detailed conversation	3
We had an in-depth conversation	4
It is an ongoing conversation	5
Not sure / can't remember [SR]	98
Prefer not to say [SR]	96

THOSE WHO HAVE DISCUSSED THEIR FUTURE WISHES WITH A DOCTOR OR OTHER HEALTH PROFESSIONAL (Q8=9,10)

Q11. When you discussed your wishes with your doctor or other health professional to what extent do you agree with the following?

SINGLE RESPONSE PER ITEM; RANDOMISE ALL STATEMENTS CAROUSEL	Strongly disagree	Mildly disagree	Neither agree nor disagree	Mildly agree	Strongly agree	Not sure
1 They were knowledgeable	1	2	3	4	5	98
2 They were comfortable with the topic	1	2	3	4	5	98
3 They were respectful	1	2	3	4	5	98
4 They were confident talking about my values and wishes	1	2	3	4	5	98

THOSE WHO HAVE DISCUSSED THEIR FUTURE WISHES WITH A LAWYER (Q8=8)

Q11a. When you discussed your wishes with your lawyer to what extent do you agree with the following?

SINGLE RESPONSE PER STATE RANDOMISE ALL STATEMENTS CAROUSEL		Strongly disagree	Mildly disagree	Neither agree nor disagree	Mildly agree	Strongly agree	Not sure
1	They were knowledgeable	1	2	3	4	5	98
2	They were comfortable with the topic	1	2	3	4	5	98
3	They were respectful	1	2	3	4	5	98
4	They were confident talking about my values and wishes	1	2	3	4	5	98

Those who have done advance care planning documents (formal and informal):

THOSE WHO INFORMALLY AND FORMALLY WROTE ADVANCE CARE PLANNING DOCUMENTS OR THOSE WHO STARTED AN ACD (Q7=4,5, OR Q7a=1)
Q12.

(Those who have informally written an advance care planning document Q7=4) What does your advance care planning document contain?

(Those who have formally written an advance care directive Q7=5) What does your advance care directive contain?

(Those who have started an advance care directive Q7b=1) What does your advance care directive contain so far?

MULTIPLE RESPONSE, RANDOMISE		Code
Medical treatments I do or don't want		1
My wishes and preferences for my future health care		2
Care arrangements		3
Appointing a substitute decision maker		4
The things that are important to me when I am close to the end of life		5
Values and beliefs about future care (e.g. religious or cultural)		6
Other (please specify) _____		95
Not sure / can't remember [SR]		98
Prefer not to say [SR]		96

Appointing a decision maker:

ASK ALL

Q13. Have you appointed a substitute decision maker for health care decisions?

A substitute decision maker is a person/s legally able to make decisions about your **health care** when you can't make decisions for yourself.

SINGLE RESPONSE	Code
Yes, formally	1
Yes, informally (and I have informed them)	2
No	3

Not sure / can't remember	98
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THOSE WHO HAVE APPOINTED AS A SUBSTITUTE DECISION MAKER (Q13=1,2)

Q14. Who did you appoint as your substitute decision maker?

MULTIPLE RESPONSE, RANDOMISE		Code
Partner / spouse		1
Adult child(ren)		2
Parent(s)		3
Sibling(s) – that is, your sister or brother		4
Other family member (please specify) _____		5
Close friend(s)		6
Other (please specify) _____		95
Not sure / can't remember [SR]		98
No one, I did not appoint a substitute decision maker [SR]		99

THOSE WHO HAVE APPOINTED A SUBSTITUTE DECISION MAKER (Q13=1,2)

Q15. Why did you pick this person as your substitute decision maker?

MULTIPLE RESPONSE, RANDOMISE		Code
I trust their judgement		1
They know me best		2
It is common in my culture		3
They understand what I want and value		4
They would respect and act on my wishes		5
They would stay calm in a <u>crisis / difficult time</u>		6
They have the confidence to speak up for me		7
They live near me		8
They understand my cultural / religious beliefs		9
They were willing to take on the role		10
They were my oldest child		11
They could manage the family dynamic		12
They were the obvious person (e.g. the role of a partner / spouse)		13
Other (please specify) _____		95
Not sure / can't remember [SR]		98

THOSE WHO HAVE APPOINTED A SUBSTITUTE DECISION MAKER (Q13=1,2)

Q16. How confident are you that your substitute decision maker can represent your voice, your wishes, and your preferences if you are not able to make your own decisions?

SINGLE RESPONSE	Code
Completely confident	1
Fairly confident	2
Somewhat confident	3
Slightly confident	4

Not confident at all	5
Not sure	98

THOSE WHO HAVE APPOINTED AS AN SUBSTITUTE DECISION MAKER (Q13=1,2)

Q17. Can you explain the reasons you feel [response to Q16]?

OPEN-END

THOSE WHO HAVE COMPLETED OR STARTED A FORMAL ADVANCE CARE DIRECTIVE (Q7=5 OR Q7b=1)

Q18.

(Those who have formally written an advance care directive Q7=5) In what state / territory did you make your advance care directive?

(Those who have started an advance care directive Q7b=1) In what state / territory did you start your advance care directive?

SINGLE RESPONSE	Code
New South Wales	1
Victoria	2
Queensland	3
Western Australia	4
South Australia	5
Tasmania	6
Australian Capital Territory	7
Northern Territory	8
Overseas	9
Not sure / can't remember	98

THOSE WHO HAVE COMPLETED A FORMAL ADVANCE CARE DIRECTIVE (Q7=5)

Q19. Where is your advance care directive stored?

MULTIPLE RESPONSE, RANDOMISE		Code
At my home		1
With my doctor		2
With my lawyer		3
With my substitute decision maker		4
Uploaded to My Health Record		5
Added to my hospital record		6
With a company that stores it online		7
With a family member or friend		8
At my care facility		9
Other (please specify) _____		95
Not sure / can't remember [SR]		98

Motivators and barriers

Barriers and triggers for those who have not undertaken:

THOSE WHO HAVE NOT DISCUSSED OR THOUGHT ABOUT THEIR FUTURE HEALTH CARE (Q7=1,2)

Q20. Here are some reasons others have told us they haven't discussed their future health care. Which apply to you? *Select all that apply.*

MULTIPLE RESPONSES, RANDOMISE	Code
I can't predict my future health	1
I trust my family / friend(s) to know what I want	2
I trust my doctor(s) to know what I want	3
I have more important things to deal with first	4
I don't have anyone to talk about it with	5
I was not aware of it	6
I don't want to burden other people with it	7
I don't have any preferences for my future health care	8
I don't like to think about things like that	9
I am too young	10
I believe if you talk/think about things like that they may come true	11
We don't talk about things like that in my family	12
We don't talk about things like that in my culture / religion	13
I do not think they (e.g. friend(s) / family etc.) would agree with what I would want	14
I don't know where to start	15
Other (please specify) _____	95
Not sure / can't remember [SR]	98
Prefer not to say [SR]	96

THOSE WHO HAVE NOT DISCUSSED OR THOUGHT ABOUT THEIR FUTURE HEALTH CARE (Q7=3,2)

Q21. Which of the following might prompt you to discuss or write down your wishes for your future health care?

MULTIPLE RESPONSES, RANDOMISE	Code
A serious illness / condition affecting me	1
A serious illness / condition affecting someone else close to me	2
A doctor or another health professional suggesting it	3
A friend / family member suggesting it	4
Feeling worried my family might not know what I want	5
Seeing something in media about it (e.g. a movie or tv show)	6
A change in life circumstances (e.g. marriage, divorce or death of a family member)	7
Getting older	8
Other (please specify) _____	95
Not sure [SR]	98

Prefer not to say [SR]	96
Nothing would prompt me	99

THOSE WHO HAVE NOT WRITTEN OR COMPLETED A FORMAL ADVANCE CARE DIRECTIVE (Q7=1,2,3,4 OR Q7=1)

Q22.

(Those who have not thought or thought about their wishes for their future health care Q7=1,2) How ready do you feel to discuss your wishes for your future health care with someone?

(Those who have discussed their wishes for their future health care Q7=3) How ready do you feel to put your wishes for your future health care in writing?

(Those who have put their wishes for their future health care into writing Q7=4 or Q7=5) How ready do you feel to sign / complete formal documents?

SINGLE RESPONSE	Code
Completely ready	1
Somewhat ready	2
Not ready at all	3
I have decided I do not want to	4
I haven't decided either way	5
Not sure	98
Prefer not to say	96

THOSE WHO SAY THEY ARE READY Q22=1,2

Q22a. And when do you think you will [q7=1,2 discuss your wishes for your future health care] / [q7=3 write down your wishes for your future healthcare] / [q7=4 or q7=5 complete an advance care directive]?

SINGLE RESPONSE	Code
In the next month	1
In the next six months	2
In the next year or so	3
In the next two to years or more	4
Not sure	98
Prefer not to say	96

THOSE WHO ARE SOMEWHAT READY, NOT READY, HAVEN'T DECIDED EITHER WAY, OR NOT SURE TO TAKE THE NEXT STEP AND THOSE WHO HAVE STARTED AND ACD BUT NOT FINISHED (Q22=2,3,5,98 OR Q7=1)

Q24. The following are some reasons people have not put their wishes into writing or completed a formal advance care directive, which apply to you?

MULTIPLE RESPONSES, RANDOMISE	Code
I haven't had the time	1
It is too expensive to do	2
I am unsure how to do it	3

I can't access a lawyer	4
The process is too difficult	5
It requires the input of multiple people e.g. Lawyer, Justice of the Peace, Doctor	6
I don't have anyone to involve / talk to it about	7
I don't think it is necessary	8
It is not a priority	9
I was advised against it	10
I don't want to do it	11
Other (please specify) _____	95
None of these apply to me	99
Not sure / can't remember [SR]	98
Prefer not to say [SR]	96

Motivations for discussing and writing:

ALL BUT THOSE WHO HAVE NOT THOUGHT ABOUT OR DISCUSSED THEIR FUTURE HEALTH CARE WISHES (Q7=3,4,5)

Q23.

(Those who have discussed with others Q7=3) Here are some reasons others have told us for discussing their wishes about their future health care with others. Which apply to you?

(Those who have informally made an advance care planning document Q7=4) Here are some reasons others have told us for putting their wishes about their future health care in writing. Which apply to you?

(Those who have formally made an advance care directive Q7=5) Here are some reasons others have told us for completing an advance care directive. Which apply to you?

MULTIPLE RESPONSES, RANDOMISE	Code
I want to ease the burden for my friend(s) or family	1
I have specific cultural practices I want to be followed	2
I have specific religious practices I want to be followed	3
I want to make sure everything is taken care of / I like being prepared	4
I don't trust other people to make the decisions correctly	6
I have specific medical wishes / needs	7
It will help doctors and nurses to make the right decisions for me	8
It will help my substitute decision makers to make the right decisions for me	9
It can help me to stay at home rather than go into care	10
It can help me get the type of health care I want	11
I saw something in the media about it (e.g. a movie or tv show)	12
It gives me peace of mind	13
I was encouraged by someone	14
I saw someone I love have a bad experience at the end of their life	15
I want to avoid conflict in the family	16
Other (please specify) _____	95
Not sure / can't remember [SR]	98
Prefer not to say [SR]	96

ASK ALL

Q25. Where would you look for more information about advance care planning?

MULTIPLE RESPONSE, RANDOMISE	Code
Social media such as: Facebook, Instagram, TikTok, YouTube	1
Google	2
Newspapers, TV, radio	3
Government websites	4
Government helplines	5
Family / friend(s)	6
Doctor or other healthcare professional	7
Lawyer	8
Other (please specify) _____	95
Not sure [SR]	98
I do not want more information about advance care planning [SR]	94

Whether someone else has discussed their wishes with them:

ASK ALL

Q26. Has anyone discussed their wishes for their future health care with you?

SINGLE RESPONSE	Code
Yes	1
No	2
Not sure / can't remember	98

THOSE WHO SOMEONE ELSE DISCUSSED THEIR WISHES FOR FUTURE HEALTH CARE WITH THEM (Q26=1)

Q27. Who discussed their wishes for their future health care with you?

MULTIPLE RESPONSE, RANDOMISE	Code
Partner / spouse	1
Child(ren) under 18	2
Adult child(ren)	3
Parent(s)	4
Sibling(s) – that is, your sister or brother	5
Other family member (please specify) _____ [KEEP UNDER R5]	6
Close friend(s)	7
Other (please specify) _____	95
Not sure / can't remember [SR]	98

THOSE WHO SOMEONE ELSE DISCUSSED THEIR WISHES FOR FUTURE HEALTH CARE WITH THEM (Q26=1)

Q28. And what did you talk about?

MULTIPLE RESPONSE, RANDOMISE	Code
Medical treatments they do or don't want	1
Wishes and preferences for their future health care	2
Living arrangements	3
Care arrangements	4
Financial arrangements	5
Funeral arrangements	6
Appointing a substitute decision maker	7
The things that are important to them when they are close to the end of life	8
Values and beliefs about health care (e.g religious or cultural)	9
Who to contact doctor / lawyer	10
Important documents	11
Other (please specify) _____	95
Not sure / can't remember [SR]	98
Prefer not to say [SR]	96

Whether have been someone else's appointed decision maker:

ASK ALL

Q29. Have you ever been appointed as someone else's substitute decision maker as part their advance care planning?

A substitute decision maker is a person/s legally able to make decisions about your health care when you can't make decisions for yourself.

SINGLE RESPONSE	Code
Yes, formally	1
Yes, informally	2
No	3
Not sure / can't remember	98

THOSE WHO HAVE BEEN APPOINTED AS A SUBSTITUTE DECISION MAKER (Q29=1,2)

Q30. Who are / were you the appointed substitute decision maker for?

MULTIPLE RESPONSE, RANDOMISE	Code
Partner / spouse	1
Adult child(ren)	2
Parent(s)	3
Sibling(s) – that is, your adult sister or brother	4
Other family member (please specify) _____ [KEEP UNDER R4]	5
Friend(s)	6
Other (please specify) _____	95
Not sure / can't remember [SR]	98

THOSE WHO HAVE BEEN APPOINTED AS A SUBSTITUTE DECISION MAKER (Q29=1,2)

Q31. How confident are you that as a substitute decision maker you can represent their voice, wishes and preferences?

SINGLE RESPONSE	Code
Completely confident	1
Fairly confident	2
Somewhat confident	3
Slightly confident	4
Not confident at all	5
Not sure	98

Perceptions and attitudes towards Advance care planning

ASK ALL

Q32. How strongly do you personally disagree or agree with the following statements about advance care planning?

SINGLE RESPONSE PER STATEMENT RANDOMISE ALL STATEMENTS GRID	Strongly disagree	Mildly disagree	Neither agree nor disagree	Mildly agree	Strongly agree	Not sure
1 You only need to do advance care planning if you are sick or have a disability	1	2	3	4	5	98
2 Thinking about declining health or end of life is depressing	1	2	3	4	5	98
3 You only need to do advance care planning if you are old	1	2	3	4	5	98
4 Talking about advance care planning is the most valuable part of the process	1	2	3	4	5	98
5 Advance care planning can help friends and family make the right decisions if a loved one cannot make them for themselves	1	2	3	4	5	98
6 Advance care planning can help reduce confusion, stress and anxiety	1	2	3	4	5	98
7 Documenting my preferences for future health care would help relieve the burden on my family / loved ones	1	2	3	4	5	98
8 I am open to talking about advance care planning	1	2	3	4	5	98
9 It's hard to know what I might want until I am in that situation	1	2	3	4	5	98

ASK ALL

Q33. Do you have any other comments you would like to share about advance care planning?

OPEN_END

NOT MANDATORY

Further demographics

And finally, just a couple more questions about you, so that we can understand how different people have answered these questions. As this is market research, it is carried out in compliance with the Privacy Act 1988 and the information you provided will be used only for research purposes.

Ask all

Q34. What is your postcode?

OPEN NUMERIC **9999** FOUR DIGITS REQUIRED

PROGRAMMER NOTE: PLEASE CREATE THREE LOCATION VARIABLES FROM POSTCODE:

- Metro / regional splits
- Socio-Economic Indexes for Areas (SEIFA) – [please add 'Decile' into data file based on this list: 2021 SEIFA Indices - WISAP.xlsx](#)

Prefer not to answer	96
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Ask all

Q35. Which of the following best describes you?

SINGLE RESPONSE	Code
Single	1
Married / de facto	2
Separated / divorced	3
Widowed	4
Prefer not to answer	96

Ask all

Q36. Do you have children?

SINGLE RESPONSE	Code
Yes	1
No	2
Prefer not to answer	96

Ask if Q34=1

Q37. How old are your children?

MULTIPLE RESPONSE	Code
0 – 4 years	1

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5 – 12 years	2
13 – 17 years	3
18 – 30 years	4
Over 30 years old	5

Ask all

Q38. Do you have parents who are 65 years of age or older, who you feel responsible for?

SINGLE RESPONSE	Code
Yes	1
No	2
Prefer not to answer	96

Ask all

Q39. What is the highest level of education you have completed?

SINGLE RESPONSE	Code
Year 11 or below (including Certificate 1 or 2)	1
Year 12 / Secondary School Certificate	2
Certificate 3 or 4	3
Diploma or Advanced Diploma	4
Bachelor degree (i.e. University Undergraduate degree)	5
Post graduate degree (i.e. Graduate Certificate or Diploma, Masters, PhD)	6
Prefer not to say	96

Ask all

Q40. Which of the following best describes where you live?

SINGLE RESPONSE	Code
Public / government housing	1
Private rental	2
Your own home (owned outright or mortgaged)	3
Retirement village - independent living	4
Residential aged care home	5
Other (please specify) _____	95
Prefer not to say	96

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Ask all

Q41. Who do you live with? Please select all that apply.

MULTIPLE RESPONSE	Code
By yourself [SR]	1
Your spouse / partner	2
A guardian	3
Children aged 18 or over	4
Children under 18	5
Other family members	6
Housemates	7
Other (please specify) _____	95
Prefer not to say	96

Ask all

Q42. What is your annual household income before tax?

SINGLE RESPONSE	Code
Less than \$25,000	1
\$25,000-\$49,999	2
\$50,000-\$74,999	3
\$75,000-\$99,999	4
\$100,000-\$124,999	5
\$125,000-\$149,999	6
\$150,000-\$174,999	8
\$175,000-\$199,999	9
\$200,000 or more	10
Not sure	98
Prefer not to say	96

Ask all

Q43. Do you identify as Aboriginal, Indigenous and / or Torres Strait Islander?

SINGLE RESPONSE	Code
Yes	1
No	2
Prefer not to answer	96

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Ask ALL

Q44. Do you have any religious affiliation?

SINGLE RESPONSE	CODE
No religious affiliation	1
Christianity	2
Catholicism	3
Islam	4
Hinduism	5
Buddhism	6
Greek Orthodox	7
Other (please specify) _____	95
Prefer not to answer	96

Ask ALL

Q45. Do you or anyone in your household have a long-term physical, mental, intellectual or sensory impairment, illness or disability that requires support with self-care, mobility or communication?

MULTIPLE RESPONSE	CODE
I have a physical impairment, illness or disability	1
I have a psychological / social impairment, illness or disability	2
I have a sensory impairment, illness or disability	3
Someone in my household has a physical impairment, illness or disability	4
Someone in my household has a psychological / social impairment, illness or disability	5
Someone in my household has a sensory impairment illness or disability	6
None of the above [SR]	95
Prefer not to say [SR]	96

Ask ALL

Q46. In general, would you say your health is poor, fair, good, very good, or excellent?

SINGLE RESPONSE	CODE
Excellent	1
Very good	2
Good	3
Fair	4
Poor	5
Prefer not to answer	96

Ask ALL

Q47. Are you the carer for anyone with a long-term physical, mental, intellectual or sensory impairment or disability?

SINGLE RESPONSE	CODE
Yes	1
No	2
Prefer not to answer	96

Ask ALL

Q48. In what country were you born?

SINGLE RESPONSE	CODE
Australia	1
Other [enter drop-down list of countries]	95
Prefer not to answer	96

Ask ALL

Q49. What language do you speak at home? Please select all that apply.

MULTIPLE RESPONSE	CODE
English	1
Mandarin	2
Arabic	3
Cantonese	4
Vietnamese	5
Italian	6
Greek	7
Hindi	8
Spanish	9
Punjabi	10
Other (please specify) _____	95
Prefer not to say [SR]	96

Ask ALL

Q50. Which of the following best describes your sexuality?

SINGLE RESPONSE	CODE
Straight / heterosexual	1
Asexual	2
Bisexual	3
Gay	4
Lesbian	5
Pansexual	6

Queer	7
I identify as (please specify)	95
I don't know	99
Prefer not to say [SR]	96

Online thanks

End with thanks (all):

Thank you for assisting us today. Your response to this questionnaire will be kept strictly anonymous and will be used only for research purposes. If you have any queries or concerns, please contact us on surveys@qmr.com.au

This survey was conducted on behalf of Advance Care Planning Australia. For more information on advance care planning please visit <https://www.advancecareplanning.org.au>.

All data and information collected from the survey will be stored appropriately and in accordance with the Australian Privacy Act 1988 and the New Zealand Privacy Act 2020. Our Privacy policy can be found [here](#).

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Level 3, 650 Chapel Street,
South Yarra, VIC 3141, Australia
research@qmr.com.au