

Advance care planning in residential aged care:

A rapid review of literature

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Advance Care Planning Australia provides national coordination and leadership in advance care planning policy advocacy, communications, advisory services, quality improvement tools, and education and information resources for consumers, the health and aged care workforce, and/or service providers. Our purpose is to build the foundation for a national collaborative approach to advance care planning. We acknowledge the valuable advance care planning work being undertaken by others throughout Australia and internationally.

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Executive summary

Significant changes are occurring in Australia to support the provision of quality aged care, including the development of the Aged Care Quality Standards and the Charter of Aged Care Rights. An important part of this process is increasing the uptake of advance care planning in residential aged care facilities. Identifying new ways to improve the uptake of advance care planning in residential aged care facilities requires insight into the benefits of advance care planning, the experiences of those involved in ACP, and an understanding of the barriers and facilitators related to ACP uptake in RACFs. This report investigates the outcomes associated with advance care planning interventions designed to improve uptake of advance care planning activities and documentation in residential aged care facilities. It also examines the perspectives of residents and their family and/or loved ones on the experience of advance care planning in aged care settings, and provides insight into what prevents and/or enables advance care planning uptake in residential aged care facilities.

ACP is linked to improved end-of-life outcomes for residents, their family/loved ones, and the staff and organisations providing care to residents

ACP uptake in RACFs is impacted by resident capacity, lack of knowledge or training about ACP and illness trajectories, staff attitudes, resistance or distress of resident or their loved ones, poor or absent resources including standardised documents and processes related to ACP, and staff lack of time. ACP policies and procedures, standardised documentation, staff training in ACP and illness trajectories, and adequate resourcing to ensure staff have the time to engage residents and their family/loved ones in ACP discussions can improve uptake of ACP in RACFs. Likewise, resident willingness to engage in ACP discussions, and recognition of advantages to having an ACP, such as being able to exert control on their end of life experiences also increased the likelihood of ACP occurring. National and jurisdictional policy should promote increased ACP awareness, understanding, uptake, implementation and quality improvement across the aged care sector.

Introduction

This report identifies and describes academic literature relating to advance care planning (ACP) implementation and uptake within a residential aged care setting. The report focuses on key themes from the literature, including evidence of barriers and enablers to ACP for the older Australian population. The report identifies limitations in the evidence and the need for additional Australian research, policy, and programs to support quality ACP and improved end-of-life care within residential aged care.

Background

In Australia, significant legislation, policy, governance, and services reform is underway to support the provision of quality aged care. Since its inception, the Aged Care Act, 1997 (the Act) and many of the Principles relating to the Act have been reviewed and amended multiple times. In 2018, the Royal Commission into Aged Care Quality and Safety was established to examine how older people are cared for by aged care providers in Australia and identify the changes needed to improve these services. This work resulted in the development of the new Aged Care Quality Standards (Standards) and the Charter of Aged Care Rights. Both the Standards and the Charter of Aged Care Rights came into effect in July 2019, and describe the level of care and services recipients can expect from aged care services, emphasising quality outcomes for consumers (1). These aged care reforms promote improvements such as enhanced choice and control in decision-making for older Australians and has focused attention on ACP and advance care directives (ACDs) for health and aged care services.

Approximately 15% of the Australian population is aged 65 years and over and this number is expected to rise in coming years (2). Older people often live with chronic conditions affecting their quality of life, and the prevalence of these conditions has significant implications for the health system and aged care services (3). For some older adults, these chronic conditions can eventually require more care than they can receive at home, and it becomes necessary to enter a residential aged care facility (RACF) to support these needs (2).

The number of older Australians living in RACFs has risen by 15% in the last ten years (4), with almost all aged care residents aged 65 years and over (2). In 2018, the most common reason for people to leave RACFs was death (5). More than 70% of all end-of-life treatment decisions in RACFs are made by a resident's substitute decision-maker because the older adult lacks the capacity to make these decisions themselves (6). This makes it especially important that the decisions made on behalf of residents at the end of life need to reflect the preferences and values of the resident.

ACP is the process of planning for future health and personal care to ensure a person's values, beliefs and preferences are appropriately documented, thereby guiding medical treatment decision-making at a time when the person cannot make or communicate their decisions (7). ACP is an ongoing process and should involve the person, their family and/or carers, and their service provider(s) or treating healthcare team. ACP involves thinking about and discussing preferences for future healthcare and decision-making. Ideally, these preferences are documented within an ACD. ACP documents aim to safeguard a person's interests, including their autonomy, and provide protections for people facing a loss of capacity. Engaging in ACP also benefits the person, their family and carers, and the treating team by enhancing feelings of preparedness, reducing anxiety about future treatments, and increasing satisfaction with the medical treatment received (8, 9).

Most state and territory legislation within Australia allow a person to record their preferences relating to medical treatments they consent to, refuse, and/or wish to withdraw from. These official documents are referred to as ACP documents or ACDs and take effect when a person loses full decision-making capacity. Health professionals have obligations to access and enact a person's ACP document (10). Despite these legal safeguards, ACP uptake and the creation of ACP documents within aged care settings remains low, and there are issues with the quality of documentation.

In Australia currently, uptake of ACP documents within hospitals, general practice, and aged care services is low (11). In a recent Advance Care Planning Australia prevalence study, only 25% of the 4,187 health records examined across 100 health or aged care service providers (15 general practices, 27 hospitals and 58 RACFs) contained an ACP document, with the highest prevalence of aged care directives identified in RACFs (11). Of those records audited from residential aged care and hospitals, the prevalence of an ACP document was approximately 38% and 11%, respectively. Moreover, 30% RACF health records contained ACP documents completed by someone other than the competent individual, and 68% of these documents limited treatment to only symptom management and comfort care. Thus, nearly half of all documented ACP documents identified within RACFs were written by someone other than the competent person, and may be clinically and legally invalid (11).

A clear barrier for effective ACP has been the transfer of relevant health documentation between health facilities (12). In Australia, My Health Record was developed as a central storage point for health practitioners to easily access and share important patient health information, regardless of the location of care. Information stored in My Health Record includes information such as known allergies, diagnosed medical conditions, prescribed medications, test results, and/or treatment preferences. As a central repository, My Health Record makes it easier to share important health information between practitioners across multiple sites. Unfortunately, the uptake of My Health

Record remains low in RACFs (11), highlighting additional barriers to the effective communication of advance care preferences for patients being treated by health professionals outside of the aged care facility they live in.

Improving the care received by consumers of aged care services, is inherently linked to improving uptake of ACP in RACFs, so that residents can receive the care they want, even if they no longer have the capacity to engage in these discussions. Examining recent literature for innovations and research outcomes is an important part of continuing to identify ways to improve the quality of ACP and ACP documents for older Australians living in RACFs. Thus, the current rapid literature review aims to:

i. identify outcomes associated with ACP interventions in the residential aged care setting,

ii. examine how residents and their families and/or loved ones perceive the experience of ACP and ACP document use in residential aged care settings, and

iii. summarise the barriers and facilitators identified in recent research affecting the uptake of ACP in RACFs.

Methods

In September 2019, a rapid literature review was conducted to identify journal articles related to ACP in residential aged care. The review focused on manuscripts published between 2009 and 2019 to reflect recent research on ACP in a residential aged care setting. Separate searches for relevant journal articles were conducted across PubMed, MEDLINE, and CINAHL. The literature search aligned with the PICO (Population, Intervention, Comparison and Outcome) search strategy and used a range of terms to identify relevant publications. Terms used in the database searches included: residential aged care, aged care, old age home, ACP, advance care plan, advance care personal plan, advance care, advance directives, advance medical planning. Further details relating to the PICO search strategy can be found in Table 1. A full list of search terms used in the rapid review is available in Appendix A.

Because of the time constraints placed on a rapid review, only randomised control trials (RCTs) and systematic reviews were included. All other study types, including primary qualitative and quantitative research studies, descriptive studies, and literature reviews, were excluded with the expectation recent systematic reviews would likely capture these articles. Articles were screened using the PRISMA checklist (see Figure 1). All identified article abstracts and executive summaries were reviewed for relevance to ACP and residential aged care. Any articles that were not removed

using the exclusion criteria were assessed for their relevance using the full text and included or excluded accordingly.

Table 1. Outline of the rapid literature review using PICO search strategy

Population	Residential aged care patients and their family and/or carers
Intervention	Prevalence of ACP within a residential aged care setting
Comparison	Studies conducted with a comparison group (i.e. RCTs) and without a comparison group were included in the review.
Outcome	All publications focusing on ACP solely within a residential aged care setting were included.
Exclusion	- Studies discussing ACP within a community aged care and/or hospital setting. - Studies focusing on ACP for specific medical conditions (e.g. stroke, cancer). - Conference proceedings, conference abstracts, editorials, letters to the Editor, news stories, and announcements. - Narrative reviews, qualitative research and descriptive research examining ACP.

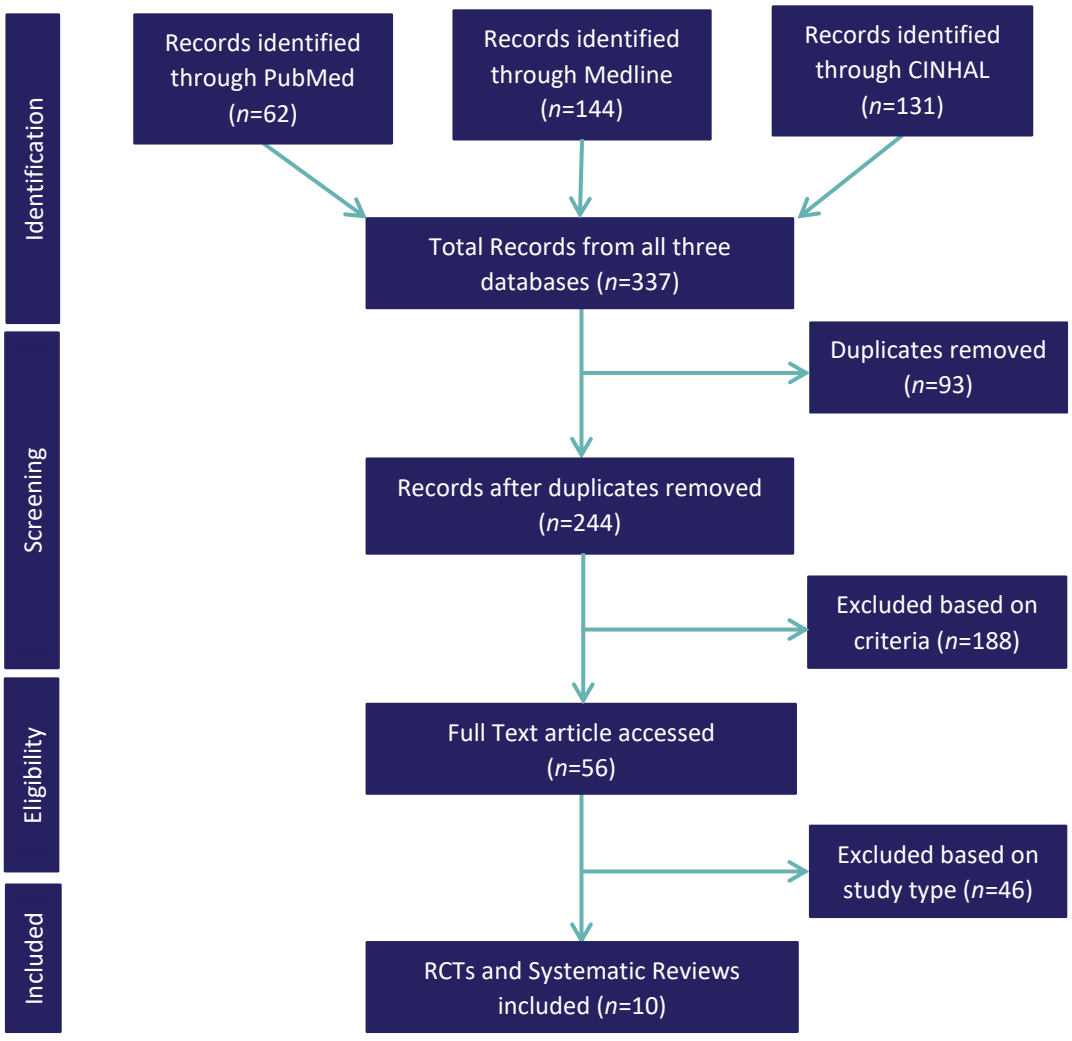

Figure 1. PRISMA flowchart describing the results of the rapid review database searches.

Results

Database searches across PubMed, MEDLINE, and CINAHL produced 337 potential articles. After removing 93 duplicate records, article screening resulted in a full-text review of 56 articles. Of these, 46 articles were excluded based on study type. Ten articles were included in this review, with six systematic reviews (13-18) and four RCTs (19-22). Of the four included RCTs, two studies were interventions related to ACP and Goals of Care (20, 21). See Table 2 for a summary of article characteristics.

Table 2. Summary of ten studies included in the literature review

Characteristics of included papers	No. of studies
Country	
- Australia	8
- Others	2
Type of study	
- RCT	4
- Systematic Reviews	6
ACP intervention studies	8
ACP and related measures studies	
- Goals of Care	2

Synthesis of Results

For the ten included articles, details about the study topic, location, applied methodologies, research aims, data collection and analysis methods, study outcomes, and conclusions were extracted and recorded in a single Excel spreadsheet. Extracted data were examined for significant outcomes related to ACP use in RACFs, consumer perspectives related to ACP, and barriers and facilitators associated with ACP implementation in RACFs. Broadly, these papers provide evidence of the efficacy of advance care planning intervention in residential aged care.

Six systematic reviews evaluated ACP implementation strategies and outcomes (14, 15), facilitators and barriers to ACP uptake (13, 15-18), and consumer and family member perspectives on ACP processes (16-18). Four RCTs described interventions to improve ACP discussions and documentation (19, 22), and outcomes related to consumer experiences of ACP and the introduction of Goals of Care (GoC) medical treatment orders in RACFs (20, 21). The following sections provide a summary of the reported outcomes of ACP interventions, perspectives of consumers related to ACP, and barriers and facilitators impacting ACP uptake in RACFs.

Outcomes associated with higher rates of documented ACP

Five articles discussed the impact of ACP interventions on health service utilisation (14-16, 19, 21). RACFs with higher rates of ACP reported lower usage of acute healthcare services and fewer hospitalisations for residents (Figure 2).

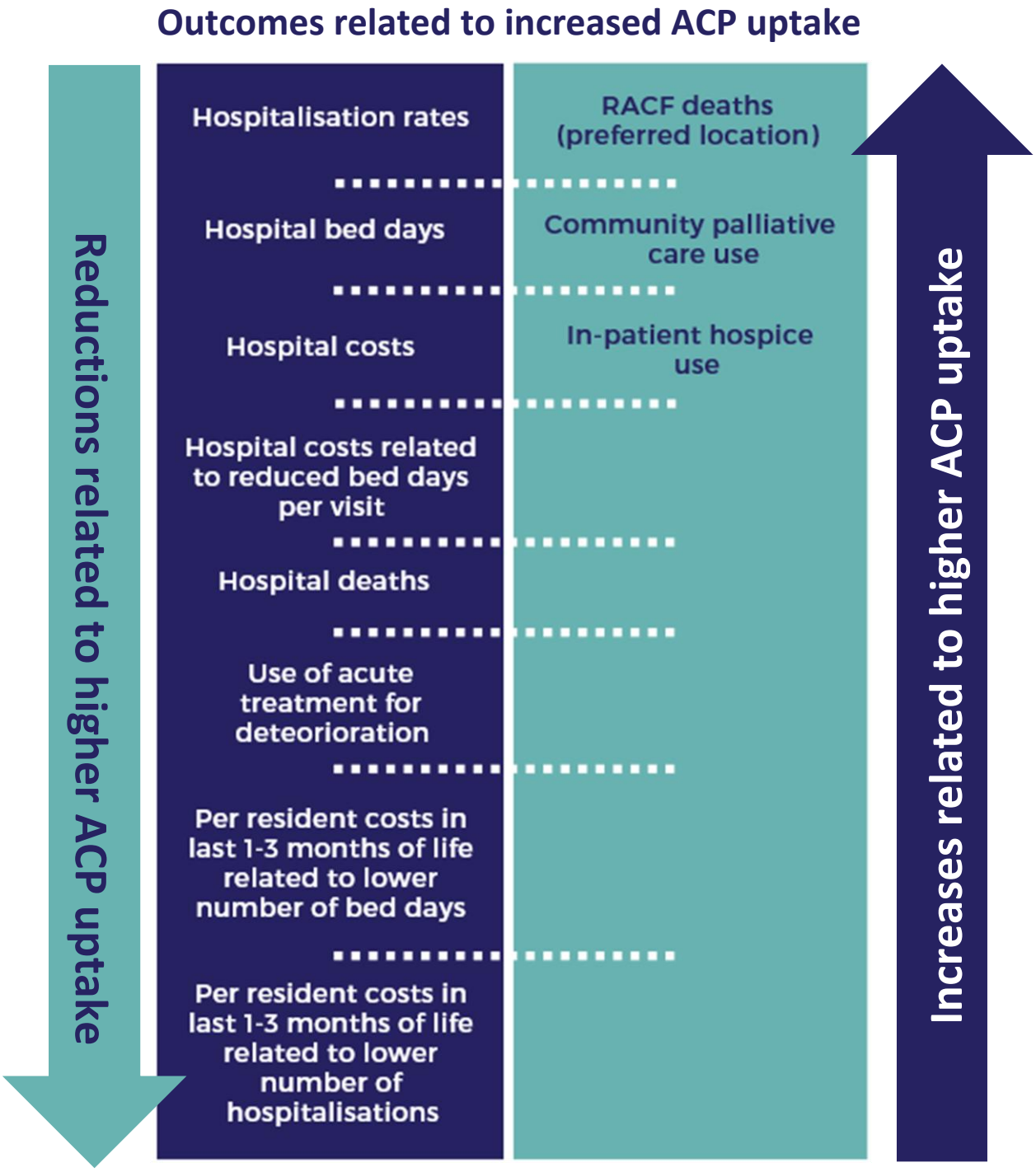

Figure 2. Outcomes associated with higher rates of ACP in RACFs

Two systematic reviews reported lower rates of hospitalisation for residents in RACFs with higher rates of ACP. In particular, higher ACP completion rates within RACFs were associated with decreased rates of terminal and non-terminal hospitalisation of residents (14), and reduced resident hospitalisation rates by between 9 and 26% (15). One study reported a 79% decrease in hospital bed days after an intervention to increase uptake of ACP documents in RACFs (15).

Reductions in the number or length of resident hospitalisations were also associated with significant per-resident cost savings across both the last month and last three months of a resident's life (15). Decreased hospital costs were reported in two papers, with an association between a reduced number of hospital bed days and the presence of ACDs for residents (15, 21). Higher rates of documented ACDs were associated with fewer resident deaths in hospital (16) and an increase in the number of resident deaths within RACFs (15). Higher rates of ACP were also associated with lower levels of acute are for medical deterioration (15, 19). One study reported 78% of residents and/or their substitute-decision makers preferred in-facility acute care over being hospitalised, and 70% of participants did not want aggressive medical treatment including CPR (19).

As shown in Figure 3, interventions promoting the combined documentation of ACDs and GoC reduced the rate of Emergency Department visits and hospitalisations for RACF residents by 40% (20, 21). Likewise, greater ACP uptake in RACFs also reduced the total number of bed days at each time of hospitalisation for residents (21).

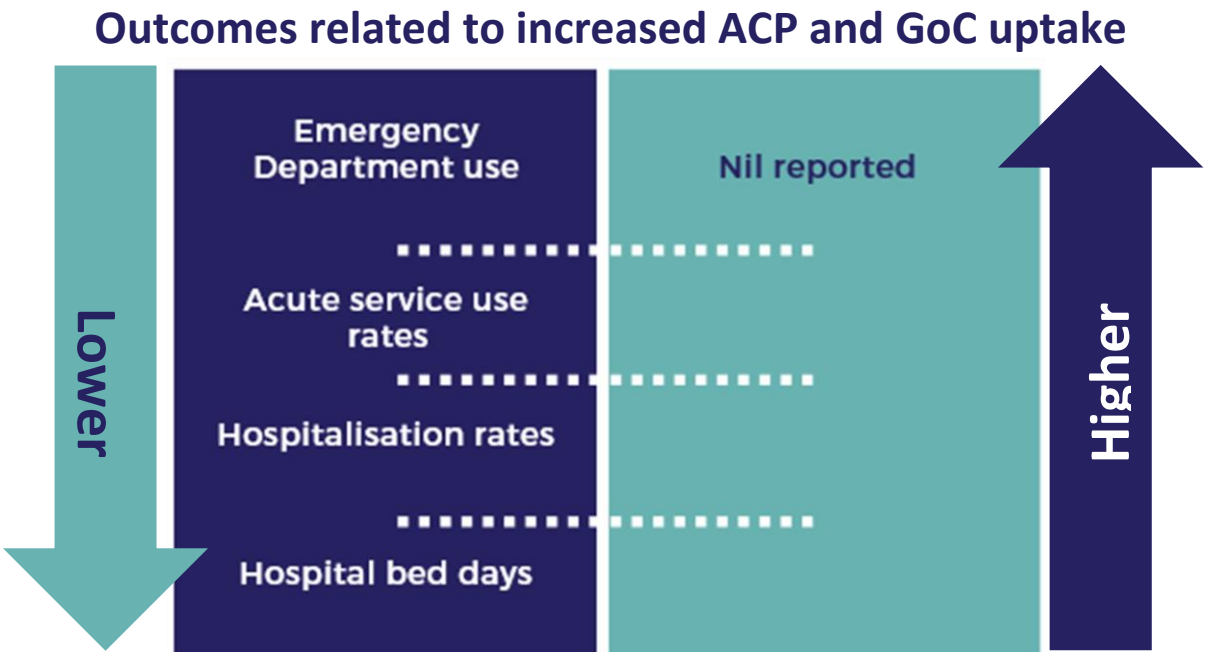

Figure 3. Outcomes associated with higher rates of ACP and GoC combined in RACFs

Consumer perspectives of ACP

Four articles included information about consumer perspectives related to ACP in RACFs (16-18, 22) Topics examined included the resident's perspectives on ACP, the perspectives of their family or loved ones on ACP, and perspectives of residents and their loved ones on the timing of ACP conversations.

Resident's perspectives on ACP

Only one article discussed resident's perspectives on ACP (16). Attitudes of residents who had completed ACP were predominantly positive, and most residents felt comfortable discussing end-of-life care preferences (16). Residents were prompted to engage in ACP discussions for several reasons. These included a need to "put their affairs in order"; experiencing changes to their medical needs or living situation; awareness of financial issues of a friend or a family member; previous experiences with death and dying of a loved one; and/or the wish to relieve family members from the burden of care, including burdens related to decision-making (16). Residents were also motivated to complete ACDs if they had limited trust family members would respect their wishes, lacked a surrogate decision-maker who would be able to speak on their behalf, or wanted to exert control over their end-of-life or avoid specific situations inducing fear, such as undergoing surgery (16).

Relative or loved one's perspectives on ACP

Family members' described the main barriers to discussing ACP with resident family members were a lack of cognitive capacity in the resident, resident personality in terms of their past life experiences, and a reluctance or avoidance by the resident to discuss end-of-life issues or engage in ACP discussions (16, 22). However, family members' also felt conversations about ACP provided them with clarity concerning their family member's preferences for medical treatment and care, and helped facilitate healthcare decision-making on behalf of the resident (22).

Among family members who had been involved in decision-making for residents, ACP had a positive effect on the perceived level of preparation for decision-making (22). However, contrasting results were found in two separate reviews in terms of family member perspectives on whether ACDs should be followed. Petriwskyj, Gibson (18) indicated the values and beliefs of Dutch family members influenced their agreement or disagreement for doctors to act on directions within an ACD, particularly where an ACD requested euthanasia or declined medical treatments. This reluctance to agree to euthanasia, however, often resulted in family members declining life-prolonging treatment as an alternative outcome. In contrast, a separate meta-synthesis reported

Dutch family members were more likely to agree that ACDs should always be followed than physicians (17) .

Facilitators and barriers to ACP implementation

Six papers described a range of facilitators and barriers impacting on ACP implementation (13, 15-18, 22). Themes related to a lack of knowledge among stakeholders (13, 17, 18), timing affecting ACP (13, 15, 16), invalid ACP documents (17, 19, 22), and the standardisation, transferability and convenience of ACP documents (13). A summary of all identified facilitators and barriers can be found in Figure 4.

Lack of knowledge among stakeholders (residents, relatives, and health service providers)

Three papers highlighted stakeholder knowledge of ACP can facilitate or impede ACP implementation (13, 17, 18). For example, Batchelor, Hwang (13) reported a lack of knowledge and understanding of ACP by residents and their family members reduced the confidence of staff to facilitate ACP conversations with residents (13). However, interventions involving training for nursing staff in identifying illness trajectories and the use of coordinated and systematic approaches to ACP with residents have been effective in increasing the uptake of ACP in RACFs (13).

Timing affecting ACP

Both the timing of, and the time allocated to, ACP are important factors that can facilitate or obstruct ACP uptake and implementation (13, 15, 16). According to one review, the amount of time available to health practitioners to engage in ACP was a key factor in ACP discussions (13). Specifically, where health practitioners had both the time and skills needed to discuss ACP with residents and their family members, ACP was facilitated. Conversely, time constraints placed on the health professional prevented ACP discussions from occurring in both residential and community aged care settings (13).

Both residents and family members stressed ACP discussions needed to occur at "the right time" and managing such a complex process required time, continuity, and stable relationships with healthcare providers (16). However, opinions about what constituted "the right time" varied, with some residents and family members believing conversations should start early, and others believing these discussions should wait until a resident's health begins to deteriorate (16). This variability is further complicated by evidence that waiting until a resident is admitted to an aged care facility may be too late for ACP conversations to take place, as only 36% of RACF residents have the degree of cognitive capacity need for ACP (15).

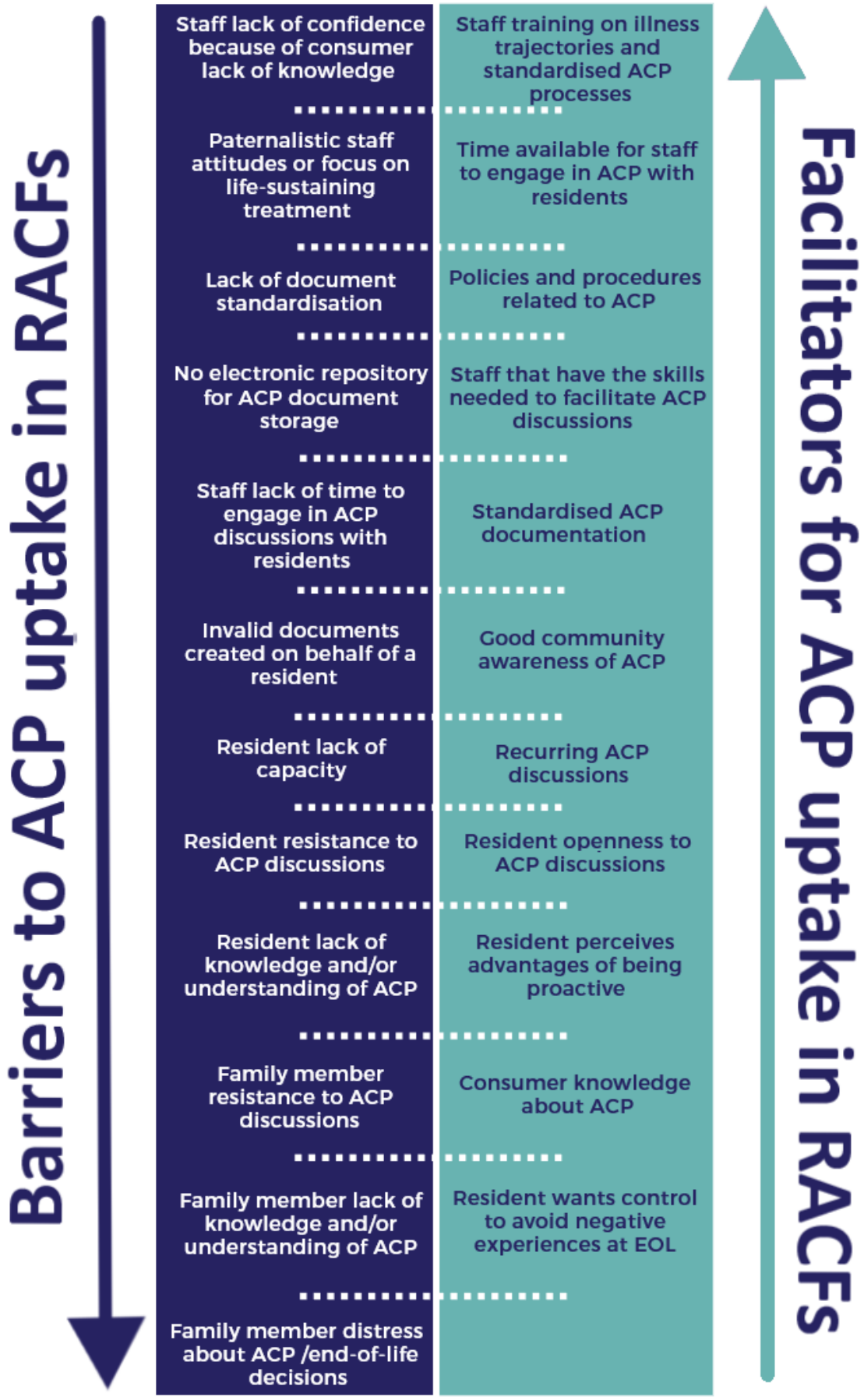

Figure 4. Facilitators and barriers to ACP implementation in RACFs

Other barriers to the implementation of ACP in RACFs included a reluctance of family members to discuss ACP, family members struggling to accept a "refusal of treatment" decision, emotional distress related to the burden of decision-making, and paternalistic attitudes of health care workers (13). Family members have also reported that inadequate information about ACDs at admission prevents ACP in RACFs (17) and this lack of information can result in incorrect decision-making on behalf of residents (18). Participants in the relevant studies also suggested additional education regarding disease progression and treatment, as well as a repeated discussion of ACP, would be beneficial (17).

Completion of advance care directives by others

Three papers examined the quality of ACP documents to find someone other than the resident completed a majority of ACP documents (17, 19, 22). For example, Harvey, Storer (19) found only 8% of residents completed an ACD themselves, despite more than half of participating residents retaining decision-making capacity as indicated by scores on the Mini-Mental State Examination (MMSE). Petriwskyj, Gibson (17) also found the children, family members, or resident's partner most often produced existing ACP agreements for residents with dementia, rather than the document being produced by the resident (17).

Standardisation, transferability, and convenience of ACP documents

Limited access by health professionals to a resident's ACP documents across health facilities can impede ACP. A review by Batchelor, Hwang (13), highlighted having accessibility and transferability of documents across care settings were imperative, but ACP uptake was limited by the lack of a central electronic registry and/or the absence of standardised ACP documents in RACFs (13). Likewise, having clear policies and procedures, and standardised documentation can facilitate ACP uptake in RACFs (13). In particular, uptake of ACP was better in facilities with clear organisational policies describing staff expectations and responsibilities regarding ACP, defined processes for facilitating ACP discussions with residents, and descriptions of local procedures regarding the documentation, storage, accessibility, and timing of ACP implementation (13).

Key findings

The current rapid review used systematic reviews and RCTs published between 2009 and 2019 to summarise outcomes associated with ACP uptake in RACFs, consumer perspectives related to the experience of ACP, and the different barriers and facilitators that can influence ACP uptake in RACFs. This section summarises the key findings of the rapid review.

ACP uptake in RACFs reduces hospital and acute healthcare service use

Higher rates of ACP uptake in RACFs reduce the use of hospital and acute services and reduce the use of unwanted acute treatments for deterioration. Likewise, a reduction in hospital and acute service use also produces per-resident cost savings in the last 1-3 months of a resident's life based on reduced hospitalisation rates and reduced hospital bed days. Increased uptake of ACP also resulted in increased use of community palliative care and in-patient hospice at end-of-life for residents and made it more likely residents will die in their preferred setting.

ACP improves end-of-life outcomes for residents and their family/loved ones

ACP is linked to improved end-of-life outcomes for residents, including increased likelihood of receiving care consistent with preferences, less aggressive treatment, and a greater probability of dying in a preferred setting and/or reduced rates of hospitalisation. Residents who had completed ACP described their experiences as predominantly positive, and most residents felt comfortable discussing end-of-life care preferences. In contrast, family and loved ones of residents reported ACP discussions were sometimes limited by the resident's capacity or willingness to engage in these discussions, and not all family members agreed ACP directions should always be followed. Family and loved ones of residents also described benefits engaging in ACP provided to them, such as greater confidence in decision-making on behalf of the resident. The timing of ACP conversations was also important to residents and their family and loved ones; however, there was little consistency about when the "best time" to have these discussions was.

Barriers to implementing ACP in RACFs

For consumers, barriers to ACP included lack of resident capacity to engage in ACP discussions, resident and family/loved ones resistance or distress related to ACP or end-of-life discussions, lack of knowledge or understanding about ACP, or paternalistic attitudes of staff towards medical decision-making. For staff, barriers included a lack of knowledge or training related to ACP and illness trajectories, lack of a central document repository, lack of time to facilitate ACP discussions with residents, lack of standardised documents and processes, invalid ACP documents created by someone other than the resident, and encountering resistance to, or a lack of understanding about, ACP by the resident and their family or loved ones.

Facilitators related to successfully implementing ACP in RACFs

ACP was facilitated in RACFs by the existence of ACP policies and procedures, standardised documentation, staff training in ACP and illness trajectories, and adequate resourcing to ensure staff have time to engage residents and their family or loved ones in ACP discussions. Likewise, ACP was facilitated by the willingness of residents to engage in ACP discussions, and when residents

perceived advantages to having an ACP, such as being able to exert control on their end of life experiences.

Limitations

By only including articles reporting on systematic reviews and RCTs related to ACP uptake in RACFs, it is possible additional outcomes, consumer perspectives, barriers, or facilitators present in other article types were not identified. Similarly, limiting the search to three databases may also have limited the number of relevant articles identified. Although all authors reviewed results, only a single researcher conducted the searches and extracted the data from relevant articles. Additionally, the current review only provides a high-level summary of outcomes, consumer perspectives, barriers, and facilitators related to ACP implementation in RACFs and does not provide an in-depth analysis of these results against existing literature.

Policy implications

This rapid review highlights the value and positive outcomes associated with ACP and ACD interventions and implementation in RACFs. Outcomes included positive person and family experience, promotion of end-of-life conversations and planning, increased uptake of ACDs and documented treatment preferences, and a reduction of hospital deaths, acute healthcare service utilisation, and associated costs. Barriers to ACP included a lack of understanding by individuals, families and health care providers, limited trust in others, family dynamics, timing, and availability of documentation. Facilitators to ACP included implementing ACP policy and systems in the RACF, education and training of both staff and consumers about ACP, and earlier interventions that involve the person, family, and treating health professional.

National and jurisdictional policy should promote increased ACP awareness, understanding, uptake, implementation and quality improvement across the aged care sector. Improving ACP uptake in RACFs will require increasing the knowledge and understanding of ACP, its processes and benefits for staff, residents, their family and loved ones, and the wider community. Organisations would benefit from implementing clear ACP policy, systems and quality improvement mechanisms, providing staff with ACP education and training, and making sure staff have enough time to engage in ACP discussions with residents and their family or loved ones. Staff would benefit from training related to illness trajectories and communication strategies to engage residents and their loved ones in ACP discussions. It would also be beneficial to enhance efforts to educate the wider community about ACP and encourage people to document their preferences before aged care services are needed.

Further ACP research in aged care settings is required to more clearly understand how to overcome barriers to uptake and improve outcomes for the person. Future research should include using RCTs that consider co-founding factors that influence ACP and the rate of health service use by aged care residents. Additional research is also needed that examines the experience of and outcomes associated with ACP for people with diverse backgrounds and with special needs.

Glossary

Term	Definition
Acute care[4]	Health services (usually hospitals) that provide care or treatment of people with short-term serious injury or illness. Medical conditions requiring acute care are typically periodic or temporary in nature, rather than long term.
Acute healthcare facility[7]	Acute healthcare facilities range from large tertiary referral centres to small district and community hospitals.
Advance care directive[2]	**Summary:** 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. **Framework:** Advance Care Directive is a catch-all term to refer to the instruments which are recognised in each jurisdiction under advance care planning legislation or common law. An advance care directive is a voluntary, person-led document completed and signed by a competent person that focus on an individual's values and preferences for future care decisions, including their preferred outcomes and care. Advance Care Directives are recognised by specific legislation (statutory) or under common law (non-statutory). They come into effect when an individual loses decision-making capacity. Advance Care Directives can also appoint substitute decision-makers who can make decisions about health or personal care on the individual's behalf. Advance Care Directives are focused on the future care of a person, not on the management of his or her assets.
Advance care directive prevalence[2]	The proportion of a study population that has a statutory or non-statutory advance care directive at the time of the study.

Term	Definition
Advance care plan[5]	Documents that capture an individual's beliefs, values and preferences in relation to future care decisions, but which do not meet the requirements for statutory or common law recognition due to the person's lack of competency, insufficient decision-making capacity or lack of formalities (such as inadequate person identification, signature and date).
Advance care planning (ACP)[5]	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 documentation[2]	ACP Documents are one way of formally recording an advance care plan. An ACP Document is a type of written advance care plan that is completed and signed by a competent adult and recognised by common law, or authorised by legislation. ACP Documents can record the person's preferences for future care and appoint a decision-maker to make decisions about health and other care. ACP Documents are focused on the future care of a person, not on the management of his or her assets.
Advance care planning documents (ACP Documents)[5]	A catch all term to include documents that results from advance care planning. This includes Advance Care Directives and Advance Care Plans.
Advance care planning legislation[5]	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[1]	Aged care means care of one or more of the following types: ▪ residential care ▪ home care ▪ flexible care.
Aged care service[3]	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

Term	Definition
Capacity[5]	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.
Carer[6]	People who provide personal care, support and assistance to people with a disability, medical condition (including terminal or chronic illness), mental illness, or frailty due to age. Carers include family members, friends, relatives, siblings or neighbours. Grandparents or foster carers providing care to a child with disability, medical condition (including terminal or chronic illness) or mental illness are included as carers.
Consumer[7]	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[3]	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)[6]	A broad and inclusive descriptor for communities with diverse language, ethnic background, nationality, dress, traditions, food, societal structures, art and religion characterise

Term	Definition
Decision-making	
Shared decision-making[7]	A consultation process in which a clinician and a patient jointly participate in making a health decision, having discussed the options, and their benefits and harms, and having considered the patient's values, preferences and circumstances.
Substitute decision-making[5]	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[5]	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[3]	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[6]	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[6]	Includes physical, spiritual and psychosocial assessment, and care and treatment delivered by health professionals 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.
Goals of care[7]	Clinical and other goals for a patient's episode of care that are determined in the context of a shared decision-making process.

Term	Definition
Health Practitioner[5]	Health practitioner refers to registered professionals such as medical, nursing and paramedicine practitioners and non-registered professionals who provide care including social workers and care workers.
Health record[7]	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[7]	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[2]	A state or territory within Australia.
Medical order[2]	A medically-driven document (usually completed by a doctor) that outlines the plan of care in relation to emergency treatment or severe clinical deterioration. Medical orders may include 'not for resuscitation' orders and other treatment limitations, as well as decisions regarding transfer to hospital. In some jurisdictions, medical orders are part of a state- or territory-based approach. Common names for medical orders include 'Resuscitation Plan' and 'Goals of Care'. Medical orders may or may not include reference to a person's known preferences.
My Health Record[7]	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[3]	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

Term	Definition
Organisation (continued)	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.
Palliative care[6]	Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-limiting illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.
Person[2]	Consumers of services provided by hospitals, residential aged care facilities and general practice. Used interchangeably with consumer, resident, patients and clients.
Person-centred care[3]	Person-centred care is care that is respectful of, and responsive to, the preferences, needs and values of patients and consumers.
Policy (organisational) [2]	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[7]	The set of instructions to make policies and protocols operational, which are specific to an organisation
Process[7]	A series of actions or steps taken to achieve a particular goal.
Substitute decision-maker[5]	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.

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3. Aged Care Quality Commission https://www.agedcarequality.gov.au/about-us/corporate-documents/aged-care-quality-and-safety-commission-glossary
4. Australian Health Sector Emergency Response Plan for Novel Coronavirus COVID-19 https://www.health.gov.au/sites/default/files/documents/2020/02/australian-health-sector-emergency-response-plan-for-novel-coronavirus-covid-19_2.pdf
5. National Framework for Advance Care Planning Documents
6. National Palliative Care Strategy https://www.health.gov.au/sites/default/files/national-palliative-care-strategy-2018.pdf
7. National Safety and Quality Health Service Standards https://www.safetyandquality.gov.au/standards/nsqhs-standards

Abbreviations

ACD	Advance care directive
ACP	Advance care planning
CPR	Cardiopulmonary resuscitation
GoC	Goal of Patient Care
MMSE	Mini-Mental State Examination
SDM	Substitute/surrogate decision-maker
RACF	Residential aged care facilities
RCT	Randomised control trial

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Appendix - Search strategy in detail

"Aged Care" OR "Residential Aged Care" OR Residential Aged Care* OR "Old Age Home" AND "Advance Care Planning" OR Advance Care Plan* OR "Advance Personal Plan" OR Advance Care* OR "Advance Health Care Planning" OR "Advance Medical Planning" OR "Advance Directives"

No.		PubMed	MEDLINE	CINAHL	Total
1	exp "Aged Care"				
2	exp "Residential Aged Care"				
3	Residential Aged Care*				
4	exp "Old Age Home"				
5	Or/1-4	2630	5,189	9,068	
6	exp "Advance Care Planning"				
7	Advance Care Plan*				
8	exp "Advance Personal Plan"				
9	Advance Care*				
10	exp "Advance Health Care Planning"				
11	exp "Advance Medical Planning"				
12	exp "Advance Directives"				
13	Or/6-12	4607	29,160	14,257	
14	5 AND 13	62	144	131	**337**
	Duplicates				**93**
	Remaining Total				**244**