



**PalliativeCare**  
WESTERN AUSTRALIA



**Curtin University**

# **Evaluation of PCWA Advance Care Planning Workshops (Full Report)**

July 2019

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# Authors

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# Introduction

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Palliative Care Western Australia (PCWA) are running workshops in local communities around WA on Advance Care Planning (ACP) in order to improve knowledge and understanding of ACP and its components, and to increase the uptake of ACP. The workshops focus on people having a conversation with family, friends, health professionals or other professionals about end-of-life (EoL) wishes, and aim to encourage the completion of ACP documentation. Curtin University has conducted an evaluation of the WA ACP workshops to ascertain if the workshops increase knowledge and change behaviour.

## Literature review

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Advance Care Planning (ACP) includes a discussion about an individual's treatment, end-of life (EoL) wishes, and care preferences<sup>1</sup>. This discussion usually involves people close to the individuals such as family members and their General Practitioner (GP). ACP also includes the completion of documentation including an Advance Care Plan, an Advance Health Directive (AHD), an Enduring Power of Guardianship (EPG), and/or an Enduring Power of Attorney (EPA). People may also have a Goals of Patient Care (GoPC) discussion in the clinical setting to ascertain goals for clinical care that align with people's values and preferences. In various clinical trials, including randomised controlled trials<sup>2-5, 13</sup>, ACP has demonstrated significant and multiple beneficial outcomes for patients, particularly those with a serious chronic or life limiting illness, families, and for the health system as a whole. For example, undertaking ACP can improve patient and family satisfaction with EoL care<sup>2</sup>, increase access to more appropriate palliative care, reduce undesired invasive and futile treatments<sup>3</sup>, reduce stress, anxiety and depression experienced by families<sup>12</sup>, and may also reduce net health expenditures<sup>4</sup>.

Approximately 82% of people believe that it is important to discuss their EoL care preferences but only approximately 14% of Australians nationally and 8% in WA have completed an ACP or AHD<sup>5</sup>. People over 65 years are more likely to complete ACP documentation if they reside in a residential aged care facility or are admitted to hospital; people living in the community seeing a GP are less likely to complete such documentation.<sup>13</sup>

According to Advance Care Planning Australia, approximately one in two people will not be capable of making their own medical decisions at EoL (based on a study in the USA), most Australians will die from a chronic illness and a third of Australians will die before 75 years<sup>11</sup>. As such, there is an urgent imperative to increase the percentage of Western Australians completing an ACP or AHD, and increase the numbers of people discussing their EoL care preferences, especially in the community.

Previous research has demonstrated that it is possible to increase ACP behaviours through ACP education. For example, two years after the implementation of a community-wide AHD education program in Wisconsin, USA, 'Respecting Your Choices', involving four healthcare providers, it was found that 85% of people who had died in that year had completed AHDs, which was considerably more than in other similar towns who had not engaged in the program<sup>6</sup>. Some of the reasons this program was deemed to be a success included: it treated ACP as an ongoing process; it focused on the facilitation of discussions about values and preferences in the community, especially in the family unit; and it focused on personal relationships rather

than just the individual.<sup>7</sup> Other research has confirmed these findings. In 2014, a systematic review and meta-analysis of the efficacy of ACP in different adult patient populations was conducted<sup>9</sup>. The authors reviewed 55 randomized controlled trials involving outpatients with various diseases. Results showed that patients in ACP intervention groups had completed an AHD and had undertaken a discussion about their EoL preferences with a healthcare professional significantly more often than the control groups.

It has been suggested that the completion of ACP documents should not be the only intended outcome of an ACP intervention, and that engaging in other discrete steps of the ACP process may also be beneficial for patients' future medical care and EoL planning, and communication with family members about EoL wishes<sup>9</sup>. These steps include contemplation of one's values and future treatment wishes; preparation and values clarification; actions such as discussions with family, friends and clinicians; preparation of ACP documentation; as well as the final step, which is maintenance and reflection on one's choices. These steps can be described in terms of the Stages of Change model<sup>10</sup>. According to this model, behavioural change (usually health behaviours) involves a five-step process. Stage one is the pre-contemplation stage where an individual may or may not be aware of a problem but has no thought of changing their behaviour. At stage two, the contemplation stage, the individual begins thinking about changing behaviour. The third stage is preparation, where the individual begins planning for change. During the fourth stage, action, the individual exhibits the new behaviour consistently. An individual finally enters the maintenance stage once they exhibit the new behaviour consistently for over six months. In the current evaluation we will mainly focus on stages two, three and four. We assume that most of the individuals involved in the workshops will be contemplating change or preparing to change, and we will evaluate whether they move to action. Stage five is not relevant in our context but may be relevant for future research.

## Methods

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### Aim

We evaluated changes in knowledge and behaviour related to end-of-life planning after WA community ACP workshops.

### Hypotheses

The overarching hypothesis was that the WA ACP workshops would change knowledge and behaviour in relation to end-of-life planning. Specifically, the ACP workshops would change behaviour in relation to conversations about end-of-life wishes; completion of end-of-life planning documentation; and knowledge in relation to ACP.

### Design

A mixed methods design was used including cross sectional surveys and in-depth, individual qualitative interviews

### Participants

Participants were recruited from consumers who attended a community ACP workshop in WA ('workshop participants') during 2018 and 2019. According to G\*Power (Version 3.1.9.2), at an alpha-level of .008, 85 participants were required for an 80% chance of capturing a 'moderate' ( $f^2 = .15$ ) association between the fixed effect (time: T1, T3) and the outcome measure.

## Inclusion criteria

- All participants were aged 18 years or over and be able to communicate in English.

## Exclusion criteria

- Participants who were unable to complete a questionnaire or participate in an interview.

## Procedure and Instruments

### Surveys

The workshop facilitator emphasised that filling out the surveys was optional. Study participants completed surveys at 3 time points:

Time 1: The *pre-workshop* survey asked for demographic information, assessed participants' prior knowledge and experience with ACP, their goals, motivation for attending and their expectations.

Time 2: The *post-workshop* survey asked participants whether their expectations were met, how they felt about the content and delivery, and what they planned to do following the workshop (in terms of ACP).

Time 3: The *follow-up* survey assessed participants' conversations with others regarding ACP, as well as completion of ACP documentation. Time 3 follow-up surveys were completed online; participants were sent a link (3-6 months following the workshop) to a website via an automatic text message or e-mail. People who did not respond were followed-up by telephone and those who were unable to complete the survey online were given the option of completing the survey via telephone with a research assistant, or were sent a paper copy to return via mail.

Our main focus was on changes from Time 1 to Time 3. Time 2 was an evaluation of the workshops, we have been previously reported the results (see Interim Report, May 2019).

### Interviews

Nine workshop participants were individually interviewed. The age range of those interviewed was 49-81 years with most people (67%) in the 72-75 year age range. Almost half were female (44%), most were born in Australia (78%), more than half lived in the Perth metro area (55%) with the rest living in Outer Metro (11%) or Regional WA (33%). Most indicated that they had no religion (88%), were retired (88%), married or in a relationship (67%), were not carers (78%), had 12 years of school or more (78%) and more than half had a chronic illness (55%) which included prostate cancer, heart problems, stroke and chronic pain.

Workshop participants were asked about:

- Motivation for participating in the workshops
- Their wishes for end-of-life care
- Their values and goals
- Barriers and facilitators to talking about wishes for EoL care
- Their thoughts about the workshops
- Gaps and challenges, including what worked and did not work, and any suggestions for changes
- Role of health professionals

## Analysis

Descriptive statistics were used to describe the sample of participants and to summarise answers to each question. Changes in behaviour over time were analysed using Statistical Package for the Social Sciences' (SPSS) generalised linear mixed models (GLMM) maximum likelihood procedure. This statistical technique is useful when there may be attrition or missing data. A significance level of  $p < .001$  was used in order to control the inflation of the familywise error rate due to multiple statistical tests. A statistician assisted with these analyses.

Thematic analysis was used for all qualitative data. Thematic analysis is a way of summarising the key themes that emerge.

## Ethics

A low risk ethics application was approved by Curtin University Human Research Ethics Committee.

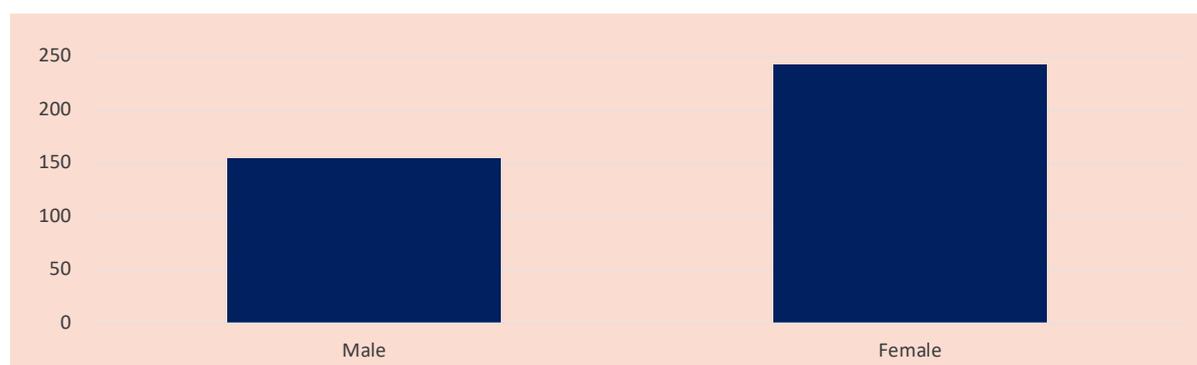
## Results

The pre-workshop questionnaire (Time 1) was completed by participants just prior to the workshop (N = 500) and the follow-up (Time 3) questionnaire was completed 3-6 months after the workshop (N = 206). The response rate was 53.5%. The mean reported response rate in a recent review<sup>14</sup> was 37.7% (SD = 21.6), with a median value of 33.3%. A small number of studies reported higher response rates. As such, 53.5% is considered a very good response rate.

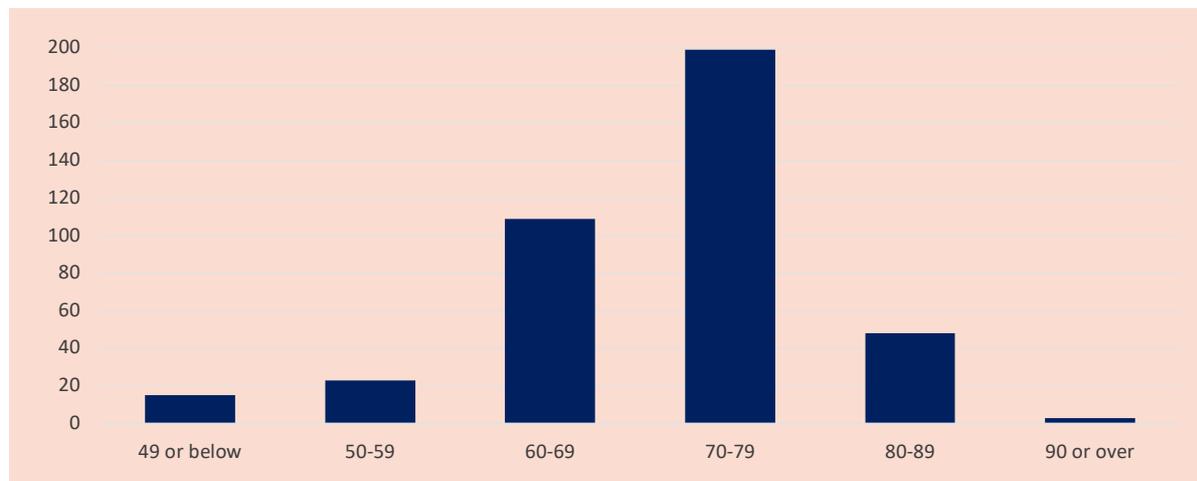
The following graphs summarise findings related to the key questions asked at each time point. The Y-axis denotes frequencies.

### Pre-Workshop (Time 1) data, N = 500

#### Gender



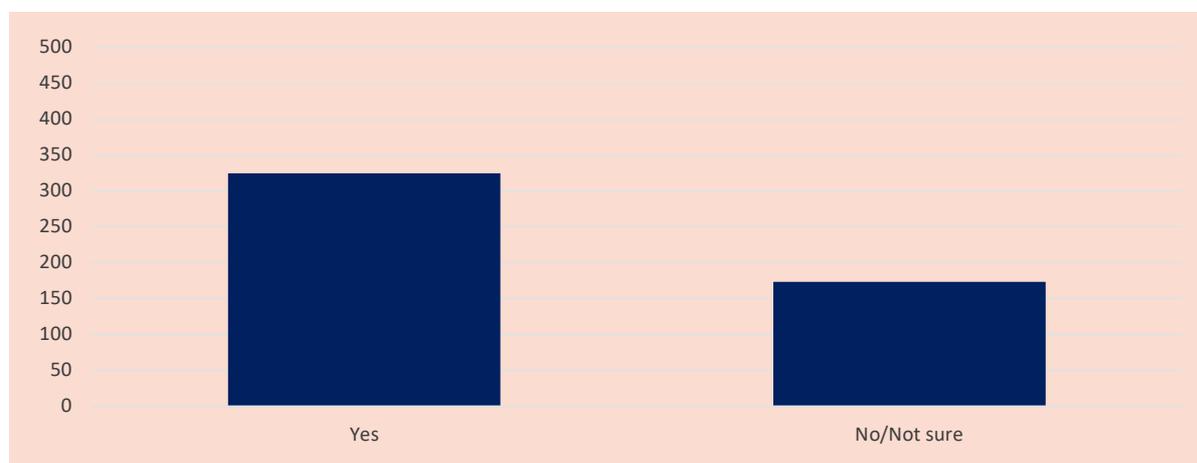
### Age (years)



### Have you thought about your preferences and wishes for the types of care and treatment you may want in the future?



### Have you discussed your end-of-life wishes prior to this workshop with anyone?

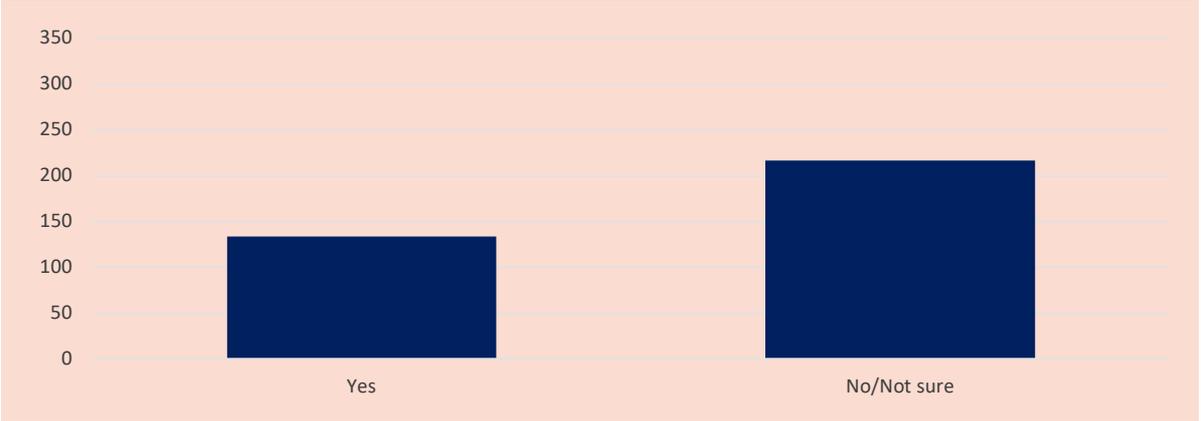


**Have you had a conversation about your end-of-life wishes prior to this workshop with any of the following people?**

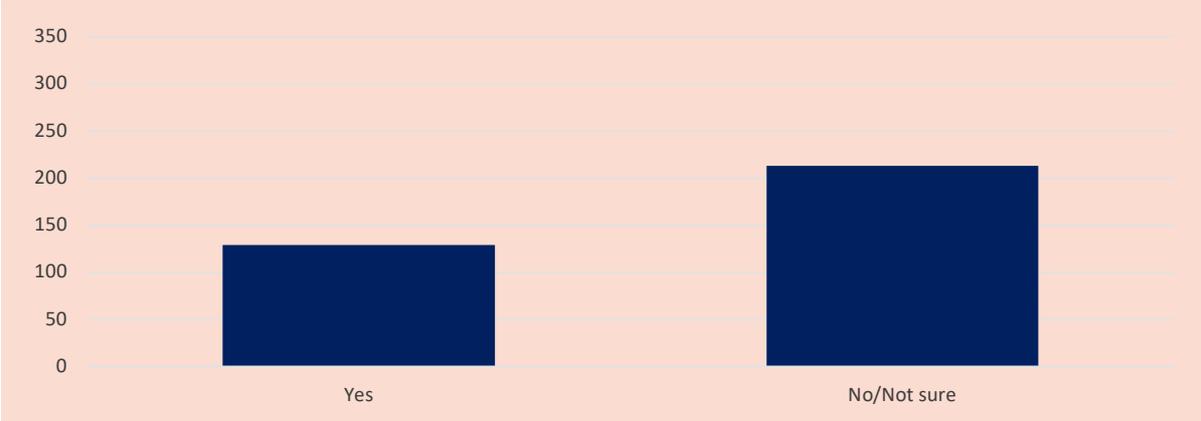
**Family member(s)?**



**Friend(s)?**



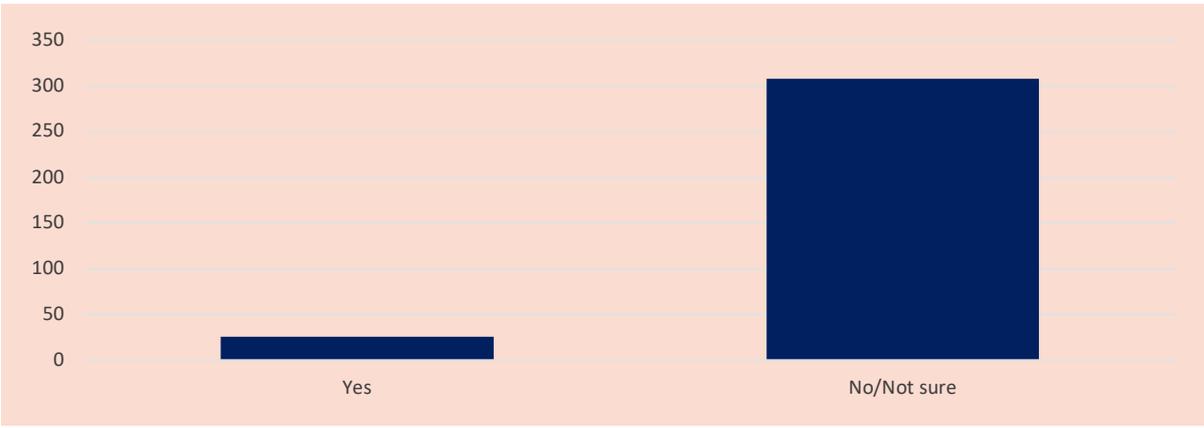
**Your appointed Enduring Guardian?**



**GP?**



**Medical Specialist?**



**Nurse?**



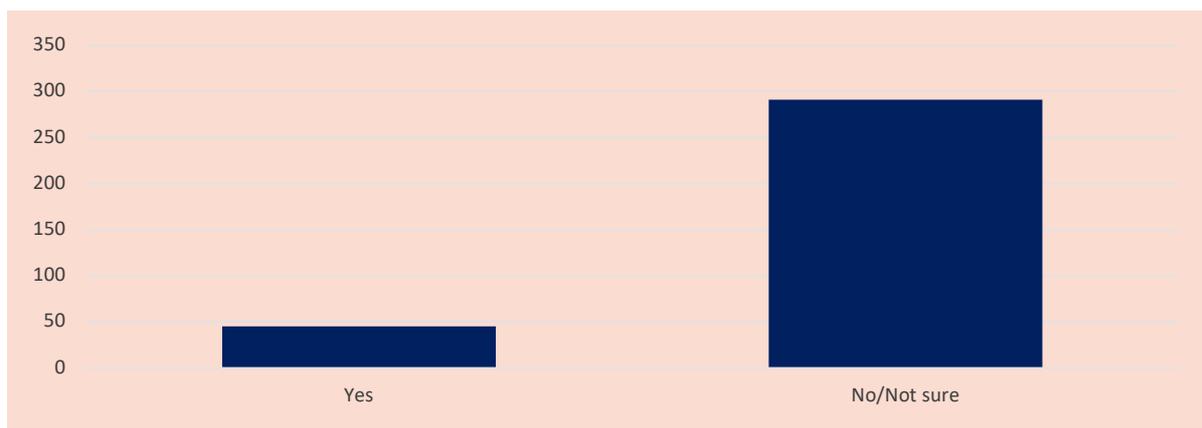
### Social worker?



### Religious or spiritual care advisor?



### Lawyer?

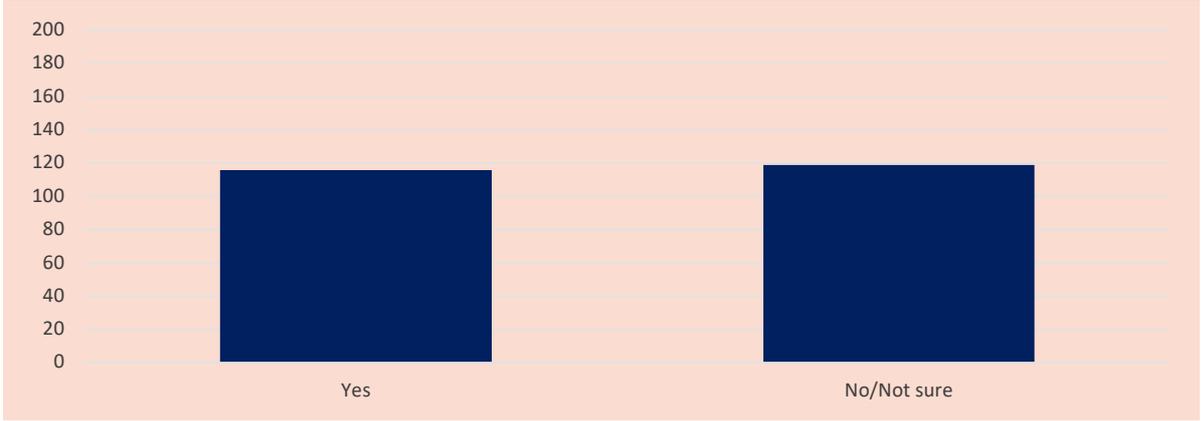


**Other?**

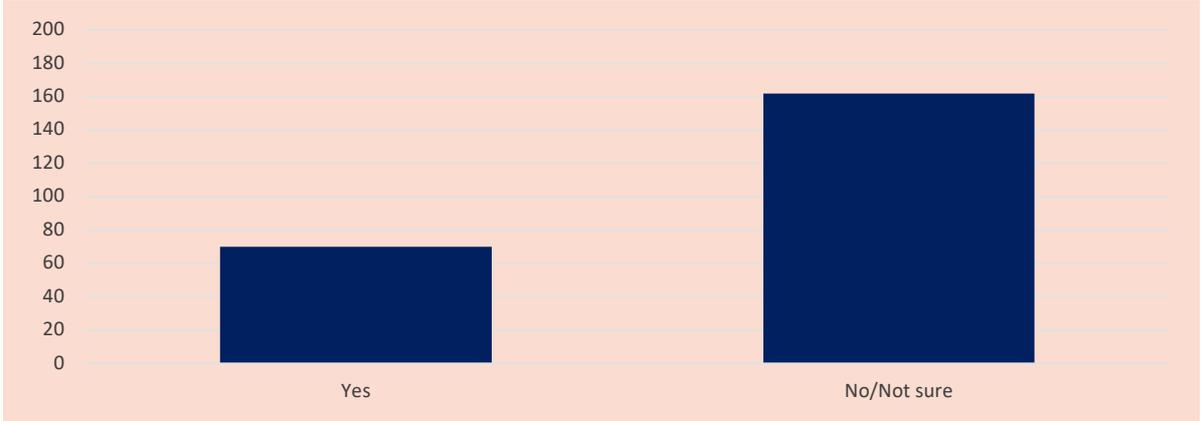


**If you have not had any conversations, why not?**

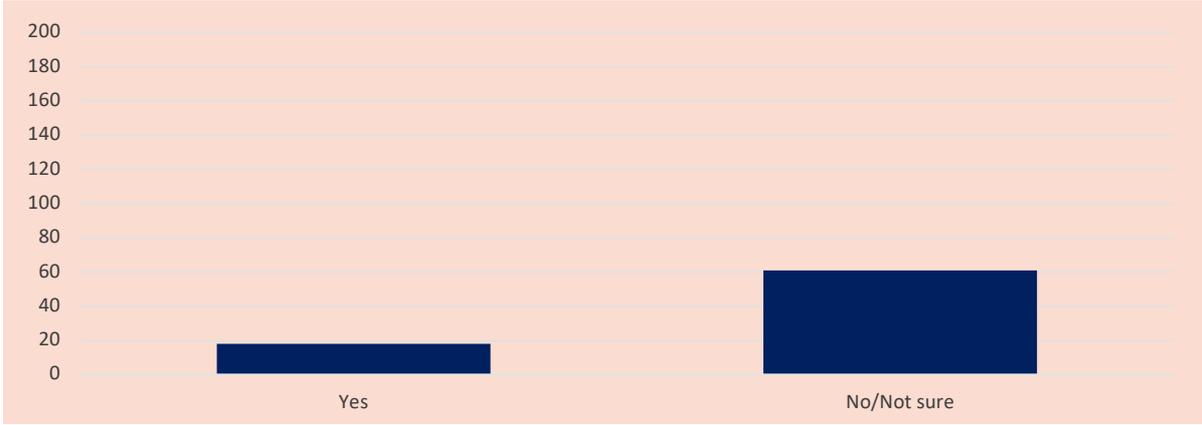
**I lack the necessary knowledge**



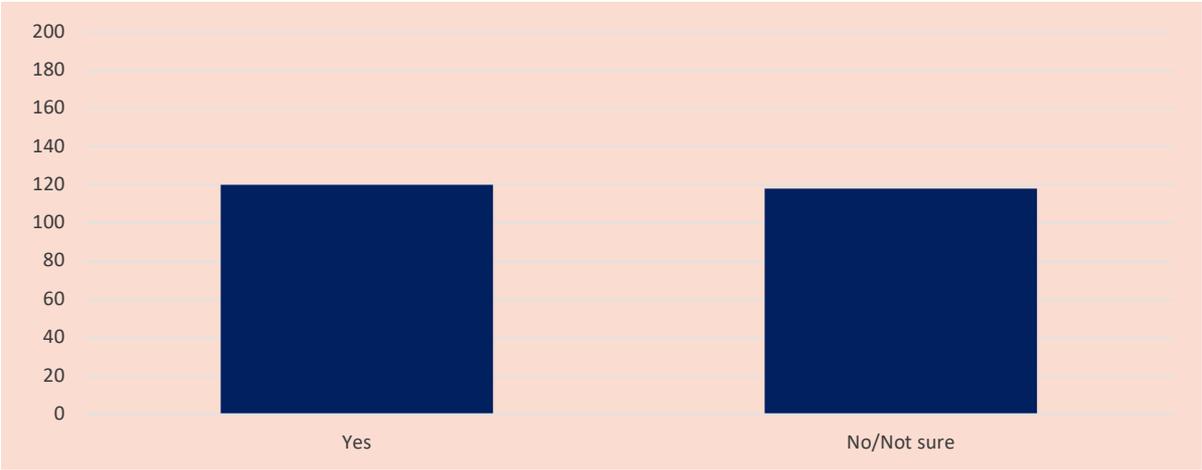
**I do not feel confident**



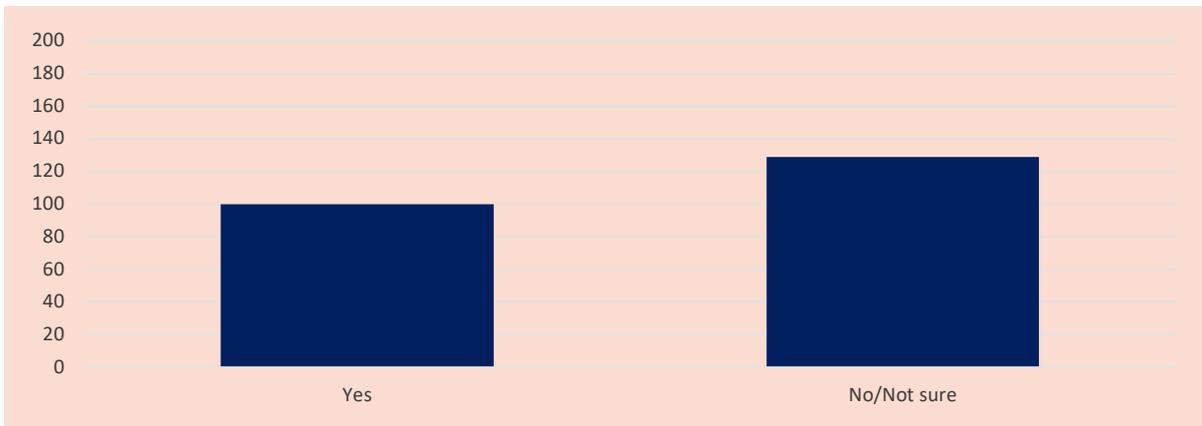
**I haven't found the right time**



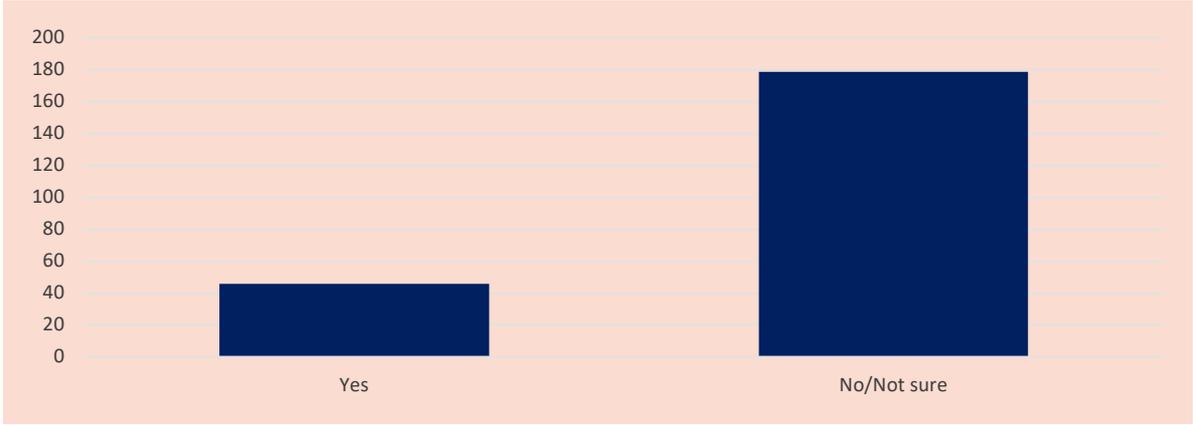
**I do not feel ready**



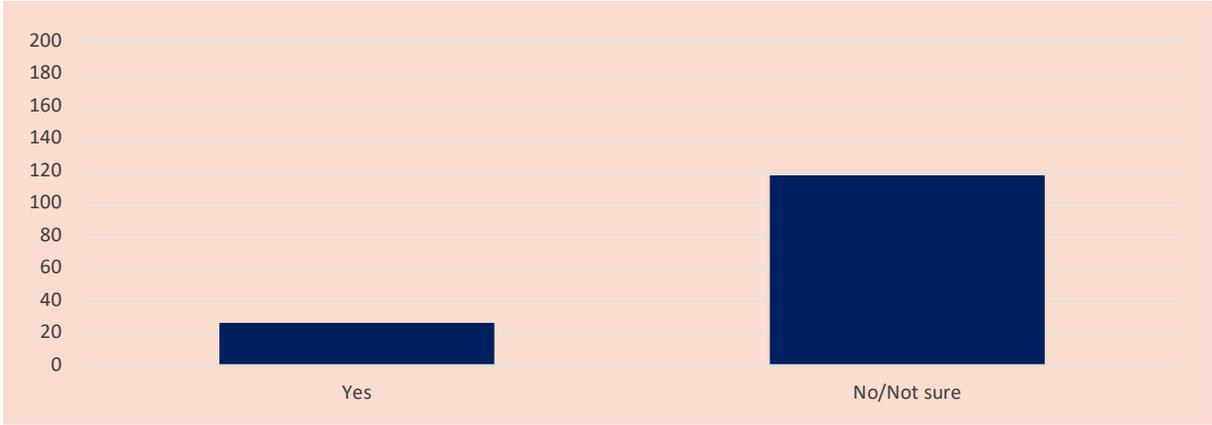
**I do not feel prepared**



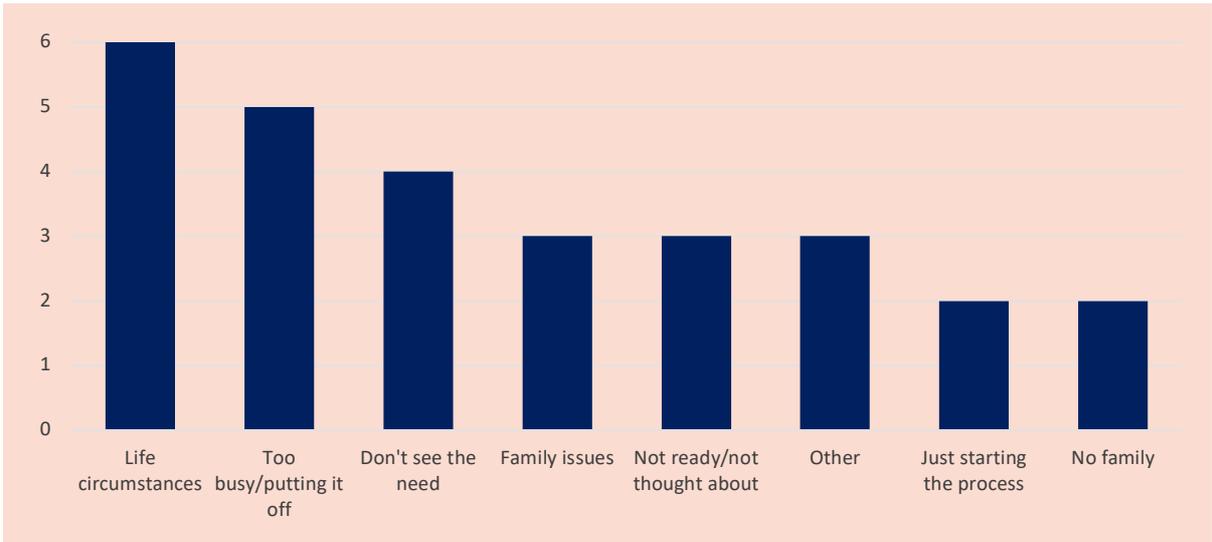
**People are not willing to discuss advance care planning**



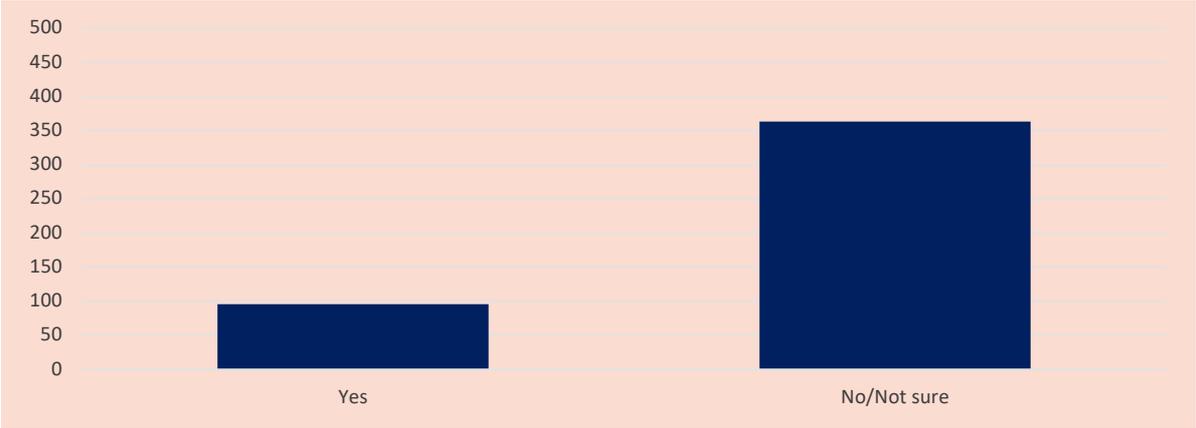
**I felt there was not enough time**



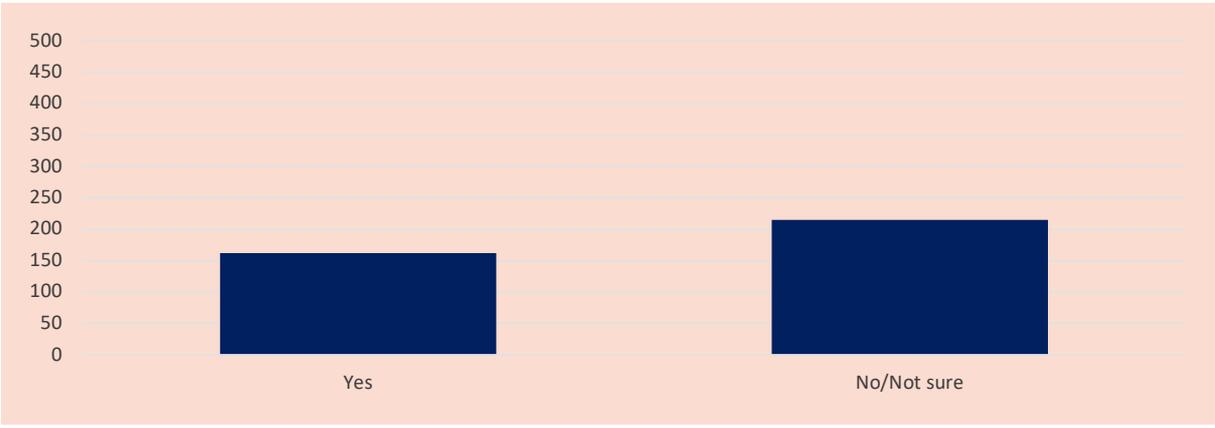
**Other reasons**



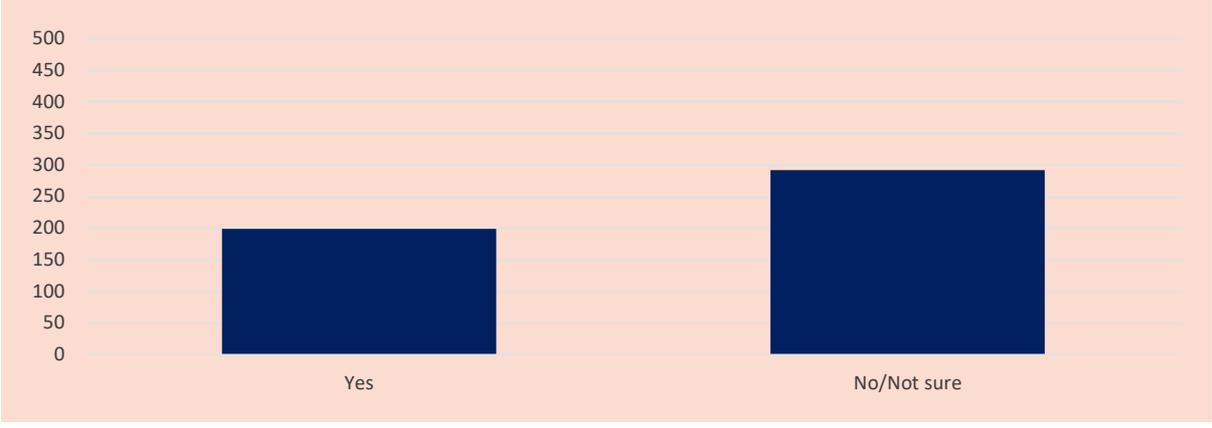
**Do you feel your end-of-life plans are adequate?**



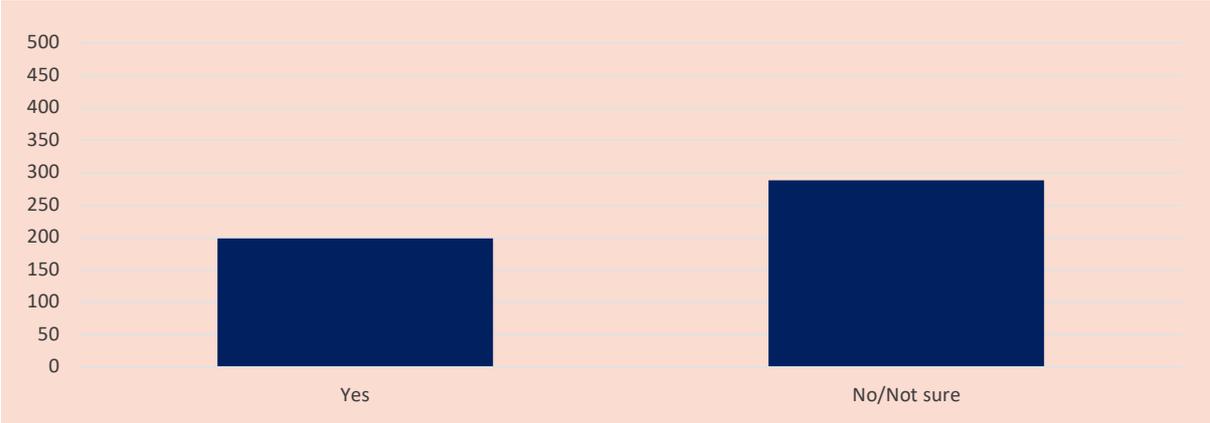
**Have you registered as an organ and tissue donor?**



**Do you know what Advance Care Planning is?**



**Do you know what an Advance Health Directive (AHD) is?**



**Do you know what an Enduring Power of Attorney (EPA) is?**

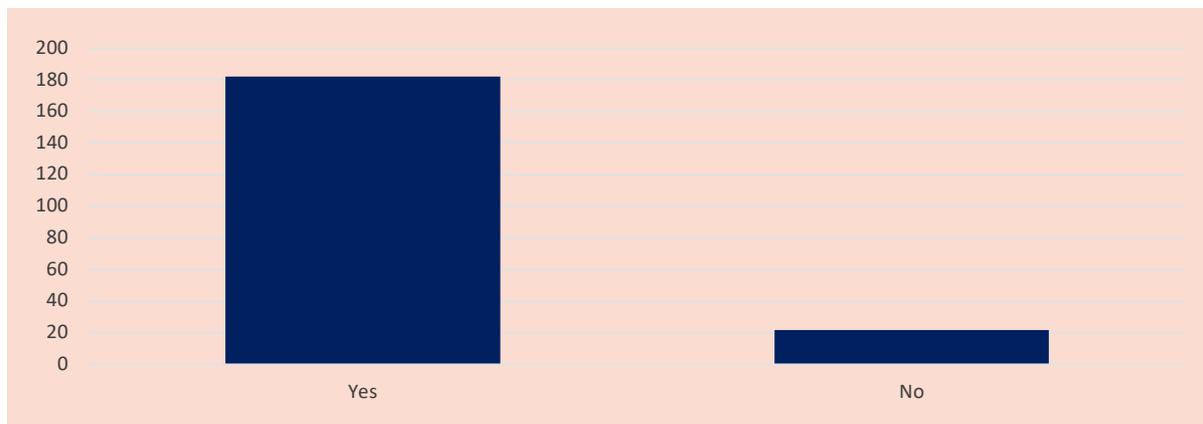


**Do you know what an Enduring Power of Guardianship (EPG) is?**

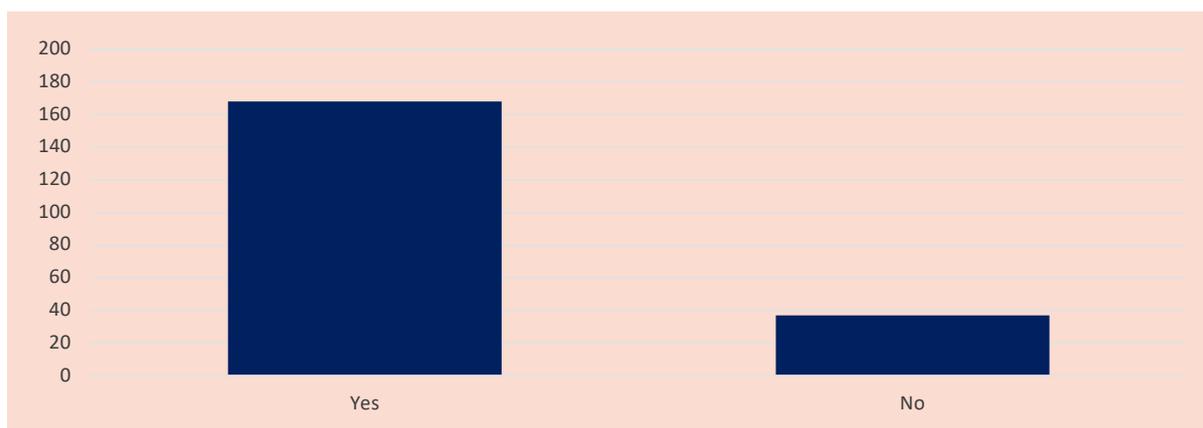


**Follow-up (Time 3) Data, N = 206**

**Have you thought about your preferences for the types of care and treatment you would like in the future?**



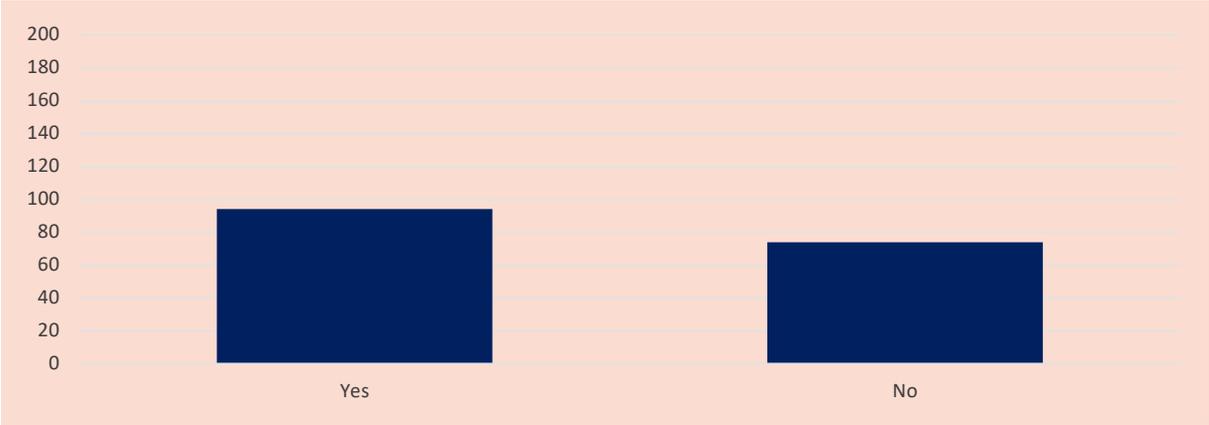
**Have you had a conversation about your end of life wishes with anyone?**



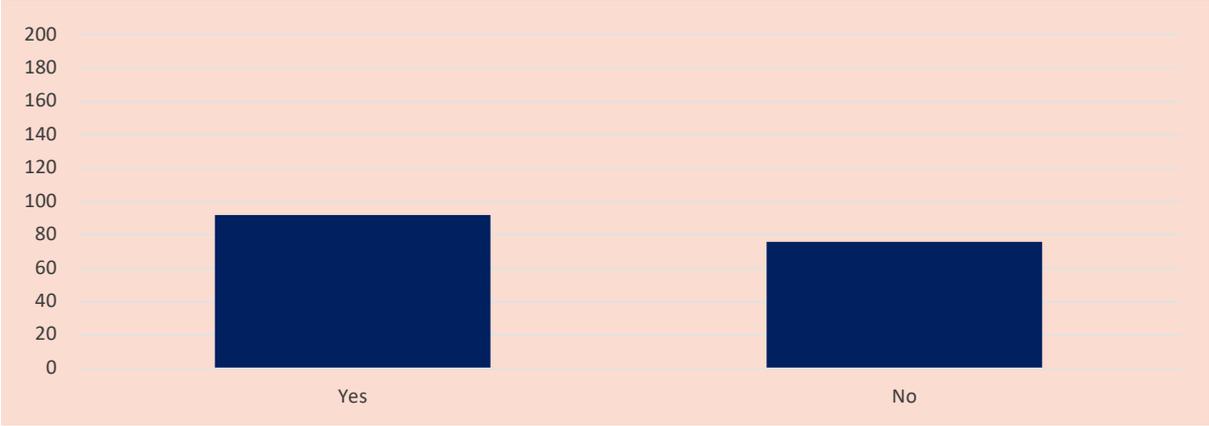
**Have you had a conversation with family members?**



**Have you had a conversation with friends?**



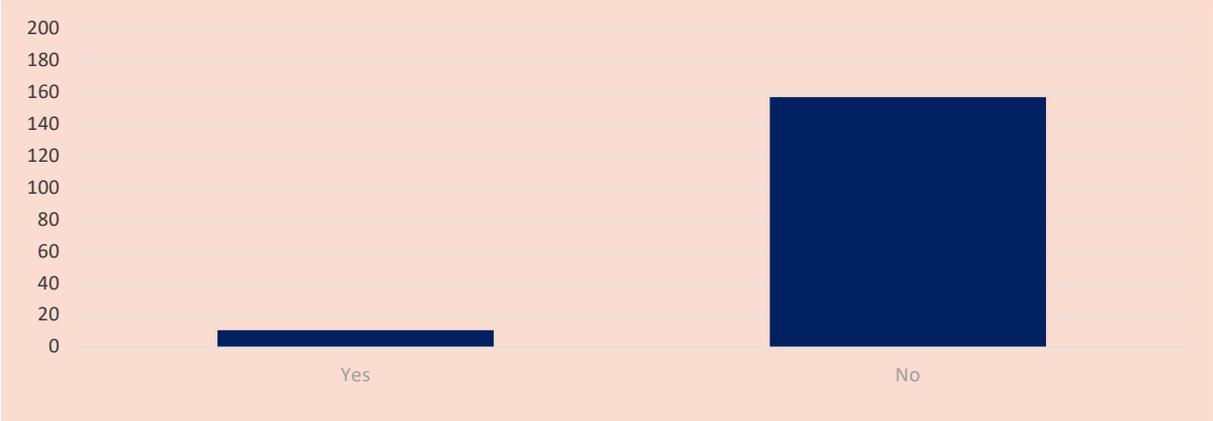
**Have you had a conversation with your appointed Enduring Guardian?**



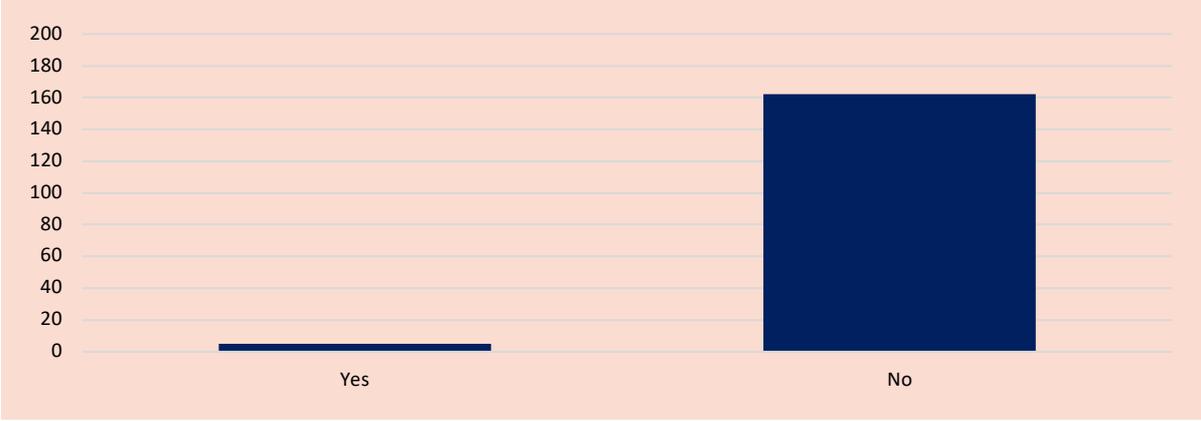
**Have you had a conversation with your GP?**



**Have you had a conversation with your medical specialist?**



**Have you had a conversation with a nurse?**



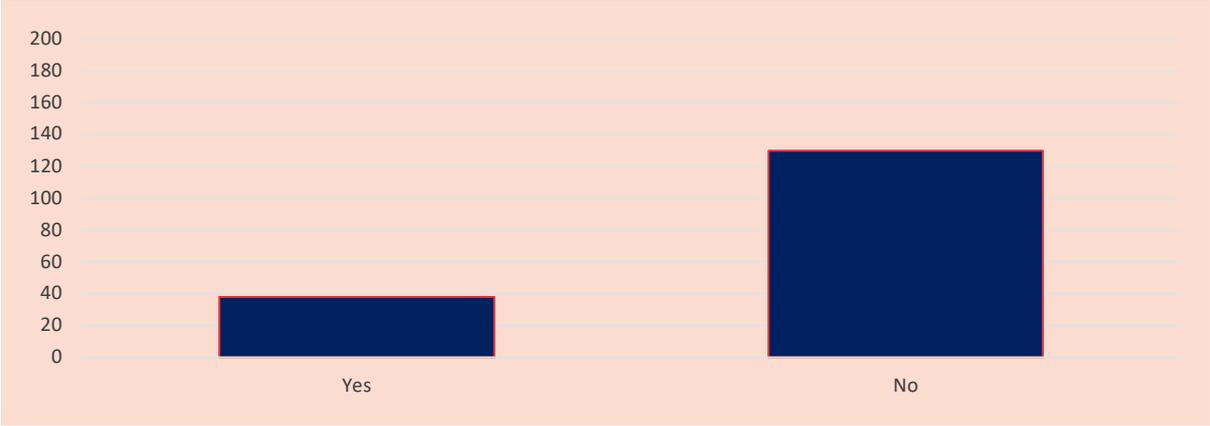
**Have you had a conversation with a social worker?**



**Have you had a conversation with a religious or spiritual care advisor?**



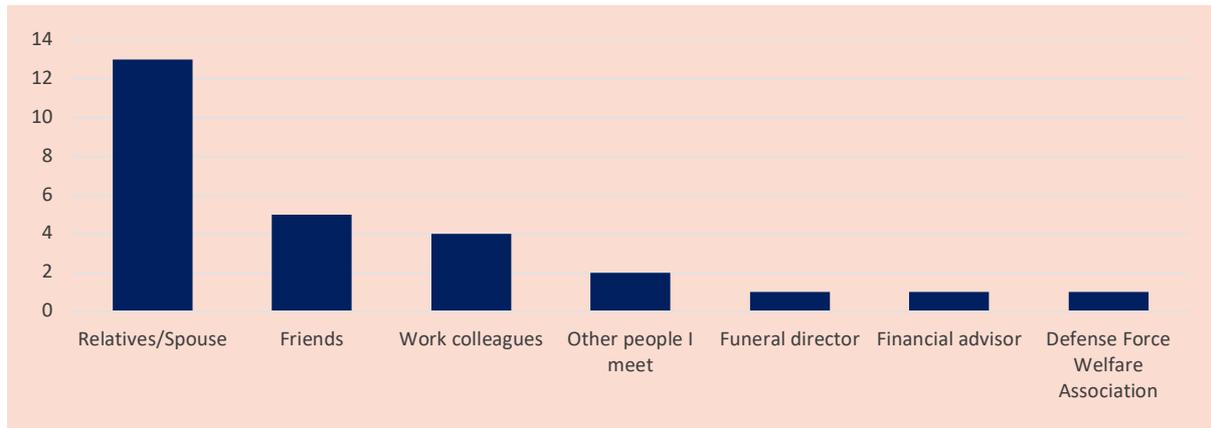
**Have you had a conversation with a lawyer?**



**Have you had a conversation with anyone else?**



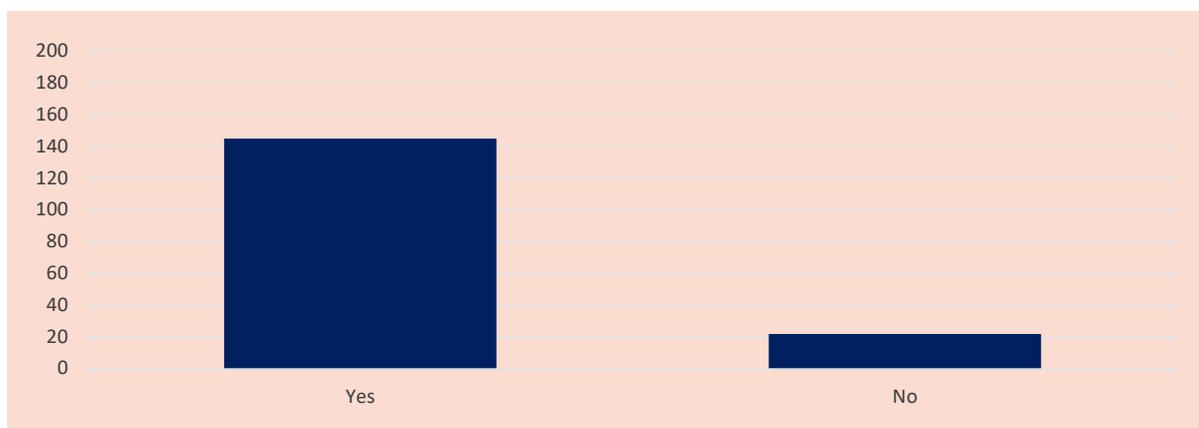
### If yes, who?



### Usefulness of the conversation on a 4 point scale from 'not at all useful' to 'very useful'

Conversation with:	% indicating "Useful" or "Very Useful"	N
Family	85	153
Friends	82	94
Appointed Enduring Guardian	90	92
GP	73	41
Medical Specialist	54.5	11
Nurse	100	5
Social worker	66.6	3
Religious or spiritual care advisor	100	6
Lawyer	92	38
Other	81	27

### Did the Advance Care Planning workshop prompt you to have any conversations about your end of life wishes?



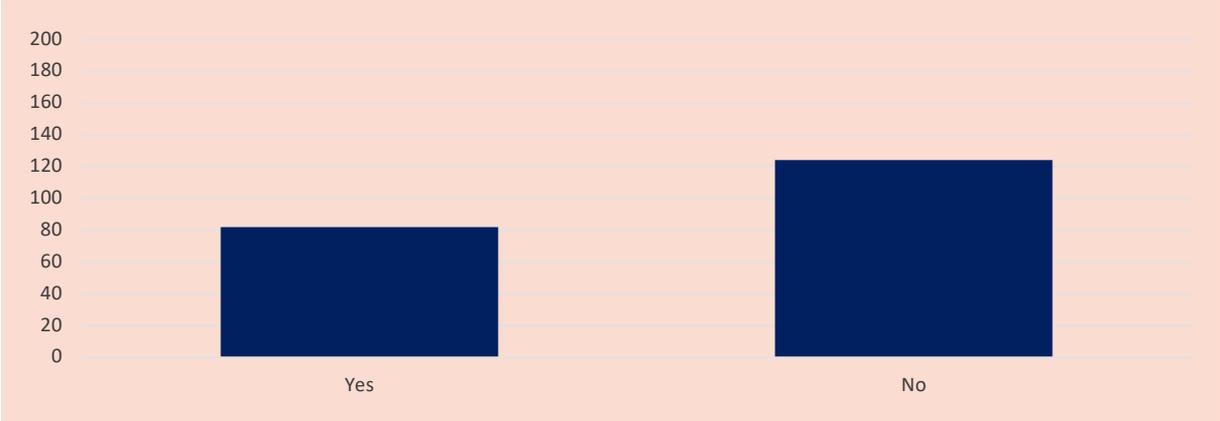
**If no conversation, what has stopped you from having a conversation so far?  
(Participants could check more than one category)**



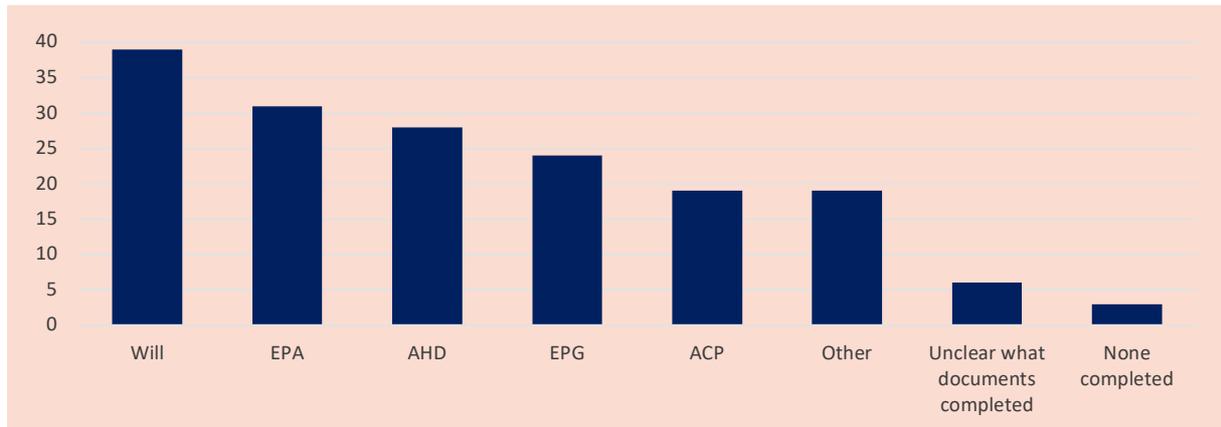
**How would you rate your intention to have a conversation?**



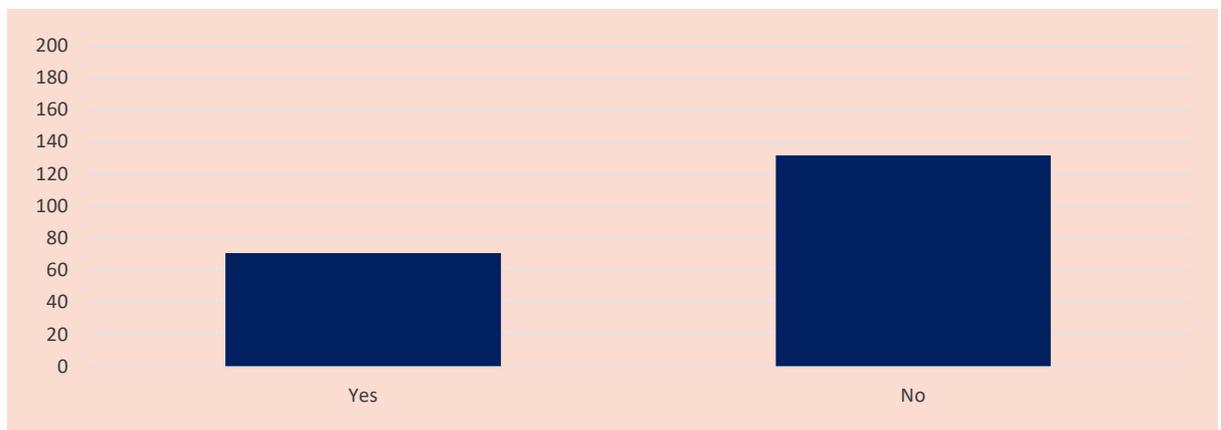
**Have you written anything down in relation to treatments or your wishes end of life?**



### If yes, what was the name of the document completed?



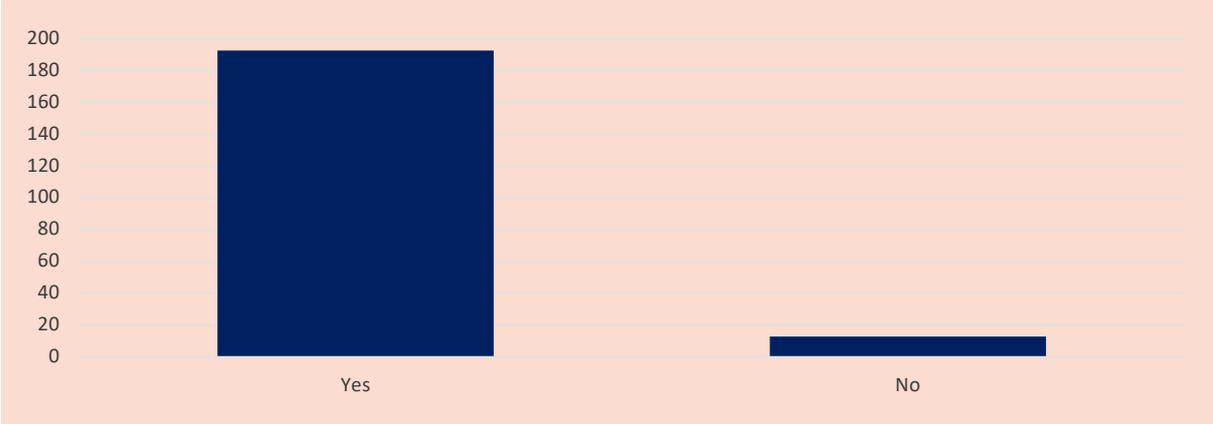
### Do you feel your end-of-life plans are adequate?



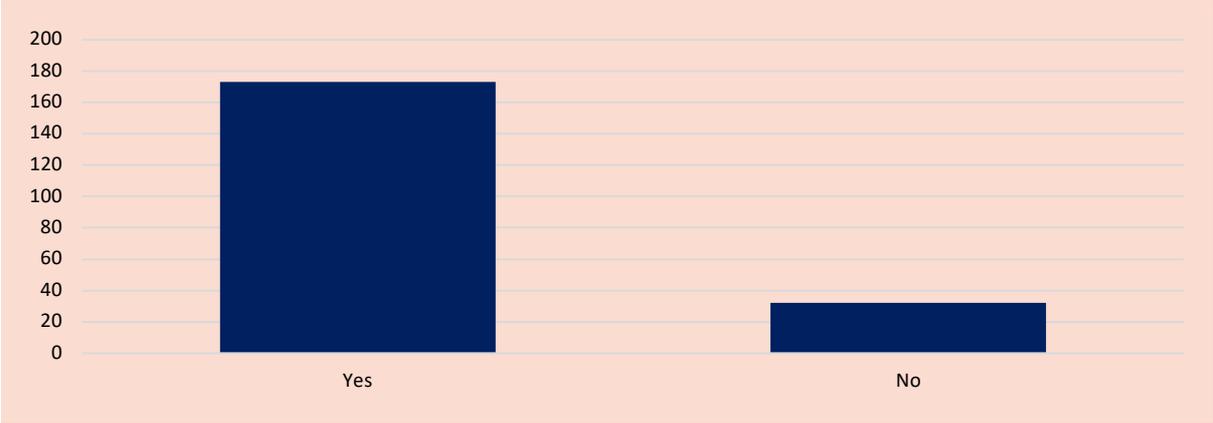
### Have you registered for organ and tissue donation?



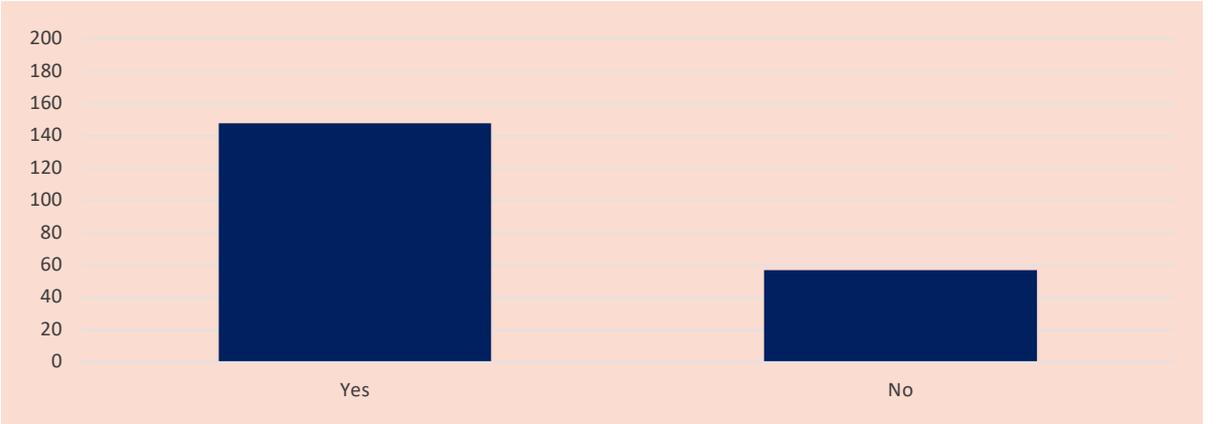
**Have you made a Will?**



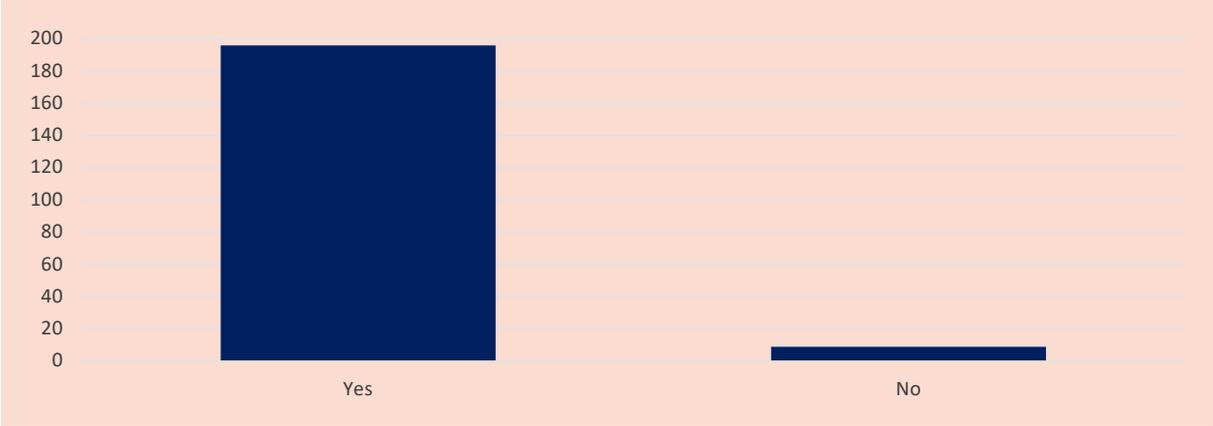
**Do you know what Advance Care Planning (ACP) is?**



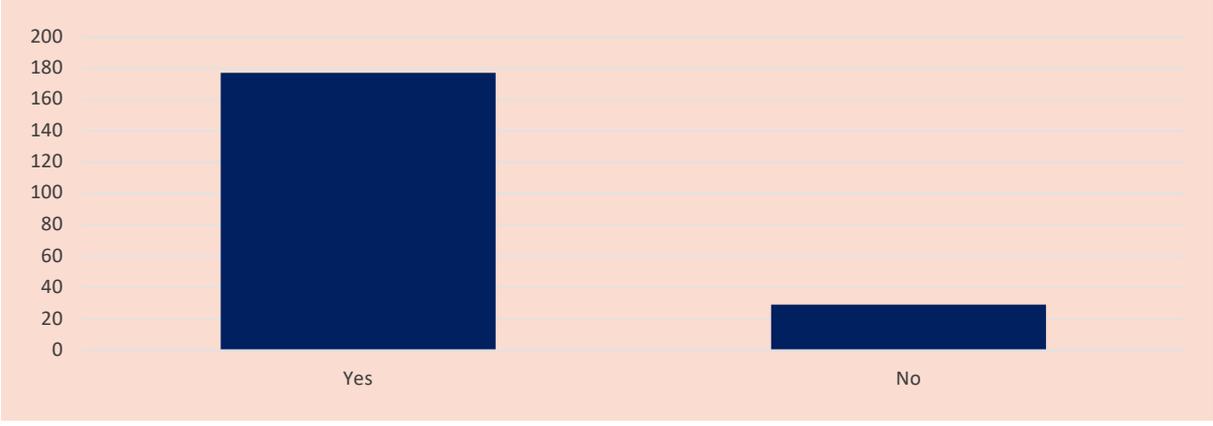
**Do you know what an Advance Health Directive (AHD) is?**



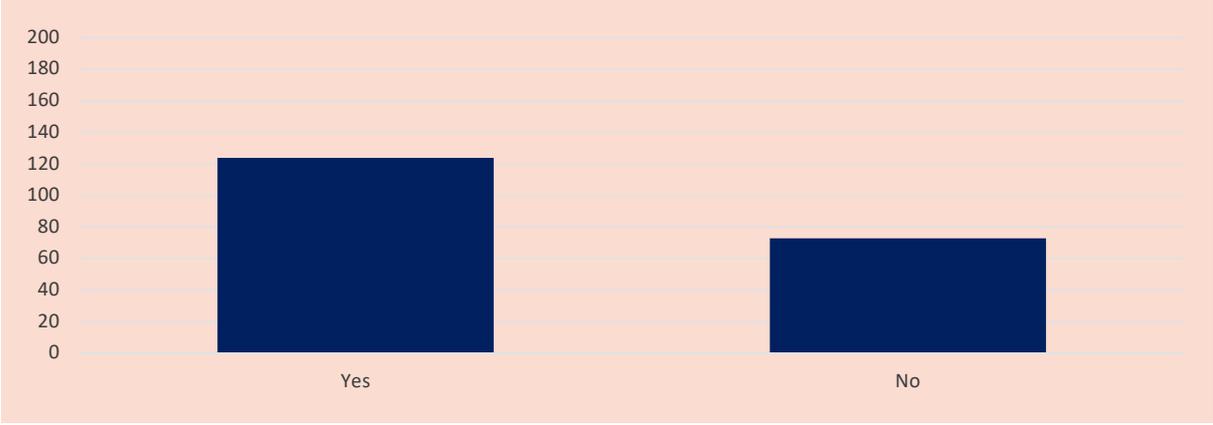
**Do you know what an Enduring Power of Attorney (EPA) is?**



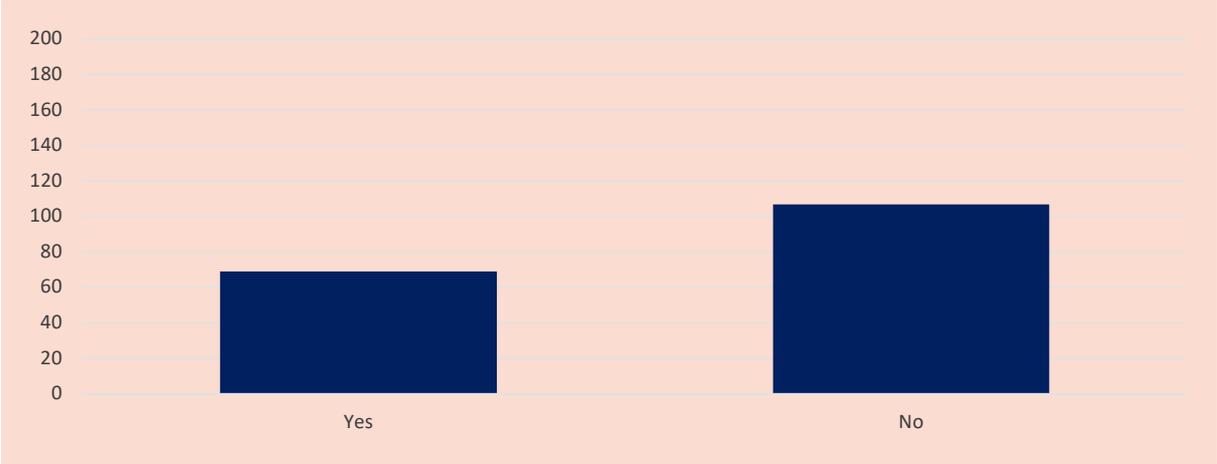
**Do you know what an Enduring Power of Guardianship (EPG) is?**



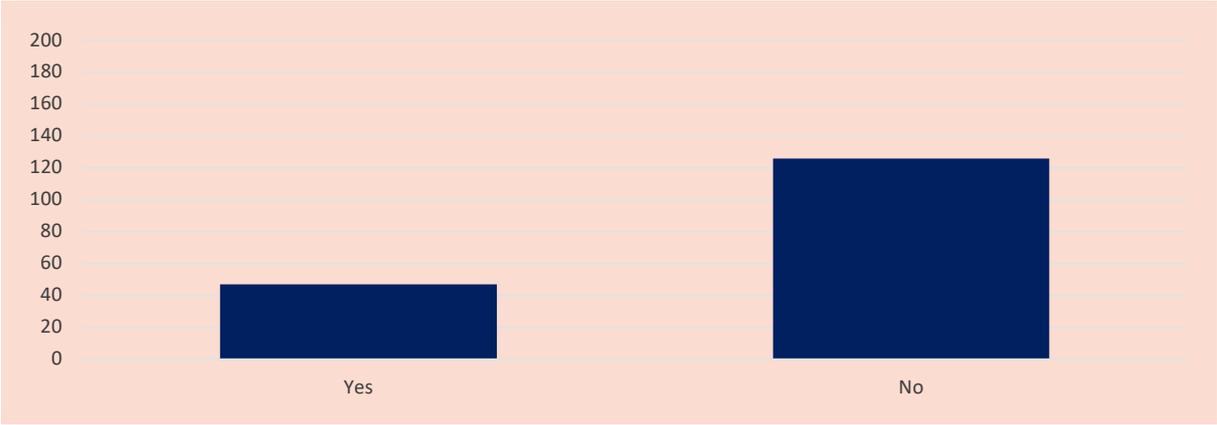
**Have you appointed an Enduring Power of Attorney to manage your finances?**



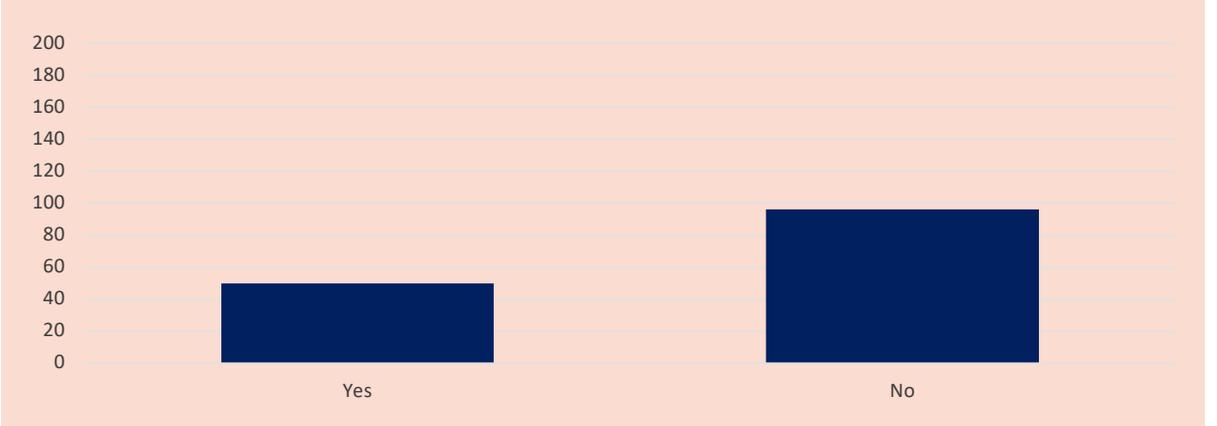
**Have you appointed an Enduring Power of Guardianship to make health and lifestyle decisions?**



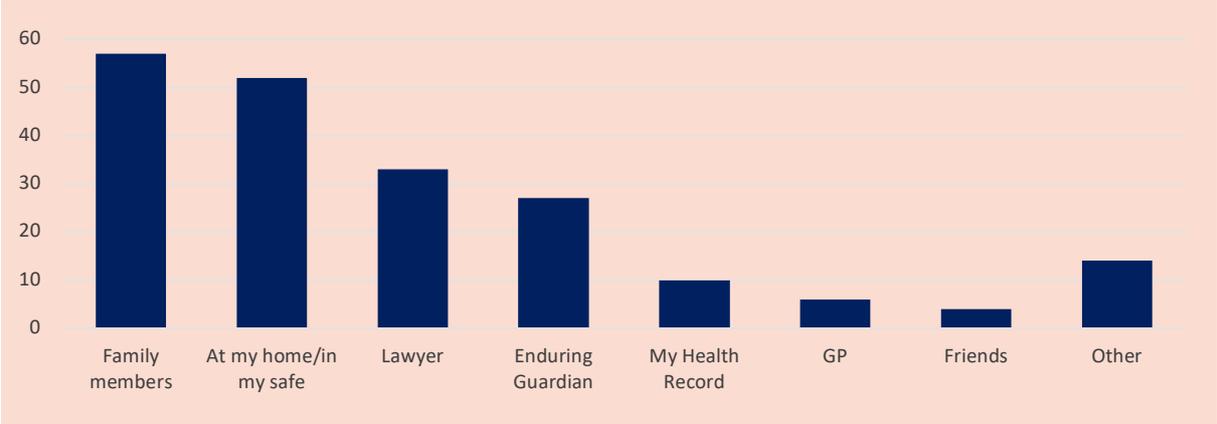
**Have you written an Advance Care Plan indicating what treatments you want or don't want at end-of-life?**



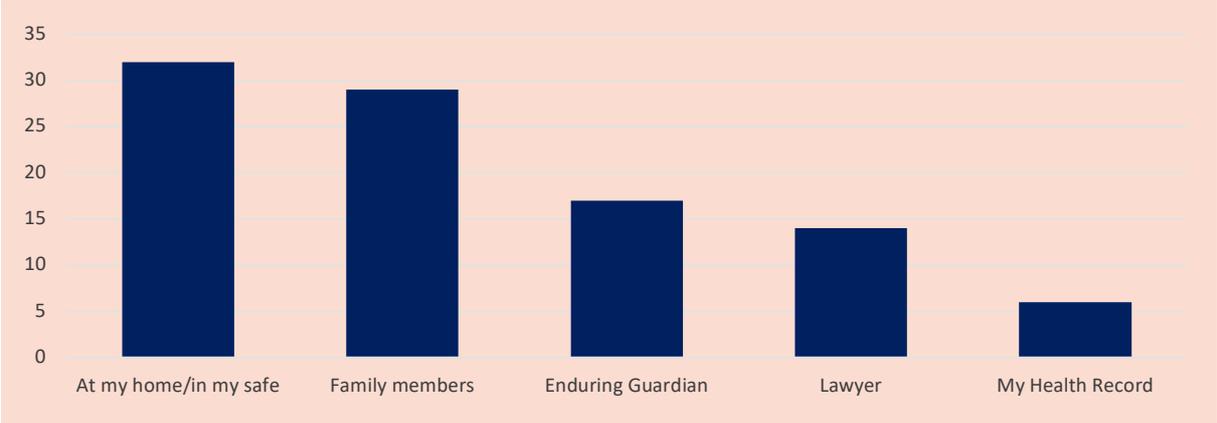
**Have you completed an Advance Health Directive?**



**Enduring Power of Attorney: Where is this document stored?**



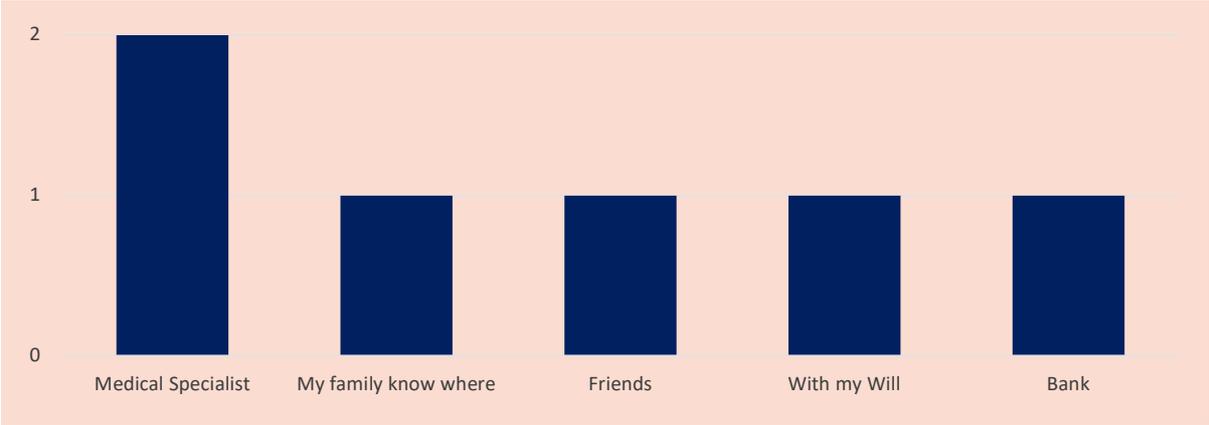
**Enduring Power of Guardianship: Where is this document stored?**



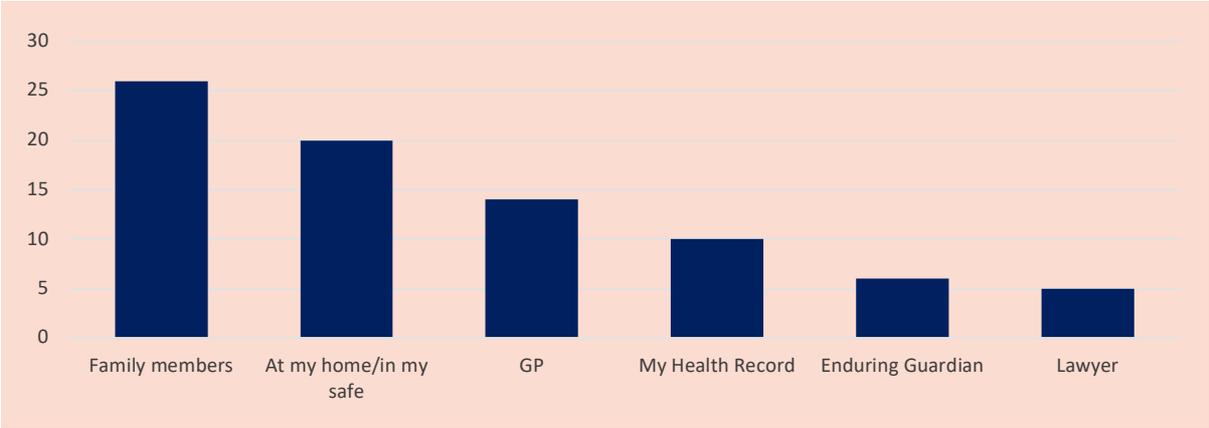
**Advance Care Plan: Where is this document stored?**



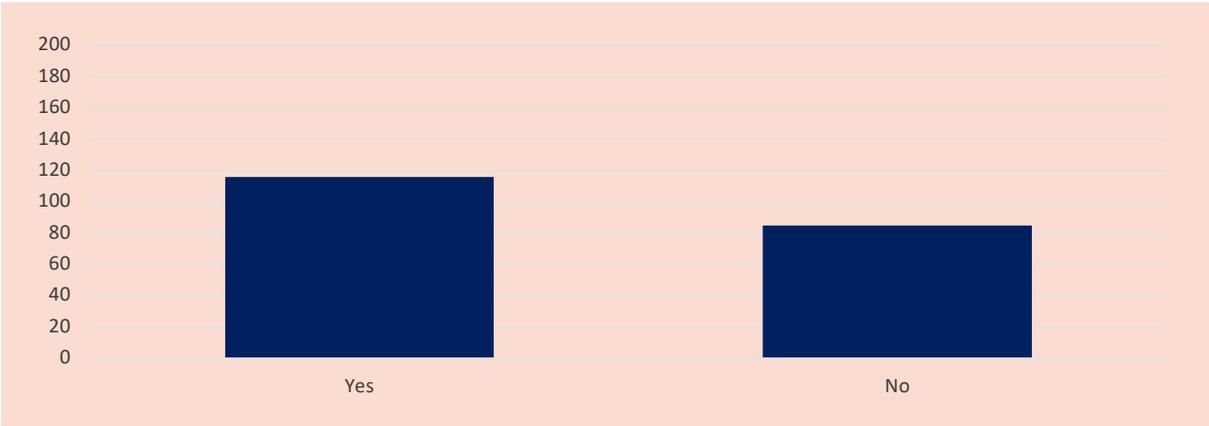
**Advance Care Plan: (If other) Where else is this document stored?**



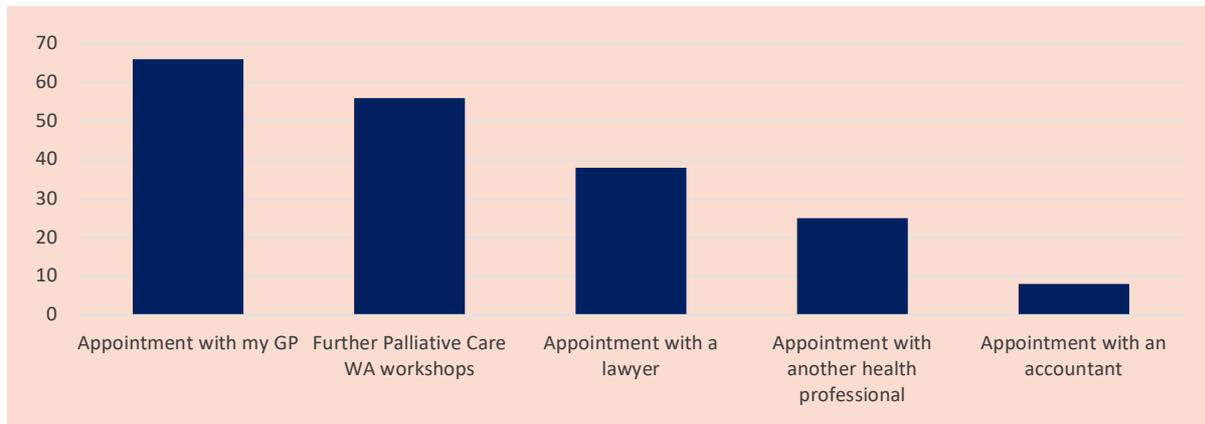
**Advance Health Directive: Where is this document stored?**



**Did the Advance Care Planning workshop prompt you to complete any documentation?**

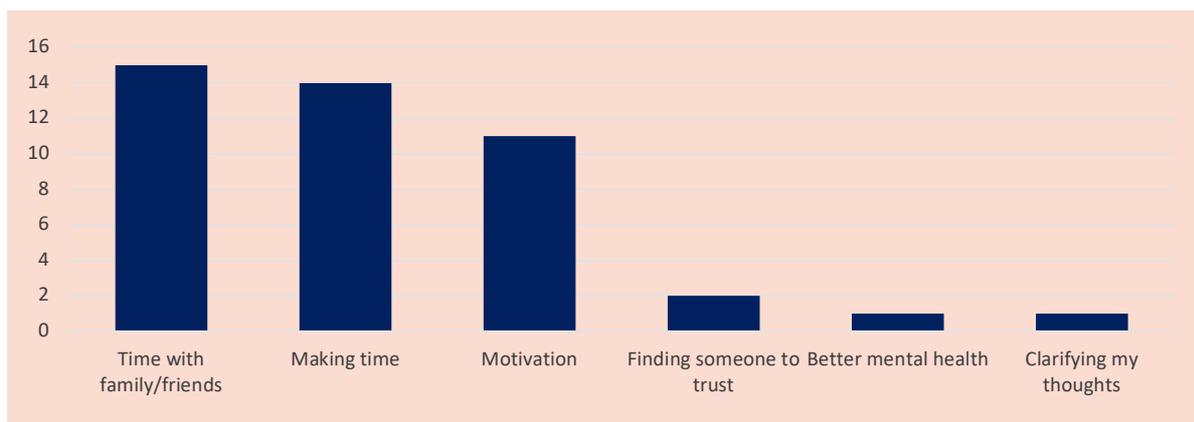


## What would help you to have conversations and complete documentation in relation to Advance Care Planning?

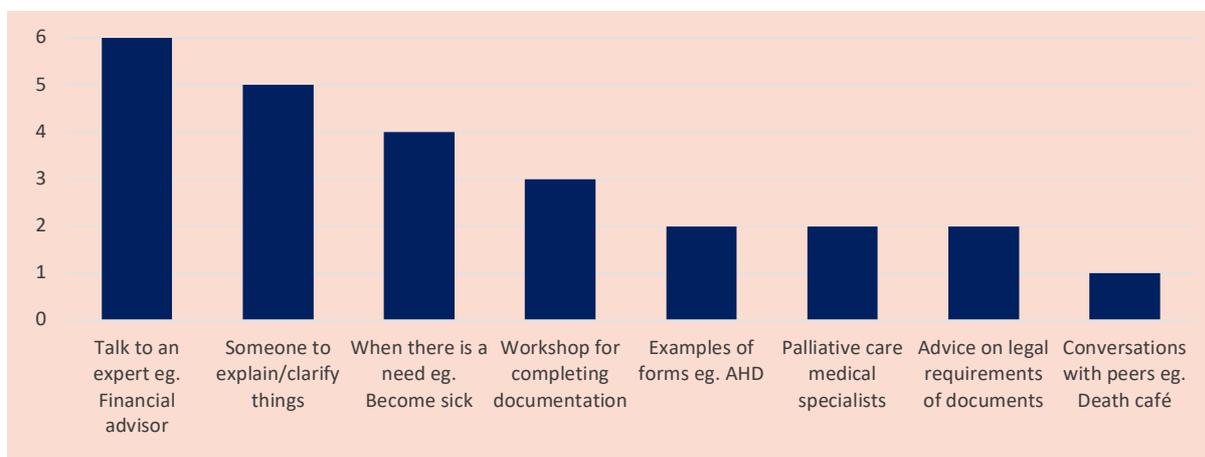


## What else would help you to have conversations and complete documentation in relation to Advance Care Planning?

### Personal factors



### Practical factors



## Selection of additional comments

Category	Comments
<b>End of Life wishes</b>	I want EVERYONE involved in my end of life care to know PRECISELY what I DO want and do NOT want!!
	I know what I want and I know what I don't want. I don't want palliative care, I don't want to go into a nursing home. I want euthanasia. The kids are busy and I don't want to burden them with anything.
<b>Workshop feedback</b>	Well run seminar, learnt a lot. Made us think about it more. Freshens things in your mind, made us get on and do something about it.
	We had already done wills and Power of Attorney, but the workshop helped very much to get on to other documents and was very enlightening.
<b>ACP documents</b>	I found the workshop very interesting though was not as immediately helpful as I had hoped. This was especially with regard to the AHD. I know what that document is but feel I need more specific details and options in order for me to complete one for myself. Comparing other States' documents is one way to go, but I would like to have heard a presenter go through the many options available and their implications. Then I feel as though I would have sufficient information on which to base decisions about what to include in my own AHD.
	I am waiting for the updated AHD form for WA to be made available before I complete.
	The forms that were given to us at the workshop were not in the correct format (EPA). It was in landscape and it needs to be in portrait for Landgate to accept it.
	It would be good to have printed documents/booklets available in prepared form with spaces to fill out.
	I am having a hard time knowing what to do and where to start.
	I would like help with documents (EPG) online.
	I didn't even know that a health directive existed prior to the workshop.
<b>My Health Record</b>	We didn't realise there were so many other legal documents to think about, we thought it was only a Will that we needed to worry about.
	I tried to ask my oncologist about uploading my AHD to My Health Record and he didn't know what to do, he directed me to the ladies at the front desk of the hospital. The ladies at the front desk said they had never seen one, didn't know what to do. They rang Patient Records and they didn't know either. In the end they said to go to your GP and ask them to upload it to My Health. GP didn't know what to do either. I tried to go to My Health but there was an ID error.
<b>Process</b>	With all of these documents to do, so people know what you want, it is hard to know where the best place is for them, especially in the case of an emergency. My GP does not want to join My Health Record, which is a shame.
	Takes time to do all the documentation and get signature
	Regarding the ACP, it was too difficult to explain what I might want in the future because I don't know what is going to happen to me.
	Although we have not completed any documents yet, the workshop did prompt us to start thinking about things. We know it is important but it is near on impossible to get all the family together to discuss things.

	<p>It prompted me to start things going but I haven't actually completed the documents.</p>
	<p>Chinese families consider preparing the end stage of life too morbid. I don't, but my wife and children will not even discuss this matter even though we have three lawyers in our extended family.</p>
	<p>Workshop prompted me to start documentation but it isn't complete, I need further conversations and information.</p>
<b>Future recommendations</b>	<p>Another workshop would be great. It's not as easy as you think.</p>
	<p>Maybe a refresher workshop in a couple of years to update about any new legislation.</p>
	<p>All Ex Service Organisations should have a presentation from the Palliative Care Association.</p>
	<p>I think that there should be more information to increase awareness for older people, perhaps at GPs and community centres and in community newspapers etc.</p>
	<p>It would be good to find a way to bring younger people to the workshop. I also think a follow-up workshop would be of benefit.</p>
	<p>It is always good when things can be reinforced and made clearer. Would like to see that more of the elderly are able to attend.</p>
	<p>It was all a lot to take in. Now I have started the conversations etc. with family I would love to have a refresher seminar.</p>

## Results (Time 1 → Time 3)

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A series of statistical tests, Generalised Linear Mixed Model (GLMMs), were run, one for each of six outcome measures: contemplation, organ donation, adequacy of plans, conversations (with anyone as well as total number) and knowledge.

### Contemplation

Time (T1 versus T3) was a significant predictor of the probability of responding 'yes' to the question 'Have you thought about your preferences and wishes for end of life?' ( $b = 1.65$ , odds ratio = 5.23,  $p < .001$ ), with 61.9% of participants responding 'yes' at Time 1 compared to 89.6% at Time 3. The odds ratio of 5.23 indicates that 'yes' responses were 5.23 times more likely at Time 3 compared to Time 1.

### Organ donation

Time was not a significant predictor of the probability of responding 'yes' to the question 'Have you registered for organ donation?' ( $b = 0.01$ , odds ratio = 1.01,  $p = .943$ ), with 43.0% of participants responding 'yes' at Time 1 compared to 43.8% at Time 3. Participants were equally likely to respond 'yes' at Times 1 and 3.

### Plans

Time was a significant predictor of the probability of responding 'yes' to the question 'Are your end of life plans adequate?' ( $b = 0.72$ , odds ratio = 2.06,  $p < .001$ ), with 20.9% of participants responding 'yes' at Time 1 compared to 34.5% at Time 3. The odds ratio of 2.06 indicates that 'yes' responses were 2.06 times more likely at Time 3 compared to Time 1.

### Conversations

Time was a significant predictor of the probability of responding 'yes' to the question 'Have you had a conversation with anyone about your end of life wishes?' ( $b = 0.90$ , odds ratio = 2.46,  $p < .001$ ), with 65.1% of participants responding 'yes' at Time 1 compared to 82.2% at Time 3. The odds ratio of 2.46 indicates that 'yes' responses were 2.46 times more likely at Time 3 compared to Time 1.

Time was also a significant predictor of the total number of conversations that were undertaken regarding end of life wishes ( $b = 0.73$ ,  $p < .001$ ). Participants reported a mean of 1.69 ( $SE = 0.10$ ) conversations at Time 1 compared to a mean of 2.42 ( $SE = 0.10$ ) conversations at Time 3.

### Knowledge

Time was a significant predictor of knowledge of four ACP concepts - EPA, EPG, ACP and AHD, ( $b = 1.18$ ,  $p < .001$ ). Participants' mean knowledge score was 2.17 ( $SE = 0.06$ ) at Time 1 which increased to 3.34 ( $SE = 0.07$ ) at Time 3.

The results show that time was a significant predictor of several key changes in thoughts and behaviours related to advance care planning, namely thinking about preferences and wishes for EoL; viewing EoL plans as adequate; an increased number of conversations with others about EoL wishes; and increased understanding of key concepts related to ACP. Conversely, time was not a predictor of a change in behavior related to registering as an organ donor. This was an observational pre-post/follow-up study with no control group, therefore we cannot state conclusively that the workshop was the causal factor in changes over time. However, it is highly likely that participation in the workshop was the main contributing factor to the observed cognitive and behavioural changes.

# Discussion

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This is the first study examining whether ACP education in the general community leads to changes in knowledge and behaviour (conversations about end of life wishes and completing documentation).

## Time 1

The findings reveal that most people attending the workshops have thought about their preferences for types of care and treatment. This reflects stage 2 of the behavioural change model where people are thinking about changing behaviour. People who have had a conversation talked to family members rather than health professionals, including GPs, about their end-of-life wishes. This is important as we can take a two-pronged approach; continuing community workshops but also working with GPs and other health professionals.

The main reasons for not having a conversation were that people do not have the knowledge and do not feel ready or prepared. Time, confidence and lack of knowledge or readiness of the other person (people) were not as salient. Most people were aware of the legal documentation known as Enduring Power of Attorney but fewer people were aware of the legal document Enduring Power of Guardianship, as well as Advance Care Plans and Advance Health Directives, with an even split between people who were aware and those not aware of these latter three health documents. Most people felt that their end-of-life plans were not adequate. Our conclusion is that we need to move people from contemplation to action<sup>10</sup>.

## Time 3

The strongest evidence for the success of the workshops in increasing knowledge and changing behaviour comes from our statistical analyses. Simply stated, and bearing in mind we did not have a control group, our findings indicate that the WA ACP workshops lead to statistically significant and substantial changes in knowledge and behaviours related to ACP. Namely, thinking about preferences and wishes for EoL; viewing EoL plans as adequate; number of conversations with others about EOL wishes; and understanding of key concepts related to ACP. These are extremely powerful findings and indicate that the ACP workshops make a difference to people who attend in terms of ACP knowledge and behaviour.

The descriptive statistics show an increase in the number of people having conversations with family members but there were still fewer people having conversations with health professionals. All these conversations were rated highly in terms of usefulness. Many people explicitly stated the workshops had prompted these conversations. Interestingly the main reasons for *not* having a conversation had changed from time 1 to time 3, and not feeling ready and not finding the right time were the main reasons (though numbers were low for both). This suggests that the workshop had met the needs of those who had little knowledge, lacked confidence or did not feel prepared. This is a salient finding which is worth noting. The workshops appear to meet the needs of people who want knowledge, want to feel confident and want to be prepared before acting (changing behaviour).

Many people had completed documentation and we need to highlight that some were still thinking about action. Given the power of the workshops to change behaviour and increase knowledge, follow up workshops could be a good investment. Storage of documentation is usually at the family home or with family members. A session on reasons for using My Health Record or a WA Register could be useful in workshops. The workshops prompted many people to complete documentation, a further argument for continuation of the workshops. People, in general, wanted help in completing the documentation mainly from further workshops or their GP, and this support needs to be free or low cost. A few participants had difficulties accessing My Health Record and also reported how their GP/other medical professionals did not know what to do.

Conversely, there was no change in behaviour related to registering as an organ donor, which could suggest that this is a different concept, is not of interest, or that people have already changed their behaviour in relation to this issue. As such, this topic could be removed from the workshop.

## **Interviews**

### *Motivation for attending*

Motivation for attending the workshop included being up to date on the issues; having the 'right' words; not to leave everything to others; and to get an understanding of what was needed. The workshops met these expectations and provided knowledge. The workshops also helped people to think about their own wishes and values and resulted in feelings of confidence, especially in starting conversations about EoL wishes. Participants also expressed a feeling of being more in control over their future. Most participants want to get things sorted so that they can have their say regarding their EoL wishes and so they are not a burden to others. One important aspect was helping participants with the 'correct' words. This was a recurring theme and something future workshops could include. Specific examples were also clearly needed.

### *End-of-life wishes*

Most participants were clear about their wishes for EoL care and did not want invasive life extending treatments that would destroy their independence and quality of life. Also, most participants would prefer to stay at home as long as possible. However, some participants hoped that they would not need to do such planning, many thought they would deal with it when the time comes, a few believed that someone else would be around to deal with it and know what to do, or a few people thought that they are too young to do anything yet.

### *Challenges*

Some participants were worried about their wishes being followed by doctors. Concerningly, many people encountered reluctance when they raised the conversation with friends, GP, solicitor. We also need to think about, and plan for, people who live alone with no family or friends, as participants without close relatives and little finances/resources struggled to know who to appoint as their EPA or EPG. Participants stressed that not all GPs are knowledgeable or willing to discuss EoL issues and many participants thought that it would be difficult for the GP to initiate the topic.

## Conclusion

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In summary, the workshops were *highly* effective for this group of participants. We know from previous evaluations that the workshops are considered useful, but we now have very powerful evidence that they are successful in meeting the aims of WA ACP workshops, namely changing knowledge and behaviour in relation to ACP.

## Recommendations

- Continue to roll out ACP workshops across the WA community.  
*The evaluation has provided substantial evidence for the effectiveness of the ACP workshops in effecting behavioural changes i.e having a conversation with others about end-of-life wishes and completing documentation. Consideration might also be given to offering a train the trainer program to facilitate other organisations to implement this approach.*
- Develop ACP workshops and/or materials for GPs.  
*Most people have a conversation about end of life wishes with family members rather than GPs. This could be because GPs do not ask. Many people would like GPs to help them to complete ACP documentation.*
- Modify workshops to remove discussion of organ donation.  
*There was no change in this area so we can conclude that ACP workshops do not lead to a change in consideration regarding organ donation.*
- Emphasise the benefits of lodging documents with My Health Record or a WA Register if the WA State Government proceeds with the Joint Select Committee on End-of-Life Choices' recommendation on this, and educate GPs and hospital staff.  
*Most people keep their documents at home or with family members.*
- Explore the development of follow up workshops and/or templates to help people complete documentation.  
*Many people wanted follow-up workshops and help completing documentation and finding the 'right' words.*
- We need to consider workshops for vulnerable groups including people who live alone with no family or friends, people living in supported accommodation such as homeless shelters, and people with mental health issues.
- Future research should look at a follow-up survey at around a year after the ACP workshop to see if people maintain behavioural changes and if people reflect on their decisions and end-of-life wishes.  
*The WA ACP workshops move people from contemplation of ACP to ACP action. However, the final stage of the behavioural change model - maintenance and reflection - was not explored.*
- Future research should look at using a matched control group.

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# Appendix 1

## Qualitative Interview findings

Themes from interviews	Quotes
<b>Motivation for attending workshop</b> <ul style="list-style-type: none"> <li>To be up to date</li> <li>To get the 'right' words</li> <li>Not to leave others in the lurch</li> <li>To gain understanding</li> <li>To see if missing anything</li> </ul>	<p>Just to be more up to date with what the current position was.</p> <p>Mainly it was I didn't want to suffer pain towards the end and things so that was really why we attended the workshop, so we could write an advanced health care plan and get the right words for it.</p> <p>It's always a good idea to have I guess plans sorted out so you're not leaving other people in the lurch if something happens to you suddenly.</p> <p>I think we felt that we may not have a comprehensive understanding of all the things that are involved and that proved to be the case so, you know, there were lots of issues that you brought up that we hadn't previously been aware of so, yes, we did benefit.</p> <p>I went there [to the workshop] to see if I was missing something.</p>
<b>Workshops were more informative than participants expected</b> <ul style="list-style-type: none"> <li>Filled in knowledge gaps</li> <li>Education about new concepts</li> </ul>	<p>This is the first time I've ever heard anything about it – I guess I wanted to understand palliative care. It is a far, far larger topic than I understood it to be. I always understood palliative care to be, you know, literally those last few months of your life, whereas it is actually quite a lot longer than that. I hadn't actually heard of an advance health directive. I was aware of the Power of Guardianship, but I'd never heard of advance care plans and advance health directives before.</p> <p>It just answered the questions which you didn't even know you were going to ask.</p> <p>I think we felt that we may not have a comprehensive understanding of all the things that are involved and that proved to be the case so, you know, there were lots of issues that you brought up that we hadn't previously been aware of so, yes, we did benefit.</p>
<b>Benefits/value of attending workshop</b> <ul style="list-style-type: none"> <li>Facilitated thinking about own wishes and facing up to issues</li> <li>Empathy from presenters and other participants led to curiosity and group participation</li> <li>Improved self-confidence and awareness</li> <li>Assisted with and prompted conversations with family and GP</li> <li>Confirmed known concepts and highlighted new issues to consider</li> </ul>	<p>It made you think what was most important. We found all the papers and pamphlets you gave us very useful.</p> <p>I think it was very useful sitting in a room with a whole lot of people who had things in common with us and I think it was very well run, the course, and as a consequence there was empathy; (from both the presenters and empathy from the other participants). I think that was a positive factor....and that would lead to us feeling comfortable, asking questions and facing up to issues.</p> <p>It was confidence-building mainly.</p> <p>It did make us more aware of things that we might be confronted with as times goes by.</p> <p>Going to the workshop made the conversation easier with my father.</p> <p>I think useful from the point of view that it just confirmed to me things that I already knew but also highlighted things that maybe I hadn't thought deeply about and it's just interesting to have someone present it to you rather than you going out all the time and doing the research.</p>

	<p>It certainly refined it a lot in that we had the words. I wasn't aware - I think my husband was more aware - of all the documents needed, like the Enduring Power of Guardianship and all those things. It wasn't just about the advance health care plan. Because of the workshop all four of us sat down and got all our words together. I mean this was a process of probably six or eight weeks. My husband and I talked about it a lot. We went and saw our local GP and we've talked about it with our children.</p>
<p><b>Aspects of completing documentation</b></p> <ul style="list-style-type: none"> <li>• Workshop helped participants to feel prepared and helped them to put ideas into words</li> <li>• Some participants found the legal documents confusing or complex</li> <li>• Others found they wanted specific examples to know what to write down</li> </ul>	<p>I don't want to wait until I'm dying and then everybody's running around trying to find information.</p> <p>I think if it's worded correctly and your thoughts are conveyed clearly, then people are quite supportive of that.</p> <p>If you look at the documents in cold blood, they're very bureaucratic. What the workshop helped us do was put what we wanted in our own words. I think all of us were surprised how easy the pieces of paper were once you got to them. It's the process before you get to them that's difficult.</p> <p>I thought they're just too convoluted and too confusing, so I typed up my own one-page document.</p> <p>I found it difficult to complete the AHD. I think that there's mostly likely a big gap in what is possible – a big gap in my mind. I don't know what is possible. If you're looking for the kinds of conditions and the kinds of treatment that may be on offer and I have not found any place which sort of gives a whole pile of samples and says, "Do you agree with this one? Do you like this one or do you think this one's crazy?"</p>
<p><b>Thinking/behaviour/feelings after workshop</b></p> <ul style="list-style-type: none"> <li>• Participants felt more in control over their future</li> <li>• Enabled in-depth conversations with family</li> <li>• Family sometimes took a while to realise the importance</li> </ul>	<p>I think we all felt really good. I mean, it's not the sort of topic that you want to have as a dinner party topic but what was good about it is it felt positive in that it gave you some control over our future.</p> <p>It's something that I've discussed generally in the past with people but certainly after attending the workshop there was more in-depth conversation around those kind of things with the family. I found [the] information really interesting and it certainly made finding things easier and having an in-depth conversation about end-of-life preferences a lot easier.</p> <p>We have been conferring with our youngest son since we've had this workshop and he has a good understanding of what we require.</p> <p>Well, our kids thought we were terribly premature about doing it but once they realised what was going on, they really came on side but it actually took them a couple of weeks.</p>
<p><b>Wishes for end-of-life care</b></p> <ul style="list-style-type: none"> <li>• Most participants were clear about their wishes for EoL care</li> <li>• Most participants did not want invasive life extending treatments that would destroy their independence and quality of life</li> <li>• Most participants would prefer to stay at home as long as possible</li> </ul>	<p>[I have] discussed about care after an accident, the fact that I didn't want to have a feeding tube, I didn't want to go onto a heart-lung machine if I was in a coma or anything like that. So no sort of life extending treatments. I only want palliative care to remove the pain.</p> <p>I feel that the value of life for me is that I'm contributing and from that point of view, I don't want to just hang about in a nursing home. If I'm not contributing, I can't really see what value life has. From that point of view, if my cognitive ability, is grossly affected, if I was incontinent, if I was confined to a bed and unable to look after myself, maybe having to be fed because I couldn't feed myself, I don't wish to be in that situation. From the legal point of view, the only opportunities to avoid are if I am in a life-threatening situation and I have any of those conditions then I don't want medical treatment to prolong my life.</p> <p>I don't want any care that requires people to do anything for me.</p> <p>Certainly, I'd prefer to stay at home for as long as possible. Until it becomes too burdensome on the family or too risky health wise to do that. I wouldn't</p>

	<p>want to be burdensome and I don't want to be in a situation where I would be suffering and be sort of bedded down and vegetated.</p> <p>I told them I am not going to a nursing home!</p> <p>I have put information with both my GP and my specialist that I'm not to have any heavy intervention should I come to that stage where I can't be brought back to what I am, so they know that I feel very strongly about this and I don't want any unnecessary interventions.</p> <p>A [friend] has actually agreed to [being] a medical guardian and she said, "As long as you write down what you want," because she said, "I don't want to be arguing with your family over your care. You don't want any type of life-prolonging treatment so you need to put that in writing, and make sure that your family is aware that that's what you want."</p>
<p><b>Challenges</b></p> <ul style="list-style-type: none"> <li>• Some participants were worried about their wishes being followed by doctors</li> <li>• Some participants thought it was difficult to decide when they would be ready for palliative care</li> <li>• Some participants encountered reluctance when they raised the conversation with friends, GP, solicitor</li> <li>• Participants without close relatives and little finances/resources struggled to know who to appoint as their EPA or EPG</li> </ul>	<p>I think the difficult issue to deal with are more about - and this is what happened with my sister - is how much the doctors would believe in what we've put down on paper.</p> <p>The most difficult one is kind of what's the point of no return, when do you say, "I've had enough," or, you know - I mean, when none of us know what we're going to die from - so that part of the journey, I think, is going to be the most difficult.</p> <p>There were probably some people [mainly friends] that you start the conversation with and you can see it's not their particular thing, sometimes for religious reasons, sometimes because they just don't want to know, so you didn't carry the conversation on. There was nobody that was actively against the conversation. It's quite confronting on one level.</p> <p>I raised the question with my GP and solicitor and both of them were unwilling to talk about it, instead referring me to talk to the other party [GP/solicitor]. The solicitor's response was - this particular solicitor - was that no, he wasn't prepared to go down that path, it was too risky for him. This guy was advertising as being involved and experienced in estate planning, so he should have been into that kind of thing.</p> <p>I think when you're sitting with family and talking about end-of-life decisions, it's never an easy thing to talk about.</p> <p>It would be lovely to have an Enduring Power of Attorney and a guardianship or whatever but if you're on your own and you don't have family, it leaves you swinging in the breeze a little bit. I just don't have that [suitable family/friends] so it highlighted to me some of the difficulties and also, you know, the Enduring Power of Attorney, you know, where do people like me really go to put those things in place? I still haven't got the answer to that. I haven't really bought it up very deeply with any close friends because I think it would distress them. If I come to a point that I'm still alive but can't live independently then what do I do? Where do I go? If you don't have the resources and the finances - yeah, it's difficult and I guess that's what it's highlighted to me, the difficulties that I may be facing but I still don't have the answers. There's nothing out there that I've seen that really covers some of those difficulties. If you get to the stage where you perhaps go a bit gaga or you can no longer live independently and you haven't got the resources, you just get stuck somewhere and it may not be to your liking. In those circumstances, I'd rather be dead. I am concerned because I haven't got everything in place I would like to have in place, the concern is growing.</p>
<p><b>Thoughts about workshop and the documentation presented</b></p> <ul style="list-style-type: none"> <li>• Most people were very positive about the workshop presentation</li> </ul>	<p>It was very well delivered and quite focused, well-spoken and well thought out.</p> <p>I know they were talking about developing a form but there's really no real form as such that's published by the state in WA. It was interesting to hear that Victoria and South Australia actually have those particular forms with examples</p>

- A few people expressed that they would like to have a form with examples like other states of Australia
- Several people expressed that they would like to receive help completing the documents
- Recommendations included holding the workshop in a community building to make it more acceptable and having small groups of participants getting together to discuss/share experiences
- Some people felt that that the workshop documents given out had too much content in them and found it difficult to know where to start. Others felt that the AHD document format was too restrictive

in rather than just a blank think to say this is what my wishes are, which is what we've got in WA at the moment.

Attending the [workshop] was more a confirmation of my ideas and reassuring me that I wasn't the only person who had those ideas.

There was a tendency for people to raise things which were I thought a bit off the topic and for too much to be spent travelling down those paths. But, you know, that's what you get when you get a mixed bag of people. Nothing wrong with the people, by the way, but just they came from all sorts of backgrounds in that sort of circumstance.

I thought it was very good. It would be the sort of thing that would be really good to be held in a community library or something like that rather than in a palliative care place. So that it became more community-oriented which would make it more kind of ordinary, kind of just made it acceptable, rather than talking just about [it] in a palliative care place. I didn't mind it being there but I just feel like – well, this is a topic that has to be made more generalised and a community library would be a better venue.

I thought that the example form given at the workshop was not very user friendly. I think the AHD document format presented by the Government's Health Department is a bit restrictive and is quite difficult to get an opinion on how much it is legally possible to amend it. For example, they only offer three sections to make health treatment decisions and I think three is a bit limiting.

What would have helped me to complete it would be a small group of people who have already done them and had them approved and signed, maybe approved by a legal professional and signed off. I think it would be beneficial to have that group of people with the experience where you can actually talk things through. Just sharing experiences and everybody learning a little.

I think the workbooks were quite good and quite informative, maybe a little bit wordy at times.

It's a difficult thing to know actually where to start. When you look at all of these circumstances, there are so many of them, and treatments, I mean, it's difficult to understand. I certainly think some help completing [the documents] would be very valuable and I think the other issue is these are quite important pieces of paper; they're not something you want to get wrong or have the wrong wording on them. By the time you come to enact them, you may not be in a position to explain or modify or discuss it properly.

I would say there were 50 people there – 50% of those people would be okay, some would be excellent, the other 50% would be not – I would say most of that second 50% wouldn't be able to get on and do it. Simply because they just don't understand it. So those legal documents would not have been done by probably 75% of the people at the function though there would be still, you know, the 25% who would be totally organised. But if they ran this function again, they would need to concentrate on the people who really don't know and to be able to give them a little bit more help or advice of where they would go to.

#### **Background/thinking of EoL situation**

- Most participants want to get things sorted so that they can have their say regarding their EoL wishes and so they are not a burden to others
- Some participants hope that they will not need it, they will deal with it when the time comes, they

I can discuss these things quite openly because I guess it comes from my background. My mother was a nurse and we both worked in the health area and allied health area.

We've had a negative experience last year with another sister dying with very little say in what happened to her, and I think that was part of the driving force for us making sure that all of those pieces of paper were in place.

It just seemed like a good idea, you know, because otherwise you end up as some sort of vegetable and a worry to everybody else.

<p>believe that someone else will be around to deal with it and know what to do, or that they are too young to do anything</p>	<p>I don't think it's necessary in my circumstances to appoint an Enduring Attorney or an Enduring Guardian. I think my wife is perfectly capable of handling things like that.</p> <hr/> <p>Well, really, I'm living in hope I don't need any of those things. One day when I do need it, then I'll probably think maybe the doctor should tell me what's going on here, or if it's a sort of legal issue, I might have to go back and see the lady and say, "What's happening here?"</p> <hr/> <p>I'm too young for that sort of thing.</p> <hr/> <p>I'm not going to die any time soon, so I don't need that sort of thing.</p>
<p><b>Attitudes towards role of GP</b></p> <ul style="list-style-type: none"> <li>• Most participants had already initiated a conversation with their GP</li> <li>• Participants stressed that not all GPs are knowledgeable or willing to discuss EoL issues</li> <li>• Some participants expressed concern that the GP might not have the time necessary to help them complete the documents</li> <li>• Many participants thought that it would be difficult for the GP to initiate the topic</li> </ul>	<p>If I want to discuss something, I'll bring it up. And I think it's possibly – I think GPs are just so overworked.</p> <hr/> <p>So I guess, although I feel that it's good to discuss with your GP because I think they need to be on board as well and know what your wishes are, I think it would be hard for them if it was something that they had to initiate with all of their patients because I don't think it would go down well with all of the patients.</p> <hr/> <p>As I reconsider things and make notes, I will approach my GP.</p> <hr/> <p>I plan to see another GP in the same medical practice who I have talked to who indicated that he thinks it's a good idea.</p> <hr/> <p>I raised the question with my GP and solicitor and both of them were unwilling to talk about it.</p> <hr/> <p>I suppose what we did was we chose the GP that we knew would listen.</p> <hr/> <p>But it's probably better if they [GP] bring it up because they sort of know what questions to ask and you're just asking general questions.</p> <hr/> <p>I'm perfectly happy to initiate it and I think that GPs should very diplomatically initiate the topic for most people but I'm not quite sure how you do that and not upset some people.</p> <hr/> <p>The GP session just isn't going to be sufficient. It might be all right if you wanted the GP to look over it in the end, but I think getting the right person to help you formulate it in the first place would be quite difficult and I don't know if a GP would have the time necessary to do that.</p> <hr/> <p>He critiqued a couple of things. One of his points was that when you're in emergency care nobody's going to look at advance health care plans. He said in Emergency, you don't have time to, you're just dealing with people. He said there's no guarantees anybody would look at it or even think about it.</p>



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