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Advance care planning with vulnerable populations

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Contents

Dedication / 1

Report purpose and structure / 2

Suggested citation / 2

Funding acknowledgements / 2

Acknowledgements / 2

Partners / 3

Disclaimer / 3

The Research Team / 4

Chief Investigators / 4

Associate Investigator / 4

Post-Doctoral Fellows / 4

Project Manager / 4

Post-graduate student researchers / 4

Governance / 4

Committees and Membership / 4

Section 1

Executive summary / 6

Conclusion / 7

Section 2

Project overview / 10

Background / 10

Aims / 11

Activities / 11

Participants and process / 11

Advance care planning in the hospital / 11

Advance care planning in the community / 11

Data analysis / 11

Themes identified / 12

Top-five recommendations from consultation with our communities and stakeholders / 12

Specific recommendations / 13

To facilitate completion of an ACD / 13

To support ACDs in acute care / 14

Conclusion / 14

Section 3

Detailed project results / 18

Advance care planning in two South Australian public hospitals / 18

Views of people living with chronic disease on advance care planning and ACDs / 19

Cancer / 19

Chronic Obstructive Pulmonary Disease (COPD) / 22

Dementia / 24

Views of Aboriginal Australians on advance care planning / 26

Aboriginal Australians / 26

Views of people from culturally and linguistically diverse communities on advance care planning / 29

Bhutanese / 29

Italian / 32

Vietnamese / 34

Professional views on advance care planning / 36

General Practitioners (GPs) / 36

Hospital healthcare professionals / 39

Lawyers / 42

Section 4

Project recommendations / 48

Creating an ACD: Supporting consumer engagement / 48

Simplify and shorten the ACD kit / 44

Change misleading terminology: 'DIY' and 'Substitute Decision-maker' / 48

Consult communities to make Kit/booklet examples more accessible / 48

Clarify the practical and legal differences between 'wishes' and 'refusals' / 49

Help people to reflect on futures and decisions that an ACD might help with / 49

Provide guidance on what to do with a completed ACD / 50

Simplify the layout of the ACD form / 50

Provide translations of ACD documentation (either in written or recorded format) / 50

Provide key information in audio format / 50

Make it easier to get hard-copies of ACD documents / 50

Interpreting and applying an ACD: supporting healthcare professionals / 51

Provide training for staff regarding the legal status of ACDs, and provider/SDM obligations / 51

Clarify responsibilities for advance care planning / 51

Provide staff training to identify and comply with existing ACDs / 51

Provide training on how to activate or de-activate an ACD and certify copies / 52

Devise and enact standardised process for storing and accessing ACDs / 52

Provide training on the role and relevance of different end-of-life documents / 52

Clarify that completion of an ACD is a choice, not a requirement / 52

Section 5

Appendix / 54

Research teams / 54

Study details / 54

Dedication



Dedicated to the memory of Dr Teresa Burgess, whose deep commitment to inclusivity and equity motivated this research and continues to inspire those privileged to know and work with her.



Report purpose and structure

This report details the activities, participants, and findings of research conducted between 2017-2023 that aimed to identify what is, what could be, and what should be done to support effective advance care planning and associated end-of-life care conversations within ‘vulnerable communities’—those at a greater risk for poor health outcomes than most of the population.^c

The report is structured with increasing level of detail. An *Executive Summary* provides a summary of the project (section 1). This is followed by a Project Overview including themes identified and

recommendations from our stakeholders (section 2). *Specific Detail on Project Results* is organised to present each stakeholder group separately, and features key points identified with each stakeholder group, with some illustrative quotes (section 3). A comprehensive list of *Recommendations* and conclusions identified and endorsed by our stakeholders can be found in section 4. Finally, an Appendix (section 5) provides information about research teams for the project, references cited throughout, as well as additional detail about participants and processes of engagement and analysis.

Suggested citation



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Investigating the inclusion of vulnerable populations in Advance Care Planning: Developing complex and sensitive public policy

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We also thank all participants who so generously shared their time, energy, and thoughts. For some, though your time and energy were limited, your thoughts and your passion were not. You made this possible.

We pay our respects to those who are no longer with us and offer our condolences to the carers who loved and supported them. They remain in our thoughts.

^cWe recognise that vulnerability is not inherent in characteristics of any population, but is a product of systemic and systematic barriers that may limit a community's engagement with, and access to, healthcare resources.

Partners

We are grateful for the additional contributions from our partners:



Disclaimer

The views expressed in this report do not necessarily reflect those of our partners.

The Research Team^a

Chief Investigators

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Governance

Over five-years of the project, members of committees and working groups changed. We thank all involved for their contribution to the project, providing guidance, support, thoughts, time, and energy, and facilitating engagement with key stakeholders and participants.

Committees and Membership

Program Advisory Committee

Chair: Dr Mary Brooksbank

Deputy Chair: Len Payne

Aged and Community Services Australia:
 Melissa Centofanti, Heather Engelhardt
Carers SA: Marianne Lewis, David Militz

Dementia Australia:

Belinda Curtis, Kaele Stokes

Health Consumers Alliance: Debra Kay

SA Health: Dorothy Keefe

Law Society of SA: Melissa Yule

Multicultural Communities Council of SA:
 Helena Kyriazopoulos

National Disability Service:
 Peter Hoppo

Northern Adelaide Local Health Network:

Tina Cockburn, Karleen Thornton

Northern Communities Health Foundation:
 Len Payne

Palliative Care SA: Tracey Watters,
 Mark Waters

SA Health:
 Zena Bonney

Project Reference Committee

Chair: Ian Olver

Australian Medical Association
SA Council: Chris Moy

Cancer Voices:
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Council For The Aging:
 Desmond Ford

Dementia Australia:
 Ian Gladstone

Modbury Hospital Foundation:
 Chris Bollen

Northern Adelaide Local Health Network:
 Kurt Towers

Palliative Care SA:
 John McMahon

Relationships Australia:
 Enaam Oudh

SA Health:
 Lee Wightman

Sonder (formerly Northern Health Network):
 Cynthia Avila, Nathan Mercurio

Working Groups

All engagement with participants from each community were guided by a dedicated working group comprised of members of that community; these variably included:

a) persons living with a diagnosis of cancer, chronic obstructive pulmonary disease, or dementia diagnosis, their carers both formal and informal, or those belonging to an advocacy organisation for those living with these diagnoses; b) Aboriginal and Torres Strait Islander Elders; and c) those identifying as being of Bhutanese, Italian, or Vietnamese heritage and/or those working with these communities.

With consent, working group meetings were included as research data. While confidentiality protocols prevent individual acknowledgement of working group contributors, we thank each one for their participation in working group meetings, in facilitating our engagement with others within their community, and for their input in our final stakeholder event, held 13 June 2022.



Publications arising^b

Crawford et al. 2021. Documenting plans for care: Advance care directives and the 7-step pathway in the acute care context. *BMC Palliative Care* 20, 138.

Nguyen et al. 2021. Problematising 'planning ahead': relationality and collective care in Vietnamese responses to advance directives. *Qualitative Health Research* 31(12), 2304-16.

Pandos et al. 2022. Lost in translation: overcoming practical barriers in the operation of Advance Care Directives and Enduring Powers of Attorney in South Australia. *Adelaide Law Review* 43(1), 271-297.

Zivkovic & Marino. 2024. 'The clock is ticking': (Dis)Orientations to ageing and end-of-life care in advanced capitalism and care directives. *Journal of Sociology Special Issue on future/tense: A sociology of temporal dis/order*. In press.

Zivkovic et al. 2024. 'Softening hedges' as analytic lens and methodological tool in research on advance care planning with Vietnamese migrants. *Qualitative Research*. In press.

^a Presented in alphabetical order

^b Contact Jaklin.elliott@adelaide.edu.au for further information and forthcoming publications

Section 1



Executive Summary

Advance care planning allows individuals to make plans for their future care, often in consultation with clinicians, family members, and important others.

These plans are intended to guide medical care and decision-making should the individual lose the capacity to make or communicate health decisions.

The Advance Care Directives Act SA 2013 (the ACD Act), based on principles of individual autonomy, encourages all adults to make and record their care preferences in case of future incapacity, and to nominate another (a Substitute Decision-Maker) to make or convey decisions on their behalf, ideally in an Advance Care Directive (ACD) Form.

However, acceptance and implementation of advance care planning and uptake of ACDs has been neither systematic nor widespread.

Through this project, we sought to document

- how advance care planning is undertaken and recorded for in-patients of two South Australian public hospitals (N = 172)

- how individuals facing life-limiting diagnoses (specifically, cancer, chronic obstructive pulmonary disease, or dementia) and their carers (both personal and professional) (N = 49), those identifying as Aboriginal or Torres Strait Islander (N = 35), or those speaking a language other than English (specifically Bhutanese, Italian, or Vietnamese) or working with same (n = 12, 27, and 36 respectively) understood and engaged with advance care planning and ACDs
- the views of professionals (medical and legal) that people might turn to for advice or help on advance care planning, and those who might be responsible for providing care guided by advance care planning or ACDs (N = 93).

We worked with our stakeholders and communities to define key issues, identify appropriate contexts for investigation, create and share knowledge, and shape project priorities, aims, and activities.

Data from each stakeholder community were independently analysed by the researchers engaging with that community. Once key themes were identified, they were collated and synthesised with four major themes (with sub-themes) identified as common to all sources.

We found that there are...

low levels of community and professional awareness of advance care planning and Advance Care Directives, due to confusion...

- of ACDs with other end-of-life documents
- on when, where, how, and with whom advance care planning should occur
- about how advance care planning is or could be embedded in healthcare systems so that they are effective in guiding care.

multiple reasons for, and consequences of, completing advance care planning and ACDs, including...

- respecting patients' wishes and refusals
- reducing (familial) conflict, distress, and confusion at a difficult time
- streamlining patient and family interactions with health systems and providers.

multiple problems or challenges in obtaining and completing the SA ACD form, because the form itself...

- is not easily accessible
- takes a blunt approach to sensitive topics about death and dying
- does not capture the complex social aspects of end-of-life planning that typically involves decisions made jointly within relationships of care
- is a long and complex document. Completing it is confusing, exhausting, and frustrating especially when unwell, busy, anxious, or experiencing cognitive decline
- presents advance care planning as a 'do-it-yourself' process which obscures or minimises the support or help (including with computer access, health literacy, English language proficiency) needed by many to complete it



- emphasises *writing down* advance care plans, which undermines the greater importance that many place on *talking* about end-of-life care.

One-size does not fit all

- Unique trusting relationships between individuals (at the personal, professional, and institutional levels) are central
- Tailored supports accommodating individual and community needs and preferences are needed to promote equity of access to advance care planning and ACDs.

Conclusion

Supporting principles of autonomy and person-centred care by improving advance care planning within vulnerable communities requires structures and processes that allow for end-of-life care needs to be raised, discussed, documented, and acted on.

To achieve this, engagement with individuals and communities will need to

- use clear, accessible language and concepts, clarifying the practical and legal distinction between treatment preferences and refusals
- follow processes understood by patients, healthcare practitioners, and legal professionals
- make space for culturally responsive end-of-life care communication. This may include oral and/or group decision-making, or the choice not to engage in advance care planning

- be scaffolded by resources to meet individual needs as shaped by cultural or disease-based parameters. This might include needs-based access to free documentation, individualised support accommodating computer and health literacy, as well as language support
- be embedded into healthcare systems through policy and practice standards, on-going practitioner training, and effective, streamlined mechanisms for storing, accessing, and enacting documented plans when and where they are relevant.



Section 2



Project Overview

Background

Advance care planning allows individuals to make plans for their future health and personal care, often in consultation with clinicians, family members, and important others.^(1, 2)

These plans are intended to guide medical care and decision-making should the individual lose the capacity to make or communicate health decisions.^(1,2)

Yet, many Australians continue to die never having had a conversation with their doctors or their family about their death, and without making and/or sharing their plans and preferences about the care they might require in the future. Indeed, a 2015 survey of Australian physicians identified that fewer than one-in-five knew their patients' preferences for end-of-life care.⁽¹⁾

Conversations about end-of-life care become even less likely when considering cultural practices and traditional ways of thinking about death—for example, within Aboriginal and Torres Strait Islander peoples,⁽³⁾ and people from culturally and linguistically diverse backgrounds.⁽⁴⁾ Those facing life-limiting illnesses, who need specialist healthcare services to meet their complex needs, also pose unique challenges for the completion of advance care planning.^(1,2)

Benefits of advance care planning include

- the promotion of autonomy and dignity
- offering individuals some control over end-of-life healthcare options
- improvements in the quality of end-of-life care that individuals receive
- increasing utilisation of hospice services and reduction in hospitalisation, and
- facilitating a reduction in stress and depression among surviving family members.⁽⁵⁻⁷⁾

Despite these benefits, acceptance and implementation of advance care planning has been poor. In 2011, the Australian Health Ministers' Advisory Council introduced a *National Framework for Advance Care Directives*,⁽⁸⁾ intended to promote a systematic approach to advance care planning, and improve implementation and uptake.

The South Australian government used this framework to inform implementation of the *Advance Care Directives Act SA 2013* (the *ACD Act*).⁽⁹⁾ Based on principles of individual autonomy, the *ACD Act* encourages all adults (regardless of age or current health status) to record their care preferences in case of future incapacity, and to nominate another (a Substitute Decision-Maker) to make or convey decisions on their behalf, preferably through completion of an Advance Care Directive Form (ACD form).

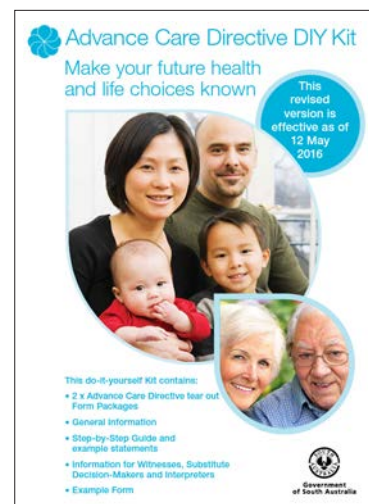
<https://advancecaredirectives.sa.gov.au/forms-and-guides>

The ACD form is intended to be readily accessible and suitable for all adults, and can document three things, allowing an individual to:

1. appoint one or more Substitute Decision-makers with legal authority to make healthcare decisions on their behalf (Part 2a)
2. stipulate what healthcare they would *not* want, and under what conditions (a 'binding refusal') (Part 4)
3. record what is important to them (their values and wishes) to guide others in making decisions (Part 3).

The first two of these are legally binding and are about decisions for future healthcare. The third is not legally binding but provides guidance for others in making decisions about the individual's future healthcare, end-of-life care, living arrangements, and other personal matters, when the individual is unable to do so themselves.

The South Australian Advance Care Directive Form is also supported with a 74-page 'do-it-yourself' kit with step-by-step instructions for completion—including example statements and instructions for any other persons involved (i.e., Substitute Decision-makers, witnesses, and interpreters).



<https://advancecaredirectives.sa.gov.au/forms-and-guides>

Aims

In a four-year research program *Investigating the inclusion of vulnerable populations in Advance Care Planning: Developing complex and sensitive public policy* (NHMRC Partnership Grant APP1133407), we aimed to document

- how advance care planning is undertaken and recorded within two South Australian public hospitals
- how people facing life-limiting diagnoses, those identifying as Aboriginal or Torres Strait Islander, or speaking a language other than English, understand and engage with advance care planning and Advance Care Directives
- the views of professionals (medical and legal) that people might turn to for advice or help on advance care planning, and those who might be responsible for providing care guided by advance care planning or Advance Care Directives.

Based on the above, we further aimed to

- provide clinicians, service providers, community organisations, and policymakers with recommendations about how to improve the accessibility and uptake of advance care planning and Advance Care Directives within the nominated communities.

Activities

Throughout this research program, we worked within a Knowledge Exchange Framework,⁽⁷⁾ engaging with our stakeholders and communities to define key issues, identify appropriate contexts for investigation, create and share knowledge, and shape project priorities, aims, and activities.

All research activities with participants received relevant Human Research Ethics Committee approvals. Research involving Indigenous Australians were approved by the Aboriginal Health Research Ethics Committee for South Australia. Site-specific approvals were obtained where research was undertaken on sites either within the South Australian public health system or with employees of same.

Working Groups (see above) guided our research activities throughout and facilitated engagement with participants

from each nominated community (see Appendix Tables for details on participants from each community).

Participant names were changed at the point of transcription before analysis. They provided fully informed consent and received an honorarium for participation (excluding those contributing within their working role). Where needed, assistance with transport was provided. These provisions included participant attendance at our end-of-project stakeholder event.

Participants and process^d

Advance care planning in the hospital

At two South Australian metropolitan public hospitals, we conducted an in-patient survey and case-note audit over two consecutive weekends. Patients within emergency, intensive care units or maternity wards, and those deemed unable to provide consent (e.g., being too unwell, actively dying, or confused), were excluded.

The case-note audit collected evidence of

- palliative care need (based on the presence of indicators of deteriorating health)
- advance care planning conversations and/or the nomination of a Substitute Decision-Maker
- advance care planning documentation, either patient-initiated (an Advance Care Directive) or clinician-initiated (a 7-Step Pathway Resuscitation Plan [7-SP]).^e

The patient survey collected information regarding

- the extent and nature of, and persons involved in, any conversations about advance care planning
- What advance care planning documents patients had completed and with whom / where the documents were
- patients' perspectives on the relevance, role, and value of advance care planning for their care.

Advance care planning in the community

We asked

- Aboriginal and Torres Strait Islander peoples, and those within three culturally and linguistically diverse (i.e., Bhutanese, Italian, and Vietnamese) communities

- people facing or caring for those facing life-limiting illness (i.e., cancer, chronic obstructive pulmonary disease, and dementia)

- professionals involved in creating and/or interpreting advance care plans (i.e., acute care healthcare professionals, General Practitioners, and lawyers)

about what they understood about and how they engaged with advance care planning and ACDs.

Data analysis^f

Quantitative data were descriptively analysed. Qualitative data were thematically analysed.

We used a Framework⁽⁸⁾ Method to analyse, collate, and summarise information gained from speaking with the different community / stakeholder groups to identify common themes across the data.

Research teams working with each target community first reviewed the transcripts of recorded conversations and researcher observations to identify themes and capture community priorities.

These themes were entered into a spreadsheet to identify areas of commonality and difference, and research teams revisited information from and about each community to provide relevant data (i.e., quotes) for each theme where available. We additionally attended to capturing different perspectives within and across communities.

^d See Appendix for further details

^e The 7-SP is an integrated care plan produced in response to specified clinical triggers indicating increased severity of symptom-burden or deterioration in health that requires medical professionals to consult with the patient/their Substitute Decision-Maker and document any limitations on interventions, the patient's 'goals of care' and any relevant end-of-life care directions.

^f See Appendix for further detail regarding theoretical orientation and analysis applied to each dataset.

Themes identified

We identified four themes common across all stakeholder groups, acknowledging that sometimes contrasting positions were evident across and within communities.

There are low levels of community and professional awareness of advance care planning and Advance Care Directives, possibly due to lack of clarity

- about differences between and roles of ACDs and other end-of-life documents
- as to when, where, how, and with whom advance care planning should occur
- about how advance care planning is or could be embedded in healthcare systems.

There are multiple reasons for, and consequences of, completing advance care planning and ACDs, which did not always align or work to produce expected outcomes. Reasons included

- respecting patients' wishes and refusals, which was viewed as paramount
- reducing (familial) conflict, distress, and confusion at a difficult time
- streamlining patient and family interactions with health systems and providers.

There are multiple problems or challenges in obtaining and completing the ACD form, because

- it takes a blunt approach to sensitive topics, such as death and dying, as well as the relationships and responsibilities required to convey or make decisions on behalf of a dying person
- in centring on an individual, the form does not capture the complex social and relational aspects of advance care planning that typically involves decisions made jointly within relationships of care
- filling in a long and complex document with unfamiliar or scary language is confusing, exhausting, and frustrating especially when unwell, busy, stressed, or experiencing cognitive decline
- the form's characterisation of advance care planning as a 'do-it-yourself' process does not reflect the support or help (including with computer access, health literacy, English language proficiency) needed by many to complete it

- the form emphasises *writing down* advance care plans, which captured a decision made at a point in time. This does not accommodate the greater importance many place on ongoing *conversations* about end-of-life care reflecting a dynamic and changing reality. In addition, changing a documented decision required repeating a process often experienced as cumbersome and confusing.

A 'one-size fits all' approach to promoting advance care planning through completion of ACDs will not work for every person regardless of social, cultural, or medical status, because

- people do not come as one-size: every person, every dying journey, every death is unique
- trusting relationships are central in advance care planning, particularly where language or concepts involved are unfamiliar. These relationships are typically developed over time between specific individuals and shape how, when, where, why, and to what extent individuals engage in advance care planning
- cultural and individual differences in how people view and experience death and dying, familial relationships, health and healthcare, and decision-making will influence what they do about (planning for) end-of-life care
- promotion of ACDs does not guarantee promotion of autonomy and person-centred care. Thus, tailored supports accommodating individual and community needs and preferences are needed to enable engagement in advance care planning in ways that are meaningful for people, families, and communities, and facilitate the provision and experience of preferred end-of-life care.

Top-five recommendations from consultation with our communities and stakeholders

We shared our findings with representatives from our communities and stakeholder groups during an interactive workshop and asked them to identify their top-5 recommendations to increase community awareness of, and engagement in, advance care planning (see Appendix for all recommendations). Our representatives suggested that:

1. healthcare policymakers and providers should work with specific local communities to build trusted relationships with trusted people to shape advance care planning messaging in response to community needs and preferences
2. more training regarding Advance Care Directives should be provided for healthcare and legal professionals. Such training should be ongoing and include clarification of
 - a. the roles and responsibilities of different parties involved
 - b. how Advance Care Directives differ from and intersect with other documents (both clinical and legal) pertaining to end-of-life care
 - c. the legal and practical differences between binding refusals and statements of preference and values
 - d. the need for a tailored and culturally responsive approach to discussions about Advance Care Directives, accounting for individual and familial needs and preferences shaped by cultural, socio-demographic, and clinical factors. This may include familial decision-making, oral rather than written expressions of preference, and/or decisions not to engage in advance care planning.
3. more public information about Advance Care Directives is needed to increase awareness and familiarity with the concept. However, this needs to be provided where and how communities look for information (e.g., adverts, council offices, GP clinics, waiting rooms, community radio, bus shelters, or within events or locations managed by respected community-based organisations etc).
4. there should be capacity to recognise or create non-written alternatives for recording an individual's end-of-life care preferences, or assistance available to help individuals understand the function and process of advance care planning, and to transcribe spoken wishes to the ACD form. This will better accommodate the needs of communities where documentation of healthcare decisions is not preferred, and support those who are non-literate.

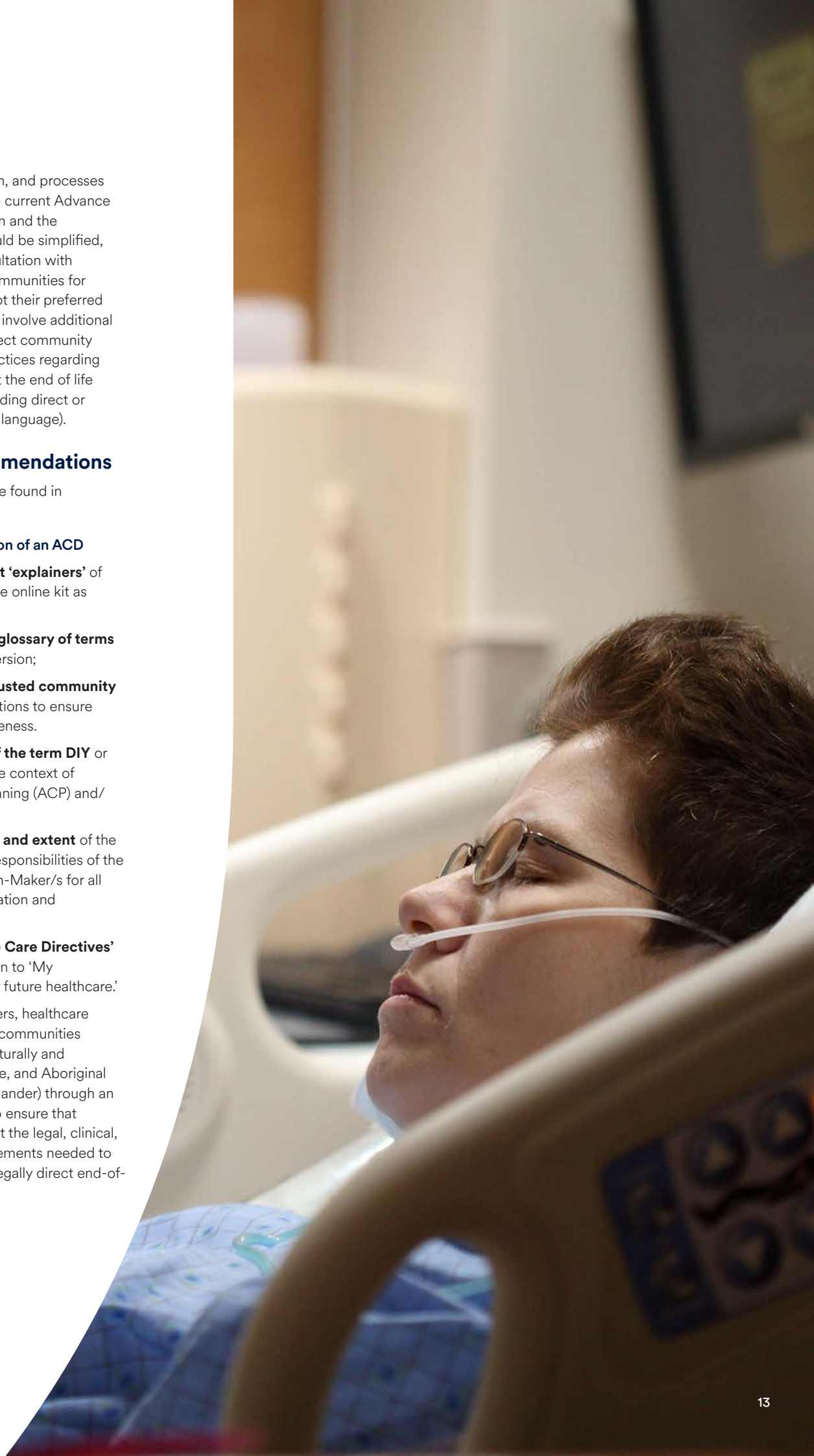
5. the language within, and processes for, completing the current Advance Care Directive form and the supporting kit should be simplified, preferably in consultation with consumers. For communities for whom English is not their preferred language, this may involve additional adaptation to respect community preferences or practices regarding decision-making at the end of life (for example, regarding direct or individual-focused language).

Specific recommendations

Details on these can be found in Section 4.

To facilitate completion of an ACD

1. a) **Include pop-out 'explainers'** of key terms within the online kit as they appear;
b) **Include a brief glossary of terms** within the paper version;
c) **Consult with trusted community** advocacy organisations to ensure cultural appropriateness.
2. **Reconsider use of the term DIY** or do-it-yourself in the context of Advance Care Planning (ACP) and/or ACDs.
3. **Clarify the nature and extent** of the involvement and responsibilities of the Substitute Decision-Maker/s for all stages of ACD creation and enactment.
4. **Replace 'Advance Care Directives'** with something akin to 'My preferences for my future healthcare.'
5. **Engage** with lawyers, healthcare professionals, and communities (including from culturally and linguistically diverse, and Aboriginal and Torres Strait Islander) through an iterative process to ensure that example texts meet the legal, clinical, and cultural requirements needed to meaningfully and legally direct end-of-life care.



6. a) **Clarify the meaning and legal status** of wishes and refusals in directing care at the end of life
b) **Regarding the layout** of the ACD form, place sections conferring legal authority together and clearly indicate the difference in legal status when addressing/documenting values and preferences.
 7. a) **Provide health professionals and lawyers** with resources and training to appropriately guide completion of ACDs
b) **Provide structures/mechanisms** for ongoing conversations between legal and medical professional bodies to increase awareness of the roles and responsibilities of each and how they might collaborate to promote completion of ACD documentation that is both legally and medically sound.
 8. **Develop a suite of documents** relevant to common disease trajectories, providing examples of the kinds of issues and decisions that might be faced towards the end of life, and suggesting wording regarding instructions or preferences.
 9. **Clarify where and with whom** to store copies of an ACD.
 10. **Improve integration of ACDs** with electronic medical healthcare records, so that they are readily and rapidly available when needed.
 11. **Provide a stripped-back, accessible version** of the ACD form in plain text, large font, with limited text per page.
 12. **Provide translated versions** of all documentation. At a minimum, provide culturally meaningful explanations of key concepts rather than 'direct translation.' Consider audio versions for those who are non-literate in their own or the English language.
 13. **Include a prominent link to an audio version** of the kit in relevant places (e.g., information page, start of kit etc). Present audio information as brief recordings associated with specific sections.
 14. **Provide GPs with copies of an information sheet** with clear advice about how a patient might access more information and/or the ACD form, so they can raise the topic with their patients and direct them to a means of accessing further documentation.
 15. **Provide a cache of ACD documentation within hospitals** for staff members involved in advance care planning discussions.
 16. **Equip community groups with resources/training** on advance care planning and ACDs.
 17. **Provide the ACD kit/form free** to people with chronic disease and/or those on limited incomes via their treating GP or other healthcare professionals.
- To support ACDs in acute care**
18. **Clarify information** about the legal status of documentation, provider obligations and potential conflicts, both in instructions for consumers and within ongoing training for healthcare professionals.
 19. **Nominate and provide dedicated trained personnel** with the valued knowledge (cultural and medical) to facilitate completion of ACDs.
 20. **Instruct healthcare professionals** to preface conversations about end-of-life care with seeking or enquiring about any existing ACP/ACDs and avoid initiating conversations about end-of-life care preferences where such documentation is identified.
 21. **Provide additional information about how to activate, revoke, and/or certify** ACDs for consumers, and within training for healthcare professionals.
 22. **Nominate and communicate a standard, accessible location** for physical copies of an ACD and processes by which it follows a patient during transfer.
 23. **Provide additional and ongoing training** for healthcare professionals outlining the relative scope and limits of various documents directing care at the end of life.

24. **Apply the system-level factors** that have been successful in achieving uptake of the 7-SP (training and system integration) to enhance uptake/use of ACDs in acute care settings.
25. a) **Clarify and legitimise patients' rights** not to complete ACP/ACDs at any point within any setting.
b) **Provide additional training** on patients' right for healthcare and RACF professionals.

Conclusion

Ultimately, to improve advance care planning and promote uptake of ACDs in vulnerable communities, policymakers and healthcare institutions will need to

- **work with vulnerable communities**, both to increase awareness of what is involved and to build trust through developing a shared understanding and accommodating cultural practices that, for example, prioritise relationships over individuals, or indirect rather than direct communication
- **resource ongoing training for professionals** involved in advance care planning, including creating or interpreting Advance Care Directives, and clarifying role responsibilities within the healthcare system
- **create and provide resources to meet individual needs** as shaped by cultural or disease-based parameters. This might include needs-based access to free documentation, individualised support accommodating computer and health literacy, as well as language support
- **embed advance care planning** in routine healthcare practices and systems, through identifying triggers for such discussions, providing dedicated staff to support completion of Advance Care Directives where desired, and establishing protocols on documenting, storing, and retrieving patient preferences for end-of-life care regardless of setting.





Section 3



Detailed Project Results

The following provides additional detail regarding the specific issues raised within conversations for with individuals within the target communities, as well as those who work with them.

Advance care planning in two South Australian public hospitals

Over two consecutive weekends, we undertook a case-note audit and administered a survey of in-patients at two South Australian metropolitan public hospitals to

- examine the prevalence of advance care planning conversations and documentation in the acute hospital setting, and
- determine agreement between hospital documentation of ACP engagement with patients' self-reported ACP experience.

Of 245 patients meeting eligibility criteria, 191 provided consent to participate (response rate 80%); complete datasets were obtained for 172 patients (response rate 70%).

Within 172 case-notes across the hospital sites, we found low evidence of advance care planning.

- only six case-notes recorded completion of an ACD, and only three included a copy of that document

- one in four case-notes documented that the patient had been engaged in some kind of discussion about end-of-life care
- one in ten recorded a discussion about a Substitute Decision-Maker, but only 6% recorded who the Substitute Decision-Maker was, and
- more than 40% of patients with evidence of increased symptom burden and/or deteriorating health had no 7-Step Pathway Resuscitation Plan [7-SP], that is, an integrated care plan commonly used within these sites.⁹
 - o nearly two out of three of such patients had no evidence of any discussion about their end-of-life care.

However, in the survey conducted with these 172 patients,

- some reported that they had expressed their preferences for future healthcare
- of 20 patients reporting having an ACD, only two had this documented in case-notes
- of 46 reporting a discussion on end-of-life care, only 21 recorded this. Possible explanations are that
 - o they had not written down their preferences
 - o if written down, their preferences were kept elsewhere (i.e., at home, on the fridge, with a GP or lawyer), or
 - o they confused advance care planning documents with other legal or financial end-of-life documents (e.g., a Will, an Enduring Power of Attorney).

Conversely, some patients did not recall conversations about advance care planning that were recorded in their

case-notes, and less than half with a 7-SP in their case-notes remembered any discussion about end-of-life care. This raises some concerns about the extent to which patients were engaged in decisions about their future healthcare, and consideration of ethical and legal principles such as 'autonomy' and 'informed consent.'

Qualitative analysis of the accounts of the 152 patients that had not completed an ACD revealed various reasons for this, including that

- they did not know about ACDs
- these ACDs were unnecessary for them as their family knew their preferences
- an ACD was not relevant to them at this stage of their life or illness
- they were too busy or had higher priorities right now (including managing illness)
- ACDs were too confronting and/or too complicated to complete, and
- they had a Will or Power of Attorney already (intimating that these rendered an ACD redundant).

⁹A 7-SP is triggered by specified clinical observations indicating increased severity of symptom-burden or deterioration in health. It requires medical professionals to consult with the patient/their Substitute Decision-Maker and document any limitations on interventions, the patient's 'goals of care,' and any relevant end-of-life care directions.

Views of people living with chronic disease on advance care planning and ACDs

Cancer

Views about advance care planning and ACDs were sought and thematically analysed from 15 participants in one urban and one rural setting. Participants included oncologists, advocates, carers, and persons living with cancer (total 9 with a cancer diagnosis; some participants had multiple roles).

Key points

1. Increasing the visibility of advance care planning and accessibility of ACDs are likely to improve low levels of awareness, acceptability, and uptake.
2. People should know that the benefits of advance care planning are both to help you to exercise their autonomy (to say and get what you want), and to relieve others (especially family) of the task and responsibility of a difficult decision at a time of stress.
3. Although about making your own choices, advance care planning is something you *should* do, or should not choose to avoid.
4. Raising the topic of or need for an ACD is emotionally and interpersonally difficult, whether as a patient or a carer.
5. The important part is making decisions about life or death and 'binding refusals' (similar to do-not-resuscitate decisions), not so much expressing values or life-style preferences.
6. The language of and processes involved in completing an ACD are barriers to completion.
7. ACDs are usually addressed along with other medical or legal end-of-life documentation, and the differences between them need to be clarified.

8. Legalisation of euthanasia (i.e. voluntary assisted dying) is likely to introduce further complexity and confusion regarding decisions and choices at the end of life, so providing clear information about how decisions about euthanasia will work with ACDs will be important.

Details

... advance care planning can help you avoid what you don't want or get what you want

When talking about the benefits of advance care planning, it was common for participants to talk about their wishes. This often centred, however, on what they wanted to avoid rather than what they wanted, suggesting thinking about the 'binding wishes' (what they didn't want) was easier than thinking about 'values' that might influence what they did want.

I'm very, very keen to make sure that it's how I want to die as far as possible. That that is what actually happens. ... I don't want somebody else making that decision. I've never, ever wanted anyone to make decisions on my behalf.

It [advance care planning] is great. It's common sense. It's reality. ...you just don't want to be a burden to anyone. It's just pointless laying there ... having to rely on someone to feed you and wipe your backside ... I couldn't bear that. It's just a waste of resources for everyone.

I don't want to be alive on a machine forever and ever and not knowing when and then, you know, everybody's just sitting and waiting ...

... advance care planning isn't as simple as 'just fill in the form'

Despite wanting to be able to make decisions about end-of-life care, participants said it would be difficult to do so in advance, partly because a) they did not know what situation they might face, and b) their wishes might change over time. Some found the language

used confusing. Others noted that it was difficult to raise with others, because they might find it emotionally challenging, and/or because it was 'putting decisions on other people.'

When we talk about advanced care, ... people wouldn't even know what it means. 'What's an advance care? Oh, are they going to advance care me, okay, fine. Yeah, they're going to advance care me to death.'

It's not that it's a hard topic. It's just that there's so many unknowns at that [time], when it gets to that stage of life, isn't it, because you can't pick the situation, what the situation's going to be like, and that's what's the tricky part, isn't it?

The more I think about this, the more it becomes serious for other people, doesn't it? It's just not all about ... yourself, is it? It's about other people, isn't it? It's putting decisions on other people ... Yeah, what I want is involving half a dozen other people ...

... there are lots of related forms which is confusing

Those who had completed advance care planning had done so with help from a lawyer, often filling in several forms at one time—things like a Will, an Enduring Power of Attorney, an Enduring Power of Guardianship, and an Advance Care Directive. However, they were not always clear about which forms they had completed or exactly what the different forms did.

When I went to the lawyer, I asked what papers I should have done. And he suggested three different things and so that's what I then did. So it's all in an envelope with the Will, the Enduring Power of Attorney, and the Enduring Power of Guardianship. ... I reckon when I filled in the form [at] the hospital there was a box to tick that said 'do you have an Advance Care Directive?' And I reckon I just left it empty... I don't know that I knew what that [was]. If I ticked it, I would have just done it in terms of this Enduring Power of Guardianship.

... it can be difficult to discuss advance care planning if it is not immediately relevant

Although advance care planning is promoted as relevant to everyone, most saw it (or thought others would see it) as applicable to 'older' people and/or those who were unwell, and not relevant to those who were young and well.

I think people, when they're relatively young and fit, don't think it's of great importance and 'it's not going to happen to me' attitude.

No, no, that's for old people to worry about. It's not for me. I'm here forever. I'm only 80 (laughs).

When you're well it's too hypothetical.

... it can be difficult to discuss because it's about death

Several participants noticed that it was difficult to raise the topic of advance care planning with others, and this made it difficult to ensure that others knew what they wanted. Most noted that raising it was associated with some form of resistance, acknowledging that the conversation was really about their future death and implied that this might happen sooner rather than later.

Most people don't, they don't want to talk about it. ... I just feel that other people get in the way of really sensible decision-making. ... Because they don't want something to happen to that person. I mean, remember, this is about dying.

[My children] are not necessarily happy talking to me about this stuff. They're a bit, 'oh mum, do we really need to talk, nothing's going to happen to you, do we really need to talk to you about this?' I'd have to be a bit gentle about it, I think. It is sort of confronting, even for me, thinking about some of that stuff.

... advance care planning is really to help minimise confusion or distress for others

Those living with a cancer diagnosis and their carers often expressed or implied that people (especially if unwell) should complete advance care planning so that their family or carers would be relieved of having to decide what to do during a crisis—as they would simply do what the

person wanted. Some suggested that future efforts to promote ACDs should be directed at family or carers, that family should be encouraged to support or prompt a person with a cancer diagnosis to complete an ACD. Some also noted that having an ACD would be useful for hospital staff, particularly during a crisis.

It's a pretty dramatic thing, to turn off life-saving stuff. ... So it just supports them in making what could potentially be a pretty difficult decision so sure that you need to direct it to the person who needs the directive. It might be better if the campaign was directed at the children, the adult children. ... Because they're the ones who are going to have to know what you want.

It is sort of confronting, even for me, thinking about some of that stuff. But I'd rather think about it than have my head stuck in the sand and then have them distressed. ... I think when they are overwhelmed, they'll say, 'oh, mum wrote this down or mum told us about



this.' ... Having one of these would be a huge advantage for the hospital. You know, if you turn up there for surgery and something doesn't go right then they can go to something like this. ... it might save critical time.

... ACP and ACDs need to be more accessible, and some suggested how to facilitate that

All observed a lack of awareness about advance care planning and how to get either information or the ACD form. Generally, they recommended placing information at places where people gathered and/or where they considered people might be receptive to learning about advance care planning/ACDs. Some considered that this would 'normalise' the topic; similarly, they said embedding conversations about advance care planning in routine medical care would work to minimise distress or at least provide support if it happened, thus embodying good care. One suggested that medical trainees be required to write their own ACD, implying this would improve their awareness of the issues involved and thus their ability to support patients and families.

The internet, they give you all the options and you read all the things and then there's so much to take in and you don't know whether is this for me or is this not for me, things like that.

It's often a stumbling block—how do I get this? And particularly for my generation who a lot are, including me, not particular computer literate. Where the hell do you get this information?

... in the library, in the Council offices, it's got to be available in a variety of places to ... give a higher percentage of people seeing it in the first place.

[They should be] building it into those sorts of [admission] procedures. And not leaving it to chance, and having it not be a big deal, just, 'this is what we do. You want to come to [Hospital], we want to give you the best care we can. This is just another form we need you to fill out. If you need some help, we can help you.'

I'd probably ask [medical trainees], ... to draft one for themselves as an assignment. I think that a lot of the issues that are in there are not consequences they would think of if they're young. So it would be a kind of awareness training. ... Maybe have it in the doctor's surgeries, as pamphlets. ... in the oncologist rooms ... Maybe on telly, ...yeah, and make it just part of life.

I honestly think this should be in schools. High schools at least. ... People are far more receptive if they're younger, to these things. ... Have you thought about having it on [Insight on SBS]? There's also 'Compass,' ... even 'Australian Story,' ... it's positioning, isn't it?

... where does euthanasia fit in?

More than any other stakeholder group, those diagnosed with cancer and their carers raised the changing landscape regarding euthanasia (using this term rather than the legislatively sanctioned term 'voluntary assisted dying') as relevant but were unsure about what this might mean for advance care planning and ACD. One person saw making a decision about euthanasia as ultimately relieving others of any decisions deemed to have life and death significance, whilst another saw euthanasia as having similarities to advance care planning, seeing it as another exercise of autonomy.

Lately they've brought in euthanasia. ... and that is totally different, but it also could be related.

It'd be so much easier if you could take matters into your own hands while you're still able (laughs), but I know it's slowly becoming more but there's gonna be so many hoops to jump through ... That's probably not going to happen that I do that, so (sigh) other people are going to have to make the decision, aren't they?

Now the other thing... is what are you going to do about including the whole concept of being able to go under the Euthanasia Bill? I'm hoping that that will definitely be part of the new, any redo of it. ... It should be that you can actually nominate that you want to be part of that.





Chronic Obstructive Pulmonary Disease (COPD)

Views about advance care planning and ACDs were sought and thematically analysed from 17 participants in focus group consultations. Participants included a specialist nurse, specialist doctor, physiotherapist, psychologist, advocate, 12 persons living with COPD, and 4 carers (some participants had multiple roles).

Key points

1. Advance care planning is not really do-it-yourself, but about doing-it together.
2. Advance care planning needs to be integrated into routine COPD care in order to raise awareness and facilitate 'cumulative' planning that will follow a patient across care settings.
3. People living with COPD may be at risk of 'falling through the cracks' in engaging with advance care planning options.
4. Specific support is needed for those living with COPD, including supporting access to the ACD form, and ongoing conversations with people who understand the typical trajectory and experiences as the end of life approaches.

Details

... advance care planning can make interacting with the hospital system easier

Participants said that it is common for people living with COPD to have many admissions to hospital in the course of their disease. They explained that written advance care plans (such as ACDs) can help streamline these admissions by stating their preferences clearly, and when consulted, can avoid the repeated, frustrating, and distressing conversations about end-of-life interventions otherwise required by hospital staff.

People living with COPD, and their carers, told us that advance care plans can help quickly connect hospital staff to those 'in the know' about the patient's wishes, such as Substitute Decision-Makers, carers, or GPs. This was particularly important in emergencies, where ACDs or equivalent documents can support quick decision-making by providing timely access to relevant people, documents, and plans.

He's listed everything [in his ACD] and... every time he goes [to hospital] he gets very frustrated because he's struggling to breathe and they're asking him the same questions over and over again. ... Because the more he gets frustrated, the more he's struggling to breathe. (carer)

... advance care planning can formalise family members' and carers' roles, and support them to advocate for the patient

People living with COPD explained that ACDs or equivalent documents are useful in making family/carers' decision-making responsibilities 'official.' Carers told us that being named in the forms empowers them to speak on the patient's behalf, can help to resolve family disputes, and can reassure family members faced with the burden of difficult end-of-life decisions.

... specific features of COPD can make advance care planning difficult

People living with COPD shared that completing ACDs can be a challenging and tiring process that often needs to be undertaken in short bursts rather than one extended sitting. Breathing issues can exacerbate tiredness, and can also affect the communication of patients' preferences, particularly if they are being assisted by someone they do not know well. Health professionals told us that memory and executive function—both required for advance care planning—can be affected as COPD progresses, and that low health literacy is often observed in this community.

Carers explained that accessing online forms can be difficult, and that physically obtaining paper forms from Service SA can be onerous for patients, and impossible for carers unable to leave their loved one alone. In addition, repeated (one-off) emergency interactions with the health system may also serve as barriers to engagement with services that introduce and support advance care planning.

Therefore, advance care planning, particularly for those with advanced COPD, appears to require a range of supports. These may include:

- raising awareness about advance care planning in general, plus specific information about the likely course of COPD and what advance care planning may offer this particular patient or community
- support in accessing, understanding, completing, and lodging documentation, which may include computer access or provision of physical forms
- provision for advance care planning to be undertaken over time in short sessions with someone who understands the cognitive and physical burden the planning process can represent.

I try and minimise the effort because I know how much it takes for people with advanced disease to just do a simple task like source an [ACD] information pack like this. (Respiratory Nurse)

You need to have internet access so that you can go online and get [ACD forms] which is not always ... easy for everybody. (person living with COPD)

I mean [someone living with] COPD's low in health literacy generally, and mild cognitive deficit is not unusual. So trying to negotiate an advanced care plan ... is not that easy for many people. (Psychologist)

... people living with COPD can face non-disease barriers to advance care planning engagement

Participants discussed a range of barriers including the cost of ACD forms, and of specialist and physiotherapy appointments in which end-of-life planning may be raised. They also suggested that many do not have the computer access and literacy required to complete do-it-yourself forms.

They also shared that symptoms of COPD can lead many patients to become socially isolated or feel physically unable to participate in programs where awareness-raising about advance care planning might occur, such as in pulmonary rehabilitation programs.

A lack of community awareness of both advance care planning and COPD was raised as a complication: participants told us that because so few people understand the nature and trajectory of the disease, advance care planning may not be routinely raised with patients, and the potential relevance of such advance care planning may not be well known or understood. Community education about both advance care planning and COPD were recommended.

... care relationships are at the centre of advance care planning for people living with COPD

Caring relationships were seen as central to all aspects of advance care planning for people living with COPD—from initial conversations to document interpretation, form completion, storage, and implementation. Several patients said that the key value of ACDs was to

formalise carers' roles and legitimise their contributions to relevant health decisions, particularly in hospitals. This focus on relationships between people involved in ACDs is different to the common understanding that it is all 'about the individual.' It also raises issues for isolated members of the COPD community.

Participants told us that engagement with advance care planning was almost always a collaborative process undertaken with the support of a (usually family) carer. They explained that carers were often responsible for raising the issue of end-of-life planning, finding, and interpreting relevant forms, and completing and storing documentation. For those living with severe COPD symptoms, carers were responsible for 'all the paperwork,' and patients told us that responsibility for advance care planning likewise 'fell to them.'

... advance care planning is not embedded clearly or consistently into COPD primary care or acute care

Patients, carers, and health professionals agreed that there was little clarity about who should take responsibility for initiating advance care planning with people living with COPD, and where, when, and how advance care planning discussions should happen. GPs may not have the time and education about COPD trajectories that patients appreciate (especially when a patient requires hospitalisation). Likewise, while hospital is a potential catchment for COPD patients, there may be limited follow-up on advance care planning. These findings, plus participants' preference that planning documents be 'cumulative' (not specific to single admissions or community care providers), suggest there is a need for consistent documentation that 'follows patients' across care settings.

Health professionals noted that advance care planning is not a routine feature of primary care pathways for people living with COPD. They explained that there is a lack of clarity as to who should initiate advance care planning discussions: GPs, occupational therapists and out-patient rehab program providers were all suggested, but participants indicated that responsibility should be more explicitly allocated if advance care planning is to become a consistent component of care.

Participants suggested that education and training for health providers around *when* and *how* advance care planning could be approached with COPD patients would support this outcome. They also advocated increased clarity around *where* advance care planning should be raised (suggesting that pulmonary rehab programs may be inappropriate if participants in that setting are focused on 'hope'), and where/how documents should be stored. Health professionals told us that supporting advance care planning with COPD patients can take considerable time and resources, which can place strain on already stretched providers.

People living with COPD and their carers shared that understanding the potential nature of COPD exacerbations would help them undertake meaningful advance care planning. They explained that knowing 'what to expect' during hospital admissions would help to prepare them emotionally and practically, and lead to 'informed' plans that would be 'actually useful' in emergency contexts. While COPD exacerbations were seen to position hospitals as a potential 'catchment' for advance care planning discussions, acute care staff indicated that there is no structured process for follow-up post-discharge if patients are given ACD forms by nurses or occupational therapists while in a general medical ward.

Finally, all stated that clearer hospital pathways for storing and accessing ACDs or equivalent documents and needed, and that scope for cumulative additions to planning documents (over multiple hospital admissions and across community providers) would be welcomed.

Doctors don't seem to tell patients about it. I think there's an awful lot of people out there who've got no idea that there is such a thing as an advanced care directive. (person living with COPD)

Dementia

Views about advance care planning and ACDs were sought and thematically analysed from 17 participants in focus group consultations. Participants included geriatricians and specialist nurses (Nightingale Nurses), one person living with dementia, and 13 carers (some participants had multiple roles).

Key points

1. Advance care planning is not really about do-it-yourself, but is about doing-it-together.
2. Advance care planning is a process, and should be ongoing.
3. Dedicated, dementia-informed advance care planning support personnel are needed to help in understanding possible future choices, and in accessing, completing, and lodging ACDs.
4. Advance care planning doesn't stop with an ACD: it is important to keep the patient at the centre of and involved in their care as much as is possible.
5. More clarity is needed on to where to store ACDs to ensure they are accessible when needed.

Details

... trust is a key issue when it comes to advance care planning within the dementia community

People living with dementia told us that the process of advance care planning can help to clarify their future care preferences and communicate these clearly to family members and health providers. This can build a sense of trust that significant others know their wishes and will advocate for them when treatment and care decisions need to be made. These participants worried that they may be vulnerable to poor or unwanted care when they lose capacity if trusted others have not been empowered to speak on their behalf.

If you don't say what you want, people will make decisions for you based on what they think. That's wrong. (person living with [PLW] dementia)

ACDs can formalise this arrangement, but participants said the foundation of trust was primarily located in 'relationships—

not a document'; that conversations with those they trust are more important than 'writing plans down.'

Advance care planning was understood as a process to build understanding between people living with dementia and trusted others. This suggests that a focus on 'the individual' in advance care planning may not fit well with its use in practice: family and/or carers often play significant roles in undertaking, communicating, and enacting plans for future care. People living with dementia often saw advance care planning as being for their families as much as for themselves and welcomed their involvement in the process. They shared that people without trusted others may face particular challenges in terms of undertaking and storing care plans, as well as advocating for them to be upheld.

... specific features of dementia can make advance care planning difficult

People living with dementia, carers and health professionals agreed that specific features of dementia make advance care planning difficult to complete. Declining mental clarity can make it hard to plan ahead, and maintaining the concentration needed to complete lengthy documentation can be a challenge.

It's a tiring thing to concentrate and hold in your mind and while you're thinking 'this is a really serious decision, I need to keep all that in my mind,' that's a big burden. (PLW dementia)

Many people living with dementia do not have the computer access or literacy needed to complete forms online. ACDs themselves can be difficult to negotiate as the language and legal terms are complex. Carers and health professionals said that behaviour changes that are common in those living with dementia can include feelings of paranoia, which can increase their reluctance to sign documents and resistance to lodging information online.

... people living with dementia would appreciate the support of someone who knows about the disease when undertaking advance care planning.

People living with dementia often need considerable support to undertake advance care planning. This may involve help accessing, completing, and lodging forms, as well as understanding the

kinds of decisions they may inform.

Dedicated, dementia-informed personnel to support advance care planning were recommended. These suggestions indicate that the 'do-it-yourself' approach to advance care planning is at odds with the support needs of people living with dementia, and that lawyer-assisted/aged care-directed advance care planning may constrain the potentially informative aspects of the process when undertaken with the support of someone with knowledge of dementia trajectories.

Participants also said it could be useful to have someone with an understanding of dementia sit with them while they complete advance care planning. They suggested this does not need to be a medical professional, or even someone they have known a long time. If the person is trustworthy and understands the kind of decisions a person living with dementia may have in front of them, they would be seen as a valuable support.

You would really want to make sure for that person to be trusted. A person could develop a relationship with you if they understood the dementia that you perhaps had. I trust you ... because I'd know that you'd be looking at all these other things that I'm talking about. (PLW dementia)

... advance care planning should be a process, not a one-off event

People living with dementia, and their carers, agreed that the timing of advance care planning conversations is complicated. They said that discussing these issues when you are well is ideal, so that they don't come out of the blue when you receive a diagnosis. At the same time, they acknowledged that it may take the diagnosis to make advance care planning a priority (and it might be too late then), and there are specific decisions that only become relevant after learning you have dementia.

Honestly if you're doing [advance care planning] at diagnosis, the horse has bolted. (PLW dementia)

Participants typically said that advance care planning ideally starts early, saying that 'the quicker you start, the clearer you are.' However, health professionals also observed that people often change their minds as treatment decisions become imminent and patients' physical and mental states shift as the end of life

approaches. Sometimes the patient might not remember why or that they had made a decision earlier or may feel differently about it when the decision was acted on.

Someone might get diagnosed with dementia here and then it might be 15 years later. So at what point along that journey is he still classified as that, being cognitively okay for him to even understand to make a decision about, 'hold on, now I know what dementia is going to look like?' (Carer)

A person ... has had dementia for quite a while ... I told him '... we're ceasing medication now' and he said, 'Oh bugger.' I thought, 'is it something that they'd agreed upon before, that when the time comes this will be what we do?' It just made me feel really, really sad.

Although participants could not suggest any single 'right time' for advance care planning, they agreed that it should not be approached as a one-off conversation—especially at diagnosis when emotions may be high. Instead, they told us it should be an ongoing process that records general preferences and adds more detailed directions as the disease and treatments progress.

In addition, one-off appointments with legal professionals (particularly in completing Advance Care Directives) may make it difficult and costly to undertake the kind of ongoing advance care planning that participants from the dementia community indicated they would prefer. Planning undertaken in hospital settings may also be 'one-off,' meaning that patients and their carers may face difficult, repeated advance care planning conversations when re-admitted subsequently.

... you can change your mind, even as 'your mind changes'

Participants talked about the importance of doing advance care planning 'while you still can' and 'before it's too late.' Yet they also discussed the possibility that that an early plan might 'say one thing,' while later, in a 'lucid moment' they might end up 'saying something different.'

I think your mind can change, particularly as you learn more about the type of diagnosis that you've got. (PLW dementia)

The idea that capacity can ebb and flow raised questions for participants about the role of advance care planning: Which 'you'



should be driving decision-making—the 'you' who wrote plans when you were deemed capable, or the 'you' of the here and now? Participants agreed this was complicated. For many, staying involved in guiding their care to the extent they are able was important, even when trusted others begin to play a bigger role. So, although advance care planning can be a means of keeping people living with dementia at the centre of their care, participants voiced concern that plans may be used instead of efforts to keep them involved in decision-making to the level that their capacity allows.

... autonomy can mean not undertaking advance care planning

People living with dementia can experience significant feelings of vulnerability. Advance care planning can address these feelings by articulating and formalising care preferences, but concerns that written plans may be manipulated, misinterpreted, or work to constrain options for 'changing your mind' can make people living with dementia reluctant to engage. For others, the idea that advance care planning is about 'understanding between people' led them to resist what they saw as 'tokenistic, meaningless' documentation encouraged by some health and aged care providers. In light of these concerns, participants agreed that supporting patients' autonomy means that advance care planning engagement should always be 'a choice,' not an expectation. For them, autonomy means having the choice not to undertake advance care planning.

... advance care planning documentation can 'help carers care'

People living with dementia, carers and health professionals agreed that advance

care planning documents such as ACDs can help to reassure family members and carers faced with difficult choices that they are supporting a patient's wishes. Patients themselves saw advance care planning documents as a way to educate health providers, particularly in hospitals, about the specific needs and preferences of people living with dementia.

In each of these accounts, participants emphasised the relational nature of advance care planning, suggesting it is about communication and understanding between people within relationships of trust.

... advance care planning should be embedded into systems to be effective

Participants told us that awareness of advance care planning is low in their community, and that embedding discussion of the issue into schools, community organisations and aged care providers would be useful. They agreed that GPs were well placed to raise the topic and provide information. Participants also said they were not aware as to where ACDs or similar documentation 'should be kept' and reported storing care plans in a range of places with different individuals and care providers. Those who had completed forms said they gave copies to trusted family members, their GP, or kept a copy on the fridge or 'in their handbag.' Many did not feel comfortable lodging their plans electronically and felt some level of concern that people may have difficulty accessing their information 'when it's needed.' This reluctance to lodge plans online led to uncertainty in ensuring plans can be accessed when they are needed and placed significant responsibility on carers.

Views of Aboriginal Australians on advance care planning

Aboriginal Australians

Views about advance care planning and ACDs were sought and thematically analysed from 35 participants through face-to-face yarns with one or two persons (urban and rural setting), or via yarning circles (with urban Elders, and a yarning circle with Elders and community). Participants included 8 urban Elders, 11 urban Aboriginal people, 13 rural Aboriginal people/Elders, one Aboriginal healthcare professional, and 2 non-indigenous healthcare professionals (some participants had multiple roles).

Key points

1. Planning for the end of life is important, especially as First Nations communities want to prevent people dying alone in hospital. Making and sharing plans with family and within community can help reduce family conflict or distress in decision-making in an emergency.
2. For Aboriginal people, being with 'our mob' is central to the provision of culturally appropriate care at the end of life. This may require additional Aboriginal healthcare staff and/or accommodation of family or community presence at the end of life.
3. Being blamed for their health and health issues they are managing is a barrier to exploring ways to get the care they needed. A focus on current and future needs and preferences may help to avoid this.
4. The ACD form does not work for Aboriginal people, and any forms or written information need to be redesigned with community input to meet specific community needs.
5. Working with trusted community organisations, with respected Elders or Ngangkari, will help to foster interest and trust in a process of planning for end-of-life care.

Details

... most Aboriginal people don't know about ACDs

Most participants in community had never heard of advance care planning or ACDs except those who had been in hospital—and not all of those had completed ACDs.

Most had heard about funeral or financial planning and view this as part of looking after family.

[Advance care planning] is never been mentioned at all, period. But I've seen on Facebook, ... advertising for Aboriginal funeral services and how you go about it and how you can layby your funeral. That's what I have seen.

Yes, I have, when I was in [Hospital], the specialist came in and said 'you are going to die.' ... I thought it was something to do with the end-of-life. I think it's a pretty good idea having one that is more culturally acceptable and accessible.

So that's more like a financial and probably preparing for, it's a family, I guess, their needs.

... many Aboriginal people do not want to talk about death and dying

Death was seen as a 'touchy' subject that is generally avoided. This sometimes meant that people did not know what to expect if they or a family member must go into palliative care.

Death is something we don't talk about, our mob, because death most people talk about in general ... It's a touchy subject, you know. And no-one wants to talk about whether someone's going to leave them, right, no-one does like to talk about it.... the end of it, you know.

A lot of our mob don't like talking about, you know. And that's just blackfellas for you. I reckon, my reason is that is too scared to even say things about it you know.

... past experiences of 'white' healthcare are a barrier to discussing preferences for healthcare

Several participants spoke of feeling unable to express their preferences in medical settings, particularly to a white person who lacked an understanding of their needs. This was typically based on personal or familial experiences of not being heard, of being blamed, and subject to culturally inappropriate care.

It is so aggravating and annoying ... We're stuck in a hard place, and that happens all the time 'oh we've got to go the white person.' No. We don't need to go to a white person. We need our own People instead. I've been there, been to the doctors and their white people. Well, you don't know what we need. Then you put us in a position

where we can't tell you, because you're ignorant, okay?

... take away that shame, that they think sometimes they think they have made the wrong choices, you take away the blame, this is your health, your life, another thing in your life, to maybe we need to factor in, and learn to live with your health, rather than make your health be a barrier to you living.

... they want to be at home; hospitals are a place to avoid

When unwell, and especially at the end of life, Aboriginal families are more comfortable at home with other family members (our mob) there to provide care and comfort. Hospitals are seen as unable to provide needed care, as unwelcoming spaces, and as a place to die alone.

... it is important for, as you know, as a family member, with another family member that's on their last hours, to be a comfort to them and to give them the care that they need, you know.

I don't want to die in a hospital, ... I want to die in my own home, not surrounded by people that don't really care.

I wouldn't want to be alone in a hospital ... Nah, I don't want to be in the hospital in the city ... not to be stuck in that corridor in that room... Get out there, be there. Take your last breath with your mob.

I met an old traditional fella, ... at Parliament House, outside and it was late at night, and so we'd finished the rally and just preparing to head home and this old Traditional fella sitting down on the ground on the asphalt ..., policemen standing over them to support him, so I stayed with him and then we called the ambulance. He had a hospital band, he was just looking for his mob, you know. And he's a drinker, so his body was craving. It's real, that they can walk out of hospital if they learn down the generations that a hospital is where you go to die, then how contradictory is that to go to hospital to get well?



... advance care planning might help identify the right person to make decisions and avoid conflicts

People suggested that there would be less distress and conflict, and fewer family disputes if one or two family-leaders were named decision-makers. Even so, it was seen as important that any future plans to ensure a good death were shared with family, to help them avoid the chaos and distress of decision-making in an emergency where there was no planning or ACD in place.

If you have a large family, make sure everybody is all on board. Everybody needs to know what's happening ... because there will be one person who will think it's not a good idea, and it can break the family up.

Well, it'd be really critical for the health and wellbeing of the whole family ... just from my own experiences with families, ... it's got greater potential to create chaos in the moment for the individual who's, for example, lying in coma. If that was me, having done my advanced care plan, I would send ... copies out to family members who I have a relationship with, so they can back me up when I'm in a coma, you know, so that it'll save a lot of family chaos, I think and distress...

... the language of Advance Care Directives doesn't work with Aboriginal Australians

The current ACDs are considered not suitable due to issues such as language barriers, including the specialist unfamiliar language in the ACD and the many Aboriginal languages across Australia.

We need more interpreting as well. For the people that come from rural areas that can't speak English properly.

... more Aboriginal specialists will help with end-of-life care and advance care planning

Our participants told us that more training initiatives within Aboriginal community health are required. They recommended that healthcare staff working with older persons and within palliative care should include Aboriginal specialists. This will mean that Aboriginal persons, familiar with Aboriginal cultural needs, will be in place with the skills and knowledge to work with Aboriginal communities and persons wherever they are.

What we need in palliative care is an Aboriginal Support worker within palliative care, someone to support the team, on delivering that [ACD instruction kit] appropriately.

I would have to ask someone from aged care sector, or the hospital to get me the right help, support, ... you have to ask someone that you know that you're close to, to just give you a little bit of, someone that can help you comfort you.

... Aboriginal input to designing culturally appropriate forms is needed

All participants said the ACD forms need to change to be culturally appropriate. This may mean that communities will design their own culturally acceptable forms that are produced in the local languages, and are accessible as a package when people are facing a medical crisis.

The questions are not culturally appropriate, (so) the one going through it with those fellas, needs to have the knowledge around how to ask those questions, to get what information they need to go into that book, but ask questions, in a culturally appropriate way, because that book, the ACD [kit and form] I found difficult to answer.

One thing I noticed about the ACD, that booklet there [Dying to Yarn], I've seen the ACP (advance care planning) one as well, what I notice that they do sort of relate to each other, but that's not the actual form that we can't use, but I find it culturally appropriate for our fellas.

It's also the words, I've been through that book, with a client, and answered it the way a client, the way our fellas want to hear those questions, but not by that book, still got the same answers what your needing, but legally, if anything happens to them, but at the moment, excuse my French, but that one is shit ...

... it's about helping Aboriginal people to get the end-of-life care they need to heal

This means working with communities to share stories on what the end of life might look like and how they can be involved in getting the care they want. This might include sharing information at things like

community events, doctors' surgeries, community health centres, or through yarning groups, or simply asking them.

A big community in Adelaide, Nungas we know where we go. ... having a meeting about palliative care and going to where ... the community, people [can] come together and have a discussion on this important milestone, where people can all listen and then they really all go away and think about it. It will open their minds up, ... giving handout flyers about this and what we're talking about, so they have this in their hand, take away and then this will give them an insight how important this is for the community and not let things just go.

When someone has an illness, where they might need one of those at some stage, the doctors should talk to them about it, and it might be a good idea to have some pamphlets or something in the waiting room so they can look at it themselves.

I guess sitting down and just asking the person 'what do you need, what would you like, how do you feel?'

... there needs to be room for what is important to them in end-of-life care

This means supporting Aboriginal persons to die in spaces that are culturally safe, able to accommodate family (including pets) being there to provide comfort and support when staying at home is not an option. Some expressed a preference to have a Traditional healer, a Ngangkari.

Like I do feel that this is where our Elders come into it, that are spiritually, strongly connected to the land and Ngangkari, because they can rub us down, they talk with us, they can lead us into places that are comforting for us, you know, at that hurting time.

I have realised that Ngangkari are quite a scarce resource, there's not many of them, but yes, one thing, that has been very helpful. I've seen a Ngangkari about three times now ...

What I would like is for the hospital to understand the family, my mob might want to come down and need space for that.

I would like my dog with me, they are like family.



Views of people from culturally and linguistically diverse communities on advance care planning

Bhutanese

Views about advance care planning and ACDs were sought and thematically analysed from 12 participants in focus group consultations.

Key points

1. Initiating conversations about end-of-life plans must heed cultural norms about discussing death as well as familial roles and expectations; these may vary across generations, so ensuring that different voices are heard may help to minimise miscommunication.

2. The provision of end-of-life care involves much more than simple choices about what medical treatment a person wants, and family are central to decisions about care, as well as the provision of care at the end of life; involving family in conversations and decision-making is essential.
3. Making and writing down a choice about end-of-life care may not be culturally appropriate, so healthcare providers should accept that oral communication is preferred.
4. Religious rituals are important to the well-being of the patient, during and after death, and thus should be identified and accommodated as much as is possible.

Details

... talking openly about death is not easy or common

Participants explained that talking about death and end-of-life plans can be confronting, particularly for members of older generations, and is often avoided. Specific interventions such as CPR are discussed with patients, but often only in conversation with immediate family. Respecting these conventions can help to build trust between family and healthcare providers.

People are very reluctant talking about death and dying, so they don't want to get themselves on a trauma or something like that. Maybe some sort of phobia about it. It's not a phobia but like, I think it's a culturally accepted way. They don't usually talk about death and dying, so, always, there is a fear of that.

... theirs is not a 'writing' culture

Participants let us know that Bhutanese culture does not usually involve writing down plans for future care. People's preferences are usually communicated verbally to close family which, they explained, can avoid frustrations between those named, or not named, in a formal document.

The thing is, we do have that one [Advance Care Plan] but it's not in a written version, form. In every family they've got 'when I grow old, I want this, I want to live with this one' because how that's we have it.

Till my generation, till now, I can say that 'I give the authority to my son,' as an example. 'I can give my authority to this son.' I can say it, that is the word of mouth but if you said, 'write in the paper and give,' I can't give that because he don't want to sign that because there will be some frustrations between the sons.

... Australian approaches to the end of life feel very 'new' and 'black and white'

We heard that some Bhutanese South Australians find dominant approaches to end-of-life care to be 'very black and white' and sometimes difficult to understand.

We have a lot of people, lot of members in the community, referring to the lawyers and working out things, how they can be treated when they are in the hospital and who will be the responsible person, whether it's the son or the daughter or those things.

We want to be part of Australian culture, [but] ... this [advance care planning and the ACD form] feels very black and white and we do not always understand.

... end-of-life discussions involve careful consideration and respect for medical advice

Participants told us that careful family discussion is important at the end of life and a responsible family member will organise these discussions. They explained that options are considered slowly and collectively, but that trusted medical advice is generally sought and accepted.

In medical field, our people, they will trust to the medical. If the situation of the CPR will come, I think they will not deny for that. They will accept that, ... they will take advice from the doctors.

... decision-making is a family process

Community members told us that it is often an expectation that older generations will eventually become reliant on younger family members. While older patients themselves are involved in end-of-life decisions if they are open to these discussions, plans will often also involve wider family members whose contribution is included as a mark of 'respect.'

We talk in family groups. If there are several sons, then they will have to talk together. They cannot make such a decision by themselves.

I think that is pretty good enough to ask the person who is laying in the bed. And also, with the family involvement maybe someone, her grandson or granddaughter, whoever is available.

... the presence of family is central to end-of-life care

Participants explained that end-of-life care is shared among family members. Although there may be some sensitivities around personal care, responsibility is generally according to the patient's choice rather than falling along gendered lines. Community members told us that a preference for care at home is common so that there are not limitations on the people able to be present, and decisions are made on practical grounds.

It really depends on the family, if they have more sons or daughters. For example, some families may only have daughters and they look after their parents whereas some families just have sons in their family, so they look after. In some cases, the sons might be somewhere else working, where the daughter has to take care and vice-versa, so it really depends.

We prefer to be at home or perhaps it is more about being with family that is important, so many people present.

... there are generational differences in approaches to end-of-life planning

Community members told us that different generations now have different expectations around care at the end of life. They explained that older generations 'still follow the old ways' while middle-aged people are now more comfortable with having it 'all out in the open.' Generational differences were also held to reflect younger community members' 'eagerness to learn' about Australian culture.

I'm talking about my generation. I'm not talking about the older generation with their fear of dying. For my generation, definitely ask me. For example, if my grandfather is lying on the bed and going to die and he's not obviously good to talk about it with him. Maybe need to talk with the family, what is happening.

For older generations to even talk or plan, I want to do this/that when I'm sick or when I'm dying, we don't think about these things. Even to start to plan their parents being ill. I'm from a really younger generation that have a wide mindset, I'm open to everything.

... food is an important part of care at the end of life

When discussing receiving end-of-life care in hospital, participants spoke about being unfamiliar with the food provided, with family-prepared food preferred. This might see family bringing food to the patient in hospital, and potentially attributing a reduction in food intake to a preference for familiar food. Clarifying that changes in appetite and reduced food intake are common at the end of life may help minimise distress regarding this, and avoid misunderstandings between families and healthcare professionals.

They won't eat the food what is provided by the hospital, that is the thing because they are not eating some of the things... They want the food whatever provided by the home, by the family.

... religion and ritual are important at the end of life

Community members told us that the many religions observed among Bhutanese communities mean that a range of rituals can be relevant before, and after, the end of life, affecting the life of the person now and in their afterlife. Enquiring after and accommodating these religious practices thus has enduring significance for the individual and those responsible for helping them to be observed, typically family members.

There are many special rituals to ensure the person goes to Heaven, both before death and after death.

There is a holy plant and water that might need to be placed in the mouth in the last stages.

Priest and monks, they want it for the cultural beliefs or the religious beliefs they have with them. When we talk about that and we talk about if priest or if monk could go to the hospital and do the rituals, they believe that they would go straight away to the heaven. There are beliefs in all these things, so they are still there.

Italian

Views about advance care planning and ACDs were sought via individual interviews (8 interviews; two persons interviewed three times) and focus group consultations involving a total of 27 participants were thematically analysed.

Key points

1. The heterogeneity of Italian communities—their socio-economic status, multiple dialects, cultural practices, and varying values, beliefs, and experiences—must be acknowledged when it comes to end-of-life care.
2. Diverse migration histories, intergenerational tensions, the migrant community, and other factors such as religion, as well as one's region of origin play a role in how families discuss and provide care.
3. To best accommodate Italian needs and preferences about care and decision-making at the end of life, the focus needs to shift from individual contexts to relational and familial contexts, where decisions around care are more likely to be made.
4. Using visual elements or scenario-based stories will help to open conversation about or communicate the purpose of advance care planning and Advance Care Directives.

5. Italian regional clubs or local Italian radio are a source of news, comfort, and familiarity, and so may be places where discussions about advance care planning and Advance Care Directives could reach those who are non-literate in English and Italian.

Details

... Italian families are unfamiliar with advance care planning processes and documents

Participants knew about wills and other documents (Medical Power of Attorney, etc.) but were unsure about how ACDs were similar to or different from these, saying 'It's new to us.' Some also confused ACDs with euthanasia, consequently finding conversations about them to be confronting.

[There is] a directive and euthanasia. ... they often get muddled and that's why people get confronted by them.

... the concept of individualised decision-making is in conflict with relational, family-oriented ways of negotiating care

Exactly how families are thinking about and planning ahead for illness and death depends upon multiple contextual and biographical factors. These include socio-economic status, age, level of education, region of origin, religion, illness

experience, access to healthcare, degree of involvement within the community, and past experiences. For some older Italians, the concept of autonomy, of making important decisions about their own lives, was completely unfamiliar.

The older, they are often told who they had to marry, even 'you are going to Australia, this is the man, this is your life, this is your cross and you bear it and this is the way it is going to be.' It is changing, but 50 years ago—this is the people getting into their 80s and 90—there wasn't much of a choice, so to have something that you can actually put a wish on how you could do it.

What do you mean, 'what do I want'? My kids know, my kids will do it for me and I just want to be home.

... the 'contextual stuff is really important' in communicating the purpose of ACDs

Our participants were unfamiliar with ACDs, and appeared unconvinced that an explicit or formal process of advance care planning was necessary. To address this, they suggested that personal stories about advance care planning and the use of images or pictures would help the community to relate to and understand more about what advance care planning entails and how it might be beneficial for them.

You can take scenarios which you can base on, and the stories I've just told you about my uncle, and from that, you can talk further because people will feel a lot more comfortable saying, 'well that's interesting but I would have preferred that'.

... translating Advance Care Directives is about more than just language

Where participants recognised the value of advance care planning, they noted the limitations of current documentation in facilitating understanding and engagement. Some suggested having dual documents in both English and Italian would be helpful. However, some elderly Italians are non-literate and speak regional dialects different from the standard Italian language. Therefore, visual aids were also recommended.



I think it should be in English and Italian so that we understand the questions in English and Italian, then we'd understand.

Something visual, a testimonial, the personal experience is in my view crucial.

Some of them are illiterate. I think probably if you also had something available like a short video.

We also heard that the Advance Care Directive form comes across as too clinical when what is really being discussed is care. Dialect translation is important when it comes to the Italian language. However, whilst interpreters/translators need to be aware of the differences between dialects (and the culture/s encapsulated within these), according to our participants, unfortunately they often are not.

Care is the key word. Directive might be sort of prescriptive.

[A bilingual worker] can put it in language that is understood or convey the message more, it's got that trust there.

... giving direct and clinical information can hinder the development of trust

Participants placed value on implicit and non-verbal styles of communication in health settings, achieved through the use of bilingual workers (rather than professional interpreters) who understand the lived experience of the patient, as well as their cultural and linguistically diverse background (even within those identifying as Italian). They held that this awareness facilitated the development of trust needed to discuss the sensitive topics involved in advance care planning.

It's about the delivery, also the nonverbal, the flow of the words that you're using, it is not just sort of technical. So a bilingual worker would actually add that dimension of nonverbal communication.

...they'll talk about the sensitive issues, not so much because of the people who are asking them the question, but because they know and trust us.

... their community is heterogenous, so be cautious in making generalisations

The Italian community includes people with multiple regional groups and dialects, diverse political persuasions, migration histories and waves, and socio-economic status. They cautioned against making assumptions and generalisations about how the Italian community respond to, for example, documenting refusals of treatment, discussing death and dying.

I think we've got to be careful that we don't assume that they won't talk about it but it needs to be spoken about in a particular context.

... it is difficult to find the right time to have these conversations

Some participants reported that talking about death might engender fear as bringing bad luck. In addition, planning too far ahead, before anyone is sick, or when people were in the middle of illness and tragedy, are viewed as culturally inappropriate times to make decisions. This sees identifying the right time to be discussing preferences for end-of-life care as inherently challenging: when is it the right time?

I think it's a very taboo subject [advance care planning, death], because we don't like to talk about death and don't like to have fear in them. Porta sfortuna, it brings bad luck! (Second generation female)

One participant recounted her response when asked by treating clinicians,

Do you want your mother to be resuscitated?

She replied,

Don't ask me that question now, I'm too emotional, I can't answer that.

... medical decision-making extends beyond the family and often includes 'higher powers'

The Catholic church is held in high regard by the community, with some also revering renowned Italian GPs, trusting in them to make or advise the family on the right decision.

I think the medici italiani (Italian GPs) are absolutely fundamental in the Italian community. They are almost, I say this cautiously but they are like God. If they are not super religious then they invest their faith in that person.

... planning ahead may be a source of pride or 'bella figura' (a good appearance)

There is an established tradition of planning funerals but planning ahead for care at the end of life was not as common. We were told that there is pride in managing one's affairs: 'She did it all by herself. Me too, I did everything—preparing funerals, headstones, mass.' A working group member explained the significance of pride when it came to migration histories:

We are dealing with resilient people who want control. It is an important aspect, resilience. You have made a long journey to be here and you survived, and you managed.

However, too much planning ahead and managing could be seen as ignoring important social and relational expectations, and be a source of shame. What happened mattered not just to the individual, or to their family, but to the community.

How the community would perceive us when very ill or close to passing on and then—it is the daughter's duty in life, that's what she has to do. Bella figura? A good face, otherwise, i ggenti parranu [Calabrian dialect for people talk...gossip]—you cannot be seen in your community to be not caring for your elderly parents.

I panni sporchi si lavano in casa [you wash your dirty clothes at your own home] stated two participants when talking with the researcher in an informal moment during fieldwork.

Vietnamese

Views about advance care planning and ACDs were sought from 27 participants via individual and focus group consultations and thematically analysed.

Key points

1. The ways that language and messaging are used in ACD documents may present barriers to the uptake of advance care planning within the Vietnamese community.
2. The use of polite forms of address or honourifics and everyday Vietnamese linguistic markers could be used to 'soften' sensitive content about end-of-life discussions and render them more culturally appropriate.
3. Alternative ways of translating the term 'Advance Care Directive' such as *nguyện vọng về chăm sóc sức khỏe và cuộc sống* which translates in English to 'wishes of health care and life' would foreground and prioritise 'care' (*chăm sóc*). This may be more appropriate in and across diverse Vietnamese contexts.
4. Decentering the individual and shifting the focus to the relational and familial contexts in which care is practised and decisions are more likely to be made is recommended to increase trust and familiarity in the process of advance care planning.
5. Using stories, third person narratives, and visual media will better communicate the purpose and value of advance care planning.

Details

... Vietnamese families rarely talk about death and dying directly

The direct approach to communication that is promoted in advance care planning contrasts with Vietnamese approaches to ageing, illness, and the end-of-life. Such matters were not to be talked about, especially in a personal, individualised context. Instead participants advised us to use indirect communication strategies such as telling stories, using scenarios, third-person narratives, or visual means to shift the focus from individual decision-making to social and familial contexts.

Death is not to be talked about really.

It's like taboo, they didn't want to talk about that.

Keep scenarios and questions in the third person. It is never about them. [Put] in that way, it's much easier for them to address.

... care decisions often fall to family members, rather than the individual

In contrast to focusing on the individual promoted in the ACD documentation, more collective and relational ways of approaching and talking about care are practiced in Vietnamese communities, with family expected to make decisions about what is needed at the end of life. In addition, relationships and differences across generations reinforced hesitancy regarding talking about preferences and planning for the future.

Most of them do not want to talk about end-of-life issues. They want their family to make decisions on their behalf.

Based on our traditional way they say when they are older, their children will look after them ... and make decisions for them.

It's not just respects but there are culture differences in generation gap. We just feel like there are certain topics that we can't just talk to our parents about or our grandparents about because we don't feel comfortable.

... it is difficult to plan for an unknown future

Our participants shared that families felt ill-prepared to forecast future scenarios and make anticipatory decisions, and questioned the need to prepare for something they couldn't predict.

Why do we have to prepare for that?

You never know in advance.

... Vietnamese GPs are called upon to assist families to navigate complex medical situations at the end of life

The attitude 'doctor knows best' is prevalent among older migrants and families will defer to trusted Vietnamese GPs in matters of end-of-life care, rather than take on the decision themselves.

When it is advanced care for death, I think it would be more like medical opinion is valued, or the doctor would have a lot more say in that as well [as the family] because they value the health professionals.

... Advance Care Directive sounds strange and punitive when translated into Vietnamese (*Sáp Đặt Chăm Sóc theo Nguyễn vọng*)

When translated, the English noun 'directive' is remade into the verb 'Sáp Đặt,' which connotes a command to be followed or an order imposed from above. This conflicts with everyday Vietnamese vernaculars and politeness markers which 'soften' sensitive content.

The Vietnamese do not use these [words] like this.

[ACD] made sense in 'Aussie' but when translated it 'sounds weird' and 'inauthentic.'

When I read these I don't quite understand, I'm confused, I don't quite get it.

... they could not understand the English language ACD kit or forms

In general, participants were unfamiliar with ACD documentation. In addition, the English 74-page ACD kit was seen as 'too complex' and inaccessible to non-English speakers and/or to older Vietnamese. This meant they were hesitant to sign anything that did not make sense to them.

This is the first time that I've seen that document and I am a carer.

Oh my god. It's so thick. Too many words. I feel a headache.

I think any form you should do in both languages, English and Vietnamese. It should be very clear ... they are very concerned about signing the form.

Even [though] it is translated, the Vietnamese form remains complicated for older Vietnamese.

... the one-page Vietnamese information sheet and brochure does not provide enough information about ACD

Whilst acknowledging that some information was provided in Vietnamese, participants said that this was not sufficient; therefore, it was not possible for individuals to give informed consent if they could not understand the document or its purpose.

It is too short. There's no detail.

I do not know what we can change and what we cannot change.

... bilingual workers approach sensitive topics more sensitively than certified interpreters

Although certified interpreters are preferred within the medical system, bilingual workers, who understood the community and were aware of cultural and linguistic nuances, were considered better placed to be involved in communicating advance care planning processes or translating documents.

Sometimes the [certified] interpreter does not put in the context, so it's all wrong, it's completely wrong.

Not only the vibe, the content wrong. They just go the wrong way, the far wrong way.

Because one word in English can translate two or three different ways in Vietnamese, in different context and because [certified interpreters] didn't put in the correct context, it has become different content all together.

... family and gendered hierarchies must be considered in advance care planning and end-of-life decision making

In Vietnamese cultural norms, care decisions often fall to family members rather than the individual and 'filial piety' (i.e., the duty of respect, obedience, and care owed to older family members, especially parents) is negotiated (and sometimes contested) in family hierarchies and gendered relations of care.

I am the eldest son. My parents live in the countryside, so all decisions are often decided by me. My parents trust me and my decisions through my reasonable and right decisions before.

In reality, females are good at caring. Vietnamese people have a saying: Children's care for fathers is not as good as wives' care. It is the case when males are sick and females care for them. In contrast, when females are sick, it is not sure males can give good care. Therefore, if the mother is sick, husband may not give good care for his wife. So the daughter often do the hand-on care duties. If there is not a daughter, the daughter in law will do.

... individuals and/or families can cultivate or lose 'face' depending on how their elders are cared for at the end of life

Some participants talked of a risk of losing face if family members promote advance care planning and sensitive issues such as moving into residential aged care or refusals of treatment. Thus, advance care planning involves more than just the individual, or even just the family.

It affects the family's reputation, individual reputation, the community shun that type of behaviour. So like end-of-life care needs to be shown in a way that the community accepts it as well, not just the individual.

... advance care planning can raise questions of trust and mistrust within families

Participants also told us that family-initiated advance care planning also raised questions of 'black purpose' which could damage familial relationships. Thus, it may be difficult to raise or discuss issues about end-of-life care, without which advance care planning is unlikely.

... they still don't want to mention about that because superstitiously they think we're talking about our parent's death, they may think that we wish them to die. So it's sensitive. Very sensitive question.

People might misinterpret it. They might think you are up to something.

You want me to die early or something, is that what you are planning? ...why you ask me these kind of questions?

... including Vietnamese people in advance care planning means sharing information in ways and in places people can hear about it

Finally, if the aim is to increase advance care planning within Vietnamese communities, participants recommended communicating information about this within familiar trusted places, such as churches and pagodas, and with familiar trusted people.

The seniors will go to the church or pagoda, where they trust best, so it is easy for them to receive information.

[They are] coming to these education sessions because they are surrounded with people of similar ages ... and then a guest speaker might talk, and they actually listen ... and they take that information home then start the conversations.



Professional views on advance care planning

General Practitioners (GPs)

Views about advance care planning and ACDs were sought and thematically analysed from 8 interviews with healthcare professionals working in general practice. Participants included 4 GPs, 1 GP registrar, 1 psychologist, 1 practice nurse, and a nurse manager.

Key points

- 1. Advance care planning is viewed as valuable to promote provision of person-centred care, but the role of General Practice in advance care planning is complex, unclear, and conflicted.
- 2. Automatic prompts within the system to ask about future care preferences, particularly for older persons, would help to improve engagement in advance care planning.
- 3. Allocation of a Medicare item number could help GPs to support engagement in the kind of longer conversations they see as required to discuss advance care planning.
- 4. More community awareness around advance care planning and the potential role of the GP is needed. At present, clients attend a GP for a particular reason and raising the topic of advance care planning is seen as imposing an agenda beyond that of the client.

Details

... advance care planning is valuable but uncommon in general practice

Participants identified advance care planning as being valuable for patients, both as an expression of autonomy and as a way of ensuring that other people were aware of an individual's wishes (particularly through completion of an ACD). Despite this, participants also noted that advanced care planning or ACDs are not commonly raised in a general practice setting.

An Advanced Care Directive is an extension of your wishes when you can no longer make decisions. It's you, it's self-autonomy.

In a daily situation, [talking about ACP] is very uncommon and it depends on what we are trying to do.

... advance care planning has value for everyone, but is often only done with older patients

There was a difference between participant assertions that advance care planning is appropriate for all adults, and how they engaged with it in practice. Although it was viewed as important for everyone to undertake, regardless of their age or health, participants reported that when they do engage in advance care planning, it is typically only with older patients.

It's a really valuable thing that everyone should consider even if they're not elderly.

... advance care planning is something that everybody should think of regardless of age and stage, because you just don't ever know what's going to happen.

The younger people wouldn't consider getting one done, usually it's more elderly people.

[With advance care planning], everybody's up front, there's not going to be any surprises on death door, and it implies that the process or the scenarios have been discussed and considered and thought out more.

... they were unsure of their responsibilities when it comes to advance care planning

Even though they considered that a GP will typically have the trust and patient knowledge needed for good advance care planning, participants expressed some ambivalence around the nature and extent of their responsibilities in facilitating advance care planning. They were unsure if they or others (including the patient) should be responsible for advance care planning.

Ideally it should be the normal GP because they have a better idea, they have a knowledge of the past of the individual and they probably have the greatest trust over time.

I feel that if I'm their primary caregiver I've got to be careful about being the person that tells them what to write on paper. I prefer if that all happened almost excluding me, and then if they've got questions about scenarios they can present them to me.

Ultimately the person who it's about should be responsible.

... currently, prompts for advance care planning only apply to certain patient groups

Participants reported that prompts within the system to talk about advance care planning are useful. However, these only activate for certain patient groups such as those who require a health plan or are aged 75 or older. For other patients, advance care planning is only raised in an 'ad hoc' manner at the discretion of individual practitioners.

It happens really well here because we've put it into our templates so it is flagged as a priority and it is one of the first things we talk to them about when we're doing the plans or the health checks.

... advance care planning should be better embedded into systems

Participants advocated for embedding advance care planning conversations into existing administrative systems as a method of improving engagement in general practice for all patients. This included creating triggers or prompts in existing systems for all patients that have not previously engaged in advance care planning, not just those who have a health plan related to their age or medical condition.

They need another tab right next to it for Advance Care Directives, and even just seeing that there would be a good prompt.

It should be embedded into the system so it's actually part of the system so that, you know, if somebody has got a trigger [for advance care planning] they are going home with one.

Where this comes up is with patients over 75 who have a 75 plus health check. We try and do that, we certainly offer it to all of our patients who are over 75 on an annual basis.

... routinising advance care planning provision in general practice could conflict with patient needs

Despite generally recommending advance care planning as relevant for all, and as more likely with embedded prompts within the system to raise the topic, participants noted a potential conflict between 'routine advance care planning provision' and ensuring patient-centred care—with each interaction directed by patient self-reported need. Although advocating advance care planning as a means of promoting autonomy, they voiced concerns that autonomy could potentially be undermined if advance care planning became prioritised above addressing a patient's self-identified health concerns.

We do talk about patient-centred care, let's help the patient with what they came about first.

People come in and they say 'I'm short of breath Doc, I need my script, I need this letter for motor registration, I need this.' Where's advance care planning going happen in 15 minutes after you've done all that? It's bottom of the list.

... time is a barrier to their advance care planning engagement

Time constraints of standard general practice appointments were identified as a major barrier to advance care planning due to the perceived complexity of necessary conversations.

Time is a huge barrier because we only get a certain amount of time to be in here with that person and there's a lot of stuff we cover in that time.

It's hard timewise because those conversations can be time-consuming and you don't want to rush those conversations with persons.



... a Medicare item number could help improve advance care planning

A Medicare item number for advance care planning appointments was seen as a way to potentially improve advance care planning in general practice, through allocation of appropriate time and resourcing. Uncertainties remained about the role of the GP, on whether the focus should be on an advance care planning conversation, or on completion of an ACD.

[A Medicare item number] would be a good idea because say if someone comes in for 15 minutes you say 'oh look we can get you to come back if you want to discuss it' and then you'd actually have a certain appointment time just to discuss that.

I suppose it's the requirements around that item number, is it just for the conversation or do you have to confirm that they have completed it, so you would sit down and complete that with them?

... community awareness needs to be improved

Participants emphasised that broader general practice engagement with advance care planning would require increased community awareness. This could include raising awareness of advance care planning outside of a general practice setting, perhaps through prominent community organisations.

Raise the profile of the issue so that we are reminded that it's a discussion that we should be having with all our patients, not only those who are likely to use the Advance Care Directive....

I think it needs to be ramped up. It needs to go through community organisations, through COTA [Council Of The Aging], through the Lions clubs, and Rotary clubs.



Hospital healthcare professionals

Views about advance care planning and ACDs were sought during two focus groups, one at each hospital site. Participants included 25 nurses, 9 emergency nurses, 7 social workers, 5 intensive care unit (ICU) specialists and 4 oncologists at one site, as well as 17 nurses and 6 social workers at the other. Focus group conversations were thematically analysed.

Key points

1. Patient-centred care is not necessarily identical to advance care planning.
2. Advance care planning documents must be accessible to avoid unwanted interventions in emergencies, but often are not.
3. More clarity about when and where advance care planning should occur, as well as who is responsible for what in the process, may improve uptake and implementation.
4. The combination of the expression of broad values and specific directions (i.e., regarding Substitute Decision-makers and binding refusals) can confuse or complicate interpretation of ACDs precisely when clarity is needed.

Details

... advance care planning can help empower patients and respect patient choice

Doctors, nurses, and social workers held that advance care planning supports patients' right to articulate their healthcare preferences, which in turn can guide treatment and care decisions. They agreed that advance care planning conversations can educate patients about relevant decisions they may face, supporting informed consent to treatment or empowering them to refuse unwanted interventions.

The features identified as valued aspects of advance care planning appear to reflect central components of patient-centred care: informed consent, transparency of patient and care providers' expectations, patient agency in decision-making, and patients' rights to refuse unwanted treatment. These 'first principles' may be supported by advance care planning, but also by other forms of end-of-life care provision, including family conferences. Advance care planning alone may not fully address each of these principles, and not

engaging with advance care planning may represent patient-centred care for some individuals.

ACDs can help promote patient autonomy, but often fail to provide appropriate guidance. [specialist]

Even just having the name of the Substitute Decision-Maker written down, it saves time and sometimes ... it means the patient's wishes are respected when they need to be. [Social Worker]

... advance care planning can help hospital staff advocate for patients' preferences

Nurses and social workers told us that written advance care planning documents can help them to advocate on patients' behalf, particularly when patients' preferences for comfort care are at odds with the curative expectations of clinicians or family members. Nurses reported that undertaking advance care planning is seen as the province of senior clinicians, even though nurses may have a greater understanding of patients' preferences and family dynamics, and an orientation to advocating for their needs.

... advance care planning increases clarity and transparency in end-of-life decisions-making

Hospital staff told us that patients often assume that family members, carers, and health providers know exactly 'what they would want' if they were to lose capacity, but this is often not the case. Importantly, conversations about advance care planning would regularly change or clarify carer and health providers' understandings of patients' expectations. Thus, clarifying care assumptions through advance care planning can support a shared understanding of all those involved in a patient's care, and promote delivery of care that the patient wanted.

[ACP] puts everyone on the same page and understanding what that [patient] wants and at the end when it is really hard, trying to still respect what that person wants instead of making it about what you need. (Emergency nurse)

In this context, however, ICU staff noted that ACPs limiting treatment made little sense when a patient ended up in the intensive care unit, suggesting a mismatch between care provided and that desired by the patient.

Sometimes Advance Care Plans are so incomplete. [The patient's] not for intervention and not for CPR but if they then still come to [ICU], what more can we do? [ICU specialist]

... advance care planning can support timely decision-making in emergencies

Emergency department (ED) staff told us that accessible ACP documentation (e.g., ACDs or 7-Step Pathway Resuscitation Plan (7-SP) can improve patient-centred care for patients presenting at the ED. Where quick decisions need to be made—particularly about CPR and intubation—forms that give clear guidance and/or contact details for Substitute Decision-Makers can help avoid unwanted interventions that may otherwise have been provided. Emergency staff also told us that such documentation can support avoidance of futile interventions that were distressing for both staff and patients, as without explicit documentation stating otherwise, patients may routinely 'get 20 minutes of likely futile' (invasive, painful) CPR.

It is distressing when somebody very old and frail comes in and nobody's ever even had a conversation, and you just think, 'somebody needs to have a conversation because potentially, we have to do everything if it doesn't say we don't.' And that's very distressing for all the nursing staff. (Emergency nurse)

Specialists explained that readily accessible documentation can improve communication between different health providers within and beyond hospital settings so that a plan can be set and followed—even in an emergency admission where staff would otherwise be unaware of a patient's history and preferences.

... there is a diffusion of responsibility around advance care planning in hospitals

Participants told us that there is a lack of clarity around who is responsible for advance care planning in hospital settings, and whether that responsibility extends to awareness-raising or support for completion. This lack of clarity about which health providers are 'responsible' for advance care planning, and about how the process connects with the work of staff in different disciplines and contexts, appears to constrain both engagement with the planning process and the implementation of resultant plans.

In part because specific responsibilities are unclear, staff told us that advance care planning is often seen as 'someone else's role.'

Instead of putting it onto a hospital base where we're already stretched to the basic limits and we're busting at the sides, let's put it back onto some of the GPs. (Nurse)

I've seen it turfed to social workers. (Intern)

Advance care planning is therefore typically reliant upon the approach of individual clinical staff members, rather than structured into routine care provision. Participants indicated that dedicated advance care planning support personnel were previously an effective means of increasing engagement, but engagement has decreased since responsibility was shifted to social workers after these positions were discontinued.

... a hospital may not be the right context in which to undertake advance care planning

While hospital was understood to be an important catchment area for advance care planning awareness-raising and the provision of documentation, some health professionals queried whether it offers an appropriate physical or emotional context: it is rushed, busy, unfamiliar and does not offer time and space for required for careful reflection; and, if a patient has undergone the stress and physical impact of an acute health crisis, they may not be in the best state to undertake careful future planning. Participants told us that heightened emotion may lead to decisions patients later regret or wish to change.

A lot of the time something could be done in the heat of emotion in hospital and then it wants to be retracted quite quickly. (Nurse)

Other health professionals suggested that hospital is an appropriate place in which to undertake advance care planning because when a patient is acutely unwell, or nearing the end of life, they may be better able to make plans that are specific, detailed, and relevant to the exact nature of their illness trajectory. Emergency staff, in particular, suggested that this may make them more useful in guiding particular care decisions.

When you're well ... it's a very abstract thought and you'd probably just say 'oh, I want everything anyway.' (Intern)

Ambivalence as to whether a hospital is an appropriate location for advance care planning may reduce health professionals' motivation to raise the issue. Debate around these issues also raised questions as to what counts as an 'authentic' representation of a person's care preferences: specifically, is it what they have 'always wanted/thought/felt' in the abstract, or what they 'want/think/feel' about specific, pressing decisions.

... there is confusion about whether Advance Care Directives should comprise 'broad values' or 'specific instructions'

ACDs that combine patients' 'broad values' with binding refusals and the appointment of Substitute Decision-Makers are complex documents to navigate in practice in acute care. The conflation of these concepts appears to muddy understandings of clinicians' responsibilities and patient expectations. In turn, questions may be raised around the legal standing of ACD inclusions that are both 'too broad' (how do general preferences inform specific treatment decisions?) or 'too specific' (if a patient's exact health circumstances are not covered by an ACD content, should providers follow 'the spirit or the intent'?). Some noted that this was further complicated in that patients were not always able to know in advance what they might want.

You can't cover every eventuality. I think they give us a general sense of the person's value set. (Nurse)

'Would you like IV antibiotics? Would you like ICU?' I mean, they are very specific questions but they don't often, ...patients themselves don't know. (Oncologist)

Some nursing staff, social workers, and doctors indicated that information about patients' values was a useful inclusion in ACDs, helping care providers understand a patient's preferred approach to care particularly where there is an emphasis on 'quality of life.'

Others suggested that broad, values-based documents can be 'useless in practice' if they fail to provide direct instructions, especially as they might be implemented in emergency situations. Finally, where contents of ACDs do not cover 'every eventuality,' health professionals reported a level of confusion as to whether treatment and interventions should be guided by 'the words or the intent.'

... there are barriers to advance care planning engagement and implementation in hospital settings

Participants told us that advance care planning is often not differentiated from 7-Step Pathway Resuscitation Plan (7-SP) documentation in hospital settings. As an integrated care pathway, the 7-SP was deemed to provide some level of information about, and involvement of patients. However, it is ultimately understood to function as a 'case note for clinicians' rather than a vehicle for supporting patient autonomy in line with the principles of advance care planning. Participants explained that because the 7-SP is well understood, associated with training and development, and 'expected' in acute care within South Australian public hospitals, it (rather than an ACD) is often 'prioritised' and seen to 'cover off advance care planning requirements' in hospitals.

A key stated benefit of advance care planning was to inform emergency decision-making to avoid unwanted interventions. Yet, participants told us that advance care planning is undertaken in an ad hoc manner in acute care, hindered by difficulty in accessing physical forms and a lack of time and dedicated personnel to support the planning process. They said that ACDs or equivalent documents need to be accessible when and where they are needed, recommending a consistent approach to storage, access, and implementation of plans that is understood by both patients and care providers. Broad engagement with the 7-SP in SA hospitals suggests that

institutional support and provider training could support this outcome. Expanding training to community providers, and a developing/promoting a storage mechanism for documents that follow patients within and across healthcare settings, was suggested.

Hospital staff also indicated a level of confusion as to the legal standing of various end-of-life documentation, as well as appropriate processes by which they may be witnessed, enacted, revoked, prioritised in relation to other forms, and over-ridden by Substitute Decision Makers and family members.

... making advance care planning a matter of 'routine' could undermine patient autonomy

Finally, some participants raised concerns that if ACP is positioned as gold standard, it may become a 'procedural expectation,' potentially undermining patient choice and capacity not to engage with the process.





Lawyers

Views about advance care planning and ACDs were sought from 8 lawyers, four each in a rural and urban setting, and thematically analysed.

Key points

1. Although *The Advance Care Directives Act SA 2013* (the *ACD Act*) aims to facilitate meaningful advance care planning, this is not fully supported in a legal setting as participating lawyers primarily took a procedural orientation to completion of ACDs.
2. There is a broad misunderstanding about the role of advance care planning in supporting patient autonomy through providing guidance for future healthcare or life-style decisions and ACDs are typically bundled with, or confused with, other medical or legal documents pertaining to the end of life.
3. According to our participants, the primary function of ACDs appears to be to minimise confusion or distress for others, rather than the promotion of patient autonomy and patient-preferred care at the end of life.

4. The concept of a do-it-yourself kit for the creation of a document that has legal authority is deemed misplaced and potentially risky, as lawyers are best placed to complete legal documents.
5. The change of language from 'Guardian' to 'Substitute Decision-maker' is deemed irrelevant and confusing, with many participants preferring and recommending the previous familiar terminology.
6. Although the intent of the *ACD Act* is to support a values-based expression of preferences, the way it is currently included in the ACD form is viewed as misplaced, misleading, and unhelpful.

... the ACD Act and associated ACD form are cumbersome, procedural, and impractical in application

All lawyers participating in this study (urban and rural) commented on aspects of the *ACD Act* and associated form that they felt did not work to support completion of an ACD form. These included the order of signing, specifications regarding the number of Substitute Decision-Makers, and other formal requirements. These requirements

typically became the focus of discussion, making it difficult to move beyond that concern to other issues raised by the introduction of the *ACD Act*.

... legislation basically requires that if a person comes in and does an Advance Care Directive, they should not sign it off completely until the carers have actually signed. Now that, in the country, well it is just completely not practical. It is just totally to the extent that I personally, I do have them sign it off before the carers have done it because it's just, it's just there's just no other way to do it.

You need to clearly identify the person making the [ACD], the SDMs, what their wishes are in the event of terminal illness, but I don't think it needs to have much else. ... There is too much information in the current one.

... the ACD is introduced as part of a suite of end-of-life documents and is not often a priority to either clients or lawyers

The lawyers all explained that they introduced ACDs in the context of documents and decisions pertaining to the end-of-life, never as a lifestyle or planning document. ACDs were rarely raised by clients independently and, in consultations, were always bundled together with Wills and Powers of Attorney. Whilst practical and cost-efficient for the client, this framed advance care planning as relevant for older or dying people, rather than as something potentially relevant for anyone regardless of age or health status.

... most people will come in for wills. Most people won't sort of come in for an Advance Care Directive but I'll always mention that and the Powers of Attorney and that kind of stuff.

I raise it as a standard part of all planning, I raise issue of wills, Powers of Attorney, and Advance Care Directives as a standard topic that we discuss.

... it is difficult for well or young/er people to see ACDs as relevant to them

All participants noted a reluctance within their clients to engage with ACDs, primarily as this required them to think about their own mortality.

People only think of this when they have to think of it, that they don't want to think. ... I just don't know how unless you culturally get people to think about advance care planning. It's a difficult subject. You're facing your own mortality.

Thus, whilst ACDs are promoted as relevant to all, many clients viewed them as only relevant for those who are old or approaching the end of life. Combined with their reluctance to think about their own mortality, this meant that many clients did not engage with advance care planning or discuss it with others, preferring to defer consideration of this.

...as far as the Advance Care Directive, they're not quite prepared to jump in. They seem to take the view 'I'll deal with that later when I'm older, when the times,' when it's just around the corner.'

Obviously those people are generally terminally-ill is a very different situation because those people know that they're going to die, so it's at the forefront, whereas if you're dealing with somebody in my age group, or even retirement age, they don't think they're ever gonna die, or have to make that decision, so they don't really want to think about that. It's hard enough to come in and think about dying, let alone thinking about the process of dying, or being in hospital and needing decisions made for them.

Young people will say, 'Oh no, I don't need that,' and it's like, 'Hmm, you actually might.' So most older people will do it but probably people maybe below 50, they just think, 'No. That's tempting fate' [laughs].

Some clients, however, deemed ACP discussions unnecessary due to a belief (misplaced, according to some lawyers) that their family know their wishes already.

... little has really changed beyond a shift in language that can be overcome

When talking with these lawyers, we noticed a slippage in language whereby they typically referred to 'carers' and 'Guardians' instead of 'Substitute Decision-Makers.' There was a generally dismissive approach to the 'new' terminology which was characterised as

confusing, bureaucratic, and unhelpful, rather than signaling a prioritisation of autonomy over best interests when voicing decisions for others.

[ACD is for] the appointment of a Guardian ... and to make directions as to ... not delaying the date of death. ... I used to like calling them Guardians. We knew what they were. ... SDM is a huge mouthful. Quite a few people say 'well, that's the bureaucrat speaking.' So I've learnt from that. When I write to them, I say 'technically they call it an SDM, but in this correspondence we'll call them Guardians,' with feedback saying 'well that makes a lot more sense.'

... despite the existence and promotion of a do-it-yourself kit, writing an ACD is beyond the capabilities of most people

All lawyers interviewed were dismissive of the South Australian do-it-yourself ACD kit, viewing it onerous and difficult to navigate. They held that most people were unable to complete the ACD with content that was compliant with the ACD Act and clearly articulated individual preferences. Some were concerned that people attempting to do so without legal advice was 'dangerous.'

I don't think I'd ever seen one where someone has completed it where I haven't had, 'What do actually mean by that?' and they're like 'Oh, good point,' or they've had the order of signing wrong. ... I always get nervous about this big ginormous legal document being available to everyone to have a go on themselves to do it, and almost being encouraged to do it themselves because, well, one, it's a legal document, you should get legal advice, but secondly, because of the people that I've seen that if they brought them in. Not one have I gone like, 'Yeah, it looks like as good as what I would do.'

And hypothetically you can [do it yourself] and just like with homemade wills, some people do get it right and they do do a pretty good job on it. But there's quite a range of ways you can leave a bit of a mess so I think it needs, it's dangerous to do it yourself.

The do-it yourself kit ... is the only DIY kit where you can't do it yourself.

A lot of people don't see the need for them, and they do need a lawyer I think to guide them around the [ACD] Act.

... there is no clarity regarding binding and non-binding statements, resulting in a vague and unhelpful directive

Some lawyers considered that the invitation provided by the official ACD form to include care 'preferences' and express 'wishes' in Part 3 was unhelpful. They observed that clients tended to include things that are typically vague and as such were unlikely to be effective in directing medical professionals at the end of life. Most viewed the ACD form as working most effectively as a legal document to appoint an individual's Substitute Decision-Makers/ (Part 2a) and record care they would not want (Part 4)—not as a vehicle to record values, preferences, or wishes.

... it's a dog of a form, but it looks very overwhelming when they get at it. But it basically boils down to two things: who's gonna be the Guardian, and, are you going to make directions about 'don't keep me alive unnecessarily?'

Some lawyers actively advised their clients to ignore the section addressing articulation of personal values, preferences, or wishes, deeming they were not helpful in guiding treatment decisions.



... the do-it-yourself nature of this means that people are drafting their views and the ways it's sort of drafted, it's sort of a values-based document, 'what's important to me?' Well, the problem is, at some stage this document may be needed to be used by a lawyer and a medical practitioner to determine what sort of treatment you're gonna get medically, and if you haven't expressed yourself clearly, what do we do?

I think it's Part 3: 'These are my wishes.' The questions in Part 3 are confusing. Hence badly written. ... So, yeah, Part 3 has a place, but hardly anyone puts anything in there. They're just interested in two things: who's gonna make the decisions and 'I don't want to be hooked up to a machine.'

Some lawyers also questioned the extent to which clients understood the legal limits of ACDs, observing that a Substitute Decision-Maker is not legally bound to observe an individual's preferences expressed in Section C. They also noted a lack of understanding within their clients that, once an ACD became relevant, decisional authority was accorded to the Substitute Decision-Maker; with this, the Substitute Decision-Maker could counteract what was recorded in the ACD, on the basis that in the given set of circumstances, the individual would have made a different decision.

But afterwards the decisions still come back to the Substitute Decision-Maker because it's just wishes, they're don't have, they're not binding, so they don't have to follow those things. ... I always explain to them that. So anything that they want to be binding needs to go under the binding refusals.

And they think that they can sort of put what they like in there and that has to be done. They don't understand that it's actually in the [ACD] Act that you can't make binding sort of requests like that but ... I think once they see in writing, they've signed it and a lawyer's witnessed it, that's what is gonna happen. ... You know, they just think whatever they put in the form overall will be followed.

... the ACD primarily functions to benefit others, rather than the client

Although ACDs are presented as enabling clients to ensure that future care matches their preferences, a common view was that ACDs primarily function to benefit and indicate care for others, specifically by minimising future familial disputes or stress during times of crisis requiring difficult decision-making. Some recommended promoting this beneficial consequence to others as a strategy to motivate more individuals to undertake the hard process of completing an ACD. In addition, some lawyers noted that completion of advance care planning was prompted by healthcare professionals and/or residential aged care facilities.

It's a challenge, ... that's why I think with the narrative is, ideally, you're doing it not for your benefit. Yes, it's tough but you're actually doing it for the benefits of the people that are going to have to make the decision. ... You know like, make the effort, not for you. Yes, it's hard. Let's accept that but we're doing it for their benefit.

I think the greater emotive response, you get a better response if the motivation was if you really care for X who you're appointing as your Substitute Decision-Maker, right, you will do this because the day probably will come where someone close to you is gonna have to make a decision, and you are gonna show your love for them by giving them some instruction, otherwise, they are in a vacuum. So it's not about you. It's actually about them.

[It's] for health practitioners and others, those people, so they know what-what they might want as well and when looking for certain people, they'll know who to direct their inquiries to if someone has lost capacity, they'll refer to that and go, 'bang, that's who we need to speak to,' and it can make them feel better, like aged care homes. I know that they're starting to ask for it when people move in.



Section 4



Project Recommendations

Creating an ACD: Supporting consumer engagement

Simplify and shorten the ACD kit

The ACD kit is perceived as too long, too complex, and thus onerous/prohibitive. This issue is especially acute for people with chronic disease/s (involving impairment to energy, concentration, and memory), and people for whom English is not their first and preferred language. Thus people (including health professionals) ignore the booklet (kit) and move straight to the form. Numerous health providers said they “just print the form, not the booklet” when introducing the concept of advance care planning. This means patients are potentially completing the ACD form without a sufficient understanding of key concepts outlined in the kit.

Recommendation 1:

- Include pop-out ‘explainers’ of key terms within the online kit as they appear;
- include a brief glossary of terms within paper versions;
- trusted community advocacy organisations should be consulted in preparing glossary and explainers to ensure that they are culturally appropriate and accessible.

Change misleading terminology: ‘DIY’ and ‘Substitute Decision-Maker’

The notion that advance care planning is a ‘do-it-yourself’ endeavour was strongly refuted in our results. People living with chronic disease, members of CALD and indigenous communities, and acute care patients routinely observed that advance

care planning exists in the context of relationship; that is that the process is about making wishes clear to trusted others, then seeking assurance they will advocate on their behalf. Moreover, for people living with disease or disability, it can be impossible to undertake advance care planning ‘by yourself’ and does not make sense to do so as decisions are made in the context of networks of care.

Thus, the language of DIY does not match the practical experience of end-of-life planning, and according to both lawyers and health professionals, those who ‘do it yourself’ are unlikely to produce a document that will provide clear guidance when needed.

Recommendation 2:

Reconsider use of the term DIY or do-it-yourself in the context of ACP/ACDs.

The term Substitute Decision-Maker (SDM) was considered misleading, obscuring that the SDM is required to speak for another, based on direct instruction from, or deep knowledge of them. This led to confusion and conflict about the nature and extent of SDM responsibilities in advance care planning, which was exacerbated by the relative lack of attention drawn to how the ACD requires and rests upon the consent and cooperation of others, including, but not limited to SDMs.

Recommendation 3:

Clarify the nature and extent of the involvement and responsibilities of the SDM/s for all stages of ACD creation and enactment.

The meaning of the term ‘Advance Care Directive’ was difficult to grasp within some communities, and this deterred engagement. The word ‘Directive’ was also seen to be loaded, particularly for people coming to Australia from political contexts in which governmental ‘directives’ are something to be feared.

Recommendation 4:

Replace ‘Advance Care Directives’ with something akin to ‘My preferences for my future healthcare.’

Consult communities to make kit/booklet examples more accessible

Examples of what could be included in the ACD can be helpful and used as a template by people when completing their own form. However, current examples were sometimes difficult to relate to. Review by diverse stakeholders of what is included in these examples and of the language used may increase the relevance for these, so that people could apply these meaningfully to their own documents without health advice. Cultural variation in use of names/scenarios will increase relevance and familiarity.

Recommendation 5:

Engage with lawyers, healthcare professionals, and communities (including from culturally and linguistically diverse, and Aboriginal and Torres Strait Islander) through an iterative process to ensure that example texts meet the legal, clinical, and cultural requirements needed to meaningfully and legally direct end-of-life care.

Clarify the practical and legal differences between ‘wishes’ and ‘refusals’

Many participants (including some health professionals and lawyers) appeared not to understand the distinction between healthcare ‘wishes’ and ‘refusals,’ potentially misleading the individual about the authority and weight of the former. The different legal status of these concepts is unclear in ACD documentation and some suggested they should be addressed through separate processes/documents. The potential for confusion is exacerbated by the current layout in that the sections conferring legal authority (Parts 2a and 4, respectively naming the SDM/s and refusing future treatment) are separated by the section documenting values and preferences (Part 3).

Recommendation 6:

- a) Clarify the meaning and legal status of wishes and refusals in directing care at the end of life;
- b) regarding the layout of the ACD form, place sections conferring legal authority together and clearly indicate the difference in legal status when addressing or documenting values and preferences.

Recommendation 7:

- a) Provide health professionals and lawyers with resources and training to appropriately guide completion of ACD;
- b) provide structures/mechanisms for ongoing conversations between legal and medical professional bodies to increase awareness of the roles and responsibilities of each and how they might collaborate to promote completion of ACD documentation that is both legally and medically sound.



Help people to reflect on futures and decisions that an ACD might help with

The ACD kit encourages people to ‘be specific’ when recording what they do and do not want. However, people often do not know the kinds of specific decisions that might become relevant in the course of their disease, or common issues that might arise when ACDs are needed. This means that instructions provided might be irrelevant or too vague to effectively guide a SDM or healthcare professionals when a decision is needed. Examples of possible scenarios and suggested wording for inclusion in an ACD may assist the individual to make more informed decisions and provide clarity for their SDM or healthcare professionals when the individual cannot make or express their wishes.

People may be prompted to complete and ACD when engaging a lawyer to complete a will or other legal document. In such cases, they may be unprepared to think about what this might mean for them and others, and a lawyer may not

be well placed to help them reflect on and document their future healthcare preferences. Health advice may be required before someone can ‘be specific’ enough to provide meaningful instructions or requests.

Recommendation 8:

- a) Develop a suite of documents relevant to common disease trajectories, providing examples of the kinds of issues and decisions that might be faced towards the end of life, and examples of wording regarding instructions or preferences;
- b) Recommend that people talk to their healthcare professional to gain a better understanding about the contexts when an ACD may be useful in guiding future medical decision-making.

Provide guidance on what to do with a completed ACD

Participants who had completed an ACD were uncertain about where to store it and who should be provided with copies. ACDs were kept in a range of settings (e.g., at home, or with their SDM, lawyer, or GP); some carried physical copies of their ACD form in their handbag. None carried the ACD wallet card provided in the SA Health ACD pack.

Recommendation 9:

Clarify where to store copies of an ACD and with whom.

Knowledge about or accessibility of completed ACDs within an acute care or general practice setting was poor.

Recommendation 10

Improve integration of ACDs with electronic medical healthcare records, so that they are readily and rapidly available where and when needed.

Simplify the layout of the ACD form

Use of sidebars, numerous heading levels, brackets, italics etc makes the ACD form visually complex. This makes it confusing and/or inaccessible to people diagnosed with early dementia and others dealing with ill-health.

Recommendation 11:

Provide a stripped-back, accessible version of the ACD form in plain text, large font, with limited text per page.

Provide translations of ACD documentation (either in written or recorded format)

Translated versions of ACD information are provided on the SA Health site. However, these translated documents are significantly shorter than the English-language booklet, which made some CALD community members suspicious about 'what they were not being told.'

Recommendation 12:

Provide translated versions of all documentation. At a minimum, provide culturally meaningful explanations of key concepts rather than 'direct translation.'

Provide key information in audio format

Information in the ACD kit may be more accessible to those who are non-literate, (either in their own or the english language) or who struggle due to age, illness, or treatment consequences (e.g., eye deterioration, fatigue) if an audio version of the text is accessible on the online version.

Recommendation 13:

Include a prominent link to an audio version of the kit in relevant places (e.g., information page, start of kit etc). Present audio information as brief recordings associated with specific sections.

Make it easier to get hardcopies of ACD documents

It is sometimes impossible for a person living with a chronic illness or those on limited incomes get to locations where hardcopy documentation might be accessible (including Service SA). It is similarly very difficult for carers to do so. GPs and hospital social workers also stated that having to print their own copies of the ACD kit form is a barrier to raising planning discussions.

Many older people struggle with or resist completing ACD documentation online. In addition, some do not have the computer access or computer literacy required to do so, or to navigate a payment portal. These factors act as disincentives to completion of ACDs online.

Recommendation 14:

- Provide GPs with copies of an information sheet with clear advice about how a patient might access more information and/or the ACD form, so they can raise advance care planning with their patients and let them know how they can get more information and an ACD form;
- Provide a cache of ACD documentation within hospitals for staff involved in advance care planning discussions.

Cost also matters:

- \$5 for a hardcopy was noted as too expensive for many people, especially those on limited incomes.
- The cost of the kit is not stated on the one-page ACD information sheet and should be.
- Printing the whole kit is prohibitive for many, including health providers (especially GPs).

Recommendation 15:

Provide the ACD kit/form free to people with chronic disease via their treating GP or other healthcare professionals, and for those on limited incomes.

Numerous participants indicated that community groups play a strong educational role regarding advance care planning and completion of ACDs. This is partly due to familiarity and trust, and partly due to their skills and knowledge about how to talk about advance care planning and ACDs in a way that is culturally safe and accessible.

Recommendation 16:

Equip community groups with resources/training on advance care planning and ACDs and support them to share information within their communities.

Interpreting and applying an ACD: supporting healthcare professionals

Provide training for staff regarding the legal status of ACDs, and provider/SDM obligations

Not all acute staff (especially social workers who most often undertook advance care planning with patients) had a strong understanding of the legal status of ACD and other advance care planning documents. Some senior clinical staff argued that doctors 'need not follow an ACD if it is not in the patient's best interest to do so.' Some nurses held that patients' preferences, as recorded in ACDs, are not always followed by doctors whose orientation can be to 'push' continued interventions.

Nurses valued documented preferences for comfort care etc using these to advocate on patients' behalf to 'let them go.' Finally, many noted a lack of clarity around the role of acute care staff in a patient's completion of ACD or advance care planning documentation.

Clarify responsibilities for advance care planning

Patients are unlikely to complete ACDs without assistance. However, responsibility for advance care planning in acute care is diffuse; staff in multiple areas and positions accept some responsibility, but a lack of clarity on exact expectations and roles often results in no-one undertaking advance care planning and/or assisting in completion of ACDs. Social workers appear most likely to provide awareness-raising and support for advance care planning documentation completion but lack sufficient time to consistently undertake this work.

Recommendation 17:

Clarify information about the legal status of documentation, provider obligations, and potential conflicts, both in instructions for consumers and within ongoing training for healthcare professionals.

Providing ACD paperwork to patients to complete independently is often meaningless as patients are often too tired/stressed/unwell to attempt advance care planning, and with limited or no additional support, rarely complete and return ACDs. Staff consistently recommended that the dedicated personnel originally charged with responsibility for supporting advance care planning in hospitals be reinstated. For Indigenous Australians, this must be an Aboriginal person.

In addition, people living with chronic disease would appreciate support from a dedicated person who understands the specifics of effective ACD documentation and the kinds of decisions that may become relevant as their illness progresses. This would facilitate completion of meaningful, informed, and specific documentation (which staff in emergency departments stated would be most useful in directing decision-making in an emergency).

Recommendation 18:

Nominate and provide dedicated trained personnel with the knowledge (cultural and medical) to facilitate completion of ACDs.

Provide staff training to identify and comply with existing ACDs

Participants living with chronic disease indicated that a key benefit of an ACD is avoidance of repeated, burdensome, distressing, and confronting conversations about their end-of-life wishes on each admittance to hospital. However, they noted that hospital staff often start advance care planning conversations without ever seeking or asking whether an ACD has been completed, or ignore documents that are provided. This was identified as a potential barrier to completing an ACD if you've heard that 'the hospital doesn't look at them anyway.'

Recommendation 19:

- a) Instruct healthcare professionals to look for or ask about any existing advance care planning or ACD documentation before initiating conversations about end-of-life care;
- b) Instruct healthcare professionals to avoid initiating conversations about end-of-life care preferences where such documentations exist.

Provide training on how to activate or de-activate an ACD and certify copies

There is confusion among clinical staff on activating or de-activating ACDs, and whether (and where) a treating doctor needs to provide a signature, statement, or letter. Certification of ACD copies is also inconsistent: some staff photocopy documentation, others tell patients/families that copies can only be certified by a Justice of the Peace, and one indicated that they have 'a favourite ward clerk who certifies everything for me.'

Recommendation 20:

Provide additional information about how to activate, revoke, and certify copies of ACDs for consumers, and within training for healthcare professionals.



Create and enact standardised processes for storing and accessing ACDs

There is not a clear process for storing or accessing ACD forms in the clinical setting or when transferring patients. Without rapid access to ACD forms, ED staff err on the side of providing CPR even when this is unlikely to be effective. Persons admitted to hospitals from residential aged care facilities (RACFs) are most likely to have accessible ACDs on admission because the RACF hold a copy and give them to the paramedics on transfer.

Recommendations 21:

Nominate and communicate a standard, accessible location to store physical copies of an ACD as well as processes to ensure it follows a patient during transfer between facilities.

Provide training on the role and relevance of different end-of-life documents

With the existence of multiple medical documents pertaining to the end of life, there is confusion on which end-of-life document take precedence. Some acute care staff thought the 7-Step Pathway Resuscitation Plan (7-SP) takes precedence because it's 'completed by a doctor,' others 'go with the most recent end-of-life document,' or the 'ACD because it's signed by a JP.'

Recommendation 22:

Provide healthcare professionals with ongoing training outlining the roles, relative scope, and limits of various documents directing care at the end of life.

Despite a general understanding that the 7-SP will 'do the work of advance care planning' in hospital settings, several patients with a 7-SP in case-notes did not recall a conversation about end-of-life options/care. This suggests that the conversations required for 7-SP documentation may not always occur, and that the 7-SP process may not always embody the goals of ACP (i.e., patient-centredness, informed consent, and autonomy).

However, compared with the ACD, the 7-SP was more often present in patients' case-notes, and processes for its completion, storage, and use were more widely understood by hospital staff. This was attributed to consistent education/training embedding the 7-SP into hospital systems and leading to a clear understanding of the processes needed to record and retrieve 7-SP documentation.

Recommendation 23:

Apply the system-level factors that have been successful in achieving uptake of the 7-SP (training and system integration) to enhance uptake/use of ACDs in acute care settings.

Clarify that completion of an ACD is a choice, not a requirement

Despite being aware of the benefits of advance care planning and ACDs, staff resisted making the process an 'expectation' or 'routine' arguing that a) respecting patient autonomy includes respecting patients' choice not to undertake ACP, and b) an expectation of end-of-life documentation may result in 'patients not being allowed to die unless they've signed a form.'

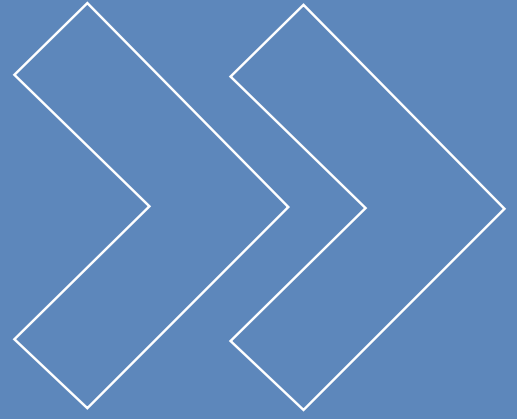
Some doctors reported feel pressure from nursing staff to complete a 7-SP so that the 'paperwork is complete.' This introduces tension in relationships, undermining clinical authority of those doctors who judge that, for a specific patient, it is potentially unwanted or inappropriate.

Finally, some reports of mandatory completion of ACP and ACDs on admission to residential aged care facilities (RACFs) raise concerns about voluntariness and informed consent.

Recommendation 24:

- a) Clarify and legitimise patients' rights not to undertake advance care planning or complete ACDs at any point within any setting;
- b) Provide additional training for healthcare and RACF professionals on patient rights.

Section 5



Appendix

Research teams^h

Aboriginal & Torres Strait Islander:
Christine Doolan, Jaklin Elliott, Ian Olver

Bhutanese: Gregory Crawford,
Jaklin Elliott

Italian: Simone Marino, Rachael de Haas,
Debbie Faulkner, Tanya Zivkovic

Vietnamese: Nga Nguyen, Rachael de
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Cancer: Ian Olver, Jaklin Elliott

Chronic Obstructive Pulmonary

Disease: Teresa Burgess, Gregory
Crawford, Katherine Hodgetts

Dementia: Teresa Burgess, Gregory
Crawford, Katherine Hodgetts

General Practice: Sean Cridland,
Teresa Burgess, Katherine Hodgetts

Healthcare Professionals:

Gregory Crawford, Teresa Burgess,
Katherine Hodgetts, Jaklin Elliott

Lawyers: Bernadette Richards,
Jaklin Elliott, Katherine Hodgetts

Study details

**Details of case-note audit and patient
survey in two metropolitan Adelaide
public hospitals**

Four nurses, with research training, sought signed, informed consent from patients and performed an audit of consenting patients’ case-notes, before the survey was administered by other researchers. Information and consent forms were available in English and the ten most common other languages among patients at those sites. All responses were recorded electronically into a survey database.

Data were collected over two consecutive weekends (both Saturdays and Sundays) from eligible patients admitted as in-patients at 0900 hours on Day 1.



Exclusion Criteria: In-patients who:

- were within paediatric, maternity, and ICU wards (number not recorded)
- were assessed by a Nurse Manager or Nurse Researcher as unable to consent due to cognitive, disease, or emotional factors (n = 101)
- were discharged before approached (n = 16)
- had language issues precluding participation (n = 12)

Of 245 patients meeting inclusion criteria:

- 54 declined to participate
- 191 patients provided consent (response rate 80%)
- 172 patients provided complete datasets (case-note and survey data; response rate 70%)

Audit Data

The following data were extracted from participant case-notes.

- socio-demographic data
- number of admissions in the preceding 12 months
- chronic disease status (evidence of meeting criteria as per the Supportive and Palliative Care Indicators Tool)

- referral to Palliative Care
- a completed 7-Step Pathway Resuscitation Plan (7-SP) (with limitations to treatment recorded)
- evidence of end-of-life care discussions
- evidence of the existence of an ACD
- a completed ACD
- an identified Substitute Decision-Maker (SDM)

Survey data

The following self-report data were collected via an administered survey.

- socio-demographic data
- completion of an ACD (including its present location)
- end-of-life care discussions
- SDM discussions

Analyses

Descriptive analyses of quantitative data were undertaken. Qualitative data obtained through the patient survey were thematically analysed.

^hLead researcher is listed first, others alphabetically.

Table 1. Hospital study: Patient demographics, hospital visits, and end-of-life documentation

TOTAL N = 172	no chronic conditions (n = 27)	≥ 1 chronic condition (n = 145)
Demographic factors		
Female	11	72
Male	16	73
Aged < 65	22	46
Aged ≥ 65	5	99
a) Aboriginal	1	6
b) Non-English-speaking background	4	19
Neither a) nor b)	22	120
Hospital visits in past 12 months		
0	27	15
1	-	52
2	-	47
≥3	-	28
Unknown	-	3
End-of-life documentation		
Referred to Palliative Care	-	15
Existence of ACD recorded	-	6
ACD present in notes	-	3
7-SP in notes	1	65
7-SP with limits on interventions	1	52
Name of SDM recorded	0	11

Table 2. Agreement between audit/survey data on end-of-life documentation

N = 172		Patient reported	
ITEM	Audit reported	Yes	No
Existence of ACD	Yes	2	4
	No	18	148
End-of-life care discussion*	Yes	21	22
	No	25	91
SDM discussion	Yes	7	10
	No	48	107

*n = 159 due to missing data



Table 3. Qualitative studies: details of participants, engagement, data, and analysis

3a. People living with chronic (life-limiting) disease and the carers (informal and professional) who support them				
Primary diagnosis (number of participants)	Engagement	Number of participants	Data collected via/in	Data source <i>Philosophical orientation</i> Process of analysis
Cancer Total: 15	Working group	6 (3 oncologists, 2 advocate/ lived experience, 1 clinical practice director)	Workplace	Meetings recorded and transcribed
	Urban consult	2 living with cancer, 1 couple (both with cancer diagnoses)	Home, workplace, zoom	Orientation: Critical Realism Analysis: Thematic
	Rural consult	1 living with cancer; 2 couples (one diagnosed)	Home, zoom	
Chronic Pulmonary Obstructive Disease Total: 17	Working group	6: 1 each advocate/lived experience, carer, specialist nurse, specialist doctor, physiotherapist, psychologist	Workplace, morning tea	Meetings recorded and transcribed
	Focus group consult	11 (3 carers)	Community hall	Orientation: Critical Realism Analysis: Thematic
Dementia Total: 17	Focus group: people living with dementia (PLWD)	1 PLWD, 1 carer of PLWD, 2 geriatricians, 2 Nightingale Nurses	Dementia Australia SA meeting room	Meetings recorded and transcribed
	Focus groups: carers of PLWD	5 (supported by Dementia consumer engagement coordinator) 7 (supported by Dementia consumer engagement coordinator)		Orientation: Critical Realism Analysis: Thematic
3b. Participants within or working with Aboriginal and Culturally and Linguistically Diverse communities				
Community (number of participants)	Engagement	Number of participants	Data collected via/in	Data source <i>Philosophical orientation</i> Process of analysis
Aboriginal Total: 35	Yarning circle	8 Elders	Community hall	Meetings recorded and transcribed Orientation: Critical Realism Analysis: Thematic
	One-on-one yarn	11 Urban participants	Home, workplace, café	
	Yarning circle	13 Rural participants	Motel conference room	
	One-on-one yarn	3 Professional Consultants (1 First Nations person)	Café, workplace	
Bhutanese Total: 12	Working group	4	Community hall	Meetings recorded and transcribed
	Focus group	8		Orientation: Critical Realism Analysis: Thematic
Italian Total: 27	Working Groups	4	Community workplaces, and community halls, university, email.	Translated and transcribed meetings, emails, fieldnotes, informal conversations Orientation: Grounded Theory Analysis: Thematic
	Focus groups	15	Participant homes, phone	
	One-on-one (ongoing)	8 (two interviewed 3 times)		
Vietnamese Total: 36	Working Groups	12	Community workplaces, and community halls, university, email.	Translated and transcribed meetings, emails, fieldnotes, informal conversations
	Focus groups	26		Orientation: Grounded Theory Analysis: Thematic

3c. Persons working as professionals who might assist with, contribute to, or interpret/apply an Advance Care Plan or Directive

Professional Groups (number of participants)	Engagement	Number of participants	Data collected via/in	Process of analysis
Acute care health professionals Total: 73	Focus groups (at two public hospitals)	9 emergency nurses 25 nurses 5 ICU specialists 4 oncologists 7 social workers 17 general nurses 6 social workers	Workplace	Meetings recorded and transcribed <i>Orientation: Critical Realism</i> Analysis: Thematic
General practice professionals Total: 8	One-on-one interviews	4 GPs, 1 GP registrar, 1 psychologist, 1 practice nurse, 1 nurse manager	Workplace	Meetings recorded and transcribed <i>Orientation: Critical Realism</i> Analysis: Thematic
Lawyers Total: 8	Urban interviews Rural interviews	5 3	Workplace, zoom	Meetings recorded and transcribed <i>Orientation: Critical Realism</i> Analysis: Thematic

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Kaurna acknowledgement

We acknowledge and pay our respects to the Kaurna people, the original custodians of the Adelaide Plains and the land on which the University of Adelaide's campuses at North Terrace, Waite, and Roseworthy are built. We acknowledge the deep feelings of attachment and relationship of the Kaurna people to country and we respect and value their past, present and ongoing connection to the land and cultural beliefs. The University continues to develop respectful and reciprocal relationships with all Indigenous peoples in Australia, and with other Indigenous peoples throughout the world.