

Content and quality assessment of advance care planning policies in Australian health and residential aged care services:

Implications for future policy development

2020



Acknowledgements

Advance Care Planning Australia is funded by the Australian Government Department of Health and administered via Austin Health.

Advance Care Planning Australia provides leadership and expertise in advance care planning policy, communications, advisory services, quality improvement, education and information resources for consumers, the health and aged care workforce, and service providers. Our purpose is to build the foundation for a national collaborative approach to advance care planning.

This initiative was undertaken with the support and advice of the research collaborative (including Ms Kim Buck, Dr Marcus Sellars, Dr Craig Sinclair and Professor Ben White) delivering the *Prevalence of Advance Care Directives in Australian Health and Residential Aged Care Services* study. We thank participating study sites who provided their advance care planning policy documentation.

Further information regarding this report can be obtained by contacting the Advance Care Planning Program Director at Austin Health on phone +61 3 9496 5660 or email <u>acpa@austin.org.au</u>. A copy of the report is available at <u>advancecareplanning.org.au</u>.

Recommended citation:

Macleod, A., Detering, K, & Nolte, L. 2020. Content and quality assessment of advance care planning policies in Australian health and residential aged care services: Implications for future policy development. Advance Care Planning Australia, Austin Health, Melbourne.

Disclaimer:

This report has been prepared by Advance Care Planning Australia for the purpose of identifying the quality of advance care planning policies and providing guidance for future development. It should not be relied upon by any other party or for any other purpose. While the Australian Government Department of Health has contributed to the funding of this project, the information contained in it does not necessarily reflect the views of the Australian Government and is not advice that is provided, or information that is endorsed, by the Australian Government. Advance Care Planning Australia is not responsible in negligence or otherwise for any injury, loss or damage however arising from the use of or reliance on the information provided in this report and will not be liable to any person who relies upon the report.



© Austin Health, June 2020

Contents

Acknowledgements 1
Introduction
Background
Methods
Results
Content assessment
Administrative policy details
Advance care planning information9
Quality assessment9
Language and presentation
Currency and relevance of policy information10
Definitions
Diversity and inclusion10
Key findings and implications
Recommendations for improving ACP policy development12
General content
ACP content
Language and presentation
Diversity and inclusion14
Glossary15
Abbreviations
References
Appendix A – Methods
Policy assessment process
Section 1: Document descriptors
Section 2: Content assessment22
Section 3: Quality assessment
Policy scoring
Appendix B – Results of policy assessment

Introduction

This report examines advance care planning (ACP) organisation-level policy data and information collected as part of the *Prevalence of Advance Care Planning Documentation in Australian Health and Residential Aged Care Services* study. In particular, the report evaluates existing organisational policies sourced from participating general practices, hospitals and residential aged care facilities. The focus of the evaluation relates to policy content and quality. The report findings identify the limited number of valid ACP policy documents and a lack of policy in general practices in Australia. The strengths and weaknesses of ACP policy documents in hospitals and residential aged care facilities are examined. Advance Care Planning Australia provides recommendations for the development of quality ACP organisation-level policy to promote the uptake of ACP and advance care directives (ACD) in Australian multi-sector health service organisations.

This report is relevant to the health and aged care workforce, service providers, health administrators and/or policymakers involved ACP and ACD implementation and organisation-level policy documentation.

Background

In Australia, there is considerable work in progress to ensure Australians have access to the right health care, in the right place, at the right time and cost. Part of this work includes ensuring people receive care consistent with their preferences. In 2006, the Council of Australian Governments (COAG) established the Australian Commission on Safety and Quality in Health Care (ACSQHC). This commission was appointed to lead and coordinate national improvements in the safety and quality of health care in all Australian hospitals, day procedure services and public dental services (1). In 2019, the Aged Care Quality and Safety Commission (ACQSC) was established. Their goal is to protect and enhance the health, safety, well-being and quality of life of Australians accessing aged care services. These bodies have worked in partnership with national, state and territory governments, health service organisations, and health practitioners to improve the Australian health system. Together, this work aims to create a person-centred, safe, high quality and sustainable health system.

Two documents of particular importance created by these bodies are the *National Safety and Quality Health Service Standards* (NSQHS Standards) (1) and the *Aged Care Quality Standards* (Quality Standards) (2). In November 2017, the second edition of the NSQHS Standards was released to provide a nationally consistent statement about the care consumers are entitled to expect from health service organisations. Specifically, Action 1.7 of the NSQHS Standards (1) states: Content and quality assessment of advance care planning policies in Australian health and residential aged care services 3

- Health service organisations use a risk management approach to set out, review, and maintain the currency and effectiveness of policies, procedures, and protocols.
- Standards promote adherence to policies, procedures and protocols and compliance with legislation, regulation, and jurisdictional requirements.

These standards encourage health and aged care organisations to create, implement, and regularly review organisational policies that protect consumers from harm and improve the quality of service consumers receive.

The primary purpose of the *Quality Standards* is to ensure consumers can expect and obtain a high standard of care and services from Commonwealth subsidised aged care service organisations. These quality standards include specific reference to the use of policy and procedures to promote positive change and high-quality services, including:

- Evidence of how the organisation makes sure the workforce has undertaken ACP training and has policy to inform ACD documentation; ensuring ACP documentation is accurate, upto-date, complete, shared and stored with relevant healthcare providers, and
- Policy and procedures document the organisation's processes for responding to deterioration or change in a consumer's condition, health, or abilities, relevant to the services they provide.

Care provision does not only happen when a consumer has decision-making capacity. Within health and aged care organisations, policies and procedures promoting planning for future health and medical treatment decision-making for a time when individuals may lose decision-making capacity are vital. ACP is the process of planning for future health and personal care so a person's values, beliefs and preferences are made known to guide clinical decision-making at a future time if the person cannot make or communicate their decisions (3). ACP helps ensure consumers are engaged with and can direct the care they receive, helping to communicate these preferences, should they lose decision-making capacity (4). Consumers who discuss their preferences for end-of-life care are more likely to choose less aggressive treatment (5) and to receive care which is consistent with their preferences (6). ACP is also associated with several improved outcomes at the end of life. Some outcomes include reduced hospitalisation, increased likelihood that the person will die in their preferred setting, and reduced stress, anxiety and depression in surviving loved ones (7-14).

The Australian Government has committed to increasing the uptake of ACP in the Australian health and aged care sector through the National Palliative Care Strategy 2018 (15). Recent data shows there are more than 1300 hospitals and over 3000 aged care providers in Australia (16-19). Despite legislation, policy, and quality standards promoting the uptake of ACP and ACDs, a national ACD prevalence study found only 25% of persons aged 65 years and over had any type of ACD documentation (20). This low prevalence rate highlights the considerable work that is still necessary to improve the uptake of ACP.

Health policy promotes the use of evidence-based practice, adherence to relevant legislation, and alignment with quality standards by health and aged care practitioners. Policy documents are developed to describe the way an organisation wants to operate; specifically, a policy outlines the "what" and "why" of organisational practices and standards. In contrast, procedures or protocols are documents that explain the "how" of implementing the standards set out in policy documents into practice. However, these terms are often used interchangeably in health and aged care settings. As such, all further reference to policy documents (or "documents") in this report collectively reflects any organisational ACP policy, procedure, or guideline document.

Effective policies documents should be well written, current, and adhere to legislation and national quality standards (21, 22). However, in both public and organisational health policy, it is sometimes difficult to define what determines an "effective" policy (23-26). As such, policymakers need to consider how to measure the success of a policy in their organisation and then provide clear, useable information to guide the evaluation process and facilitate quality improvements. Regularly reflecting on the effectiveness of the organisational policy will help to refine policy documents to improve service delivery and can support staff in their roles.

Health care policy documents set out the organisation's expectations for staff and standard of care required for consumers and should include (21):

- Title
- Rationale/purpose statement
- Scope statement
- Date policy becomes/became effective
- Details about who is responsible for what aspects of the policy
- Definitions
- Information about related policies and procedures
- Date of endorsement
- Date of policy review
- Descriptions of policy compliance and evaluation procedures

Currently, there is little information available that describes how ACP policies are written in various health service organisations. An analysis of this kind will provide a better understanding of the content and quality of existing ACP policy documents. This report examines the strengths and Content and quality assessment of advance care planning policies in Australian health and residential aged care services 5

weaknesses present in ACP policy documentation used across Australian general practices, hospitals, and residential aged care facilities to develop recommendations for future service organisation-level ACP policy development.

Methods

Sixty-two organisations from across 100 sites took part in the *Prevalence of advance care directives in Australian health and residential aged care services* study. The research reported herein is a subset of the larger study. At enrolment, sites were asked, "Does your site have an advance care planning policy or guideline?" If they answered "yes", they were requested to upload all relevant documents.

Two researchers independently conducted the policy analysis, with one scoring all policy documents, the second scoring 50% of documents to ensure evaluation consistency and to calculate interrater agreement. Scoring the documents involved reading each section of the policy document as if they were a reader who intended to use the policy in their workplace. The policy was then scored based on the ability of the document to provide the information a health practitioner would need to engage and direct the ACP process in their role successfully.

See Appendix A for further details about document screening and policy assessment processes.

Results

In 2018, sixty-two organisations from across 100 sites took part in the *Prevalence of advance care directives in Australian health and residential aged care services* study. Of these, 35 organisations (62 sites) reported they had one or more ACP policies or guidelines, resulting in a total of 93 documents being collected. Twenty organisations uploaded a single document; all other organisations uploaded two or more documents.

After collating all documents, 41 duplicates were removed. An additional ten documents were excluded as invalid document types because they were not an ACP policy, procedure, protocol, or guideline. The remaining 42 documents were screened using the selection criteria, resulting in only 18 policy documents included in the final analysis. These documents represented ACP policy for 18 organisations across 29 sites from all states and territories of Australia excluding the Northern Territory and Tasmania. See Table A1 for a full list of exclusion reasons.

Interrater agreement was assessed by calculating the average document content and quality scores for each researcher separately and then comparing these scores. Acceptable interrater agreement scores were those within +/-4 points.

Document type

Of the 18 included documents, nine were identified as policies, four as procedures, four as guidelines or clinical guidelines, and one document was referred to as a policy compliance procedure. Documents were between two and 74 pages long with a median length of 8 pages. All included documents were from hospitals, residential aged care facilities, and multi-sector organisations across six states and territories, with none identified from Northern Territory or Tasmania. General practices did not submit any valid policy documents. See Table 1 for a summary of descriptive details for included policy documents.

		Count
Resource type	Policy	9
	Procedure	4
	Guideline	4
	Protocol	0
	Other	1
Organisation type	General practice	0
	Hospital	10
	Residential aged care facility (RACF)	7
	Multi-sector (Hospital & RACF)	1
Jurisdiction	ACT	3
	NSW	2

	NT	0
	QLD	3
	SA	2
	TAS	0
	VIC	4
	WA	2
	Multiple jurisdictions (Both RACFs)	2
Resource length (pages)	Minimum	2
	Maximum	74
	Median	8
	Interquartile range 1 (0-25%)	4.25
	Interquartile range 2 (26-50%)	8
	Interquartile range 3 (51-75%)	9.75
	Interquartile range 4 (76-100%)	74

Content assessment

Content assessment produced a mean score of 29 out of 50 (range 17-46). Most policy documents produced fair (67%) or good (28%) content scores (see Tables B1 and B2 in Appendix B). Detailed descriptions of content ratings are located in Table B3.

Administrative policy details

Policy documents were expected to include a range of details important to effective policy administration. Expected information included details about when and why the policy was developed, how the policy would be reviewed and endorsed, whom the policy applies to, and how the organisation will determine the success of the policy. Broadly, policy documents produced fair scores on the 3-point rating scale, with an overall average administrative detail score of 11.7 out of a possible 22.

Most policy documents included the date the document came into effect or was approved, the date the document was last reviewed, and details about who approved or endorsed the document (89%, 83% and 78%, respectively). All but one document provided information about which staff members the policy applied to. However, only eight documents (44%) provided detailed descriptions of how the policy relates to staff members in different roles throughout the organisation. Just over half of the policy documents included the storage location of the policy document.

All but one document included a policy statement outlining why the policy was created. However, most of these statements did not include the intended outcomes of the policy. Specifically, 13 documents included the intended outcomes of the policy (72%), but only seven documents (39%) included measurable outcomes. Of the seven documents that included measurable outcomes, only

four (22%) provided both a measurable outcome and a detailed description of the evaluation or audit process used to determine the success of the policy. Although almost half of the included policy documents (44%) referred to assessing the success of the policy, only four documents (22%) provided detailed descriptions of the evaluation process.

Advance care planning information

Policy documents were expected to include information that provided staff with enough knowledge and/or guidance to facilitate ACP activities with consumers effectively. Overall, documents contained fair to good detail about ACP on the 3-point rating scale, with an average score of 17.5 out of a possible 28.

All policy documents included information about how to document, store and access ACP records. However, the amount of detail provided varied substantially, with just over half providing detailed descriptions of these topics, including whether (and where) templates were available. Policy documents were least likely to include information about the transfer of ACP documents between facilities, with document transfer between facilities mentioned in roughly a third of documents but with only two documents including a description of these processes.

All but one document referred to who should be involved in ACP processes. Of these, less than twothirds outlined staff roles within these processes. Only a fifth of the policy documents included detailed information about who should receive a copy of ACP documents and how this handover would occur. Most documents referred to assessing or ensuring ACP documents were valid, but just under two-thirds of the documents referring to assessing ACP document validity also provided detailed information about these processes. Similarly, almost two-thirds of the policy documents included when and/or how an ACP document or ACD was activated. However, less than half of these included detailed descriptions about the process used to activate an ACP document or ACD, and whether this activation is temporary.

Only half of the included policy documents provided detailed descriptions of relevant legislation active at the time of the study or included links to the relevant legislation. Just over half of the policy documents provided information about how staff could access additional resources about ACP. However, only two-thirds of the documents referring to additional sources provided enough information to make these resources easily accessible to staff.

Quality assessment

Policy documents were expected to use clear, easy-to-read language and use white space, headings and bullet points to improve the readability of the document. Good policy documents should be in-Content and quality assessment of advance care planning policies in Australian health and residential aged care services 9 date and use relevant and current information about the topic, including clear definitions and information about diverse populations to ensure the policy is inclusive. The average quality assessment score for the ACP policy documents assessed was 16 out of a possible 21 (range 10-20). Most policy documents (61%) received a quality score of good on the 3-point scale, with the remaining policies producing fair quality scores (see Tables B1 and B2 in Appendix B). Detailed descriptions of quality ratings are in Table B4.

Language and presentation

Most policies (83%) used clear and easy to understand language, and avoided using jargon, clichés, and unfamiliar words and phrases in the text, however only 13 policies clearly defined any technical words or acronyms including abbreviations of the organisation's name (72%). All documents used clear headings and bullet points where possible to present information. Only one document (6%) did not use white space effectively, making the text appear cluttered and difficult to read.

Currency and relevance of policy information

All documents used up to date terminology, and most documents were in date based on the date they were uploaded (16 documents, 89%). Jurisdiction-specific legislation that was in force at the time of data collection was referenced in most policy documents (83%), with just three (17%) failing to reference relevant legislation. All but one document targeted staff and organisational behaviours.

Definitions

Most documents used relevant ACP language but did not always include a definition for these terms, making the use of these terms more ambiguous. All but one policy document referred to advance care directives or health directives but included definitions in just 15 (83%). Likewise, most policy documents referred to capacity but only half of these documents also included a definition of capacity. Just over half of all policy documents referred to consent but only three provided a definition. Substitute decision-makers (or other jurisdiction-specific terms) were discussed in all but one policy document. However, less than two-thirds described what a substitute decision-maker was.

Diversity and inclusion

All documents included information about respecting the values and preferences of consumers. Inclusive decision-making was discussed all but two documents. However, only three-quarters of policy documents were written to ensure the focus of the ACP process was on the consumer and ensuring their preferences were respected. Only a third of included policy documents contained information about engaging diverse populations in ACP processes.

Key findings and implications

Few Australian multi-sector health service organisations have ACP policy documentation that is current and refers to active legislation. Of the 100 sites across 65 organisations, only 35 organisations uploaded ACP policy documentation. Of these, only 18 organisations were considered to have a valid ACP policy, procedure, protocol, or guideline, representing just 28% of the sampled organisations. The absence of valid ACP policy documents in Australian health service organisations highlights the need for promoting quality ACP policy development across the health sector.

Most health service organisations produced policy documents that were well presented and that focused on information about respecting the values and preferences of consumers. Policy documents generally included information about the policy version, who approved the document, why the policy was developed and to whom it applies. Most documents were in-date and used clear, easy-to-read language and current terminology, and used white space, headings and bullet points to improve the readability of the document. However, most policy documents scored better on the quality assessment measures than on content measures. This result suggests that those developing ACP policy documents may be experienced in policy development, but may lack the required expertise in ACP to develop effective policies. No documents reflected ACP policy in general practices, nor were any documents provided from organisations in the Northern Territory or Tasmania.

Where ACP policy documents were provided, important details were often missing or only briefly discussed. Policy documents were expected to include information that provided staff with enough knowledge and/or guidance to engage with and facilitate ACP activities with consumers effectively but often lacked this level of detail. Clear definitions were not often included in policies, creating ambiguity for individuals who may not have prior knowledge of ACP. Similarly, policy documents rarely included information about diverse populations to ensure the policy is inclusive.

Information about how to ensure all relevant parties (including those external to the organisation such as the nominated substitute decision-maker) receive a copy of the ACP documentation were often absent. This information is vital to the success of ACP and must be communicated to staff to ensure the preferences and values of consumers are available when needed. Information about the intended outcomes of the policy and details outlining the policy review process, including evaluating the success of the policy, were often absent or poorly described. Where intended outcomes were discussed, these were rarely measurable, limiting the ability of the organisations to identify whether the policy generated a positive impact in terms of ACP within the facility.

Recommendations for improving ACP policy development

There is substantial opportunity to improve organisation-level ACP policy throughout Australian multi-sector health service organisations. Improvements can be made in both the general content of policies as well as content specifically related to ACP. Significant improvements can also be made that help health service organisations evaluate the success of their policies and identify opportunities to promote ACP uptake in their organisation. Key recommendations for ACP policy development include:

General content

- Policy authors and approvers should ensure ACP policy documents do not use out of date terminology.
- Policy authors and approvers should ensure ACP policy documents refer to current
 legislation relevant to the state or territory where the organisation is located.
- Policy documents should be written in a way that targets organisational and staff behaviours.
- Policy documents should be kept up to date with regular, scheduled reviews.
- Dates should be recorded, including:
 - when the policy came into effect or was approved,
 - when the policy was last reviewed,
 - when the policy is due for review.
- Administrative information should be provided that describes:
 - where the policy is stored,
 - who should be involved in the review process (including the relevant policy approver/endorser),
 - what the review process will entail (e.g. document audits, checking whether legislation has changed, etc.)
- □ Specific details related to the purpose of the policy and how the intended outcomes will be measured should be included in the policy. These details should include:
 - a clear statement of intent outlining why the policy was created, what the intended outcomes of the policy are, how these outcomes will be measured (e.g. ACP document on file for every consumer etc.),

• what the evaluation/audit processes to evaluate the success of the policy will involve, Content and quality assessment of advance care planning policies in Australian health and residential aged care services 12

- the specific measure that would demonstrate policy success (e.g. increase of x% in ACP documents on file etc.)
- Scoping information should also be included explaining whom the policy applies to, and what their role is.

ACP content

- Delicy documents related to ACP should include a clear reference to ACP
- Policy background information should include:
 - A clear explanation of regulations and legislation relevant to the jurisdiction of the facility (including links to legislation),
 - Descriptions of when and how an ACD is documented, stored, accessed and activated, including:
 - how a decision to activate an ACD is made
 - who decides to activate an ACD
 - what processes are involved in activating an ACD
 - whether this activation is temporary (e.g. in the case of delirium or unconsciousness)
 - Information to staff about how to make sure ACPs are valid and regularly reviewed for consumers.
- Policy documents should outline who needs to be involved in ACP (including consumers and their family and/or loved ones), and what their role in the process is.
- Detailed information should be provided in the policy with regards to how ACP is documented within the facility (e.g. whether templates exist and where they are located, etc.), including:
 - how ACDs should be stored and accessed within the facility (e.g. role of My Health Record)
 - making sure all relevant parties have a copy of ACP documentation
 - the importance of transferring ACP documents when involving external facilities and/or health practitioners in medical decision making.
- □ Where possible, links to additional sources of information relating to ACP should be included, including ways to access additional training if desired.

Language and presentation

Documents should use clear and easy to understand language and avoid using any jargon,
 Content and quality assessment of advance care planning policies in Australian health and residential aged care services
 13

clichés, and unfamiliar words and phrases.

- Documents should use clear headings and bullet points (where possible) to present information in a concise and easily read format.
- Documents should use white space effectively to improve readability and ensure any technical words or acronyms used are clearly defined.
- At a minimum, ACP policy documents should include the following terms and their definitions:
 - Advance care directive/health directive/health direction/advance personal plan
 - Advance care planning
 - Capacity
 - Consent
 - Inclusive decision-making
 - Substitute decision-maker (or other jurisdiction-specific terms)

Diversity and inclusion

- Policy documents should include specific information related to engaging with consumers
 from diverse backgrounds, including CALD and/or Indigenous groups
- ACP policy documents should refer to, and be written to reflect the importance of respecting and discussing values and preferences of the consumer and engaging in inclusive and informed decision-making
- Documents should be written so that the focus of the ACP process remains on the consumer.

Glossary

Term	Definition
Advance care directive	A written advance care planning document completed and signed by a competent adult (i.e. person-driven document). In Australia, advance care directives are recognised either by specific legislation (statutory advance care directive) or by common law (non-statutory advance care directive). Advance care directives can record the person's preferences for future care, and/or record the appointment of a substitute decision- maker to make decisions about the person's health care.
Advance care planning (ACP)	Advance care planning is a process of planning for future health and personal care whereby the person's values, beliefs and preferences are made known. Formal ACP programs usually operate within a health, institutional or aged care setting and involve the assistance of trained professionals. However, people can choose to discuss their advance care in whatever context they desire.
Advance care planning legislation	A catch-all term to refer to jurisdictional legislation that promotes advance care planning and advance care directives. Legislation, including, but not limited to advance care directives, advance personal planning, guardianship and administration, and medical treatment decisions.
Aged care	 Aged care means care of one or more of the following types: residential care home care flexible care.
Aged care service	 The Australian Government subsidises approved aged care providers to deliver aged care services. Aged Care services include: entry-level support at home a higher level of support for senior Australians who are able to keep living at home with assistance care options and accommodation for senior Australians who are unable to live independently at home
Audit	A systematic review of clinical care against a predetermined set of criteria.

Term	Definition
Capacity	The ability to make a decision for oneself.
	Decision-making capacity can be assessed by trained professionals, and its assessment depends on the type and complexity of the decision to be made.
	Capacity assessment does not assess whether the decision is considered "good" or "bad" by others such as clinicians or family, but rather considers the person's ability to make a decision and comprehend its implications.
	 Generally, when a person has capacity to make a particular decision they can do all of the following: understand and believe the facts involved in making the decision understand the main choices weigh up the consequences of the choices understand how the consequences affect them make their decision freely and voluntarily communicate their decision
	By default, people are assumed to have capacity, unless there is evidence to the contrary.
Competency	Competency is a legal term used to describe the mental ability required for an adult to perform a specific task. Competency is recognised in legislation and in common law as a requirement for completing a legal document that prescribes future actions and decisions, such as a will or an ACP Document.
	A person is deemed to be either competent or not competent - there are no shades of grey. Competency must be assumed unless there is evidence to suggest otherwise.
Consumer	A consumer is a person who has used, or may potentially use, multi-sector health services, or is a carer for a patient using health services. A healthcare consumer may also act as a consumer representative to provide a consumer perspective, contribute consumer experiences, advocate for the interests of current and potential health service users, and take part in decision-making processes.
Consumer-centred care	Care and services that are designed around an individual's needs, preferences and background. It includes a partnership between consumers and providers.
Culturally and Linguistically Diverse (CALD)	A broad and inclusive descriptor for communities with diverse language, ethnic background, nationality, dress, traditions, food, societal structures, art and religion characterise
Decision-making	
Shared decision-making	A consultation process in which a clinician and a patient jointly participate in making a health decision, having discussed the

Term	Definition
	options, and their benefits and harms, and having considered the patient's values, preferences and circumstances.
Substitute decision-making	Decisions made by a nominated decision maker on behalf of the individual is substitute decision-making. A substitute decision seeks to replicate the decision it is thought the person would have made.
Supported decision-making	Supported decision-making encompasses a range of processes to support individuals to understand and consider their options about health of social care. Ultimately, it is the individual that makes the decision.
Diversity	The varied needs, characteristics and life experiences, which may be social, cultural, linguistic, religious, spiritual, psychological, medical, or care needs of consumers. Also refers to diverse gender and sexuality identities, experiences and relationships, including lesbian, gay, bisexual, transgender or intersex.
End-of-life	The period when a patient is living with, and impaired by, a fatal condition, even if the trajectory is ambiguous or unknown. This period may be years in the case of patients with chronic or malignant disease, or very brief in the case of patients who suffer acute and unexpected illness or events, such as sepsis, stroke or trauma.
End-of-Life Care	 Includes physical, spiritual and psychosocial assessment, and care and treatment delivered by health practitioners and ancillary staff. It also includes support of families and carers, and care of the patient's body after their death. People are 'approaching the end of life' when they are likely to die within the next 12 months. This includes people whose death is imminent (expected within a few hours or days) and those with: advanced, progressive, incurable conditions general frailty and co-existing conditions that mean that they are expected to die within 12 months existing conditions, if they are at risk of dying from a sudden acute crisis in their condition life-threatening acute conditions caused by sudden catastrophic events.
Guideline	Guideline documents provide broad advice related to a specific procedure or process. Guidelines are more often used to outline specific steps in a process, instead of providing a set of precise requirements or standards as in policy documents. In some organisations, however, this distinction is not made, and the terms 'guideline' and 'policy' may be used interchangeably.
Health Practitioner	Health practitioner refers to registered professionals such as medical, nursing and paramedicine practitioners and non-

Term	Definition
	registered professionals who provide care including social workers and care workers.
Health record	Health record includes a record of the patient's medical history, treatment notes, observations, correspondence, investigations, test results, photographs, prescription records and medication charts for an episode of care.
Health service organisation	A separately constituted health service that is responsible for implementing clinical governance, administration and financial management of a service unit or service units providing health care at the direction of the governing body. A service unit involves a group of clinicians and others working in a systematic way to deliver health care to patients. It can be in any location or setting, including pharmacies, clinics, outpatient facilities, hospitals, patients' homes, community settings, practices and clinicians' rooms.
Jurisdiction	A state or territory within Australia.
My Health Record	The secure online summary of a consumer's health information, managed by the System Operator of the national My Health Record system (the Australian Digital Health Agency). Clinicians are able to share health clinical documents to a consumer's My Health Record, according to the consumer's access controls. These may include information on medical history and treatments, diagnoses, medicines and allergies.
Organisation	The provider of care and services. Currently, aged care legislation uses the term 'approved provider', but this term doesn't include providers that deliver Commonwealth Home Support Programme (CHSP) and certain grant funded National Aboriginal and Torres Strait Islander Flexible Aged Care Program (NATSIFACP) services. As the Standards apply to all organisations that receive Australian Government subsidies or funding to provide aged care (whether they are currently an approved provider or not), the term 'organisation' has been used.
	 The Standards apply to organisations providing: residential care home care flexible care, including innovative care services, multi- purpose services (in line with the spirit and intent of the Standards), short-term restorative care and transition care CHSP NATSIFACP services.
Person	Consumers of services provided by hospitals, residential aged care facilities and general practice. Used interchangeably with consumer, resident, patients and clients.

Term	Definition
Person-centred care	Person-centred care is care that is respectful of, and responsive to, the preferences, needs and values of patients and consumers.
Policy (organisational)	An organisational document that outlines the agreed-upon decision making processes related to the specific topic of the policy and describes the way that work in the organisation should be carried out.
Procedure	The set of instructions to make policies and protocols operational, which are specific to an organisation
Process	A series of actions or steps taken to achieve a particular goal.
Protocol	An established set of rules used to complete tasks or a set of tasks.
Substitute decision-maker	Substitute decision-maker is a person appointed or identified by law to make substitute healthcare decision(s) on behalf of a person whose decision-making is impaired. A substitute decision-maker may be appointed by the person, appointed for (on behalf of) the person, or identified as the default decision- maker within legislation. Substitute decision-makers listed in Advance Care Directives are statutory appointments. Substitute decision-makers listed in Advance Care Plans are not.

Abbreviations

ACP	Advance care planning
ACD(s)	Advance care directive(s)
CALD	Culturally and linguistically diverse
GP(s)	General Practitioner(s)
SDM(s)	Substitute decision-maker(s)
RACF	Residential aged care facilities

References

1. Australian Commission on Safety Quality in Health Care. National safety and quality health service standards. Sydney: ACSQHC; 2017. Report No.: 9781925665178.

2. Commission S. Guidance and resources for providers to support the Aged Care Quality Standards. 2018.

3. Sudore RL, Lum HD, You JJ, Hanson LC, Meier DE, Pantilat SZ, et al. Defining advance care planning for adults: a consensus definition from a multidisciplinary Delphi panel. Journal of pain and symptom management. 2017;53(5):821-32. e1.

4. Sudore RL, Heyland DK, Lum HD, Rietjens JA, Korfage IJ, Ritchie CS, et al. Outcomes that define successful advance care planning: a Delphi panel consensus. Journal of pain and symptom management. 2018;55(2):245-55. e8.

5. Wright AA, Zhang B, Ray A, Mack JW, Trice E, Balboni T, et al. Associations between end-oflife discussions, patient mental health, medical care near death, and caregiver bereavement adjustment. Jama. 2008;300(14):1665-73.

6. Mack JW, Weeks JC, Wright AA, Block SD, Prigerson HG. End-of-life discussions, goal attainment, and distress at the end of life: predictors and outcomes of receipt of care consistent with preferences. Journal of Clinical Oncology. 2010;28(7):1203.

7. Caplan GA, Meller A, Squires B, Chan S, Willett W. Advance care planning and hospital in the nursing home. Age and ageing. 2006;35(6):581-5.

8. Detering KM, Hancock AD, Reade MC, Silvester W. The impact of advance care planning on end of life care in elderly patients: randomised controlled trial. Bmj. 2010;340:c1345.

9. Molloy DW, Guyatt GH, Russo R, Goeree R, O'brien BJ, Bedard M, et al. Systematic implementation of an advance directive program in nursing homes: a randomised controlled trial. Jama. 2000;283(11):1437-44.

10. Rhee JJ, Zwar NA, Kemp LA. Why are advance care planning decisions not implemented? Insights from interviews with Australian general practitioners. Journal of palliative medicine. 2013;16(10):1197-204.

11. Silvester W, Fullam RS, Parslow RA, Lewis VJ, Sjanta R, Jackson L, et al. Quality of advance care planning policy and practice in residential aged care facilities in Australia. BMJ supportive & palliative care. 2013;3(3):349-57.

12. Jeong SYS, Higgins I, McMillan M. The essentials of Advance Care Planning for end-of-life care for older people. Journal of clinical nursing. 2010;19(3-4):389-97.

13. Dixon J, Karagiannidou M, Knapp M. The effectiveness of advance care planning in improving end-of-life outcomes for people with dementia and their carers: a systematic review and critical discussion. Journal of pain and symptom management. 2018;55(1):132-50. e1.

14. Martin RS, Hayes B, Gregorevic K, Lim WK. The effects of advance care planning interventions on nursing home residents: a systematic review. Journal of the American Medical Directors Association. 2016;17(4):284-93.

15. Ministers AH. National Palliative Care Strategy 2010: Supporting Australians to live well at the end of life. In: Australia CGo, editor. Canberra, Australia2010.

16. Britt H, Miller GC, Charles J, Henderson J, Bayram C, Pan Y, et al. General practice activity in Australia 2009–10. General practice series. 2010(27):2009-10.

17. Welfare AloHa. Aged care Canberra: Australian Institute of Health and Welfare; 2019 [Available from: Available from: <u>https://www.aihw.gov.au/reports/australias-welfare/aged-care</u>.

18. Welfare AloHa. Hospital resources 2017–18: Australian hospital statistics Canberra: Australian Institute of Health and Welfare; 2019 [Available from: Available from:

https://www.aihw.gov.au/reports/hospitals/hospital-resources-2017-18-ahs.

19. Welfare AloHa. Primary health care in Australia Canberra: Australian Institute of Health and Welfare; 2019 [Available from: Available from: <u>https://www.aihw.gov.au/reports/primary-health-care/primary-health-care-in-australia</u>.

20. Buck K DK, Sellars M, Sinclair C, White B, Kelly H, Nolte L. Prevalence of advance care planning documentation in Australian health and residential aged care services. Austin Health, Melbourne.: Advance Care Planning Australia; 2019.

21. Irving AV. Policies and procedures for healthcare organisations: A risk management perspective. Patient Safety & Quality Healthcare [Internet]. 2014; 13.

22. A. ET. Policies and Procedures in Healthcare2019 29/06/2020 cited 2020 June 29]. Available from: Available from: [https://www.ausmed.com.au/cpd/articles/policies-and-procedures-in-healthcare].

23. Newman J. Measuring policy success: Case studies from Canada and Australia. Australian Journal of Public Administration. 2014;73(2):192-205.

24. Hanberger A. What is the policy problem? Methodological challenges in policy evaluation. Evaluation. 2001;7(1):45-62.

25. Turnpenny J, Nilsson M, Russel D, Jordan A, Hertin J, Nykvist B. Why is integrating policy assessment so hard? A comparative analysis of the institutional capacities and constraints. Journal of Environmental Planning and management. 2008;51(6):759-75.

26. Rütten A, Lüschen G, von Lengerke T, Abel T, Kannas L, Diaz JAR, et al. Determinants of health policy impact: a theoretical framework for policy analysis. Sozial-und Präventivmedizin/Social and Preventive Medicine. 2003;48(5):293-300.

27. Council AHMA. National framework for advance care directives. In: Australia CGo, editor. Canberra, Australia2011.

Appendix A – Methods

		No. Documents
Organisations that subn	nitted documents	35
Individual sites that sub	mitted documents	62
Documents submitted		93
Include documents if:	They are policy documents focusing on ACP and referred to relevant/up-to-date legislative requirements	
	They are policy documents focusing on ACP and refer to relevant/up-to-date legislative requirements, but are overdue for review	18
	They are policy documents focusing on ACP without reference to legislation that was active at the time of the study but contain information that is not out-of-date	
	They are not a valid document type	10
	They are a duplicate of policy documents uploaded by another site	41
Exclude documents if:	The document references ACP, but it is not the primary focus of the document	1
	The documents mention ACP but are not about ACP specifically	13
	They refer to incorrect or out-of-date legislation	7
	They include incorrect or out-of-date information	0
	They are consumer information documents about ACP	2
	They have been produced by an organisation outside of the facility (e.g. national/state guidelines published by a government department)	1
	Total excluded	75

Policy assessment process

The scorecard used to analyse documents was developed using expert opinion and academic literature describing policy development guidelines. The scorecard is divided into three sections: document descriptors, content assessment, and quality assessment.

Section 1: Document descriptors

Document details including the name of the organisation that produced the document, the year the document was produced, the type of resource, and the jurisdiction(s) the document should reflect, based on the location of the organisation.

Section 2: Content assessment

Policy contents were examined for administrative policy information and ACP-specific information. A series of 16 items; six items use "yes", "no", and "unsure" response options and ten items use "not

included in document", "referred to but not described in document", "referred to, with minimal detail provided" and "referred to in detail". Items relating to administrative policy details examined the type of content expected to appear in most policy documents. Items related to ACP information examined content directly related to ACP that would be expected to be present in ACP policy documents based on information collected from expert opinion, academic literature and the National Framework for Advance Care Directives (27).

Section 3: Quality assessment

Policy quality was assessed based on the currency and relevance of information, the language and presentation used within the document, inclusion and description of key ACP principles, and the presence of information related to diversity and inclusion. This included 21 questions using "yes", "no", and "unsure" response options and any unsure responses were reviewed collectively by the authorship team.

Policy scoring

For the content and policy assessment sections, each item scores from 0-3 depending on the response (see Appendix). The maximum possible score for document content was 50, and the maximum possible score for document quality was 21. Score rating categories of poor, fair, and good were set for content and quality separately to provide further structure to how polices were discussed (Table A2).

Table A2: Description of scores relevant to each policy rating for content and quality assessments
using a 3-category rating system

	Cont	Quality	
Rating	Admin	ACP	
Poor	0.0 - 7.5	0.0 - 9.5	0.0 - 7.5
Fair	7.5 - 14.5	9.5 - 18.5	7.5 - 14.5
Good	14.5 - 22.0	18.5 - 28.0	14.5 - 21.0

Appendix B – Results of policy assessment

Assessment type		Score
Contents (out of 50)	Minimum	17
	Maximum	46
	Average	29
Quality (out of 21)	Minimum	10
	Maximum	20
	Average	16
Interrater agreement (average	point Contents (+/- point difference)	3.72
difference of document scores) Quality (+/- point difference)	1.89

Table B1. Score summary of content and quality analysis of included policy documents (n=18)

Table B2. Distribution of content and quality scores of included documents

3-point scale	Content rating	% of documents	Quality rating	% of documents	
Poor	1	6%	0	0%	
Fair	12	67%	7	39%	
Good	5	28%	11	61%	
Overall Average	I	Fair	Good		

Table B3. Scores produced in the content assessment of policy documents

		Not incl docu	uded in ment		ided in ument		ed to but escribed	Refer minima	red to, al detail	Referred detail	l to in
	Policy content	No.	%	No.	%	No.	%	No.	%	No.	%
	Date the document came into effect/was approved is recorded	2	11%	16	89%				-		
ails	Date policy was last reviewed is provided	3	17%	15	83%				-		
details	Policy storage/file location is provided	10	56%	8	44%	-					
policy	Document approver/endorser is listed	4	22%	14	78%				-		
od a	Policy statement/statement of intent explains why the policy was created	1	6%	17	94%	1	6%	5	28%	11	61%
Administrative	Intended outcomes of the policy are stated	5	28%	13	72%	4	22%	6	33%	3	17%
istra	Intended outcomes of the policy are quantifiable/measurable	11	61%	7	39%	2	11%	1	6%	4	22%
min	Details are provided outlining which staff members the policy applies to	1	6%	17	94%	3	17%	7	39%	7	39%
Ad	Policy review process is outlined, including review frequency and who is involved	6	33%	12	67%	8	44%	4	22%	0	0%
	Evaluation/audit processes to be used to determine success of policy are described	10	56%	8	44%	2	11%	2	11%	4	22%
	Policy title includes reference to ACP	0	0%	18	100%						
	Details provided outlining who needs to be involved in ACP processes, and what their specific role in the process is	1	6%	17	94%	2	11%	4	22%	11	61%
	Details provided about how to document ACP within the facility	0	0%	18	100%	4	22%	5	28%	9	50%
	Details provided about how to store and access ACP within the facility	0	0%	18	100%	3	17%	3	17%	12	67%
tion	Details provided about how to make sure all relevant parties have a copy of the ACP documentation	4	22%	14	78%	3	17%	7	39%	4	22%
ACP information	Details provided about how an ACP is activated, including how this decision is made, by whom, what processes are involved in activating an ACP, and whether or not this activation is temporary	7	39%	11	61%	6	33%	0	0%	5	28%
AC	Details provided about how to make sure ACP documents are transferred with consumers when external facilities/health professionals are engaged in treatment	11	61%	7	39%	3	17%	2	11%	2	11%
	Details provided about how to make sure ACPs are valid and regularly reviewed for consumers, [if applicable]	2	11%	16	89%	3	17%	3	17%	10	56%
	Refers to regulations and legislations relevant to the jurisdiction of the facility that were active at the time of data collection	2	11%	16	89%	2	11%	5	28%	9	50%
	Sources, including ways to access additional training for ACP are included	7	39%	11	61%	2	11%	2	11%	7	39%

	Not i	ncluded	Included		
Quality measure	No.	%	No.	%	
Document does not use out of date terminology	0	0%	18	100%	
Capacity is referred to	3	17%	15	83%	
Capacity is defined	10	56%	8	44%	
Consent is referred to	8	44%	10	56%	
Consent is defined	15	83%	3	17%	
Respecting values and preferences are discussed	0	0%	18	100%	
Inclusive decision-making is discussed	2	11%	16	89%	
Substitute decision-maker (or other jurisdiction-specific terms) is referred to	1	6%	17	94%	
Substitute decision maker (or other jurisdiction-specific term) is defined	7	39%	11	61%	
Advance care directive/health directive is referred to	1	6%	17	94%	
Advance care directive/health directive is defined	3	17%	15	83%	
Relevant legislation based on facility jurisdiction is referenced	3	17%	15	83%	
Language used is clear and easy to understand (including avoidance of jargon, clichés, and unfamiliar words and phrases)	3	17%	15	83%	
Document refers to ACP for CALD and/or Indigenous groups	12	67%	6	33%	
Document uses clear headings	0	0%	18	100%	
Document uses bullet points where possible to present information	0	0%	18	100%	
Document uses white space effectively to improve readability	0	0%	18	100%	
Any technical words or acronyms used are clearly defined	5	28%	13	72%	
The document is written in a way that targets staff and organisational behaviours	1	6%	17	94%	
The document is written so the focus of the ACP process remains on the consumer	4	22%	14	78%	
The document is <i>in</i> date	2	11%	16	89%	

Table B4. Detailed descriptions of policy document quality measures

Appendix C - Policy scorecard details

Analysis	Item	Coding
Document details	Resource type (e.g. policy document, procedural guidelines, clinical guidelines etc.)	[text, no scoring]
	Organisation type	[text, no scoring]
	Jurisdiction	[text, no scoring]
	Resource length (pages)	[text, no scoring]
Content	Date the document came into effect/was approved is recorded	[Yes/No]
Assessment	Date policy was last reviewed is provided	[Yes/No]
	Policy storage/file location is provided	[Yes/No]
	Document approver/endorser is listed	[Yes/No]
	Policy statement/statement of intent explains why the policy was created	[Likert scale 1-4*]
	Intended outcomes of the policy are stated	[Likert scale 1-4*]
	Intended outcomes of the policy are quantifiable/measurable	[Likert scale 1-4*]
	Details are provided outlining which staff members the policy applies to	[Likert scale 1-4*]
	Policy review process is outlined, including review frequency and who is involved	[Likert scale 1-4*]
	Evaluation/audit processes to be used to determine success of policy are described	[Likert scale 1-4*]
	Policy title includes reference to ACP	[Likert scale 1-4*]
	Details provided outlining who needs to be involved in ACP processes, and	[Likert scale 1-4*]
	what their specific role in the process is	[Likert scale 1-4*]
	Details provided about how to document ACP within the facility	
	Details provided about how to store and access ACP within the facility	[Likert scale 1-4*]
	Details provided about how to make sure all relevant parties have a copy of the ACP documentation	[Likert scale 1-4*]
	Details provided about how an ACP is activated, including how this decision is made, by whom, what processes are involved in activating an ACP, and whether or not this activation is temporary	[Likert scale 1-4*]
	Details provided about how to make sure ACP documents are transferred with consumers when external facilities/health professionals are engaged in treatment	[Likert scale 1-4*]
	Details provided about how to make sure ACPs are valid and regularly reviewed for consumers, [if applicable]	[Likert scale 1-4*]
	Refers to regulations and legislations relevant to the jurisdiction of the facility	[Likert scale 1-4*]
	Sources, including ways to access additional training for ACP are included	[Likert scale 1-4*]
Quality	Document does not use out of date terminology	[Yes/No]
Assessment	Capacity is referred to	[Yes/No]
	Capacity is defined	[Yes/No]
	Consent is referred to	[Yes/No]
	Consent is defined	[Yes/No]
	Respecting values and preferences are discussed	[Yes/No]
	Inclusive decision-making is discussed	[Yes/No]
	Substitute decision-maker (or other jurisdiction-specific terms) is referred to	[Yes/No]
	Substitute decision maker (or other jurisdiction-specific term) is defined	[Yes/No]
	Advance care directive/health directive is referred to	[Yes/No]
	Advance care directive/health directive is defined	[Yes/No]
	Relevant legislation based on facility jurisdiction is referenced	[Yes/No]

Analysis	Item	Coding
	Language used is clear and easy to understand (including avoidance of jargon, clichés, and unfamiliar words and phrases)	[Yes/No]
	Document refers to ACP for CALD and/or Indigenous groups	[Yes/No]
	Document uses clear headings	[Yes/No]
Quality	Document uses bullet points where possible to present information	[Yes/No]
Assessment	Document uses white space effectively to improve readability	[Yes/No]
	Any technical words or acronyms used are clearly defined	[Yes/No]
	The document is written in a way that targets staff and organisational behaviours	[Yes/No]
	The document is written so the focus of the ACP process remains on the consumer	[Yes/No]
	The document is <i>in</i> date	[Yes/No]
Comments/n	otes	
	r "no" / "not included in document"; 1 for "referred to but not described in	
· · · .	ses; 2 for "referred to, with minimal detail provided" responses; and 3 for "r	referred to in deta
responses).		

