

Final Report: Review of ACP resources for priority populations

Western Australian Department of Health

29 March 2023



Nous Group acknowledges Aboriginal and Torres Strait Islander peoples as the First Australians and the Traditional Custodians of country throughout Australia. We pay our respect to Elders past, present and emerging, who maintain their culture, country and spiritual connection to the land, sea and community.

This artwork was developed by Marcus Lee Design to reflect Nous Group's Reconciliation Action Plan and our aspirations for respectful and productive engagement with Aboriginal and Torres Strait Islander peoples and communities.

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1 Executive summary

Background and approach

The Department of Health (the Department) has recently developed resources including videos, brochures and guides to assist consumers in undertaking advance care planning (ACP). This report provides recommendations as to how these resources could be improved or supplemented to better meet the needs of priority population groups, recognising that these groups can face additional barriers or challenges in completing ACP documents. The priority groups considered in this assessment are Aboriginal people, people from Culturally and Linguistically Diverse (CaLD) backgrounds, people experiencing disadvantage, people experiencing mental health illness, people living with disability and people living in regional areas.

The recommendations were formed through a desktop review of the resources, interviews with key organisations, and focus groups with consumers representing the priority populations. The resources were assessed on three key criteria:

- Readability – people can read and understand the content.
- Understandability – people can process and explain key messages.
- Actionability – people can identify what they can do based on the information presented.

Desktop review

The resources were assessed through desktop review as being generally highly understandable and actionable. Although the printed documents are long, they are easy to understand due to the word choice and design. Printed documents are also actionable as they provide clear explanations and instructions. Audio-visual resources are moderately understandable, lacking relevant imagery and signposting of topics. However, most audio-visual materials are highly actionable due to the content, style and visual aids.

Consultation findings

Interviews with key organisations included relevant WA and Commonwealth government agencies and peak bodies for health professionals and social service providers. These interviews were used to identify what the key challenges and opportunities are for ACP on a system-wide level and informed the questions asked of priority populations in the focus groups. The key findings from these interviews were:

- Representation and language play a key role in the uptake of ACP amongst priority populations.
- Uptake of ACP requires support from the whole health system.

Focus groups with consumers representing the six priority populations revealed a range of perspectives, concerns and suggestions. Many comments were repeated by multiple priority populations or reflected different perspectives on similar ideas. Some key themes across focus groups were:

- Representation within the resources is important for all priority populations to help them see ACP as a process intended for them.
- ACP could be promoted more proactively with support from organisations and service providers who are frequently in contact with priority populations.
- Some cohorts of people will not undertake an advance care plan due to cultural reasons.

Recommendations

This review has identified **sixty-three recommendations** to better support priority groups in undertaking ACP. Many of these recommendations are around recognising that people come to ACP at different points in their journey and will require different resources and information depending on where they are in the process. For ease of tracking implementation, the recommendations have been grouped into **seven themes**, reflecting similarities and opportunities to address multiple recommendations within one resource (or versions of one resource).

Many of the recommendations would have a wider impact than the intended priority population group, as there is significant overlap in terms of people as well as need. Some recommendations would also be beneficial to general consumers as well as priority populations, as the questions, concerns and needs of each group may be reflected in the broader population.

Themes and priority populations that have a related recommendation

	PEOPLE LIVING IN REGIONAL AREAS	PEOPLE FROM CALD BACKGROUNDS	ABORIGINAL PEOPLE	PEOPLE WITH DISABILITY	PEOPLE WITH MENTAL HEALTH ISSUES	PEOPLE EXPERIENCING DISADVANTAGE
1 Promote and frame ACP to spur people to action	●	●	●	●	●	●
2 Provide additional information, either in new resources or by updating existing resources	●	●	●	●	●	●
3 Provide more options for people to talk with others and get advice about ACP	●	●	●		●	●
4 Improve the accessibility of existing resources	●	●	●	●	●	
5 Create high-level guides that are informative but approachable	●		●	●	●	
6 Create videos that reflect a diversity of experiences and values		●	●	●	●	●
7 Add more diverse examples to existing (and future) resources		●	●	●	●	

The individual recommendations have been sorted by priority group and impact. Some recommendations are relevant for multiple groups with only small differences and are assigned the same number for clarity.

Summary of recommendations for each priority population

Recommendations

People living in regional areas (6 recommendations)

1. Position ACP as an expression of choice and a means of reducing future burden on loved ones (theme 1)
2. Provide a broader range of options for talking to health professionals (theme 3)
3. Place ACP resources where people living in regional areas will interact with them (theme 4)
- 4a. Develop an accompanying leaflet which is region-specific and lists treatments available in each hospital (theme 2)
5. Use local community groups to reach people living in regional areas (theme 3)
6. Create a 20–30-minute video that accompanies the ACP workbook (theme 5)

People from CaLD backgrounds (12 recommendations)

7. Provide closed captions for videos in the 20 most spoken languages in WA (theme 4)
8. Provide voiceovers for videos in the 20 most spoken languages in WA (theme 4)
9. Include direction to interpretation services in the videos (theme 4)
10. Include questions about cultural customs in the Values and Preferences form (theme 7)
11. Provide specific examples illustrating the factors people should consider when answering questions about their day-to-day life (theme 2)
12. Expand the range of translated resources to include all of the 20 most spoken languages in WA (theme 4)
13. Use existing spaces in CaLD communities to open up conversation about ACP (theme 3)
14. Empower people to promote ACP within their community (theme 3)
15. Create a document that provides more information about life-sustaining treatments to help people make informed decisions (theme 2)
16. Create videos that enable people from CaLD backgrounds to see themselves reflected (theme 6)
17. Create videos that explain the importance of ACP for CaLD communities and society (theme 6)
18. Promote ACP using different forms of social media used by different CaLD communities (theme 1)

Aboriginal people (10 recommendations)

19. Include more representation of Aboriginal people as consumers in resources (theme 7)
20. Add Aboriginal Health Practitioners to the list of health professionals (theme 3)
21. Emphasise how ACP will benefit the individual and their family (theme 1)
- 22a. Move 'Checklist for making an Advance Health Directive' to the first few pages of the guide (theme 5)
23. Create a wider range of translated resources for different regions (theme 4)
- 4b. Develop an accompanying leaflet which is region-specific and lists treatments available in each hospital (theme 2)
24. Partner with organisations to organise 'yarning circles' within the community (theme 3)
25. Create ACP videos where Aboriginal people are represented as subjects (theme 6)
26. Create more videos that combine storytelling with information (theme 1)
27. Create a one to four page overview of the ACP process (theme 5)

People living with disability (15 recommendations)

28. Position ACP as a way to safeguard medical rights (theme 1)
29. Include workbook examples specifically for people living a disability (theme 7)
30. Include more pictures of people living with a disability (theme 7)
31. Reframe the prompting questions to expand people's view of what they need to live a fulfilling life (theme 7)
32. Provide consistent, closed captions on all advance care planning videos (theme 4)
33. Add a pop-out box of someone communicating in sign language to the existing ACP videos (theme 4)
34. Print materials that are accessible for people with reading disabilities (theme 4)
35. Print materials with different colour backgrounds (theme 4)
36. Develop a series of punchy next steps videos (theme 5)
37. Address frequently asked questions on the legal framework for ACP and how it relates to people living with disability (theme 2)
38. Take key aspects of the resources and turn them into standalone leaflets (theme 5)
39. Develop resources particularly for Carers (theme 2)
40. Create documents that explain the quality-of-life treatments (theme 2)

Recommendations

- 41. Create more interactive ways of accessing the resources (theme 5)
- 42. Create a video that tells the story of people living with a disability who have used, or been in situations where ACP would have benefited them (theme 6)

People living with mental health illness (11 recommendations)

- 43. Add trigger warnings to the start of videos and to the insider cover of existing and future booklets (theme 4)
- 44. Position ACP as a form of legal and medical protection (theme 1)
- 45. Emphasise which supports and resources are free, especially legal advice (theme 2)
- 46. Place resources where people living with mental health illness will interact with them (theme 1)
- 47. Include more examples of people living with mental health illness (theme 7)
- 22b. Move the 'Checklist for making an Advance Health Directive' to the first few pages of the guide (theme 5)
- 48. Provide consumers with more options to store their ACP documents (theme 2)
- 49. Partner with service providers to support people living with mental health illness through the ACP process (theme 3)
- 50. Create flashcards to prompt action during the 'Think' and 'Talk' elements of ACP (theme 2)
- 51. Create a series of resources split into Think, Talk, Write and Share (theme 5)
- 52. Create videos targeted to younger people (theme 6)

People experiencing disadvantage (7 recommendations)

- 53. Frame conversations with medical and legal professionals as an enabler of ACP rather than a prerequisite (theme 3)
- 54. Make it obvious which ACP support services are free (theme 2)
- 55. Place ACP resources where people experiencing disadvantage will interact with them (theme 1)
- 56. Create a brochure that positions ACP as a means of reducing future burden (theme 1)
- 57. Create videos that show people in familiar settings (theme 6)
- 58. Create videos that tell the story of people experiencing disadvantage (theme 6)
- 59. Partner with health and social service providers to encourage ACP and support people experiencing disadvantage through the ACP process (theme 3)

General recommendations (4 recommendations)

- 60. Explore ways of working with other organisations to encourage ACP and support people throughout the ACP process (theme 3)
 - 61. Introduce ACP at appropriate points through existing systems (theme 1)
 - 62. Create videos that combine the storytelling element with informational elements (theme 5)
 - 63. Update the Taking Care of Dying Time video to make it more engaging and relevant to WA (theme 1)
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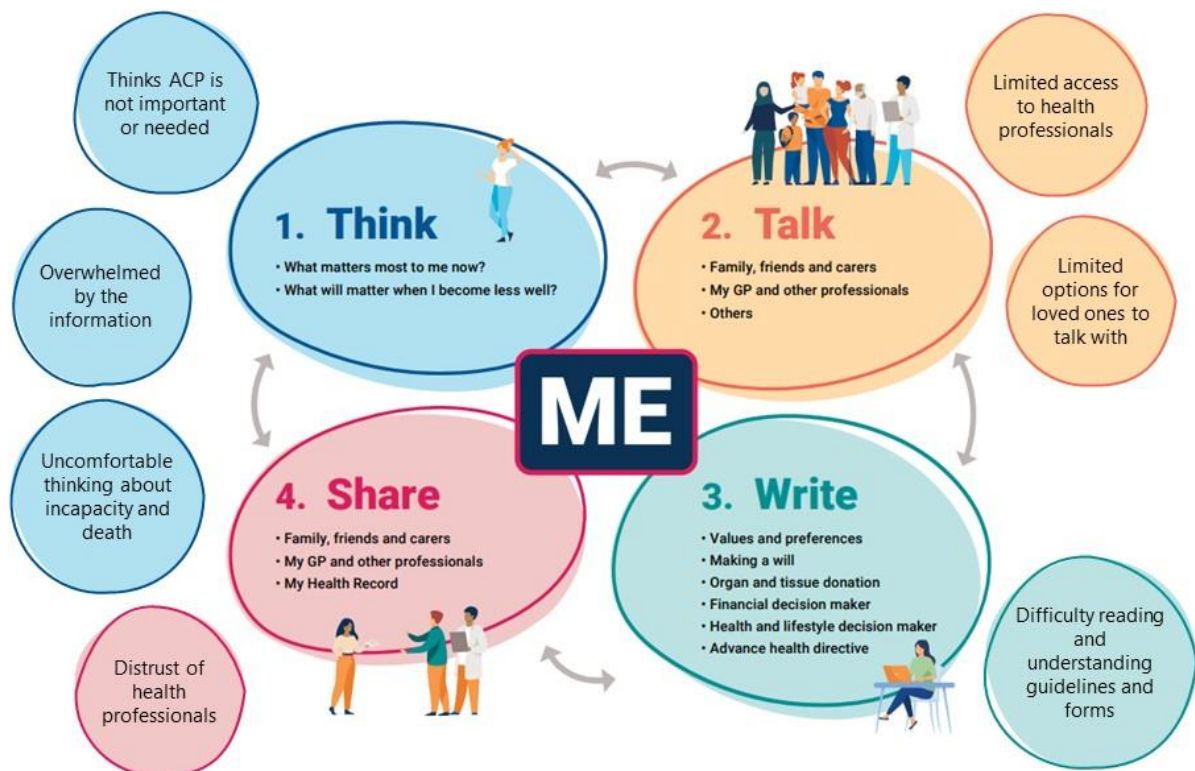
2 Background and approach

2.1 Context

The Department has recently developed introductory videos, brochures and guides to raise community awareness and assist consumers with ACP. This report provides an assessment of the extent to which these resources meet the needs of priority population groups. It provides recommendations on changes to existing resources and new resources required to assist each group. The priority groups considered in this assessment are Aboriginal people, people from CaLD backgrounds, people experiencing disadvantage, people experiencing mental health illness, people living with disability and people living in regional areas.

ACP is voluntary, so convincing people of its value and reducing barriers to undertaking it are critical to encouraging uptake. It is a highly complex and involved process, requiring deep thinking about difficult issues, a significant time commitment and the ability to discuss challenging subject matters with health professionals and loved ones. People, in particular those in the priority populations, may face challenges throughout every stage of the ACP process as illustrated in Figure 1 below.

Figure 1 | People can face challenges throughout the ACP process¹



¹ Adapted from *Your Guide to Advance Care Planning in Western Australia*, WA Department of Health. Nous Group | Final Report: Review of ACP resources for priority populations | 29 March 2023

2.2 Assessment approach

Gathering information for the assessment involved a desktop review, interviews with key organisations and focus groups with consumers representing the priority populations. The desktop review used a modified version of the Patient Education Materials Assessment Tool (PEMAT), a framework for evaluating the understandability and actionability of print and audio-visual patient materials.² The interviews and focus groups were designed to gather diverse insights on ACP resources and identify opportunities to better support the six priority groups.³

Findings from the desktop review, interviews and focus groups have been synthesised into actionable recommendations for each priority population group. Figure 2 below outlines the assessment approach.

Figure 2 | Approach to assessing ACP resources and developing recommendations



² See Appendix B.

³ See Appendix C.

The resources developed by the Department focus on educating people about the ACP process, providing examples, prompts and support services. The key resources examined in this review include:⁴

- 'Your Guide to Advance Care Planning in Western Australia' booklet (ACP workbook).
- 'A Guide to Making an Advance Health Directive in Western Australia' booklet (AHD guide).
- 'Advance care planning in WA: what it is and what it means for you' video.
- 'Taking care of dying time' video.
- 'Advance care planning: Planning for your future health and personal care' brochure (ACP brochure).
- 'Advance care planning: Planning for your health care' Aboriginal brochure.

2.3 Priority population groups and their ACP needs

WA is home to a diverse population with different life experiences, social and cultural perspectives, and needs. The six priority groups focused on in this review have specific needs that are not addressed in supports designed for the broader population. Many people fall within multiple priority groups, compounding the challenges. An overview of the characteristics of each priority group including factors for consideration is detailed below.

People from CaLD communities

People from CaLD communities are a broad group capturing a huge diversity of languages, cultures and traditions. WA has a large CaLD population, with 17.7 per cent of the population speaking a language other than English at home.⁵ Addressing language barriers and cultural appropriateness will be key to helping people from CaLD communities to navigate the ACP process.

Aboriginal people

WA covers many Aboriginal communities which have different languages and cultural norms. Many Aboriginal communities do not openly speak about death due to cultural reasons and have cultural traditions relating to dying. The Department will need to consider language barriers and cultural appropriateness in developing supports for Aboriginal people to navigate the ACP process.

People living in regional and remote areas

People living in regional WA experience a disproportionate burden of chronic disease, lack of infrastructure, poor access to specialised health care and other challenges in comparison to people in metropolitan areas.⁶ Identifying ways for people living in regional and remote areas to access support is a central issue for helping them complete an advance care plan.

⁴ A complete list of the resources part of this review can be found in Appendix A.

⁵ Department of Local Government, Sport and Cultural Industries. Cultural and Linguistic Diversity in Western Australia (WA) 2016 Census. (2017)

⁶ Australian Institute of Health and Welfare. [Rural and remote health](#). (2022)

People living with disability

People living with disability actively consider how to manage their disability throughout their life, in contrast to people without disability who may only begin thinking about the impacts of health when they experience a significant health crisis or reach the end of their life. Further, additional or adjusted ACP resources and supports may assist people with disability to access ACP resources and complete the forms.

People living with mental illness

People experiencing mental health illness face unique challenges in managing their health and wellbeing. People experiencing mental health illness may require additional or adjusted supports to navigate the ACP process safely and confidently, as well as address other unique concerns.

People experiencing disadvantage

People can experience different forms of disadvantage including housing insecurity and homelessness, financial stress and family issues. People in these situations face complicated challenges and often interact with multiple social support services. The Department will need to consider how this priority population will prioritise ACP and how they will access the support required to complete advance care planning documents.

There are other groups that could be considered priority

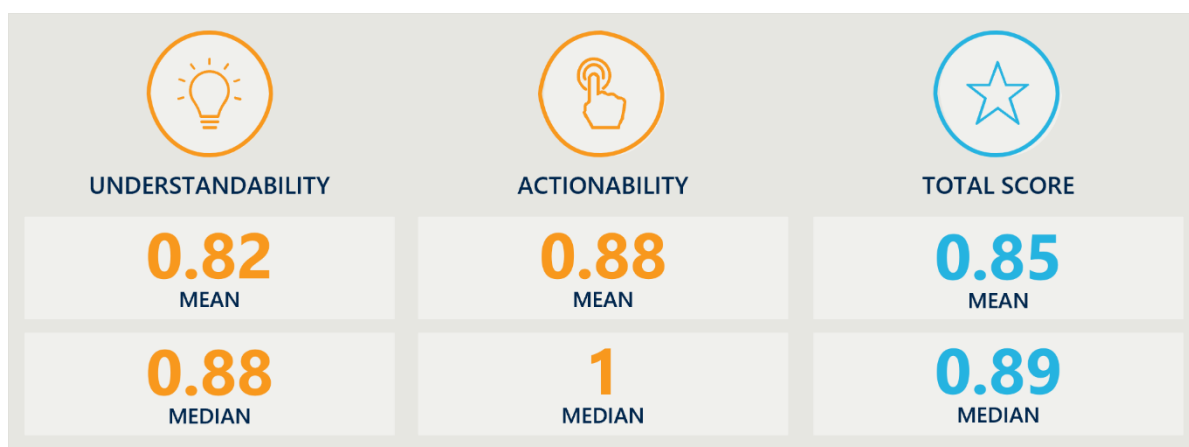
Other cohorts such as LGBTQIA+ people, children and older individuals could be considered priority population groups as they are vulnerable and experience unique challenges. This review does not directly consider these cohorts but acknowledges that they may require specific supports to undertake ACP. The Department undertook extensive engagements with older individuals during the development phase of current resources, so they are not considered as a priority group within this project.

3 Desktop review findings

ACP documents were reviewed for understandability and actionability using a modified version of the PEMAT, a framework for systematically evaluating print and audio-visual health information materials targeting patients.⁷ The print resources assessed included all guides, brochures, forms and webpages. The audio-visual resources assessed included all videos available on the Department of Health website.

Overall, current ACP resources scored well in understandability and actionability as assessed using the PEMAT. The overall scores are outlined in Figure 3, and the assessment criteria are explained below. A full list of all questions used to assess understandability and actionability can be found in Appendix B.

Figure 3 | Overall PEMAT scores (from zero to one) for all print and audio-visual ACP materials



Understandability

Resources are considered understandable when people of diverse backgrounds and with varying levels of health literacy can process and explain key messages. For a resource to effectively portray meaning and be understood by readers, careful consideration of the content and visual elements within it is required. The key criteria used to assess understandability of resources include:

- **Content:** How well the purpose of the document and key messages are conveyed.
- **Word choice and style:** How easily the document can be read with consideration to the choice of words and language conventions such as grammar, punctuation, capitalisation, and spelling.
- **Use of numbers:** If numbers are easy to understand.
- **Structure:** Whether sections have a logical sequence and effective summaries.
- **Layout and design:** The use of visual cues to draw attention to key messages.
- **Use of visual aids:** The use of visual aids to support key messages.

⁷ The PEMAT was modified by adding clear titles and captions as a criteria for audio-visual documents and allowing a 'Not Applicable' response where relevant. The assessment findings should be taken into consideration with insights from stakeholder engagements as the PEMAT has a bias towards western communication styles.

Actionability

Resources are considered actionable when people from diverse backgrounds and varying levels of health literacy can identify what actions they can take based on the information presented. Actionability is critical for people to follow through on developing ACP documents. The key criteria used to assess actionability include:

- **The inclusion of actions** that the reader can undertake after viewing the resource.
- **Language and presentation** of actions.
- **Use of visual design and visual aids** to support actions.

3.1 Print materials

Understandability – Although the print documents are long, they are easy to understand and scored an average PEMAT score of 0.88/1. Key findings include:

Word choice, style and document design were consistent across documents which make it easier for readers to follow and understand the content.

Most visual documents did not have a summary. Due to the length of the documents, having a summary would help readers better identify the key messages.

Actionability – Print materials scored high on the PEMAT assessment, with an actionability score of 0.93/1. Key findings include:

Word choice, style and document design were consistent across documents which make it easier for readers to follow and understand the content.

Most visual documents did not have a summary. Due to the length of the documents, having a summary would help readers better identify the key messages.

3.2 Audio-visual materials

Understandability – The audio-visual documents are moderately understandable, with an average PEMAT score of 0.68/1. Key findings include:

Audio-visual documents followed a logical sequence however, there was minimal use of headers to identify the separation of key topics which could make videos difficult to follow.

Some audio-visual documents did not have imagery that directly reflected the key topics discussed. For example, the 'Taking care of dying time' video took a storytelling approach with a keynote speaker throughout the video.

Actionability – Audio-visual materials scored high on actionability, with an average PEMAT score of 0.90/1. Key findings include:

The audio-visual materials made strong use of content, style and visual aids to make the recommended actions clear to viewers.

Most audio-visual materials had a perfect actionability score, however the 'Taking care of dying time' video did not provide explicit instructions to viewers about the next steps they should undertake.⁸

⁸ This tool assesses resources using a Western perspective, therefore input from Aboriginal people is required to determine if it is fit-for-purpose.

4 Expert interviews

Interviews with experts and key organisations were used to identify what the biggest challenges and opportunities are for ACP on a system-wide level and informed the questions asked of priority populations in the focus groups. Six one-hour interviews were conducted with representatives from the following organisations:

- Advance Care Planning Australia.
- The Royal Australian College of General Practitioners WA.
- Western Australian Council of Social Service.
- Office of the Public Advocate.
- Palliative Care WA.
- End-of-life and Palliative Care WA Clinical Leads in the Department of Health WA.

Representation and language play a key role in the uptake of ACP amongst priority populations

Priority populations often feel disempowered in the health system and find it difficult to communicate their values due to mental or language barriers, making people less inclined to begin ACP. This is further exacerbated when there is no representation of their cultural, regional or financial backgrounds within documents. Furthermore, language is important for the comprehension of the ACP process and the documents for priority populations. Aside from using simple, every-day language, there are other culturally relevant nuances in language to consider. For Aboriginal people, this includes using culturally sensitive terms such as 'passing on' or 'sorry business'; for CaLD people, this would require having the documents in various languages.

Uptake of ACP requires support from the whole health system

A key barrier to many people completing ACP is the reluctance to think about the possibility of incapacity or death. It is in key moments, such as a diagnosis or a loved one dying, that people realise the importance of doing ACP. Participants noted that the best way to reach people about ACP is at key milestones in life and that service providers and healthcare workers are pivotal to initiating the conversation. However, it was also noted that ACP is a journey and that simply being exposed to ACP is not enough. People need ongoing support, whether it be through one-on-one conversations with family, friends, GPs or through community workshops, and need to know where to go to get these supports.

5 Consultation findings and recommendations

The sections below detail the consultation findings and recommendations for each of the priority populations. The final section includes 'general' recommendations that were raised as broadly beneficial across all populations.

5.1 People living in regional areas

Consultation findings

PARTICIPATION | The seven participants in this focus group were consumers living in regional areas including Bunbury, Cookernup, Moora, Katanning, Manjimup, Kalgoorlie and Esperance. All participants joined the focus group online.

SUMMARY | The focus group participants living in regional areas found the resources to be very comprehensive and addressed every aspect of ACP through relevant questions, explanatory text and examples. However, participants noted that the 55-page guide and the 32-page workbook would take a long time to complete due to the length of the documents. This may make ACP inaccessible to people who do not have the time, reading literacy or digital literacy to be able to work through the booklets.

Key suggestions raised by this group



Suggest other professionals for consumers to speak with about ACP in addition to GPs



Promote ACP more directly within the community



Explore alternative ways to complete an advance care plan and AHD

Responses to specific resources

ACP VIDEO | The 'Having the Conversation' video was very surface level and the text and illustrations did not explain what ACP is. The video primarily targets older people.



AHD GUIDE | The guide is an extremely detailed document and addresses all aspects of making an AHD. However, this makes it difficult for people to complete, particularly those who aren't digitally literate.



ACP WORKBOOK | The workbook is long and very detailed, with better representation of different cohorts of people in the imagery and examples than the guide.



ACP BROCHURE | No brochures were shown during this consultation.



ADDITIONAL RESOURCES | Safe spaces to talk about ACP for people who can't talk to family or a doctor and more ways to complete ACP forms.



Recommendations

RECOMMENDED CHANGES TO EXISTING ACP RESOURCES

Participants in the regional focus group were generally happy with the range of ACP resources available. The main points of feedback reflected the need for resources to acknowledge the challenges that people living in regional areas face due to their location and limitations on the services available.

Participants in this focus group expressed a need for resources to address the challenges of living in regional areas and to provide options for people to engage with ACP in a way that reflects what care options are available to them.

On that basis, the recommended changes to existing resources include:

- Promotional material acknowledging the difficulty of accessing certain services in the regions and placing emphasis on alternative options.
- Enhancing the accessibility of different resources so that consumers living in regional areas can engage with ACP.

1. Position ACP as an expression of choice and a means of reducing future burden on loved ones

People living in regional areas can face constraints in the types of care available in their area, and participants expressed that these constraints increase the importance of making certain preferences clear through ACP. For example, friends and family may have to choose between a person staying at home or travelling to Perth or a regional centre to receive treatment.

It is recommended that ACP is positioned in promotional material for people living in regional areas as a way to express their choices as well as reduce the burden on loved ones in making these decisions. This could be done by changing the subtitle of current brochures from “Planning for your future health and personal care” to “Making choices for your future health and personal care” to reflect ACP as an expression of choice.

2. Provide a broader range of options for talking to health professionals

Participants in the focus group felt that current resources place a strong emphasis on talking to a doctor before or during the ACP process. This is to ensure that people fully understand the treatment options available to them and how their decisions will affect their future care. However, the scarcity of doctors in regional areas means that they are often limited to 15-minute appointments and people tend to use appointments for more urgent medical issues. Additionally, limited appointments means that people do not have a consistent GP who they see regularly and trust to go through ACP with.

It is recommended to place more emphasis on discussing ACP with other healthcare providers in promotional material, to prevent people being discouraged against ACP if they can't see a doctor. This could be done by expanding the list in the ACP workbook on page 11 to include as examples:

- support worker
- nurse
- psychologist/therapist
- Palliative Care WA or Advance Care Planning Australia helpline.

3. Place ACP resources where people living in regional areas will interact with them

Most ACP resources, including promotional material, are only accessible through the ACP website as the physical copies are provided on request. This creates an additional barrier for people living in regional areas as computer and internet access is limited compared to people living in metropolitan areas.

It is recommended that the Department should be promoting ACP directly within the community by placing resources including the brochures, ACP workbook and AHD guide where people will interact with them. Examples of places include:

- hospitals
- local shires
- community resource centres
- libraries
- club centres.

RECOMMENDED ADDITIONAL RESOURCES

Focus group participants emphasised the need for more targeted resources for ACP reflecting their experience of living in regional areas, especially with regard to limitations as to what healthcare services and treatments are available. Consumers need to know what options are available to them to get the care they want to receive.

Participants said that it is most feasible for them to rely on the existing systems that are available and familiar to them, and that these are best placed to support people on their ACP journey.

On that basis, additional resources are recommended to:

- Regionalise ACP depending on what resources are available to people living in regional areas.
- Use existing systems to encourage and support people living in regional areas in ACP.

4a. Develop an accompanying leaflet which is region-specific and lists treatments available in each hospital

People living in regional areas face constrained choices reflecting the healthcare and treatment options that are available in their location. Focus group participants noted that there are some treatments that people living in regional areas would need to travel away from home to receive. Therefore, their decision on whether to undertake particular treatments may be dependent on whether they are willing to travel. Some treatments that are only available in Perth include:

- major surgeries
- high-risk chemotherapy services
- specialist care.

Additionally, WA Country Health Service has a wide network of locations to receive healthcare including health campuses, hospitals, health centres and nursing posts that can provide more general care such as:

- emergency and hospital services
- Aboriginal health services

- drug and alcohol services
- population, public and primary healthcare
- mental health services.

It is recommended that the Department create region-specific brochures detailing the availability and location of different treatments. These brochures would supplement the ACP workbook and AHD guide by providing additional information about what services people would need to travel away from home to receive.

5. Use local community groups to reach people living in regional areas

People in regional areas have strong connections to local community groups who play a major role at sporting events, community events, workshops and group gatherings. Particularly in regional areas, community groups such as the Lions Club and Rotary Club have a strong community presence.

It is recommended that the Department work with these community groups to reach more people and give consumers a familiar place to go to for further support. This can be through:

- providing physical resources to local community groups to distribute
- partnering with local community groups to host ACP workshops
- encouraging local community groups to start the conversation about ACP at community events.

6. Create a 20–30-minute video that accompanies the ACP workbook

Focus group participants found the ACP workbook and AHD guide to be comprehensive and helpful, but also long. The videos provided a good introduction, but participants expressed a desire to be able to gain a deeper understanding of the whole process by having it explained in a more digestible form.

It is recommended that a 20–30-minute video adaptation of the guide is created that includes all the crucial steps to completing an AHD. This would be particularly valuable for people living in regional areas, who are likely to face difficulty in attending a workshop or seminar such as those hosted by Palliative Care WA. This could include:

- information on the four stages of ACP: Think, Talk, Write, Share
- an overview of each section and an explanation of the questions
- guidance on where to go for further support
- links to relevant phone numbers and websites for further research.

5.2 People from CaLD backgrounds

Consultation findings

PARTICIPATION | The fifteen participants in this focus group were from Indian, Chinese, Malaysian, Japanese, Brazilian, Argentinian, Indonesian, Persian and Bangladesh backgrounds. Several participants had experience as health professionals or prior familiarity with ACP. The focus group was hosted in-person.

Key suggestions raised by this group



Create a wider variety of translated resources in more languages



Introduce more resources that explain why ACP is important with examples of situations where it has helped



Engage people from CaLD backgrounds through common community spaces

SUMMARY | Focus group participants from CaLD backgrounds felt that the resources explained the process of ACP thoroughly but did not address the initial barrier of why ACP is important. Furthermore, greater specificity in the questions and examples in the resources will provide greater guidance for people when undertaking ACP.

Responses to specific resources

ACP VIDEO | The 'Advance Care Planning in WA' video was very informative and portrayed the step-by-step process of ACP well. Participants felt that the video did not explain why they should undertake ACP.



AHD GUIDE | Participants felt that the guide should have more specific prompts and examples of situations for people to narrow down their values and preferences.



ACP WORKBOOK | Participants felt that the language in the workbook could be more simplistic and more aligned to the language in the guide. For example, the workbook used the term 'statutory', whereas the guide used the term 'legal' which is easier to understand.



ACP BROCHURE | No brochures were shown during this consultation.



ADDITIONAL RESOURCES | Videos that show examples of when ACP is beneficial, as well as a wider variety of translated resources.



Recommendations

RECOMMENDED CHANGES TO EXISTING ACP RESOURCES

Consumers in the CaLD focus group were mainly concerned with the accessibility of the resources for people with CaLD backgrounds in terms of language, cultural references and points of contact. The main points of feedback reflected the need for resources to accommodate the diversity of CaLD populations and their language barriers to enable broader understanding.

Consumers recognised that creating new resources for every language group is a time-consuming and costly exercise and encouraged the Department to focus on the ensuring understandability and accessibility of resources.

On that basis, the recommended changes to the existing resources include:

- Explore alternative ways to translate current and future resources into a wider variety of languages.
- Highlight the guidance for consumers on what is required to complete an effective AHD.

7. Provide closed captions for videos in the 20 most spoken languages in WA

People from CaLD backgrounds may have difficulty understanding current resources due to language barriers. The 'Having a Conversation' video is translated in 15 languages, which reflects many of the most spoken languages in WA. The 'Advance Care Planning in WA' video is not currently translated, but automatically generated closed captions are available on YouTube in a wide range of languages. Focus group participants noted that manually translated captions would make current videos more accessible to people who speak different languages, without having to record new audio.

It is recommended that closed captions for the videos are provided in the top 20 languages spoken by Western Australians, as outlined in Table 1.

Table 1 | Top 20 languages other than English spoken by Western Australians⁹

• Mandarin	• Tagalong	• Hindi	• Tamil
• Italian	• Arabic	• Gujarati	• Urdu
• Vietnamese	• Afrikaans	• French	• Portuguese
• Punjabi	• Spanish	• Malayalam	• Thai
• Cantonese	• Indonesian	• German	• Persian

8. Provide voiceovers for videos in the 20 most spoken languages in WA

Participants raised that in addition to closed captions, it is easier for some people to understand information spoken in their native language. Providing voiceovers for existing videos in the top 20 languages spoken by Western Australians, as outlined in Table 1, would therefore also increase understandability for people from CaLD backgrounds.

⁹ Australian Bureau of Statistics, [2021 Census: Cultural Diversity](#)

9. Include direction to interpretation services in the videos

The ACP guide and workbook have a note on the inside cover to contact interpretation services if people need help when completing the documents. This is valuable for people from CaLD backgrounds as it lets them know that support is available to help them understand the resources.

It is recommended that a phone number for interpretation services also be included at the end of ACP videos should they need support or have further questions about ACP. The phone number for interpretation services provided on page 31 of the ACP workbook could also be added to the inside cover to make it more obvious.

10. Include questions about cultural customs in the Values and Preferences form

Focus group participants emphasised that people from CaLD backgrounds are diverse with a variety of cultural customs that they may wish to follow. An ACP can help medical professionals to understand an individual's cultural needs.

It is recommended that there is a long-form question included in the ACP workbook and Values and Preferences that would enable individuals to express their cultural customs and explain how these should be followed. This could be done by combining the following checklist items on page 8 of the ACP workbook and creating one standalone question with space for people to write their response:

- What beliefs or cultural or religious values are important for you to maintain in the future? (e.g., prayer, attending religious services, engaging in cultural or community activities, eating halal food, meditation, living as an atheist).

11. Provide specific examples illustrating the factors people should consider when answering questions about their future and their day-to-day life

The questions provided in the ACP workbook are broad and enable people to interpret the questions differently and emphasise what is important to them. Most of the questions provide examples for things people should consider, however focus group participants noted that the vagueness of some questions may make it difficult for people from CaLD communities to understand what types of answers are required.

It is recommended that the questions starting on page 8 of the ACP workbook all have specific examples showing how the question can be answered, or checklists of topics that people can write about. These could include:

- 'Do you have any worries about your future? If so, what are they? (e.g., Being able to look after my parent/spouse/child, having to live apart from my family).
 - An example response could be: *'I am worried about not being able to look after my parents because they rely on me to pay bills, prepare meals, look after the garden and do household chores.'*
- 'Does your health affect your day-to-day life? Does ill health stop you doing things you like to do? If so, how? (e.g., I can't go for a daily walk, but I can sit in the park.)
 - An example response could be: *'I have had to stop going on daily walks because of the arthritis in my knees. However, I am still able to sit in the park and enjoy watching the lake.'*

RECOMMENDED ADDITIONAL RESOURCES

Overall, consumers in the CaLD focus group found the materials to be very detailed and informative. Although this is helpful for those who are already undertaking ACP, they felt that the resources could better address the initial barrier of understanding why ACP is important and how it is applicable to the individual.

In addition to addressing barriers, consumers noted that people from CaLD backgrounds would benefit from support tailored to their needs to undertake ACP.

On that basis, it is recommended to:

- Create resources that explain the reasoning behind why people should undertake ACP.
- Provide people and places that people from CaLD backgrounds can go to for support both before and during the ACP process.
- Translate the guide and workbook into Gujarati, French, Malayalam, Tamil, Urdu, Portuguese, and Thai.

12. Expand the range of translated resources to include all of the 20 most spoken languages in WA

There is great value in having resources that are specific to different CaLD groups, through representation and language, for greater accessibility and uptake of ACP. Although the resources are available in fifteen languages, WA is diverse and only four of the thirteen participants' languages were included in the translated resources. Of the twenty most spoken languages in WA outlined in **Table 1**, those not currently translated for the guide and workbook include Gujarati, French, Malayalam, Tamil, Urdu, Portuguese and Thai. In addition to these, the other languages represented in the focus group were Bengali, Farsi and Japanese.

Advance Care Planning Australia provides information through translated webpages in text and audio form, as well as in fact sheets.¹⁰ This includes several languages that the WA resources are not available in, and the WA resources are also translated into several languages not available through Advance Care Planning Australia. The additional languages could be utilised to provide information for people who are not able to access the WA resources in their first language. In addition to the languages the WA resources are already translated into, the Advance Care Planning Australia website also includes other commonly used languages in Australia, as outlined in **Table 2**.

Table 2 | Languages for which Advance Care Planning Australia has a translated webpage and WA does not have translated resources

-
- | | | | |
|-------------------------|------------|-----------|-----------|
| • Cantonese | • Japanese | • Russian | • Turkish |
| • Chinese (Traditional) | • Mandarin | • Serbian | |
-

¹⁰ Advance Care Planning Australia website, [Languages](#)

13. Use existing spaces in CaLD communities to open up conversation about ACP

People from CaLD backgrounds may feel more comfortable talking with people who speak the same language and may be more likely to engage with material presented in settings they already frequent. Focus group participants noted that having spaces where people in the community can get together and talk may increase the uptake of ACP. This can include:

- Workshops run for (and facilitated by) specific CaLD communities, similar to the Palliative Care WA workshops but tailored for communities. One participant raised that workshops had previously been run through Chung Wah Association and another suggested working with the Indonesian embassy to promote ACP.
- Booths promoting ACP at different community events where people are already gathering.
- GPs from CaLD backgrounds discussing ACP with their patients.
- Service providers in regular contact with people from CaLD backgrounds providing support.

It is recommended that the Department work with service providers, GPs and community groups to proactively create spaces in the community for people to discuss ACP.

14. Empower people to promote ACP within their community

People from CaLD backgrounds are often most comfortable talking with people who speak the same language as them and share a cultural background and may be more receptive to being introduced to ACP through people they already know. Focus group participants suggested that 'ACP Cultural Ambassadors' could be established within the community to promote ACP and assist people who need further support. These 'Cultural Ambassadors' could be trained through a seminar delivered by the Department or a partner such as Palliative Care WA and provided with materials to distribute to people or place in community spaces.

15. Create a document that provides more information about the life-sustaining treatments to help people make informed decisions

The AHD lists life-sustaining treatments that consumers can choose to receive (or not receive) when they do not have capacity to make decisions. Although these treatments are briefly explained on page 28 of the AHD guide, focus group participants expressed the need for more thorough explanations of these treatments.

Department of Health clinicians indicated that the suitability of treatment options is dependent upon the individual's personal circumstances, and that providing more information in this form may not be feasible. However, due to interest from participants, it is recommended that the Department further investigates the feasibility of providing more information about treatments. This could be done through a separate document, such as a small booklet, that explains the treatments in the AHD in-depth, including:

- What is the process of receiving the treatment, and what does it involve? (e.g., a blood transfusion usually involves a narrow tube being inserted into a vein in your arm to provide healthy blood. This process generally takes 1-4 hours to complete and does not require an overnight stay in hospital unless there are other circumstances.)
- When is it used? (e.g., a blood transfusion may be used to replace blood lost during surgery or after an accident, or to provide nutrients such as iron.)
- What are the implications of the treatment? (e.g., a blood transfusion is generally considered a minor procedure, however medicinal alternatives may be feasible in certain circumstances.)

ACP Australia provides explanations of several life-sustaining treatments on its website which could be drawn on, including¹¹:

- cardiopulmonary resuscitation
- artificial ventilation
- tube feeding
- dialysis
- palliative care.

16. Create videos that enable people from CaLD backgrounds to see themselves reflected

Focus group participants wanted more videos that tell the story of people from CaLD backgrounds to help them understand how ACP would apply to them. When people see real-world examples of where ACP would be beneficial, they can better understand its purpose and may be more inclined to begin ACP.

It is recommended that videos similar to the 'Taking Care of Dying Time' video be made that show these situations and are tailored to represent the experiences and priorities of different CaLD communities. New videos could include:

- Someone working with an interpreter to better understand the advice from their healthcare provider, or to express their preferences in the AHD.
- Cultural customs being followed through the use of an AHD or Values & Preferences form, making it easier for the family to communicate the person's wishes with health professionals.

17. Create videos that explain the importance of ACP for CaLD communities and society

Current resources place emphasis on explaining the ACP process and the steps required to complete an AHD, including the ACP in WA video. Although this is useful for people who want to make an AHD and need further information, there should be more resources that explain why people should complete an AHD for those who don't yet see the value of ACP.

It is recommended that the Department create more videos targeted toward those who have not begun ACP, focusing on the following topics:

- Why is ACP important?
- How does having an AHD benefits the individual?
- Where to go for more information?

18. Promote ACP using different forms of social media used by different CaLD communities

People from CaLD communities frequently use online spaces to connect with others who speak the same language. Each community group has different preferences for the social media platform that they use. For example:

- people from Chinese backgrounds tend to use WeChat
- many Perth-based cultural communities have language-specific Facebook groups.

It is recommended that promotional material is tailored to each community group and is made available on the specific platform that they use.

¹¹ Advance Care Planning Australia website, [Life prolonging treatments](#)

5.3 Aboriginal people

Consultation findings

PARTICIPATION | The ten participants included public health officers from the Aboriginal Health Council of WA (AHCWA), clinicians based in regional and remote WA, and a nurse working in an Aboriginal Health Service. Five participants joined online, and five attended in-person.

Key suggestions raised by this group

-  Create intermediate resources that bridge the gap between the brochures and the guide/workbook
-  Establish yarning groups to open up conversation about ACP within the community
-  Introduce more Aboriginal-specific audio-visual resources

SUMMARY | Aboriginal people felt that representation within the resources, through imagery and language, was one of the key factors on whether they connected with a resource. However, it was noted that there are cultural barriers that negate the need for ACP for some Aboriginal communities.

Responses to specific resources

- ACP VIDEO** | The 'Advance Care Planning in WA' video was quite fast-paced and did not go into detail on what ACP is. Alternatively, participants connected well with the 'Taking Care of Dying Time' video due to the representation and language used in it. 
- AHD GUIDE** | Language should be consistent between the easy-read version and the original version of the guide. 
- ACP WORKBOOK** | Although the document was detailed, some key information is lost in the visual design of the document, such as which parts of the AHD are necessary and which can be left blank. 
- ACP BROCHURE** | The brochure is very good and the right information is there. However, there is shame surrounding death in the community and people will not pick up or bring home the brochure. 

ADDITIONAL RESOURCES | Establishing yarning groups and more targeted videos 

Recommendations

RECOMMENDED CHANGES TO EXISTING ACP RESOURCES

Overall, participants in the Aboriginal focus group recognised that there was an increased effort to represent Aboriginal people within the resources. However, their main points of feedback reflected a greater desire for representation within the text, such as in the examples provided in the guide.

Focus group participants stated that representation within resources not only allows people to see themselves in the ACP process, but also allows for greater understanding of the context of the information provided.

On that basis, the recommended changes to the existing resources include:

- Greater representation of Aboriginal people in both current and future resources.
- Enhancing accessibility and understandability of resources.

19. Include more representation of Aboriginal people as consumers in resources

Focus group participants recognised that there is visual representation of Aboriginal people in the guide and the 'Taking Care of Dying Time' video, and that Aboriginal people may be more likely to engage if they see themselves reflected in the material. However, there are more ways that Aboriginal people can be incorporated in the resources. This includes:

- more images of Aboriginal people in the workbook
- more examples of Aboriginal stories in the guide, such as on page 8 of the guide
- including Aboriginal people in more videos.

20. Add Aboriginal Health Practitioners to the list of health professionals

Participants in the focus group emphasised that it is important for Aboriginal people to talk about these sensitive topics with people they know and trust. Many people may not have a GP or other healthcare professional they see regularly and may be reluctant to seek out an unfamiliar GP or other professional recommended in the ACP workbook or AHD guide. To provide more options, it is recommended to expand the list of healthcare professionals in the ACP workbook on page 11 to include Aboriginal Health Practitioners.

21. Emphasise how ACP will benefit the individual and their family

Participants in the focus group said that making the purpose of an ACP clear and framing it as something done to benefit an individual and their family may make it more appealing to Aboriginal people, as the current brochure does not explain why the Department wants people to complete ACP documents. It is recommended that the brochure for Aboriginal people be adapted by changing the inside text to have more similar messaging to the front ("If you become very sick or have a serious injury, who will help make care decisions for you?"). The new inside introductory text could be changed from "Advance care planning is about planning for your future health care" to "Advance care planning is about protecting your health choices and helping your family make the hard choices when you can't do it yourself."

22a. Move 'Checklist for making an Advance Health Directive' to the first few pages of the guide

Focus group participants had difficulty understanding which parts of the AHD were essential to complete based on the introductory brochures, videos and initial sections of the ACP workbook and AHD guide. This information is included in the checklist on page 30 of the guide and on the AHD itself but is not clear upfront or in an overview. It is recommended that this checklist is moved to the first few pages of the guide to ensure that people are able to see which parts of the AHD are important, as well as provide a place for them to keep track of where they are in the ACP process.

RECOMMENDED ADDITIONAL RESOURCES

Although there is some representation of Aboriginal people within the resources, focus group participants expressed a desire for more inclusive resources that address the diversity of Aboriginal people. This is important as Aboriginal people from different regions and language groups have differing needs.

Additionally, culture and cultural understanding is important to Aboriginal people. Resources are only as good as the support systems behind them. Focus group participants stated that there needs to be more culturally sensitive support systems for ACP.

On that basis, the recommended additional aim is to:

- Broaden the number of translated resources, with a focus on Aboriginal languages.
- Create opportunities for peer and professional support before and during the ACP process.

23. Create a wider range of translated resources for different regions

Many Aboriginal people speak English as a third or fourth language, presenting a barrier to reading the ACP materials or talking to professionals about it. Focus group participants suggested that there should be more resources similar to the brochure that are designed for Aboriginal people, including with more appropriate language and images. Although there is an easy-read version of the workbook, it was noted that there were inconsistencies between the two resources, such as differences in the four stages of ACP (Think, Explain, Record, Share for the easy-read version and Think, Talk, Write, Share for the workbook). Neither of these resources have language which are catered toward Aboriginal people.

It is recommended that resources are translated in the top 10 Aboriginal languages spoken by Western Australians. These are outlined in **Table 3**.

Table 3 | Top 10 Aboriginal languages spoken by Western Australians⁹

- | | |
|-----------------|----------------|
| • Kriol | • Kukatja |
| • Nyungar | • Yindjibarndi |
| • Ngaanyatjarra | • Wangkatha |
| • Martu Wangka | • Walmajarri |
| • Jaru | • Wajarri |

Additionally, there should be resources that are localised and translated to be region-specific. The Australian Digital Health Agency is working with some regional health services in Bunbury and the Kimberly to trial localised resources.

4b. Develop an accompanying leaflet which is region-specific and lists treatments available in each hospital

Many Aboriginal people live in regional areas and have a strong relationship with the land. In particular, focus group participants mentioned that Aboriginal people may prefer to stay on country when they are sick or dying. Therefore, the type of care they can receive will be dependent on what is available in their region and where they are willing to travel to.

Locations for treatment in regional areas include:

- major regional hospitals
- smaller rural hospitals
- nursing posts
- outreach services.

It is recommended that the Department create region-specific brochures detailing the availability and location of different treatments. These brochures would supplement the ACP workbook and AHD guide by providing additional information about what services people would need to travel away from home to receive.

- showcasing Aboriginal people completing an AHD
- showcasing Aboriginal people having the conversation about ACP
- inclusion of Aboriginal symbolism in the background, such as flags and props.

24. Partner with organisations to organise 'yarning circles' within the community

Aboriginal people use 'yarning circles' as a way to learn as a collective and encourage respectful, trustworthy relationships. Focus group participants suggested that having yarning circles in the community would encourage people to come together to learn about ACP as well as provide a place to go to for support.

It is recommended that the Department work with local community groups and service providers to establish regular yarning circles to discuss ACP. This can include:

- Aboriginal Health Council of WA
- Aboriginal Controlled Community Organisations.

Additionally, 'yarning circles' are more accessible to people who wouldn't understand the written material and provides a place where they can go to get help.

25. Create ACP videos where Aboriginal people are represented as subjects

The 'Taking Care of Dying Time' video was highly regarded by focus group participants due to the representation of Aboriginal people and the recognition of language and values. Apart from this video, there were no other Aboriginal people represented in videos. Focus group participants stressed the importance of having representation within videos such as 'Advance Care Planning in WA' to showcase Aboriginal people being an active participant in ACP.

It is recommended that videos include more representation of Aboriginal people. This can come in many forms:

- Showing Aboriginal people undertaking ACP overlaid with descriptive audio, such as in the 'Advance Care Planning in WA' video.
- Aboriginal people discussing how they approached completing an ACP document, including discussing their cultural perspectives and how they relate to the questions.

26. Create more videos that combine storytelling with information

People resonate most with resources that help them to visualise themselves in the process. The 'Taking Care of Dying Time' video connected well with focus group participants as it described the personal experience of an Aboriginal person, including use of language and struggles faced by Aboriginal people. However, participants stated that the video could provide more information about next steps.

It is recommended that more videos be made that follow this storytelling format of scenarios where ACP was beneficial, such as an Aboriginal person describing a time when their AHD contributed to a good outcome. This could also detail how they approached ACP step by step, for example by including their answers to some questions from the 'Think' section and examples of who they spoke to for the 'Talk' section.

27. Create a one to four page overview of the ACP process

Focus group participants stated that the videos and brochures are good resources to give people an introduction to ACP, whereas the guide and the workbook are good resources for those who have already begun the ACP process. Participants expressed a desire for resources that provide more information than the introductory resources but less detail than the guide or workbook to make the ACP process seem more approachable.

It is recommended that booklets are created that are one to four pages long that provide more information than the brochure but are less overwhelming than the guide and workbook. This will make ACP more accessible to people and give a digestible start to the ACP process. Advance Care Planning Australia provides information designed for Aboriginal people, including 'Taking control of your health journey' and 'Journey to dreaming toolkit and diary', which could be adapted to align with the WA process.¹²

¹² Advance Care Planning Australia website, [Advance care planning for Aboriginal and Torres Strait Islander peoples](#) (note that 'Journey to dreaming' specifically addresses end-of-life care)

5.4 People living with disability

Consultation findings

PARTICIPATION | The six participants included three people who live with a disability and three people who are carers of a person living with a disability. Several participants had completed an ACP document for themselves or a family member, and others were unfamiliar. All participants joined in-person.

Key suggestions raised by this group



Improve representation with examples and inclusive language



Create a series of punchy videos which tell an impactful story, split into Think, Talk, Write and Share to reduce complexity



Make stylistic changes to improve accessibility for people with impaired vision or conditions such as dyslexia

SUMMARY | The focus group of people with disability found the materials to be comprehensive and easy to understand, with most suggestions being around how to make them more inclusive and creating a spur to action. People with disabilities may see ACP as a valuable mechanism to protect their medical rights, rather than a way to exercise choice.

Responses to specific resources

ACP VIDEO | The 'Advance Care Planning in WA' video is brief and surface-level, but serves as a good introduction to the concept of ACP. The 'Taking Care of Dying Time' video is much more compelling in terms of spurring people into action.



AHD GUIDE | The writing style of the guide is easy enough to understand, and the guiding questions are helpful. However, much of the language and examples provided are discouraging or exclusionary to people living with disabilities.



ACP WORKBOOK | Similar to the guide, the writing style and prompting questions are easy to understand. However, the resources don't have images of people with a disability.



ACP BROCHURE | Similar to the video, the brochure serves as an introduction but does not provide a strong impetus to go on to develop an ACP.



ADDITIONAL RESOURCES | A series of videos with broader representation of priority populations, more information about quality-of-life treatments and more ways to complete ACP forms.



Recommendations

RECOMMENDED CHANGES TO EXISTING ACP RESOURCES

Overall consumers in the disability focus group found the materials valuable and informative. However, their main points of feedback reflected a greater desire to see themselves being represented within the existing resources through stories and images. This is important as it motivates and drives action in ways that resonates with this priority population group.

When asked if this need could be met by developing separate, mirror resources targeting and speaking to disabled people, the overwhelming response was for greater inclusion in the resources.

On that basis, the recommended changes to the existing resources include:

- Introducing framing and narratives that reflect the experience of people living with disability and their Carers.
- Enhancing the accessibility of different resources such that consumers living with disability can engage with ACP.

28. Position ACP as a way to safeguard medical rights

Participants in the focus group said that the main motivation for completing an ACP for people with disability is around safeguarding their medical rights and ensuring that their complex care needs were met. Consumers noted that current resources, such as the 'Advance Care Planning in WA' video, positioned advanced care planning as a process of preparing for death, rather than one of ensuring that your medical rights as a citizen were safeguarded.

It is recommended that brochures are developed with different messaging to appeal to people living with a disability. This could be achieved, for example, by changing the subtitle of the existing brochure from the choice focused 'Planning for your future health and personal care' to:

- 'Safeguarding your medical rights', which recognises that people living with disability sometimes receive differential treatment in the medical system because of their disability; or
- 'Empowering your loved ones' which recognises the significant role that Carers play.

29. Include workbook examples specifically for people living with a disability

Consumers commented positively on the ethnic, gender and age diversity of people reflected across the resources including in the examples provided on page 7 of the ACP workbook or on pages 14-15. However, none of the examples were of people living with a physical disability. We recommend that the guide reflect this; for example, page 14 with treatment options can include an example of someone with a disability who must refuse treatment decisions because of their condition. Other examples can also reflect stories of a parent who is a Carer for their adult child who is living with an intellectual disability.

30. Include more pictures of people living with a disability

Representation is important to people living with a disability. Consumers noted that the resources did not include any images of people with an evident physical disability. Further, the existing resources are targeted toward older people, however, this again did not include people living with disabilities.

It is recommended that the resources be updated to include images of people of all ages who are living with an evident physical disability. This could be achieved by printing alternative versions of the ACP brochure or workbook with different images.

31. Reframe the prompting questions to expand people’s view of what they need to live a fulfilling life

A key point of discussion was that much of the language in the ACP workbook and the AHD guide reinforces the perspective that ‘normal’ people are physically healthy and consequently devalues the lives of people living with disabilities. The checklist on page 7 of the workbook of what makes a good life is often unattainable for people living with a disability. For example, quality of life questions including ‘playing sport’ and ‘gardening’ as examples of keeping active do not relate to someone who needs a wheelchair.

While the checklist and examples within the AHD guide cannot be changed as they mirror the AHD form, the checklist and language within the ACP workbook can be revised to better encompass the richness of life for all consumers including those living with disability. Within the ACP workbook, the quality-of-life questions can use a different starting point and expand the view of what a person needs to live a fulfilling life. Examples of being ‘active’ could be changed to:

- communicating with neighbours
- getting outside
- doing a puzzle.

Items such as being able to shower and using the bathroom independently could be removed.

32. Provide consistent, closed captions on all ACP videos

Closed captions allow for easier accessibility of information for people who have hearing difficulties or find text easier to comprehend.

- The ‘Taking Care of Dying Time’ video does not have any closed captions. This video is in a story-telling format, meaning there are limited visual elements for people to understand it’s context. As such, for the video to be accessible to people who are deaf, it is recommended that closed captions are added.
- Currently, the ‘WA Advance Health Directive’ video only allows captions autogenerated by YouTube, which can have mixed quality. It is recommended that these captions are reviewed and/or integrated into the videos themselves.

33. Add a pop-out box of someone communicating in sign language to the existing ACP videos

Some people who are deaf or have hearing impairments may prefer to view materials and communicate through sign language. Currently, there are no resources that visualise content in this format.

It is recommended that the videos ‘WA Advance Health Directive’ and ‘Taking Care of Dying Time’ videos be updated to include a pop-out box of someone communicating in sign language. By using a pop up box, the video of someone communicating in sign language can be superimposed on the existing video, eliminating the need to redo the entire video.

34. Print materials that are accessible for people with reading disabilities

In the focus groups, a consumer with dyslexia reflected on the challenges they had with reading the ACP workbook. While this is only one data point, it is worth noting that one in ten people have dyslexia, making it a worthwhile consideration for the Department to reproduce the existing ACP workbook or the easy read workbook in dyslexia friendly fonts.

Some consumers noted that current resources may be hard to read due to the size of the font. Making fonts bigger will allow for easier reading for all people, particularly those with visual impairments. That notwithstanding, it was noted that the Department already consulted with Visibility WA on the readability of the printed resources.

35. Print materials with different colour backgrounds

Certain colour combinations are more accessible for people with vision impairments to read. Red-green colour blindness is the most common form of colour blindness worldwide. This makes it difficult for people to differentiate between stage three and four of the workbook, which are green and red consecutively. Additionally, diagrams with low contrast, such as the ACP diagram on page 6 of the workbook, may be difficult to read for people with complete colour blindness.

It is recommended that consumers be offered the option to request printed resources in colour-blindness friendly formats, such as:

- using colour-blindness friendly colour palettes
- printing in black and white or high contrast grayscale versions.

There are other visual impairments that the Department may want to cater for in the ACP materials, however, they were not explicitly raised in the focus group.

RECOMMENDED ADDITIONAL RESOURCES

Compared to other population groups, consumers in the disability focus group were more prepared to act on ACP. Taking this into consideration, they wanted resources that provided more detailed information for those who were ready to take the next steps. They and their Carers also had specific considerations and questions that were answered within the existing resources but were not easy and obvious to find.

Represented within this group were Carers, predominantly parents of adult children living with intellectual disability who had particular questions that were not immediately obvious or easy to answer. The engagement of participants within the focus group demonstrated a need for more navigation resources for parents and Carers.

On that basis, the recommended additional aim is to:

- Enable action and next steps on their ACP and AHD.
- Develop standalone shorter resources that speak to key concerns of people living with disability and their Carers.

36. Develop a series of punchy next steps videos

To support those consumers who are ready to take the next step, build on the introductory video with four follow on videos covering the Think, Talk, Write and Share aspects of advance care planning as presented in the ACP workbook and the AHD guide. To help people retain the information, each video could present a small number of concepts and repeat them in different ways.

37. Address frequently asked questions on the legal framework for ACP and how it relates to people living with disability

People with disability and their Carers had more questions regarding the legal aspects of the Advance Care Directive, for example:

- Whether someone with Enduring Power of Guardianship can complete an AHD for the person in their charge who has been deemed unable to make decisions; and
- Whether an AHD is binding throughout Australia.

While the ACP factsheet touches on some of these questions, it does not directly answer some of the pertinent legal questions that are relevant for this priority population group. It would be beneficial for people living with disability and their Carers if there was a short video or two page factsheet on the legal aspects of advance care planning. This would cover topics including:

- what Enduring Guardians can and cannot do
- capacity
- the hierarchy of decision making, and
- the steps required to complete an ACP or an AHD.

38. Take key aspects of the resources and turn them into standalone leaflets

There are some pages in the ACP workbook that consumers living with disability kept referring to. These are the pages that are most relevant for people who are ready to act. Compared to other priority population groups, people living with disability were more inclined to act and move quickly from the introductory information. As such, it would be worthwhile to take these pages and turn them into standalone leaflets, they are:

- the conversation starters on page 12
- the hierarchy of treatment decision makers on page 18
- the summary of advance planning related documents on page 19.

Each leaflet can also include introductory information on ACP.

39. Develop resources particularly for carers

Carers of adults living with complex mental health illness, intellectual disabilities and physical disabilities were prominent participants in the focus group. They are an important consumer segment who are not clearly catered for within the existing resources. They spoke clearly about their frustration in trying to navigate ACP for the person they are a carer for, and that while they had read the documents thoroughly, it was still challenging to get the right sequence of events and prerequisites needed to help the person they are a carer for engage in ACP and document their preferences.

Simple resources can be developed particularly for carers including a guide that cross references page numbers in the AHD form and the ACP workbook. The ACP workbook is a valuable resource in working through and articulating the desires and preferences, but it became unwieldy in trying to transfer the information from the workbook to then completing the Values and Preference form and the AHD. A cross reference guide will make this easier. Further, there are slight variations in writing style between the AHD form and the ACP workbook, that the consumers we engaged with had picked up on, likely because they had used the documents extensively. This variation in writing style makes sense because the two resources

have different purposes, but it can be confusing to a consumer. A cross-reference guide can explain the distinction between the two and help the consumer look past these.

40. Create documents that explain the quality-of-life treatments

A person with a disability is more likely to have complex healthcare requirements, and therefore more complicated implications from treatment decisions expressed in their ACP. Understanding and anticipating these implications is critical to the success of the AHD, and it may be beneficial for them to consult with more health professionals than indicated in the current resources.

It is recommended that documents are created that explain quality-of-life treatments in depth so that individuals are fully informed of what they entail. It should be emphasised in the document that the implications of quality-of-life treatments are unique for everyone and consultation with health professionals should be encouraged for people with complex care requirements.

41. Create more interactive ways of accessing the resources

Focus group participants remarked on the already wide range of resources made available for people to undertake ACP. It was noted that the ACP workbook is a comprehensive resource, but it could be provided in a more interactive, self-paced or easy to digest format.

For example, it was suggested that an app be developed that would be ideal for neurodiverse individuals including people with autism. It was remarked that because mobile apps are easy to use, clear and present information in bite size components, they would be valuable for conveying ACP information to consumers. Should the Department decide to invest in an ACP app, we recommend this be for the AHD guide so that more consumers from this priority population group can work through the form.

42. Create a video that tell the story of people living with a disability who have used, or been in situations where ACP would have benefited them

The 'Taking Care of Dying Time' video was well-received by consumers due to its storytelling format and how it described a situation for the individual where ACP would have benefited them. By positioning ACP in this way, it allows people to understand when and why it is important and encourages people to begin the process.

It is recommended that the story telling video feature a person living with a disability as the protagonist. There are many possible videos that the Department can develop in this vein across the entire advance care planning process. They include:



- Why a person with a certain disability or chronic medical condition can protect their medical rights by putting in place an AHD.
- Young, healthy person with a disability speaking in a group setting about the benefits of ACP.
- The process of having a conversation on ACP with a loved one.
- A scenario in which an AHD was applied to the direct benefit of the person who is then telling the story in their own voice.

5.5 People living with mental health illness

Consultation findings






PARTICIPATION | This focus group had four participants (of nine expressions of interest). Three participants had lived experience of mental health illness, and one was a Carer and Carer's Representative. All participants attended in-person.

Key suggestions raised by this group

 <p>Include people living with mental illness in examples, but do not make separate resources</p>	 <p>Be clear about how the AHD interacts with individuals rights under the Mental Health Act</p>	 <p>Make changes to the layout of the resources to improve accessibility</p>
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SUMMARY | ACP and determining capacity is a big issue for people living with mental illness. Participants felt that some language within the resources was 'condescending' and needed to be more actionable. Participants also wanted more examples and stories as a guide throughout the resources.

Responses to specific resources

ACP VIDEO The 'Advance Care Planning in WA' video was easy to understand but needed more people from diverse backgrounds. The 'Taking Care of Dying Time' video was far more effective at connecting with people, but needed additional information about ACP.	
AHD GUIDE Some participants described language in the guide as 'condescending', and noted that it contained some difficult words that were not explained. The examples highlighted in the document were considered helpful.	
ACP WORKBOOK The workbook was very detailed but very long. Like the guide, the examples and stories included in it were extremely helpful.	
ACP BROCHURE The brochure was considered to be a good introductory resource but could benefit from more urgent and actionable language to get people to start ACP.	
ADDITIONAL RESOURCES Supporting resources both before and during ACP and more videos that combine storytelling with crucial information.	

Recommendations

RECOMMENDED CHANGES TO EXISTING ACP RESOURCES

Consumers in the mental health focus group emphasised that there are specific needs and barriers that ACP resources should reflect and address. This could improve the uptake of ACP by helping people to feel safe and supported in undertaking the process.

Focus group participants felt that the resources had sufficient information to undertake ACP, but felt that there should be a change in the framing of the resources to be more inclusive for people living with mental health illness.

On that basis, the recommended changes to the existing resources include:

- Ensuring appropriate measures are in place to allow for informed consumption of resources.
- Addressing barriers to ACP for people living with mental health illness.

43. Add trigger warnings to the start of videos and the inside cover of existing and future booklets

ACP involves sensitive discussions around incapacity to make decisions, personal health circumstances and death. ACP is a broad term and may not immediately convey that the subject matter involves sensitive topics which may be distressing to some people.

Including a trigger warning at the start of videos and the inside cover of the ACP workbook and AHD guide, as well as any future resources, could allow people to prepare themselves and get support before engaging with the resources. It is recommended to include trigger warnings in each resource:

- Trigger warnings in videos can be a standalone statement or included as a call-out box. Example text could be 'This video discusses themes of death and dying, terminal illness, medical treatments and hospitalisation.'
- Trigger warnings for the booklets can be presented similarly to the call for interpreter services on the inside cover of the guide and workbook. Example text could be 'Undertaking ACP requires you to think deeply about future situations in which you are unwell and unable to make decisions about your health care. If this is distressing, please seek the support of a family member, friend or healthcare provider.'

44. Position ACP as a form of legal and medical protection

Focus group participants expressed that when a mental illness has been disclosed, there is opportunity for family, friends or medical personnel to use a person's mental illness against them. A key concern for focus group participants is the potential for a person's mental health illness to be used as a means of claiming a lack of capacity in order to override their decisions. For people living with mental health illness, it is important that an AHD is fight-proof and is a document that they can use to protect themselves.

It is recommended that a brochure is developed that positions ACP, and in particular the completion of an AHD, as a way to provide with legal and medical protection for when they have an incapacity to make decisions. This could be done by changing the subtitle of the existing brochure to 'Safeguarding your medical rights', which recognises that people may receive differential treatment in the medical system due to their mental health illness. This brochure could also show the hierarchy of treatment decision-makers, and where ACP documents fit into the hierarchy.

45. Emphasise which supports and resources are free, especially legal advice

Focus group participants stressed the importance of the legality of the documents, due to issues of discrimination within the medical system. The availability of free legal advice and other professional supports in undertaking ACP is crucial for the peace of mind of people living with mental health illness. Organisations that can provide free legal advice are already listed on page 32 of the AHD guide and 31 of the ACP workbook. It is recommended that this is highlighted for people who are not already familiar with these organisations.

46. Place resources where people living with mental health illness will interact with them

Increasing the visibility of ACP in physical spaces could prompt more people to begin the process. It is recommended that physical resources including brochures, the ACP workbook and AHD guide are provided in appropriate locations. Focus group participants stated that the best place to reach people living with mental health illness are:

- Places that they go to for support, such as NDIS offices, drug and alcohol services, and not-for-profit organisations.
- Touchpoints with relevant services, such as schools, life skills courses, emergency departments and during applications for disability.

47. Include more examples of people living with mental health illness

Focus group participants stressed that they do not want specific 'mental health' resources separate to the mainstream resources. Having and using mental health specific resources could create a privacy concern by making their personal situation visible to others. However, focus group participants expressed that representation within the resources is still important.

Representation of people living with mental health illness can be reflected in various places throughout the resources, including:

- Examples of people living with mental health illness to complement examples of other cohorts provided in the resources, such as on page 4 of the ACP workbook.
- Symbolism for people living with mental health illness within the visual elements of resources, such as setting and background props.

22b. Move the 'Checklist for making an Advance Health Directive' to the first few pages of the guide

Focus group participants expressed the need for people living with mental health illness to have a checklist that helps them keep track of where they are in the ACP process and suggested moving the checklist provided on page 30 of the AHD guide towards the front of the booklet. Focus group participants noted that people living with mental health illness may be more likely to be more rigorous when undertaking ACP, due to concerns or experience of discrimination within the health system. Having a checklist enables people to work through the documents systematically and provide an overall picture of the steps required in completing an AHD.

It is recommended that the checklist on page 30 of the AHD guide be moved to the first few pages of the guide for easy access and provide consumers with an overview of the ACP process from the start of their journey.

RECOMMENDED ADDITIONAL RESOURCES

Compared to other population groups, people with mental health illness may seek more support in undertaking ACP, particularly from people that they know and trust.

Participants within this focus group also requested for the current resources to be modified into smaller, more manageable resources. Participants found the length of the AHD guide and ACP workbook to be overwhelming, and suggested exploring more iterative ways of presenting information.

On that basis, the recommendations for additional resources are to:

- Break down resources into a more manageable length.
- Provide a wider support network for people living with mental health illness.

48. Provide consumers with more options to store their ACP documents

Focus group participants stated that people living with mental health illness may be apprehensive to upload their ACP documents to My Health Record due to concerns regarding privacy and medical discrimination. However, ACP documents are less accessible when there is only a physical document available, particularly when there is an emergency, or the person is away from home.

It is recommended that consumers are given a variety of options to upload their ACP documents, to reduce reliance on physical copies which may be difficult to access in an emergency. This could include:

- Uploading the document to a Google drive, One Drive or Dropbox, setting restricted access so that only people you specify can view the document through a link you provide.
- Give trusted people the document on a thumb drive, which can be password protected for privacy.

49. Partner with service providers to support people living with mental health illness through the ACP process

Focus group participants stated that people living with mental health illness are often stigmatised in the health system and can be taken advantage of by family, friends or health professionals. People living with mental health illness may be more likely to engage in the ACP process if they are provided with advocacy and support from service providers they can trust to understand their needs and provide unbiased advice.

It is recommended that the Department partner with service providers who work closely with people living with mental health illness to provide people that they can trust to support them through the ACP process. Service providers to partner with include:

- National Disability Service
- People with Disabilities WA
- Consumers of Mental Health WA
- Mental Illness Fellowship of WA
- WA Association of Mental Health
- WA Alcohol and Drug House
- RUAH Community Services
- The Salvation Army.

These partnerships could involve sharing existing resources or offering training.

50. Create flashcards to prompt action during the 'Think' and 'Talk' elements of ACP

ACP is a lengthy process that requires people to consider many personal topics, and may involve discussing these with family, friends, and professionals. Focus group participants expressed that the flashcards presented in the 'Elements of ACP' portion of the 'Advance Care Planning in WA' video would be helpful in having these conversations. These flashcards are already available through Palliative Care WA, and Advance Care Planning Australia also has 'conversation starters'. It is recommended that these are added to the Department of Health website, and that printed versions are made available through the request form.

51. Create a series of resources split into Think, Talk, Write and Share

Focus group participants found the length of the AHD guide and ACP workbook to be daunting and expressed apprehension to begin working through them. Splitting the guides and workbooks into four smaller, focussed booklets, may make it easier for people to understand the stages of ACP and where they are in the process.

It is recommended that separate booklets are made for each section ('Think', 'Talk', 'Write' and 'Share') that go into detail about what to do in each stage and address frequently asked questions. These would utilise the same content that is currently within the ACP workbook and may be more accessible to some people. Each booklet could provide an estimate of the time commitment required to help people prepare themselves and plan around it. This could include wording such as "You can expect to complete this booklet within 2-3 hours. You might choose to do this in a few sessions to give yourself time for reflection."

52. Create videos targeted to younger people

Participants highlighted that the videos are an effective way to reach people, particularly younger people. However, the 'WA Advance Health Directive' video is aimed at older people through the tone and representation of individuals, such as the geriatrician positioned as the primary health provider in the video.

It is recommended that videos are created that target younger people. Elements in the video may include:

- subjects talking to their peers about ACP
- subjects talking to younger medical or legal professionals
- settings where younger people frequent, such as parks, cafes and libraries
- information on organisations that specialise in younger people where they can go to for further support, such as Youth Focus or Mission Australia Youth Service.

5.6 People experiencing disadvantage

Consultation findings

PARTICIPATION | This focus group had eight participants, who all work for social service providers across the not-for-profit sector. All participants attended in-person.

Key suggestions raised by this group



Help people find support networks to talk about ACP



Reach people experiencing disadvantage through the services they use



Have greater representation of people in a multitude of different socioeconomic situations

SUMMARY | Although the resources were very well-explained, service providers involved with people experiencing disadvantage felt that the language used should be at a lower reading level. Furthermore, the images in the resources did not represent people from diverse socioeconomic backgrounds.

Responses to specific resources

ACP VIDEO | The 'Advance Care Planning in WA' video did not actually explain what an AHD is. It also needs more diversity and has a 'middle-class feel' to it, leading people to believe that ACP is only for those who are in a good financial position.



AHD GUIDE | The guide is easy to work through and has enough information for service providers to explain ACP to people. However, the language should be at a lower reading level to be more widely accessible.



ACP WORKBOOK | The workbook is easy to read and understand, but it would be beneficial to include more diverse examples and stories within the text.



BROCHURE | The brochure was easy to understand and had lots of graphics that draw people in and lets them grasp the topic quickly.



ADDITIONAL RESOURCES | Booklets and videos that further explain the ACP process and tell people where to go to for support.



Recommendations

RECOMMENDED CHANGES TO EXISTING ACP RESOURCES

Overall, service providers in the disadvantage focus group found the resources easy to understand, and they had helpful information to discuss the resources with consumers. However, focus group participants noted that ACP is usually a low priority for people who face other competing demands.

Participants highlighted that encouraging ACP is not only about exposure, but about addressing the barriers that prevent people from undertaking ACP to begin with.

On that basis, the recommended changes to the existing resources include:

- Enhancing the accessibility of current resources such that people experiencing disadvantage can engage with ACP.
- Increasing exposure of people experiencing disadvantage to ACP resources.

53. Frame conversations with medical and legal professionals as an enabler of ACP rather than a prerequisite

Current resources stress the importance of talking through the ACP process with friends, family, medical professionals and/or lawyers. These support networks are often not available to people experiencing disadvantage, or there is hesitancy to approach them. Focus group participants noted that this can be due to the following reasons:

- when people experiencing disadvantage are able to visit a GP, there are more urgent health matters that need to be addressed
- they cannot afford to see a lawyer
- they do not have the support of family or friends to have the conversation with.

It is recommended that conversations with medical and legal professionals, as well as family and friends, are framed as an option to support the ACP process rather than a requirement to undertake ACP. This can be incorporated:

- as a call-out box in the videos
- at the back of the ACP brochures.

54. Make it obvious which ACP support services are free

Focus group participants noted that people experiencing disadvantage are less likely to engage with ACP due to the need for medical and legal professional support, as these services can be too expensive. It is recommended that the availability of free support from the organisations listed on page 32 of the AHD guide and 31 of the ACP workbook are highlighted within the text.

55. Place ACP resources where people experiencing disadvantage will interact with them

People experiencing disadvantage often do not have digital access and are unable to reach ACP resources that are primarily found online. Focus group participants stressed the importance of having physical resources available in places that people experiencing disadvantage frequent and can access.

It is recommended that physical ACP resources be placed at the following locations:

- libraries
- women's shelters
- homeless shelters
- GP offices
- not-for-profit groups
- places with free Wi-fi.

RECOMMENDED ADDITIONAL RESOURCES

Service providers in the disadvantage focus group felt that the resources achieved their purpose in explaining ACP and what it involves. However, they reflected that current resources portrayed ACP as an action targeted toward middle-class people, and that reflecting a broader range of experiences is important to encouraging uptake.

Focus group participants expressed the need for resources to take into consideration the nuanced pressures that people experiencing disadvantage face and to address these barriers to encourage uptake of ACP.

On that basis, the recommended additional aim is to:

- Introduce framing and narratives that reflect the experience of people disadvantage.
- Providing different avenues of support for people experiencing disadvantage.

56. Create a brochure that positions ACP as a means of reducing future burden

Focus group participants stressed that people experiencing disadvantage won't see ACP as a priority amongst competing demands on their time and energy. In order to increase uptake of ACP, it needs to be positioned as a way to reduce burden for people experiencing disadvantage.

It is recommended that there should be a brochure that has a central message of ACP as a means of reducing burden on either the individual or their loved ones. This could be done by repurposing the existing brochure with a new subtitle such as 'Preparing for difficult healthcare decisions' which reflects the burden of making choices under difficult circumstances.

57. Create videos that show people in familiar settings

Participants found that the representation of people within the resources does not reflect people experiencing disadvantage. As images and videos depicted people in a medical, café or middle-class home setting, focus group participants stated that it gave the impression that ACP is only for people who have the financial capability to do so.

It is recommended that there should be more scenarios of people in different socioeconomic situations, reflected in both imagery and examples within the resources. This could include:

- having conversations about ACP at a park with family and friends
- receiving support from more diverse service providers at their office
- a wider range of home settings in the background
- completing ACP documents at a library.

58. Create videos that tell the story of people experiencing disadvantage

Focus group participants wanted more videos that tell the story of people experiencing disadvantage in the process of ACP. Although people understand the concept of ACP, having these real-world examples enables people to see themselves in the situation and better understand how ACP can alleviate pressure when they need to receive care without having the capacity to voice their healthcare preferences. This can include:

- Someone who is experiencing financial disadvantage and had previously completed an AHD. Because they were able to thoroughly research treatment options, the costs and implications of the treatment, there were no surprise costs or lifestyle changes upon release from care.
- The family of someone who is experiencing financial disadvantage and did not have an AHD when they were no longer able to make decisions. The family were unaware of the person's financial disadvantage and were not able to make informed decisions on the degree of care the person wanted. This results in added pressure on the person upon release from care.

It is recommended that videos similar to the 'Taking Care of Dying Time' video be made that show these situations and are tailored to represent the experiences and priorities of people experiencing disadvantage.

59. Partner with health and social service providers to encourage ACP and support people experiencing disadvantage through the ACP process

Service providers who are in regular contact with people experiencing disadvantage can be helpful in introducing people to ACP. Focus group participants stated that people experiencing disadvantage trust their service providers, who understand their financial situation and have been a point of contact for support. Examples of service providers and organisations include:

- case workers
- financial councillors
- Western Australian Council of Social Service.

It is recommended that the Department partner with service providers to support people experiencing disadvantage through the ACP process. To do so effectively, service providers need to be trained in how to sensitively initiate the conversation, as well as providing ongoing support throughout the ACP process. Advance Care Planning Australia provides online modules and webinars designed for health workers which could be utilised.¹³

¹³ Advance Care Planning Australia website, [Online courses](#)

5.7 General recommendations

The following recommendations were raised in multiple focus groups or are likely to have a much broader range of impact than the priority population group being discussed.

60. Explore ways of working with other organisations to encourage ACP and support people throughout the ACP process

Participants across the focus groups identified organisations that work with vulnerable populations and are actively working to improve uptake of ACP. This includes developing supplementary materials and offering support to people who have questions about their plan. A good working relationship with these organisations could create opportunities to build on similar programs of work.

A broader range of organisations and individuals (such as support workers) may be a critical contact point for people wanting information about ACP. Providing training resources for these organisations may improve their ability to help people complete the ACP documents, or to answer specific questions people may have as they progress their plan. Advance Care Planning Australia provides guidance on considering the different needs of patients, which may be helpful to support workers.¹⁴

It is recommended that working relationships are formed with the following organisations:

Table 4 | Potential ACP partner organisations

Organisation	Current activities	Possible ways of working together
Australian Digital Health Agency	Development of localised and translated versions of the materials alongside regional health services.	Promoting materials developed by the ADHA and regional health services.
Aboriginal Health Council of WA	Development of a booklet to help health and support workers talk to people about ACP.	Work together on exploring ways to make ACP and ACP documents more culturally appropriate. Organise or facilitate yarning groups.
Mental Health Commission	Review of the Mental Health Act.	Collaborate on a Frequently Asked Questions about the legal interactions between an AHD and the Mental Health Act.
Mission Australia	Development of information and tools for carers of people with a disability to think about ACP.	Promote materials developed by Mission Australia.
Citizens Advice Bureau	Minimal current involvement in supporting people to undertake ACP.	Provide training and resources to enable the organisation to support people seeking advice or information, for example through the Advance Care Planning Australia online courses. ¹⁵
Service providers	Some involvement in supporting people to undertake ACP.	Collaborate on the organising of workshops or seminars. Service providers could distribute brochures and other materials.

¹⁴ Advance Care Planning Australia website, [Health professionals roles and responsibilities](#)

¹⁵ Advance Care Planning Australia website, [Online courses](#)

Organisation	Current activities	Possible ways of working together
Health workers (nurses, hospital workers, allied health) Support workers	May be asked for advice on an ad-hoc basis.	Training could be provided on the terminology, processes and documents involved in ACP to enable better support and raise awareness about when to introduce ACP to patients or clients. As above, this could make use of existing ACP Australia courses.
Aboriginal Controlled Community Organisations	May be asked for advice on an ad-hoc basis.	Collaborate on the organising and facilitating of yarning groups. Organisations could distribute brochures and other materials.
Multicultural community organisations such as Culture Care WA or consulates	Minimal current involvement in supporting people to undertake ACP.	Recruit and train 'ACP cultural ambassadors' and run community-specific workshops.

61. Introduce ACP at appropriate points through existing systems

Focus group participants raised that people could be introduced to ACP at touch points with services. Having ingrained points of contact where people are naturally introduced to ACP may result in more people undertaking ACP in the future. It is recommended that ACP is introduced to people at appropriate points through systems they already interact with such as: annual health check at the GP; upon pregnancy/giving birth; admission to hospital and/or the ER; or getting or renewing a driver's licence.

62. Create videos that combine the storytelling element with informational elements

Focus group participants found that the two videos to be effective in communicating different aspects of ACP. The 'Advance Care Planning in WA' video succinctly explains the steps of ACP and provides information on where to go to learn more, whereas the 'Taking Care of Dying Time' video personalises the ACP process and explains its importance through storytelling. Participants expressed that ideally, a video about ACP would combine these two elements to be compelling and informative. Some participants also expressed a need for clearer identification of the different ACP documents, including Enduring Guardianship.

It is recommended that a video is developed that combines the drive to action through storytelling with actionable steps and key information. This could be done by:

- Showing stories of people who describe their experiences for each stage of ACP, and how they approached each step, and ending with next steps and information about where to get resources.
- Starting with someone briefly telling their story about when their (or a loved one's) ACP was used, followed by an outline of the steps involved in ACP, and ending with next steps and information about where to get resources.

Advance Care Planning Australia has developed 'The questions that matter most' and 'Love is not enough', which feature people discussing their experiences and the importance of ACP.¹⁶ While these videos focus on storytelling over information, with permission they could be adapted to include the steps outlined in the ACP workbook or prominently display next steps.

¹⁶ Advance Care Planning Australia website, [Engaging videos](#)

63. Update the Taking Care of Dying Time video to make it more engaging and relevant to WA

All focus group participants found the Taking Care of Dying Time video to be compelling, however had some editing suggestions to make it more engaging and relevant. The recommended edits include:

- The extended video is ten minutes long, and the short version is four minutes long. The first minute of the video shows introductory text including an acknowledgement of country, and a brief explanation ACP, followed by Chris introducing his story. Participants expressed that this made the video overall less engaging. The video may be more engaging if, after the acknowledgement of country, it begins with Chris describing how he was told about his uncle being taken to hospital.
- As the videos are long, viewers may want information about next steps and where to go for resources earlier on. Instead of next steps and resources being shown in the whole image towards the end of the video they could be overlaid with Chris's story, for example by adding details to the bottom of the video in every frame.

Appendix A Key terminology and acronyms

Definitions for some key terminology used within this document can be found in Table 5, and acronyms are defined in Table 6.

Table 5 | Key terms used in this document

Terminology	Definition
Advance care planning (ACP)	A process of planning for future health and personal care whereby the person's values, beliefs and preferences are made known to guide decision-making at a future time when that person cannot make or communicate their decisions.
Capacity to make and communicate decisions, also known as legal capacity and competency	Full legal capacity refers to the capacity to make a formal agreement and to understand the implications of statements contained in that agreement. Competency is recognised in legislation and in common law as a requirement for completing a legal document that prescribes future actions and decisions, such as a will or an Advance Care Directive. Decision-making capacity can be assessed by trained professionals, and its assessment depends on the type and complexity of the decision to be made.
Yarning groups	Yarning groups are used by Aboriginal and Torres Strait Islanders to talk and share stories and knowledge. They prioritise culturally appropriate and respectful ways of communicating.

Table 6 | Acronyms used in this document

Acronym	Definition
ACP	Advance care planning
AHD	Advance Health Directive
AHCWA	Aboriginal Health Council of Western Australia
CaLD	Culturally and linguistically diverse
NDIS	National Disability Insurance Scheme
LGBTQIA+	Lesbian, gay, bisexual, transgender, queer, intersex, asexual, and other sexually or gender diverse people
PEMAT	Patient Education Materials Assessment Tool

Appendix B ACP resources

The resources that were assessed as part of this review are detailed in Table 7.

Table 7 | ACP resources

Resource	Link
Quick Reference - advance care planning resources in WA	https://www.healthywa.wa.gov.au/~media/HWA/Documents/Healthy-living/End-of-life/ACP-resource-quick-reference.pdf
Values and Preferences Form	https://www.healthywa.wa.gov.au/~media/HWA/Documents/Healthy-living/End-of-life/Values-and-Preferences-Form.pdf
Advance Care Planning: Planning for your health care (Brochure)	https://www.healthywa.wa.gov.au/~media/Files/HealthyWA/New/Advance-Care-Planning/Aboriginal-Advance-care-planning.pdf
Your Guide to Advance Care Planning in WA (Workbook)	https://www.healthywa.wa.gov.au/~media/HWA/Documents/Healthy-living/End-of-life/ACP-Guide-workbook.pdf
Advance Care Planning: Planning for your health care (Easy-read Workbook)	https://www.healthywa.wa.gov.au/~media/HWA/Documents/Healthy-living/End-of-life/Easy-Read-ACP-workbook.pdf
A Guide to Making an Advance Health Directive in Western Australia	https://www.healthywa.wa.gov.au/~media/HWA/Documents/Healthy-living/End-of-life/AHD-Guide.pdf
Advance Health Directive Form	https://www.healthywa.wa.gov.au/~media/HWA/Documents/Healthy-living/End-of-life/Advance-health-directive
Advance Care Planning: Planning for your future health and personal care (A4 factsheet)	https://www.healthywa.wa.gov.au/~media/HWA/Documents/Healthy-living/End-of-life/Advance-Care-Planning-A4-Fact-Sheet.pdf
Advance Care Planning: Planning for your future health and personal care (Brochure)	https://www.healthywa.wa.gov.au/~media/HWA/Documents/Healthy-living/End-of-life/Advance-Care-Planning-DL-Brochure.pdf
Taking Care of Dying Time - Aboriginal Videos	https://www.youtube.com/watch?v=7d2gzy5kl8A
Taking Care of Dying Time - Aboriginal Videos (Extended Version)	https://www.youtube.com/watch?v=BFPkqL-tU
WA Advance Health Directive: What it is and how to get started (video)	https://www.youtube.com/watch?v=4Z0JQRCsvf0

Resource	Link
Advance Care Planning in WA: What it is and what it means for you (video)	https://www.youtube.com/watch?v=TWfCWOurvaU&feature=emb_imp_woyt
Have the Conversation (Also translated into 21 other languages) (video)	https://www.youtube.com/watch?v=vXWexCnRslg
Advance Care Planning Webpage	https://www.healthywa.wa.gov.au/Articles/A_E/Advance-care-planning
Advance Health Directives Webpage	https://www.healthywa.wa.gov.au/Articles/A_E/Advance-Health-Directives
Advance care planning process Webpage	https://www.healthywa.wa.gov.au/Articles/A_E/Advance-care-planning/Process

A list of translations is provided in Table 8 below. The resources not listed in this table are only available in English.

Table 8 | Advance care planning resources - translations

Language	Guide to Making an AHD in WA	Your Guide to ACP in WA	ACP Fact Sheet	Values & Preferences Form	'Have the Conversation' video
Afrikaans	✓	✓	✓	✓	✓
Arabic	✓	✓	✓	✓	✓
Chinese simplified	✓	✓	✓	✓	✓
Chinese traditional					✓
Croatian	✓	✓	✓	✓	✓
Dutch					✓
Filipino					✓
French					✓
German	✓	✓	✓	✓	✓
Greek	✓	✓	✓	✓	✓
Hindi	✓	✓	✓	✓	✓
Indonesian	✓	✓	✓	✓	✓
Italian	✓	✓	✓	✓	✓
Macedonian	✓	✓	✓	✓	✓
Malay					✓

Language	Guide to Making an AHD in WA	Your Guide to ACP in WA	ACP Fact Sheet	Values & Preferences Form	'Have the Conversation' video
Polish	✓	✓	✓	✓	✓
Punjabi	✓	✓	✓	✓	✓
Serbian					✓
Spanish	✓	✓	✓	✓	✓
Tagalog	✓	✓	✓	✓	
Turkish					✓
Vietnamese	✓	✓	✓	✓	✓

Appendix C PEMAT assessment criteria

The PEMAT questions used to assess the print and audio-visual resources are detailed in Table 9. The applicability of questions for print and audio-visual resources slightly differed, as identified by the ticks.

Table 9 | PEMAT assessment criteria

Questions	Print materials	Audio-visual materials
UNDERSTANDABILITY		
Content		
The content makes its purpose evident	✓	✓
The material does not include information or content that distracts from its purpose	✓	✗
Word choice and style		
The material uses common, everyday language	✓	✓
Medical terms are used only to familiarise audience with the terms. When used, medical terms are defined	✓	✓
The material uses the active voice	✓	✓
Use of numbers		
Numbers appearing in the material are clear and easy to understand	✓	✗
The material does not expect the user to perform calculations	✓	✗
Structure		
The material breaks or chunks information into short sections	✓	✓
The material's sections have informative headers	✓	✓
The material presents information in a logical sequence	✓	✓
The material provides a summary	✓	✓
Layout and design		
The material uses visual aids whenever they can make content more easily understood	✓	✓

Questions	Print materials	Audio-visual materials
Text on the screen is easy to read	✗	✓
The material allows the user to hear the words clearly	✗	✓
Use of visual aids		
The material uses visual aids whenever they can make content more easily understood	✓	✗
The material's visual aids reinforce rather than distract from the content	✓	✗
The material's visual aids have clear titles or captions	✓	✓
The material uses illustrations and photographs that are clear and uncluttered	✓	✓
The material uses simple tables with short and clear row or column headings	✓	✓
ACTIONABILITY		
The material clearly identifies at least one action the user can take	✓	✓
The material addresses the user directly when describing actions	✓	✓
The material breaks down any action into manageable, explicit steps	✓	✓
The material provides a tangible checklist/next steps where possible to help the user take action	✓	✓
The material explains how to use the charts, graphs, tables or diagrams to take action(s)	✓	✓

Appendix D Stakeholder engagements

This section details the key questions discussed in interviews and focus groups.

D.1 Interview questions

D.1.1 Advance Care Planning Australia

1. What do you think consumers need to be able to understand and undertake the ACP process?
 - a. What does this look like for each priority group? (Aboriginal people, people from CaLD backgrounds, people experiencing disadvantage, people experiencing mental health illness, people living with disability and people living in regional areas)
2. What do good resources look like to you?
3. What steps did you take to developing your resources?
4. What have you learnt during your resource development process?
5. What do you think are the strengths and opportunities for improvement for WA's current resources?
6. What additional supports do you provide alongside current resources? (e.g., options for people to get support from an interpreter or counsellor)?
7. What plans do you have for additional resources?

D.1.2 Royal Australian College of General Practice

1. What do you think consumers need to be able to understand and undertake the ACP process?
 - a. What does this look like for each priority group? (Aboriginal people, people from CaLD backgrounds, people experiencing disadvantage, people experiencing mental health illness, people living with disability and people living in regional areas)
2. Do General Practitioners share ACP resources with their patients to introduce them to the process?
 - a. If they do, what resources do they typically share?
 - b. If they do not, why?
3. Do you think ACP resources adequately prepare patients, their family, and friends to make informed decisions about their future health?
 - a. What additional resources, information and supports do you think consumers need to undertake ACP?
4. Do you think the way patients write ACP's enable medical professionals to make decisions that align to patient preferences?

D.1.3 Western Australian Council of Social Service

1. What do you think consumers need to be able to understand and undertake the ACP process?
 - a. What does this look like for each priority group? (Aboriginal people, people from CaLD backgrounds, people experiencing disadvantage, people experiencing mental health illness, people living with disability and people living in regional areas)
2. Do General Practitioners share ACP resources with their patients to introduce them to the process?
 - a. If they do, what resources do they typically share?
 - b. If they do not, why?
3. Do you think ACP resources adequately prepare patients, their family, and friends to make informed decisions about their future health?
 - a. What additional resources, information and supports do you think consumers need to undertake ACP?
4. Do you think the way patients write ACP's enable medical professionals to make decisions that align to patient preferences?

D.1.4 Office of the Public Advocate

1. What do you think consumers need to be able to understand and undertake the ACP process?
 - a. What does this look like for each priority group? (Aboriginal people, people from CaLD backgrounds, people experiencing disadvantage, people experiencing mental health illness, people living with disability and people living in regional areas)
 - b. What questions do you think we should ask participants within each priority group?
2. What do you think are the strengths and opportunities for improvement for WA's current resources?
 - a. Do you think current resources for Advance Health Directives effectively support consumers?
 - b. What additional resources are required?
3. What are the challenges to the ACP process when an individual does not have decision making capabilities?
 - a. Are there opportunities to better support this cohort using resources?

D.1.5 Palliative Care WA

1. What do you think consumers need to be able to understand and undertake the ACP process?
 - a. What does this look like for each priority group? (Aboriginal people, people from CaLD backgrounds, people experiencing disadvantage, people experiencing mental health illness, people living with disability and people living in regional areas)
2. What do you think are the strengths and opportunities for improvement for WA's current resources?
 - a. Do you think they adequately inform consumers about the process?
3. How could ACP resources encourage younger people to consider developing an ACP or Advance Health Directive?

D.2 Focus group questions

D.2.1 Focus group with people living in regional areas

Table 10 | An overview of the resources and key questions discussed

Resource	Questions
'Have the Conversation' Video	<ul style="list-style-type: none"> Do you have a better understanding of ACP? Was the video easy to understand? Is there anything about the video that could be improved?
Your guide to advance care planning: A workbook to help you plan for your future care	<ul style="list-style-type: none"> How easy is it to read and follow the content? What supports would you need to undertake ACP? How could it be improved?
Guide to making an AHD	<ul style="list-style-type: none"> How easy is it to read and follow the content? Do you understand what actions you should undertake? Does it provide helpful information that answers some of the questions you have? How could that section be improved?
Plenary	<ul style="list-style-type: none"> What are your overall perspectives of the guide? Do you find it useful? What other supports would you need to complete an AHD? How could it be improved?

D.2.2 Focus groups

Table 11 | An overview of the resources and key questions discussed

Resource	Questions
'WA Advance Health Directive' video	<ul style="list-style-type: none"> Do you have a better understanding of ACP? Was the video easy to understand? Is there anything about the video that could be improved?
'Taking Care of Dying Time' video	
Your guide to advance care planning: A workbook to help you plan for your future care	<ul style="list-style-type: none"> How easy is it to read and follow the content? What supports would you need to undertake ACP? How could it be improved?

Resource	Questions
<p>Guide to making an AHD</p>	<ul style="list-style-type: none"> • What are your overall perspectives of the guide? Do you find it useful? • What other supports would you need to complete an AHD? • How could it be improved?
<p>'A Guide to Making an Advance Health Directive in Western Australia' brochure</p> <p>'Advance care planning: Planning for your health care' brochure</p>	<ul style="list-style-type: none"> • Is there enough information for people to go on, including contact information and resources? • Are the next steps for developing an ACP clear? • Where should these brochures be provided to maximise consumer access?
<p>Plenary</p>	<ul style="list-style-type: none"> • Do you have any final questions or comments?