



**PalliativeCare**  
WESTERN AUSTRALIA

# FINAL REPORT

## Grant Agreement

WA Department of Health (2016 50) to Palliative Care Western Australia (PCWA) for the delivery of Advance Care Planning workshops to metropolitan and rural areas of Western Australia and associated defined project activities

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*PCWA, November, 2017*

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## **1.0 PROJECT DESCRIPTION**

### **1.2 Approved Purpose of Grant**

The purpose of the grant was to provide funding to Palliative Care Western Australia (PCWA) to deliver Advance Care Planning (ACP) workshops to metropolitan and rural communities in Western Australia. This included the delivery of four (4) ACP workshops in the metropolitan area and two (2) in regional Western Australia.

### **1.2 Project Definition and/or Anticipated Activities**

The following activities were to be delivered as follows:

1.2.1 Delivery of four (4) Advance Care Planning workshops in the Perth metropolitan area and two (2) in regional Western Australia.

1.2.2 Establish a cross sector consortium to further develop a collaborative approach, and introduce a public awareness campaign to increase understanding of the limits of medical interventions, the benefits of palliative care and the importance of Advance Care Planning.

1.2.3 Research, pilot and evaluate approaches to engaging and informing Aboriginal and Torres Strait Islanders (ATSI), Culturally and Linguistically Diverse (CALD) communities and those in remote and rural locations on Advance Care Planning

## 2.0 ADVANCE CARE PLANNING WORKSHOPS

***Output: Deliver four (4) Advance Care Planning workshops in the Perth metropolitan area and two (2) in regional Western Australia.***

### 2.1.1 Workshop dates and locations

Between November 2016 and October 2017, twelve (12) ACP workshops were delivered.

The locations, dates and workshop hours are summarized below.

#### **Perth Metro Workshops:**

- Melville Workshop one on 10 November, 2016 from 9 – 12.15pm and Workshop two on 17 November, 2016 from 9am – 12.15pm
- Cockburn – Workshop one on 16 March, 2017 from 9am -12.15pm and Workshop two on 23 March, 2017 from 9am – 12.15pm
- Mandurah – Workshop one on 11 May, 2017 from 9am -12.15pm and Workshop two on 18 May, 2017 from 9am -12.15pm
- Joondalup – Workshop one on 11 October, 2017 from 9am -12.15pm and Workshop two on 18 October, 2017 from 9am -12.15pm
- Chung Wah Aged and Community Care – 20 October, 2017 from 10am – 12.30pm

#### **Regional:**

- Geraldton – one day workshop on 14 September 2017 from 9am – 2.30pm
- Midwest Carers (Greenough) – one day workshop from 9.30 – 2.30pm
- Bunbury - one day Workshop on 31 October 2017 from 9am – 2pm

It was originally planned that the workshops in regional centres would be held over two half days consecutively. Workshops in Busselton and Geraldton were scheduled for June 2017 however the number of registrations failed to reach 20 so the workshops were postponed. The program for the regional workshops was then reviewed and restructured to a one day workshop. With this format we achieved 66 registrations for the Geraldton workshop and 38 for the Bunbury workshop.

PCWA intends to deliver future workshops in regional areas in the one day format, as this model appears to be the most suitable for regional participants who may have to travel from satellite towns to the regional centre. This model is also more sustainable and cost-effective for PCWA with regards to travel, accommodation and contracted speaker costs.

A number of additional presentations and workshops were delivered and included:

- A one hour presentation to the Geraldton GP Network meeting on Advance Care Planning on 15 September 2017; the presentation focused on what had been delivered to community members the previous day reinforcing the fact that we had 88 attendees with many now motivated to progress ACP. While PCWA didn't undertake any evaluation process the Chair of the group, Dr Ian Taylor, verbally indicated in his thanks at the end of the session that it was the best they had participated in all year
- PCWA presented a 45 minute overview on the community ACP workshops as a component of a PaSCE ACP training workshops for primary health providers in Bunbury, Mandurah , South Metro and North metro during October & November, 2017; again the purpose was to reinforce the increasing number of community members keen to progress ACP processes
- A one day workshop for health professionals, using the PCWA community workshops model, via the Palliative and Supportive Care Education (PaSCE) calendar of training on 27 October, 2016

### **2.1.2 Number of participants**

In total number of 435 people participated in the 17 workshops with an average of 26 participants per workshop.

### **2.1.3 PCWA model**

PCWA partnered with Local Government Authorities (LGAs) in the delivery of the ACP community workshops. Under this model, PCWA provided the facilitator, speakers and written resources for participants while the LGAs provided the venue, AV equipment, morning tea (and lunch for regional workshops), managed registrations, and promoted the workshops through their networks and local newspaper and radio. The LGA was co-badged on the promotional material along with WACPCN.

Significant preparation was required to ensure each workshop was well organised and delivered successfully.

A summary of the PCWA tasks included:

- Initial engagement and on-going liaison with the LGA
- Negotiation with presenters to determine a line-up that meets all the information sets that needed to be delivered NB: this is the most challenging task given that most presenters delivered as part of their professional role and of course had many other competing tasks
- Developed and distributed promotional flyers
- Ongoing review and finalisation of the workshop program as part of a continuous development process
- Preparation of workshops resources including:
  - Program
  - Registration List
  - Name Tags
  - Pre and post surveys
  - Workshop Activity Sheets
  - *Dying to Talk* card sets
  - Information Pack Handout including EPG and EPA Guides , Advance Care Planning Guides and Advance Health Directive Guides provided by WA Department of Health
- Workshop venue set-up and close-down, “meet and greet” participants and ongoing liaison during the workshop
- Collate, consider and record participant feedback
- Maintain project records

Additional organisational tasks for regional workshops included:

- PCWA directly managed registrations via Eventbrite rather than the LGA managing registrations through their customer service officers
- For the Bunbury Regional Workshop PCWA was also required to organize and cover catering costs due to Bunbury City Council policy.

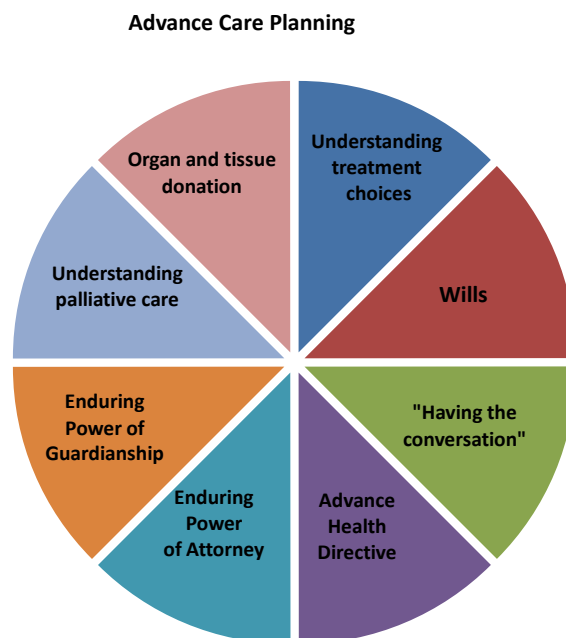
#### **2.1.4 Workshop design**

When PCWA commenced the delivery of ACP workshops three years ago, the focus was on the completion of forms for Enduring Powers of Attorney, Enduring Powers of Guardianship and Advance Health Directives. With this in mind, PCWA recruited expert speakers from the Office of the Public Advocate, Public Trustee, Health Department and Silver Chain.

However, it became increasingly apparent that many participants were not ready to complete these forms but were more interested to engage in a facilitated conversation about why planning was desirable for end-of-life, what processes were available, which of these processes was most appropriate for them and how to begin these important conversations with family, friends and health providers.

In response to the complexity of the workshop information that PCWA was presenting, and in recognition that many of our participants were older, a **Components of ACP** pie chart was developed to provide a high level summary (Figure 1). This model has been keenly embraced by our participants who have been invited to begin at the “having the conversation” component and work anti-clockwise from there.

**Figure 1 – Components of ACP**



Another useful resource has been the Dying to Talk Discussion Starter Kit including booklet and cards as developed by Palliative Care Australia (Figure 2). The cards have been a very useful tool to facilitate conversations on ACP as they contain short statements on approaches to both maximising life and living and plan for dying and death. The PCWA experience has been that they have resulted in highly engaged conversations within the workshop setting with many participants requesting a set of cards to take home for further use with family and friends.

**Figure 2 – Dying to Talk cards**



The current PCWA workshop approach still includes expert speakers from the Office of the Public Advocate, Health Department, DonateLife and Silver Chain but greater emphasis is placed on facilitated conversations and other activities that stimulate engagement with the ACP process.

While many jurisdictions across Australia are providing ACP training to primary and tertiary health providers, not many are engaging directly with community members. As a reflection of this, and as part of our desire to reflect participant feedback and achieve continuous improvement, PCWA has developed a number of resources to guide workshop activities:

- How to start the conversation
- Exploring quality of life
- What to do first

***Example of the PCWA developed resources are attached at Appendix 1***

***Examples of the Perth metro and regional workshop programs are attached at Appendix 2***



### **2.1.5 Participant resource pack**

Recognizing the limited time available to engage with community members regarding ACP, PCWA identified the significant value in developing a hard-copy resource pack that participants could take away with them. It was also recognised that while significant information is available on the net, people of these age-groups are still more comfortable with hard-copy material.

***Examples of resource material provided to participants is attached at Appendix 3***

### **2.1.6 Promotion of the workshops**

PCWA developed promotional flyers for each workshop for use by the host LGA to its seniors' networks and the local community. PCWA promoted the workshops to our own members, stakeholders, professional networks and supporter database (with over 900 contacts).

The flyers were produced using Publisher software and the converted to a 'clickable' and 'printable' PDF for distribution.

City of Joondalup chose to produce their own promotional material for the workshops which reflected the priority and value they placed on the workshop.

Palliative Care WA placed paid advertisements in various newspapers:

- Cockburn Gazette
- The Geraldton Guardian
- Busselton-Dunsborough Mail
- Mandurah Coastal Times
- Have-A-Go Newspaper

PCWA also produced media releases and liaised with local print and radio media outlets to promote the workshops. Additional publicity of the workshops was generated including:

- Two Interviews on ABC Local and Regional Radio Drive
- Editorial in the Have-a-go newspaper
- News article in the Geraldton Guardian and Midwest Times

***Examples of the advertising and promotion is attached in Appendix 4***

### 2.1.7 Participant feedback

PCWA invited workshop participants to complete both pre and post surveys. While a significant number of responses were received it needs to be noted that not all participants completed the surveys and of those who did, not all respondents answered all the questions.

***A spreadsheet summary of all the data is attached at:***

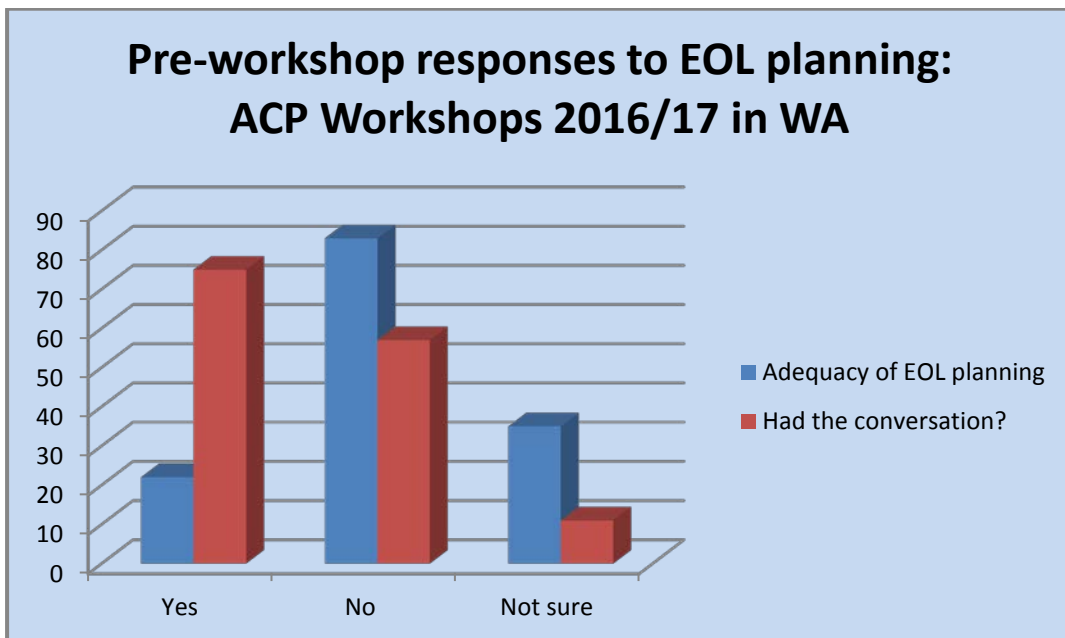
***Appendix 5a – Pre Workshop Survey Data and***

***Appendix 5b – Post Workshop Survey Data***

#### Pre-workshop surveys

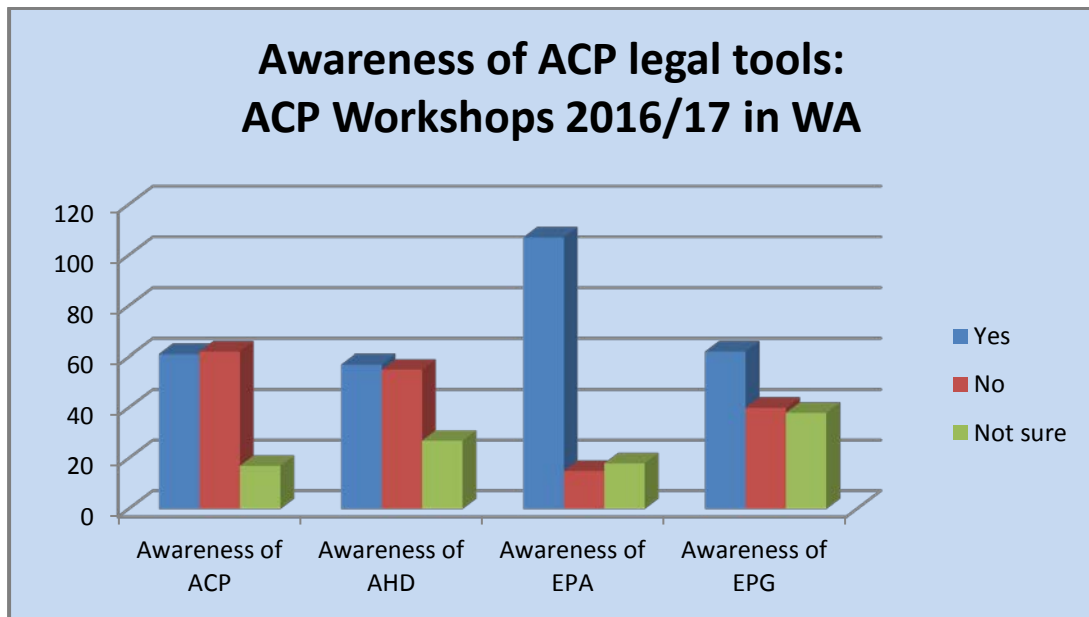
The pre-workshop survey was designed to gather information about participant’s awareness of ACP and the legal tools available to them as well as assess their level of engagement with end-of- life planning. The results outlined in Figure 3 reinforce the need for ACP workshops with 60% believing their end-of-life plans were inadequate. A surprising 52% reported that they had had some end-of-life discussions with their partner and family although our anecdotal sense after facilitating 17 workshops is that those conversations were generally not substantial in either breadth or detail.

**Figure 3**



In terms of awareness of ACP legal tools available, most people were familiar with the Enduring Powers of Attorney (EPA) while Advance Care Planning, Advance Health Directives and Enduring Powers of Guardianship had similarly low levels of awareness (see Figure 4).

**Figure 4**



**Post workshop surveys**

During the period November 2016 to November 2017, PCWA was involved in the delivery of 17 ACP workshops and directly organised and facilitated 12 of them. Unfortunately evaluation forms were not prepared for one of the Cockburn workshops and a translated evaluation form was not developed for the Chung Wah Association workshop. Therefore, of the 12 workshops delivered by PCWA, data was collected for 10.

The participant feedback is very positive and suggests that the format of the workshops met the needs of those attending. It is perhaps not unexpected that 78% of those who attended workshops were female as is demonstrated in Figure 3. A challenge for PCWA will be to lift the attendance levels of men at future workshops.

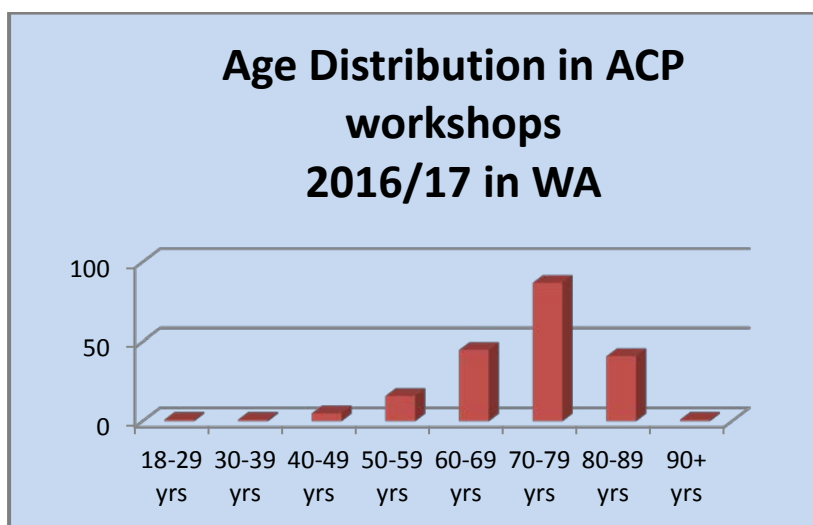
**Figure 5:**



PCWA anticipated that the vast majority of those attending might be people who had recently retired e.g. 60 to 69 year olds who were attempting to “get things in order”. Somewhat surprisingly the greatest number of attendees was in the 70 to 79 age-group with significant numbers of 80 89 year olds as well (see Figure 6).

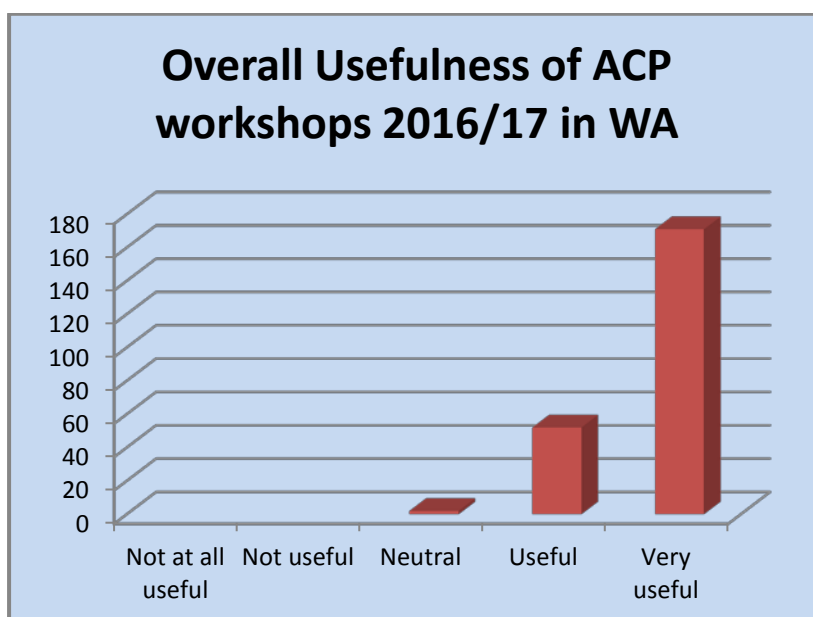
It is recognised that the workshops were all held in business hours and therefore not available to working people. Providing workshops out-of-hours needs to be a priority consideration for future workshops.

**Figure 6:**



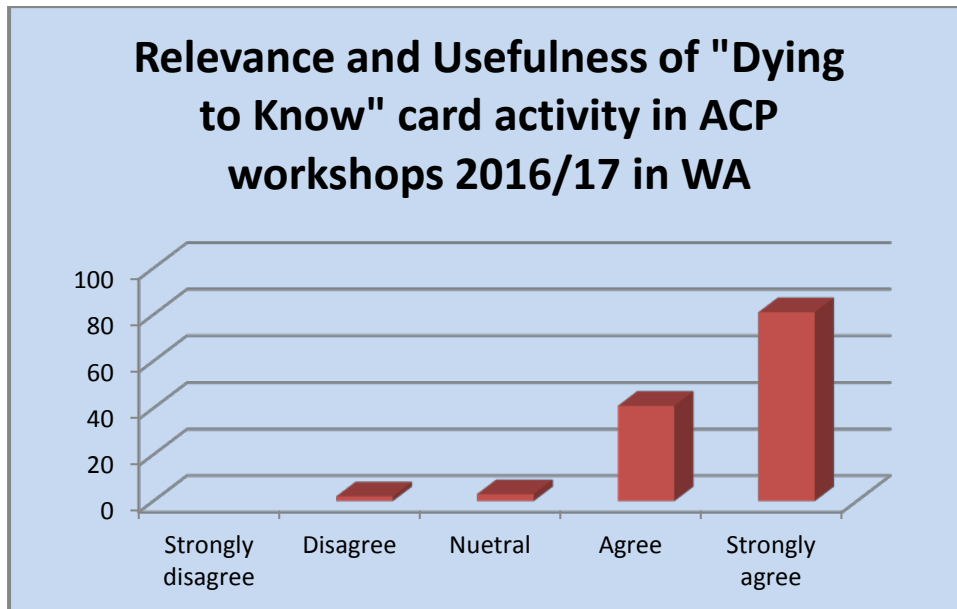
When asked about their perceptions of the “overall usefulness” of the workshops, a very positive **76% reported that they found the workshop “very useful”** with a further 23% reporting them as “useful” (see Figure 7).

**Figure 7:**



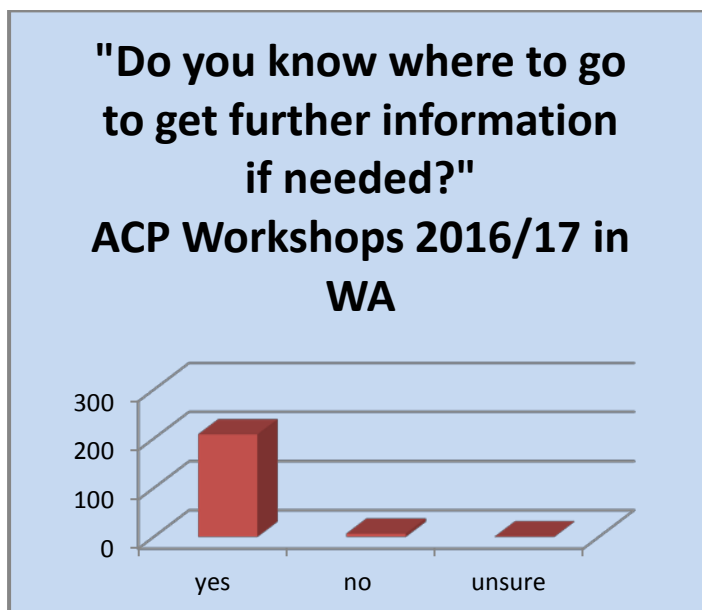
**Dying to talk** is an initiative of Palliative Care Australia to encourage discussion and planning regarding wishes for end-of-life care and includes a card game and discussion starter kit. PCWA included this resource for the last five of its workshops with 65% reporting its use as highly relevant and useful (See figure 8).

**Figure 8:**



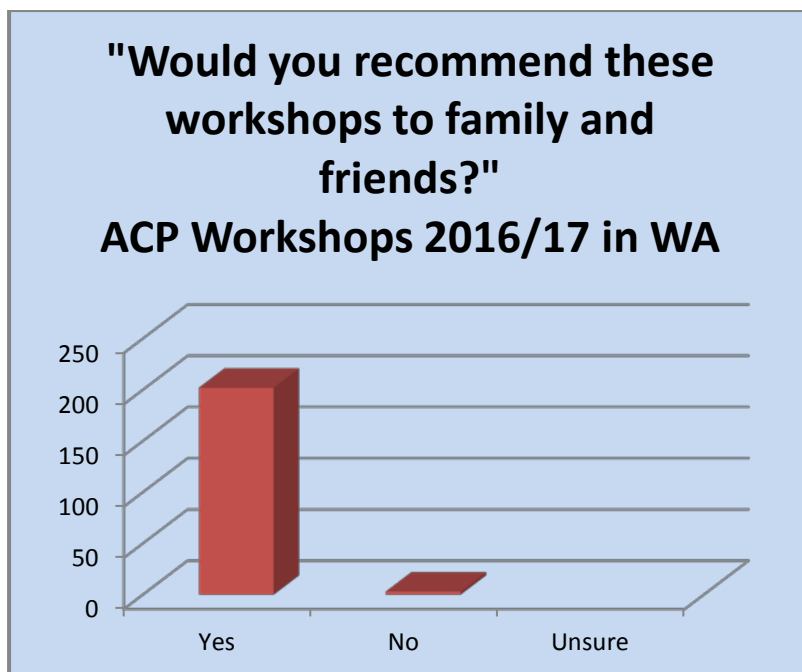
PCWA recognised that they were limited by the time available and could not present all the ACP information required. An important strategy was to ensure participants were clear where they could go to obtain further information. A very significant **96% reported that they knew where to go to get further information by the conclusion of the workshops** (see Figure 9).

**Figure 9:**



As an indication of their satisfaction with the workshops, participants were also asked if they would recommend them to family and friends. Again a very significant **98% indicated that they would recommend the workshops** and our anecdotal experience backed this up with a number of our participants reporting that they attended because it was recommended by family and friends (see Figure 10).

**Figure 10:**



#### Qualitative data

Respondents were given the opportunity to provide broad comments at the end of the survey tool and a sample of responses is attached in the data summary document. While not methodologically rigorous, the sample responses were taken to reflect respondents priorities and were allocated across 10 broad themes as follows:

- Useful and easy to understand information (25 responses)
- Quality speakers and facilitation (18 responses)
- The opportunity to actively engage in the workshop (15 responses)
- Focus on Enduring Powers of Attorney and Enduring Powers of Guardianship (9 responses)
- Focus on Advance Health Directives (6 responses)
- Focus on Wills and managing assets (5 responses)
- Providing motivation to progress Advance Care Planning (5 responses)
- Provision of quality resources (4 responses)

- Reinforcing the importance of “having the conversation” (3 responses)
- Providing the “To do” list to assist with prioritising (2 responses)

It is PCWA’s view, backed-up by informal and anecdotal feedback from all the presenters, that the top three themes identified in the qualitative feedback could accurately inform the future development of ACP workshops in WA (See Figure 11).

**Figure 11**

*Feedback suggested that the provision of easy-to-understand information, delivered by knowledgeable and engaging speakers with a format that encouraged active engagement with participants were the keys to successful Advance Care Planning workshops for community members in WA.*

### 3.0 ACP CONSORTIUM

***Output: Establish a cross sector consortium to further develop a collaborative approach, and introduce a public awareness campaign to increase understanding of the limits of medical interventions, the benefits of palliative care and the importance of Advance Care Planning***

In March 2016, PCWA established the Advance Care Planning Consortium. The purpose of the consortium was to establish a network of agencies committed to jointly promoting the development and delivery of information, educational opportunities and promotional strategies to facilitate the uptake of ACP in WA.

Many of the 16 member agencies were individually attempting to progress strategies to encourage uptake of ACP but it was recognised that a collaborative approach was likely to be more effective.

Current members include:

- DonateLife
- WA Cancer & Palliative Care Network
- Council of the Ageing (COTA WA)
- Office of the Public Advocate
- Cystic Fibrosis WA
- Office of the Public Trustee
- Cancer Council WA
- Silver Chain
- Carers WA
- WA Primary Health Network (WAPHA)
- Dr Simon Towler
- Dr Scott Blackwell
- Alzheimer's WA
- Future Living Trust
- Health Consumer's Council
- Program of Experience in the Palliative Approach (PEPA)

The Advance Care Planning Consortium met three times in 2017 on 16 February, 31 August and 9 October. An example of the Consortium's meeting minutes is attached in ***Appendix 6 - Notes ACP Consortium Meeting 31 August 2017***

At the meeting of the 31 August, Joy Cocker, an ACP expert employed by the ACT Department of Health, presented the findings of her recent Churchill Fellowship tour exploring ACP in the USA, Australia and Canada. Her stand out message was that no single program or agency can do everything to raise awareness of ACP in the community.



At the meeting on the 9 October, the Consortium worked on the development of its Strategic Plan.

The WA ACP Consortium made a submission to the Sustainable Health Review regarding the importance of building health systems capacity and community awareness and uptake of ACP to minimise futile and unwanted healthcare treatments in the last stage of life.

## 4.0 ENGAGING SPECIFIC COMMUNITIES IN ACP

***Output: Research, pilot and evaluate approaches to engaging and informing Aboriginal and Torres Strait Islanders (ATSI) and Culturally and Linguistically Diverse (CALD) communities and those in remote and rural locations on Advance Care Planning***

### 4.1 Culturally and Linguistically Diverse (CALD) communities

In October 2017, PCWA developed and delivered a half day workshop to a group of 16 older Chinese participants at the Chung Wah's day centre in Willetton. Most of the participants spoke Mandarin or Cantonese and very few had any English speaking skills. Fortunately the Chung Wah Association had accredited interpreters on staff who actively assisted throughout the workshop and PCWA arranged for both the Components of ACP and the Dying to Talk cards to be translated into Cantonese.

PCWA also utilised the Cantonese ACP video featuring Chung Wah Aged Care and Community Association CEO Theresa Kwok.

Despite several day centre staff suggesting that cultural norms might result in a reluctance to talk about planning for end-of-life, the event was a wonderful success with most participants highly engaged. Chung Wah is now negotiating with PCWA regarding future workshop dates for both their Willetton and Balcatta centres.

***The translated versions of the workshop program, example of the Dying to Talk Cards and Components of ACP are attached in Appendix 7***

PCWA participated in the Department of Health WACPCN's ACP for Culturally and Linguistically Diverse Communities Working Group meeting in August 2017.

### 4.2 Rural and Remote ACP workshop delivery format development

The delivery of PCWA's one and two day workshop formats involving a range of guest speakers is unlikely to be a feasible or cost-effective method of engaging rural and remote communities in ACP.

In October 2017 Palliative Care WA partnered the Midwest Commonwealth Care Link Centre to deliver a pilot workshop to a Carer's Group in the small town of Greenough. For this PCWA developed a 5 hour workshop program that did not involve guest presentations or the use of any audio-visual tools or teaching aids except for participant hardcopy handouts. PCWA developed a new presentation "Advance Care Planning Tools" to inform participants of the key elements of ACP and how to progress completing the tools (refer to 2.1.4).

This workshop format was well received by Carers and the Midwest Commonwealth Care Link Centre has requested PCWA to replicate the workshop with carers groups in remote centres in the Gascoyne and Pilbara regions in 2018.

This workshop format is low-tech and can be delivered in an indoor and outdoor setting so its delivery in any location, particularly rural and remote areas of the state, is very feasible and cost-effective compared to PCWA's standard model.

### **4.3 Aboriginal and Torres Strait Islander communities**

Palliative Care WA has consulted with Aboriginal health leaders to investigate how to best to engage their communities in ACP.

PCWA met with Dr Christine Clinch, Director of Aboriginal Health at St John of God Hospital Midland and CEO Michael Hogan to explore a collaborative approach to engaging with the ATSI community in that region. At this meeting PCWA presented the *Dying to Talk* activity (using PCA *Dying to Talk* cards for Aboriginal and Torres Strait Islander communities) and outlined the PCWA's highly interactive approach to community engagement regarding ACP.

Dr Clinch felt that this was an appropriate model of delivery for the local aboriginal community, but emphasised that the setting of the workshop would be important to ensuring participants felt comfortable to engage in discussions. Dr Clinch indicated that increased engagement around ACP would have beneficial impact for Aboriginal communities particularly recognising their shortened life expectancy and higher rates of chronic disease. PCWA and Dr Clinch are progressing discussions to find a suitable partner organisation and location to deliver workshop in 2018.

A similar process has been undertaken with the Moorditj Koort Aboriginal Health and Wellness Centre in Armadale. Jonathan Ford, CEO with Moorditj Koort, has expressed considerable interest in progressing a pilot ACP workshop and work is underway to deliver this in 2018. It is important to note that Moorditj Koort are a community-based Aboriginal Community Controlled Organisation (ACCO) and are therefore well engaged with their local community and importantly have a health and wellbeing focus.

It is important to recognise that engagement with ATSI organisations and communities takes time as relationships need to be built and trust established. PCWA recognises that it would have been good to have reported on the outcomes of a pilot workshop but significant connections have been made, collaborations are being explored and a commitment to undertake two pilot workshops in 2018 has been achieved.

## LIST OF APPENDICES

Appendix 1	<i>PCWA developed resources for use in ACP community workshops</i>
Appendix 2	<i>PCWA Advance Care Planning Workshop Programs</i>
Appendix 3	<i>Workshop Participant Resources</i>
Appendix 4	<i>Workshop Promotion</i>
Appendix 5a	<i>Pre Workshop Survey Data</i>
Appendix 5b	<i>Post Workshop Survey Data</i>
Appendix 6	<i>Notes ACP Consortium Meeting 31 August 2017</i>
Appendix 7	<i>Bilingual Workshop Resources</i>