

Prevalence of advance care planning documentation in Australian health and residential aged care services report 2019

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Acknowledgements

Advance Care Planning Australia is funded by the Australian Government and administered by Austin Health. Advance Care Planning Australia provides national leadership and expertise in advance care planning, community engagement, workforce education, translational research and advance care directive prevalence, information resources and advisory services. Our purpose is to build the foundation for a national collaborative approach to advance care planning.

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Disclaimer:

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Glossary

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 either recognised by specific legislation (statutory advance care directive) or 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 directive prevalence	The proportion of a study population that has a statutory or non-statutory advance care directive at the time of the study.
Advance care planning	The process of planning for future health and personal care, whereby the person's values, beliefs and preferences are made known so they can guide decision-making at a future time when that person cannot make or communicate their decisions.
Advance care planning documentation	The collective term for all advance care planning documentation completed by the person, a health professional or by someone else (e.g. family/carer or substitute decision-maker) and miscellaneous advance care planning material.
Advance care planning documentation by a health professional	The collective term for documentation related to advance care planning completed by a health professional. This may include an advance care plan completed on behalf of the person, an advance care planning discussion record, an advance care planning alert, or progress notes.
Advance care planning documentation by someone else	The collective term for documentation related to advance care planning completed by someone other than the person or a health professional, such as the person's family/carer or substitute decision-maker. This documentation may include an advance care planning document completed on behalf of the person, notes about the person's preferences, or documentation about the family's preferences.
Advance care planning documentation by the person	The collective term for statutory advance care directives and non-statutory advance care planning documentation completed by the person.
Clinical care plan	A medically-driven document recording a plan for care. These may be referred to as medical orders if completed by a doctor. A clinical care plan may or may not include specific reference to a person's preferences.

Data collector(s)	Staff member(s) who collected the data at each site. Data collectors had experience in retrieving information from health records, and may be quality managers, nurses or allied health professionals such as social workers. All data collectors were trained in the data collection procedures.
End-of-life	The period when a person is living with a fatal condition, even if the trajectory of illness is unknown. The period may be years for individuals with chronic life-limiting illnesses, or very brief in the case of acute and unexpected illnesses or events.
Health record/file	A comprehensive compilation of information traditionally placed in the medical record but also covering aspects of the person's physical, mental and social health that do not necessarily relate directly to the condition under treatment. The record(s) may be paper-based, electronic or both. Also referred to as records, files, case notes, electronic health records, medical records, patient file, client file and care plan.
Jurisdiction	A state or territory within Australia.
Medical order	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.
Miscellaneous advance care planning documentation	Other advance care planning material or resources, such as a pamphlet, brochure, flyer or information sheet, advance care planning invitation, advance care planning policy document, etc.
Non-statutory advance care directive	A structured written advance care planning document that is not a legislated state-based advance care directive. Non-statutory advance care directives should be completed and signed by a competent adult.
Non-statutory advance care planning documentation	Any advance care planning documentation completed by the person that is not a statutory advance care directive.
Palliative care	According to the World Health Organisation (2018), "palliative care is an approach that improves the quality of life of people and their families facing the problems associated with life-threatening 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. Palliative care can be

	provided by a specialist palliative care service or by generalist clinicians with skills in palliative care.
Person	Consumers of services provided by hospitals, residential aged care facilities and general practice. Used interchangeably with resident, patients and clients.
Statutory advance care directive	A written advance care planning document that is recognised by specific legislation. Statutory advance care directives should be completed and signed by a competent adult. Titles, content and requirements for validity vary between states/territories.
Study Lead	A staff member at each participating site who was the key contact for ACPA and responsible for coordinating the research at their site.
Study protocol	Study design and methodology approved by Austin Health Human Research Ethics Committee. Contains details about how the study will be implemented. This includes the data collection tools.
Substitute decision-maker	The person called upon to make medical treatment decisions on behalf of a person whose decision-making capacity is impaired. A substitute decision-maker can be: ▪ someone chosen (and appointed) by the person ▪ someone assigned as a decision-maker for the person by law (identified by a legislated hierarchy), or ▪ someone appointed on the person's behalf by a guardianship tribunal. For the purposes of advance care planning, only a person chosen and appointed by the person is relevant.

Abbreviations

ACT	Australian Capital Territory
ECOG	Eastern Cooperative Oncology Group
GP	General Practice
HREC	Human Research Ethics Committee
LPT	Life-prolonging treatment
QLD	Queensland
NMA	National Mutual Acceptance
NSW	New South Wales
NT	Northern Territory
SA	South Australia
SDM	Substitute decision-maker
RACF	Residential aged care facilities
TAS	Tasmania
VIC	Victoria
WA	Western Australia

Executive summary

This report describes data and information relating to the *2018 Prevalence of Advance Care Planning Documentation in Australian Health and Residential Aged Care Services Study*. The data represents the most comprehensive Australian evidence of advance care planning implementation in a selection of general practices, hospitals and residential aged care facilities across all jurisdictions.

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 to guide decision-making at a future time when that person cannot make or communicate their decisions.

Advance care planning is a priority for quality person-centred, palliative or end-of-life care and promotes an individual's choice and control over health care decisions. There are approximately 22 pieces of legislation related to advance care planning in Australia as well as jurisdictional and national policy, strategies, frameworks, accreditation standards and end-of-life review reports that support and prioritise advance care planning.

Informed by a 2017 pilot advance care planning documentation prevalence study, the purpose of this study was to investigate the prevalence, characteristics and accessibility of statutory and non-statutory advance care directives for older people at the point of care in Australian health and residential aged care services. This was achieved through conducting an audit of 4187 health records of individuals aged 65 years or more in participating general practices, hospitals, and residential aged care facilities. In addition, the study explored individual and site characteristics associated with advance care directives being available in the health record.

A total of 100 sites participated in the study, representing all eight Australian jurisdictions: the Australian Capital Territory (*n* = 3), New South Wales (*n* = 29), Northern Territory (*n* = 6), Queensland (*n* = 22), South Australia (*n* = 9), Tasmania (*n* = 1) and Victoria (*n* = 26) and Western Australian (*n* = 4). Participating sites included 15 general practices, 27 hospitals, and 58 residential aged care facilities.

The overall prevalence of having at least one advance care directive in the person's health record was 25%. Of these, only 6% of participants had a statutory advance care directive outlining their preferences for care, 12% of participants had a statutory advance care directive appointing a substitute decision-maker and 12% had a non-statutory advance care directive.

Prevalence rates were highest in residential aged care facilities, with 38% of residents having one or

more advance care directives (range 0%-100%). In comparison, approximately 11% of people in hospitals and 6% of people attending general practices had an advance care directive in their health record.

Overall prevalence rates were highest in South Australia (40%), Queensland (33%), and New South Wales (26%). Statutory advance care directives outlining preferences for care and statutory advance care directives appointing a substitute decision-maker were most common in South Australia (21% and 21%, respectively). Non-statutory advance care directives were most common in Victoria (17%) and New South Wales (17%).

People with dementia were no more likely to have at least one advance care directive (32%) than people with other medical conditions (prevalence range: 26% for persons with endocrine/metabolic conditions to 34% for persons with mental illness). Overall, only 17% of people with dementia had formally appointed a substitute decision-maker to make medical decisions on their behalf if they could not make or communicate decisions for themselves.

The prevalence of advance care planning documentation completed by someone else (e.g. family member, carer, substitute decision-maker) and not a competent person, was 18%. By health care sector, prevalence was much higher in residential aged care facilities (30%) compared to hospitals (3%) and general practices (0.3%). Advance care planning legislation does not allow for someone to document binding instructions on behalf of a non-competent person. Therefore, nearly half of the advance care planning documentation in aged care is possibility invalid (30% documented by someone else, compared to 38% documented by a competent person).

The majority of advance care directives were identified by data collectors in less than five minutes (80-89%). Approximately 72% of statutory advance care directives: preferences for care, 72% of non-statutory advance care directives and 32% of statutory advance care directives: substitute decision-maker were located in a specified advance care planning section of the patient health record.

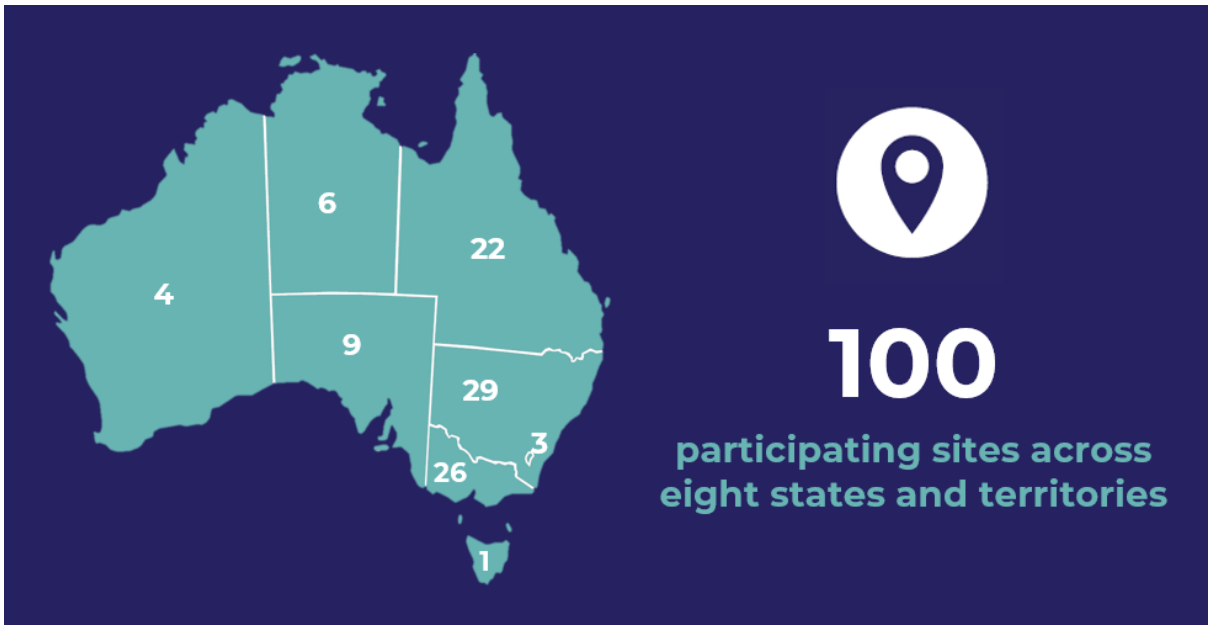
Sixteen (of a possible 1240) advance care directives were identified in the person's My Health Record. Fifteen of these were non-statutory advance care directives and one was a statutory advance care directive: substitute decision-maker. Only 32 of the 100 sites and only two of the 58 residential aged care facilities reported being connected to My Health Record.

In summary, this study identifies a number of important findings relating to advance care planning document uptake relevant to policy makers, health and residential aged care service providers and workforce, palliative care services, researchers, and the general public. Advance care planning

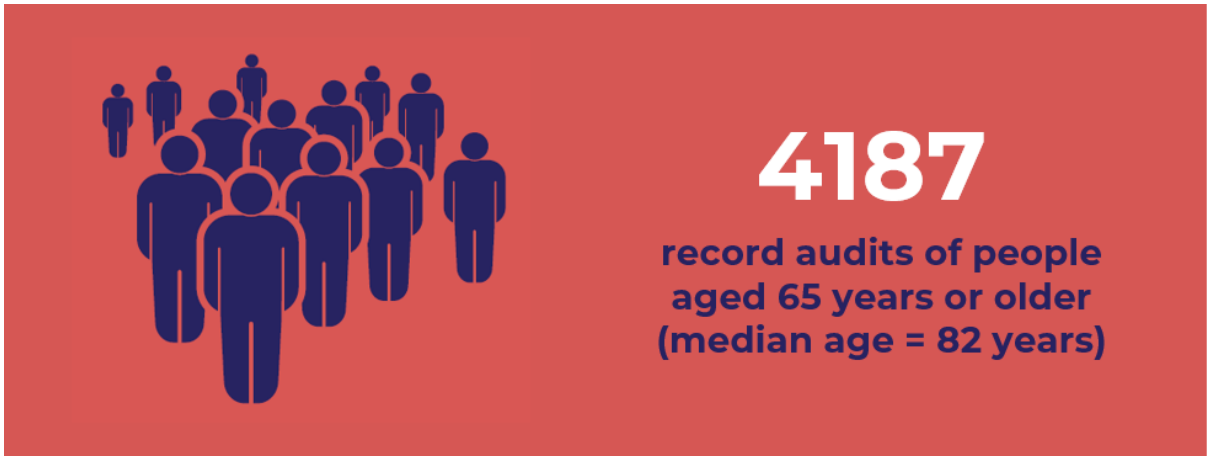
documentation prevalence remains low across all sectors and priority medical conditions such as dementia and oncology, limiting a person's ability to achieve choice and control over medical treatment decisions and end-of-life care. The prevalence of advance care directive documentation completed by someone else, rather than a competent person as per legislation, may be affecting legal and clinical validity and end-of-life care. The availability of existing advance care directives within My Health Record remains very low, limiting transferability between sectors and accessibility at the point of care. Further action and resources are required to achieve increased awareness, uptake, quality and regulation.

Infographics

Site and participant characteristics







Prevalence of advance care directives



25.3%

Of audited records contained at least one statutory or non-statutory advance care directive

5.9%

Statutory advance care directives: preferences for care

12.2%

Statutory advance care directives: substitute decision-maker

11.5%

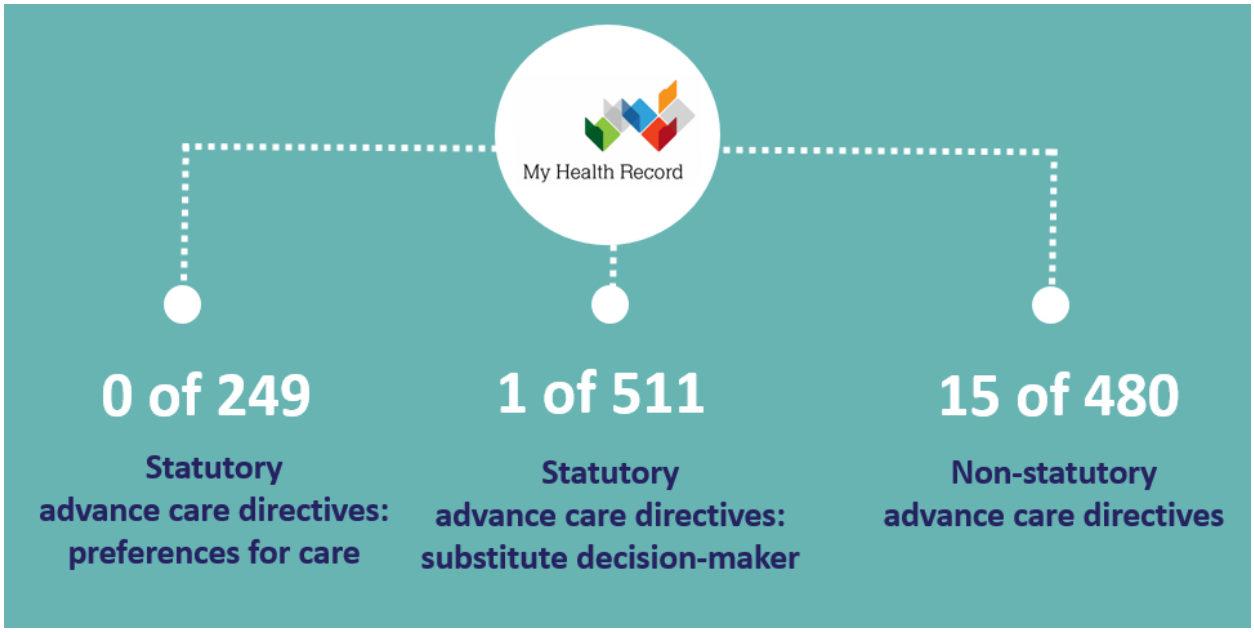
Non-statutory advance care directives

The prevalence of advance care directives was highest in residential aged care facilities compared to general practices and hospitals

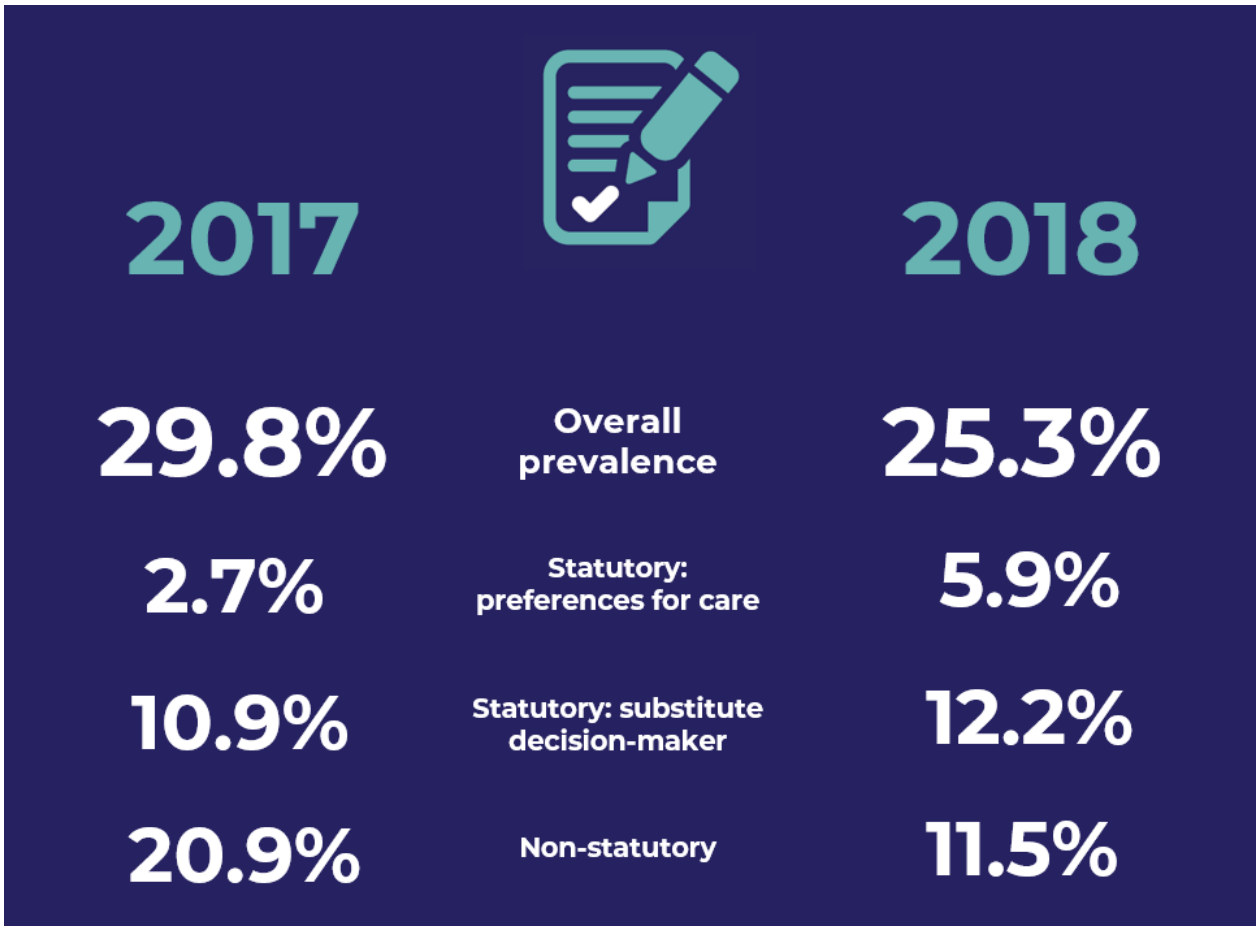
17%

of people with dementia appointed a substitute decision-maker

Advance care directives identified in My Health Record



Advance care directive prevalence: 2017 versus 2018



Introduction

This report describes data and information relating to the *2018 Prevalence of Advance Care Planning Documentation in Australian Health and Residential Aged Care Services Study.* The data represents the most comprehensive Australian evidence of advance care planning implementation for people aged 65 and over in a selection of general practices, hospitals and residential aged care facilities. The findings inform recommendations to improve advance care planning and advance care directive awareness, uptake, quality and regulation.

Background

Advance care planning is the process of planning for future health and personal care whereby a person's values, beliefs and preferences are made known so they can guide clinical decision-making at a future time when that person cannot make or communicate their decisions.[1] Advance care planning is an ongoing process. The ultimate goal of advance care planning is to align the care the person actually receives with their preferences for care.

While conversations related to advance care planning are valuable in their own right, ideally the outcomes of any discussions will be documented in a written advance care plan.[2] Documentation of a person's preferences helps substitute decision-makers, healthcare professionals and services make informed decisions about care when a person is unable to express their preferences. Missing, ambiguous or inaccurate documentation of a person's advance care planning preferences may lead to inappropriate or unwanted care for people at the end-of-life or undue stress and burden on family members.[3]

An advance care directive is a type of written structured advance care plan recognised by common law or specific legislation that is completed and signed by a competent adult.[4] An advance care directive will typically document the person's values, beliefs and specific preferences for future care and/or include the appointment of a substitute decision-maker. A substitute decision-maker may be required to make medical treatment decisions on behalf of a person whose decision-making capacity is impaired.[4,5]

Currently all Australian states and territories offer an advance care directive form that is accorded legal status under either state legislation (statutory advance care directive) or common law/policy (non-statutory advance care directive). Statutory advance care directives aim to document a person's instructions for future treatments for a specific medical condition and/or to appoint a

substitute decision-maker. Non-statutory documents focus more broadly on a person's values, beliefs, and goals for future care.[4,5] New South Wales and Tasmania use only non-statutory advance care directives as there is no legislative framework in place. Non-statutory advance care directives are in use in all states or territories however the legal standing of these documents remains unclear in other jurisdictions.[5]

An advance care directive provides evidence of a person's views and preferences to assist substitute decision-makers and healthcare providers to make informed decisions about care. Documentation of a person's preferences in an advance care directive is linked to a number of improved outcomes at the end-of-life, including reduced hospitalisations, increased likelihood that the person will die in their preferred setting, and reduced stress, anxiety and depression in surviving loved ones.[3,6-9] Advance care planning can also reduce the application of unwanted medical treatments, which has important implications for the cost-effectiveness of future healthcare.[10] Despite the recognised benefits of formally documenting one's advance care planning preferences, available estimates suggest less than 30% of Australians have completed an advance care directive.[11-15]

Australian Governments have committed to addressing the palliative care and advance care planning needs of Australians through the National Palliative Care Strategy 2018[16] and A National Framework Advance Care Directives 2011.[4] Many states and territories have advance care planning strategies and programs prioritising awareness and uptake of advance care planning and directives. The development of a national advance care planning documentation dataset provides important evidence to inform governments, policies, programs and services.

In 2017, Advance Care Planning Australia undertook a pilot study assessing the prevalence of advance care planning documentation in Australian health and residential aged care services.[2] This initiative aimed to provide essential data regarding the prevalence and accessibility of advance care directives among people aged 65 years or more in general practice, hospitals, and aged care facilities across multiple Australian jurisdictions. The study also aimed to evaluate whether medically-driven plans developed for the person were consistent with the preferences specified in the person's advance care directive.

A total of 51 sites participated in the 2017 pilot study, including 13 general practices, 12 hospitals and 26 residential aged care facilities located in six Australian jurisdictions. Findings revealed a prevalence of 29.8%. Only 2.7% of participants had a statutory advance care directive outlining their preferences for care. Only 10.9% of participants had a statutory advance care directive appointing a substitute decision-maker. Rates of non-statutory advance care directives were higher at 20.9%.

There was considerable variability in the prevalence of advance care directives across participating sites, sectors and jurisdictions.[11]

The *2018 Prevalence of Advance Care Planning Documentation in Australian Health and Residential Aged Care Services Study* builds upon the findings and methodology of the pilot study.

The aims of this study were to:

1. Determine the prevalence of advance care directives and other documented outcomes of advance care planning in paper and/or electronic health records of people aged ≥65 years admitted to hospitals or residential aged care facilities, or attending general practices.
2. Assess the content and quality of identified advance care directives.
3. Explore consistency between medical orders and the person's documented preferences for care in their advance care directive.
4. Explore the characteristics of individuals and study sites where advance care directives are present in the health record.

Methods

The protocol for the pilot study was published in *BMJ Open*.[2]

Ethics approval

Ethics approval was provided by Austin Health Human Research Ethics Committee (reference number: HREC/18/Austin/109) under the National Mutual Acceptance (NMA) agreement. The NMA agreement provided single ethical review for public health organisations in the participating states of the Australian Capital Territory, New South Wales, Queensland, South Australia, Victoria and Western Australia. Separate ethics approval was obtained for the Northern Territory and Tasmania. General practices and residential aged care facilities that were privately owned/operated were not mandated to obtain ethical review but were supported to obtain ethical clearance as required. Public health organisations were supported to obtain site-specific assessment approvals via local research governance departments.

Project governance

This study was led by Advance Care Planning Australia in collaboration with other national investigators. It was overseen by a national research advisory group that was chaired by Advance Care Planning Australia, and included academics and clinicians with interdisciplinary expertise relevant to this study including in medicine, nursing, psychology and law. The advisory group also included representation from the hospital, general practice and aged care sectors participating in this study.

The research collaboration and advisory group were responsible for reviewing and endorsing the project methodology; providing advice regarding site recruitment across sectors, risk management, intellectual property and ethical concerns; and overseeing the collection and interpretation of data within the contextual and jurisdictional aspects of the study.

Design

The study was a national multicentre cross-sectional study consisting of two parts:

1. A survey of study sites to collect information on site demographics and current advance care planning practices, and
2. An audit of health records of people admitted to or attending participating services.

Part 1. Site survey

Sample

Participating organisations were general practices, hospitals and residential aged care facilities located in all eight Australian states and territories who met the assessment criteria outlined in Table 1. Study sites were required to nominate a Study Lead and 1-3 data collectors.

Recruitment

Sites were recruited through an expression of interest process, coordinated by Advance Care Planning Australia and promoted via state and territory departments of health and stakeholder networks utilising newsletters and websites. Additional sites were approached by the project team to promote representativeness across health sectors and jurisdictions.

Data collection

All prospective sites were required to complete an online expression of interest survey. Section one of the survey assessed site eligibility (see Table 1). Sites needed to meet all criteria before proceeding to the following section. Section two of the survey collected information on site demographics and current advance care planning practices. Data items are presented in Table 2.

Table 1. Site eligibility criteria.

General criteria
General practices, hospitals and residential aged care facilities are eligible to apply if they: 1. Are an accredited organisation according to sector requirements 2. Have the approval and endorsement of their executive team 3. Can nominate one staff member as the Study Lead (responsible for coordination of the study at the site and will be the key contact person for the research team) 4. Have internet, email and telephone access 5. Have access to devices for online data collection (e.g., computer, laptop or iPad) 6. Have policies in place about privacy and confidentiality 7. Agree that the information provided in their application will be used to generate a Research Collaboration Agreement if successful and are willing to sign this preferably within four weeks of being notified of successful application 8. Meet all sector-specific eligibility criteria.
Sector-specific eligibility criteria
Hospitals and residential aged care facilities are eligible to apply if they: 1. Expect that their site will have at least 50 patients/ residents on the day(s) of the study that are aged 65 years or older and have been admitted for at least 48 hours* 2. Have a records management system with the ability to extract a list of all admissions of people aged 65 years or older who have been admitted for more than 48 hours on the day(s) of the study 3. Can nominate up to two additional staff members to collect the data for the study. 4. Are willing to support the Study Lead and data collectors(s) to undertake mandatory online training in data collection procedures 5. Have the capacity to review a minimum of 30 health records. Hospitals will also be required to obtain additional ethics approval and/or a site-specific assessment at their site, within six-eight weeks of notification of successful application. * A minimum of 30 health records will be randomly selected from eligible records on the day(s) of the study. General practices are eligible to apply if they: 1. Expect that at least 30 patients aged 65 years or older will attend their practice on the day(s) of the study 2. Have a records management system with the ability to extract a list of all people aged 65 years or older attending the practice on the day(s) of the study 3. Can nominate up to two additional staff members to collect the data for the study OR agree to data collector(s) being provided by Advance Care Planning Australia.

Table 2. Site-level data variables

Category	Variable(s)
Demographic information	Jurisdiction, location, funding (government, not-for-profit, private), record management system used
Size of service	Capacity/number of beds, number of registered health professionals currently employed
Advance care planning program/activity	Current advance care planning program/activity within the service, when this commenced, advance care planning training available for staff and how advance care planning is funded and/or implemented Presence/absence of advance care planning policy, consumer resources, and advance care directive templates/forms. (*Sites were asked to upload their advance care planning policy documents and/or blank advance care directive templates/ forms utilised in their service)*

Part 2. Health record audit

Sample

Audit participants were people aged 65 years or older who were admitted to a participating hospital or residential aged care facility for at least 48 hours prior to the audit, or were attending a participating general practice on the nominated day(s) of the study.

Recruitment

In hospitals and residential aged care facilities, health records were randomly selected for the audit from a list of eligible people obtained on the first day of the study at that site. In general practices, consecutive eligible records were audited until the required number was achieved.

Data collection

The audit was conducted by staff of participating sites who were trained in the audit methodology using a pilot-tested and standardised approach. The training materials and online data collection instrument were tailored to each Australian state and territory, reflecting jurisdictional differences in legislation, documentation and terminology.

After obtaining the paper and/or electronic health records selected for the audit, data collectors searched each record for a maximum of 15 minutes for four broad categories of advance care planning documentation, which were classified based on who completed the document:

1. Advance care directives completed by the person
2. Advance care planning documentation completed by a health professional
3. Advance care planning documentation completed by someone else (e.g., a family member, carer or substitute decision-maker), and
4. Miscellaneous advance care planning documentation (e.g., advance care planning pamphlets or brochures).

Data collectors were provided with clear definitions and examples of each category of documentation, together with flowcharts to assist in identifying and classifying documents. An example flowchart is provided in Figure 1.

If any of the four types of relevant documentation were identified during the audit, data collectors completed the applicable section(s) of the audit tool. If no relevant documentation was found, only the demographic section of the audit tool was completed. A full list of data items collected during the audit is provided in Table 3. The search timeframe of 15 minutes was applied because in order to be useful in practice, advance care planning documentation needs to be quickly and easily accessible. All data were entered and stored on a secure online database specifically built for the study.

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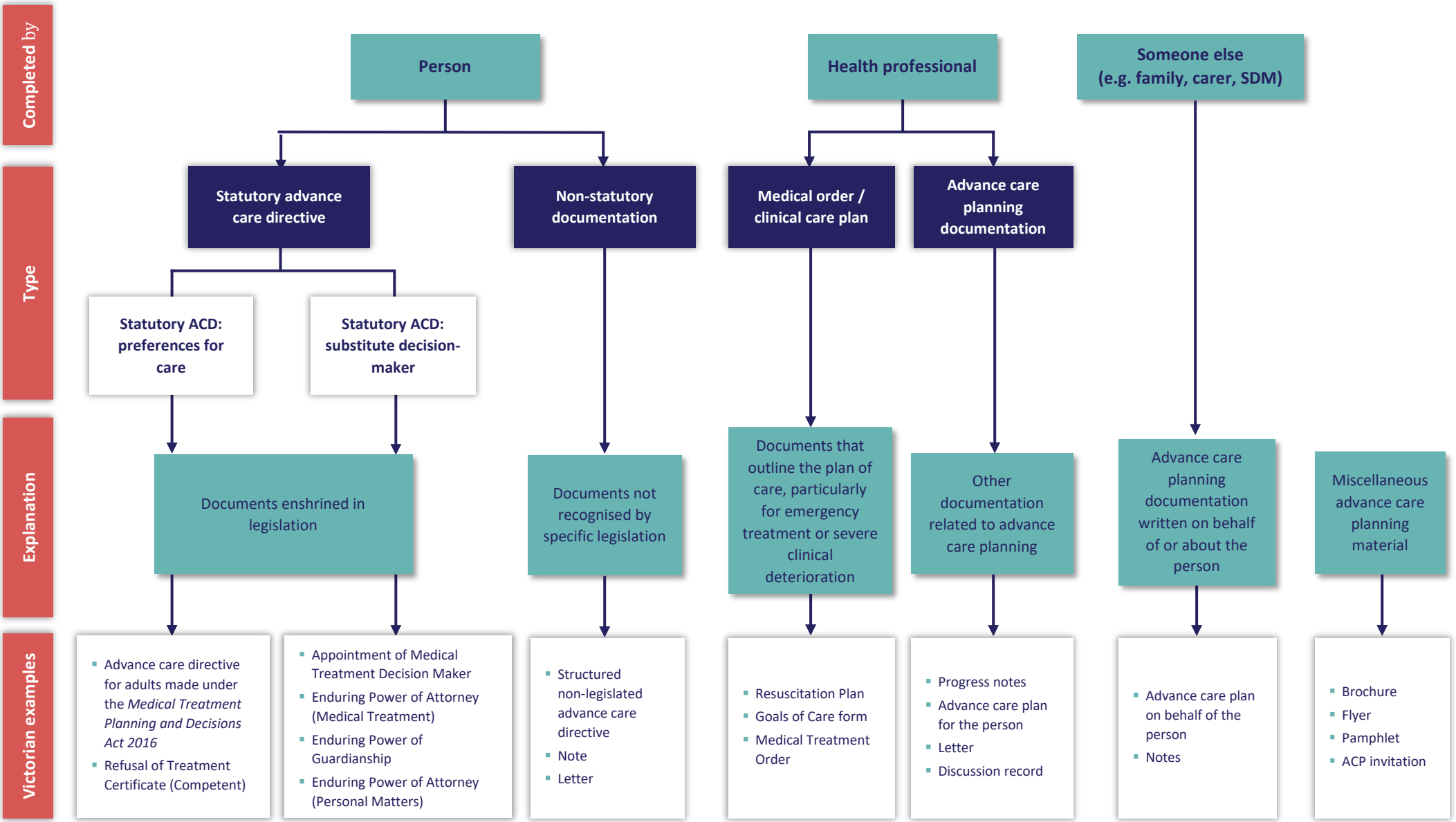

Table 3. Participant data variables.

Category	Variable(s)
Demographic information	Age, gender, postcode, country of birth, Indigenous status, relationship status, religion, English or other language spoken
Clinical information	Date of admission/visit, current/active medical conditions (categorised by organ systems), palliative care status, Eastern Cooperative Oncology Group (ECOG) status (or estimated functional status if ECOG not available)
Type of documentation (see Figure 1) *Classified based on who completed documentation*	Completed by: • The person (statutory and non-statutory advance care directives; other e.g. letter) • A health professional (medical orders/clinical care plans; advance care planning documentation) • Someone else (advance care planning documentation by family, substitute decision-maker etc) • Miscellaneous advance care planning material (e.g. brochure)
Details of documentation	Time taken to find document, location of document in the health record, date of document, whether the document contains the person's name, address and date of birth, information regarding who signed documentation (including witnesses where appropriate), treatment preferences and/or other preferences specified in the document, characteristics of medical orders

Outcome measures

The primary outcome was the prevalence of at least one advance care directive completed by the person (statutory advance care directive: preferences for care, statutory advance care directive: substitute decision-maker and/or non-statutory advance care directive) in the health record. Secondary outcomes included the characteristics (e.g., content and quality) of advance care directives completed by the person, as well as the prevalence and characteristics of medical orders, advance care planning documentation completed by a health professional, advance care planning documentation completed by someone else (e.g., family, substitute decision-maker) and miscellaneous advance care planning material.

Reliability analysis

Reliability analysis was undertaken for primary and secondary outcome variables based on two data collectors' independent audit of the same 40 health records. Reliability was assessed using percentage agreement and the kappa statistic. For the primary outcome, percentage agreement between the two data collectors was 100% and the kappa statistic level of agreement was very high. [17] For the secondary outcome variables, percentage agreement ranged between 97.1% and 100% and the kappa statistic level of agreement was good to very good.

Statistical analysis

Statistical analyses were conducted using SPSS v24.0 (IBM). Descriptive statistics were used to profile the characteristics of participating sites and demographic characteristics of audit participants.

Advance care directive prevalence overall, and for the three types of advance care directives completed by the person (statutory advance care directive: preferences for care, statutory advance care directive: substitute decision-maker and non-statutory advance care directive), was calculated for the total sample and separately for settings and jurisdictions. Advance care directive prevalence rates were further broken down by participant demographic and clinical characteristics.

Secondary analyses were conducted to describe the prevalence and characteristics of medical orders, advance care planning documentation by a health professional, advance care planning documentation by someone else and miscellaneous advance care planning material.

Findings

Study sites

During October 2018 to January 2019, auditors collected data from 100 sites. Sites included 15 general practices, 27 hospitals and 58 residential aged care facilities representing all eight Australian states and territories. Just under half were located in metropolitan areas (46%). Approximately one-third of sites and only two of 58 residential aged care facilities had access to My Health Record. Site characteristics are presented in Table 4.

Table 4. Site characteristics (*n* = 100).

Characteristic		*n* (%)
Jurisdiction	Australian Capital Territory	3 (3.0)
	New South Wales	29 (29.0)
	Northern Territory	6 (6.0)
	Queensland	22 (22.0)
	South Australia	9 (9.0)
	Tasmania	1 (1.0)
	Victoria	26 (26.0)
	Western Australia	4 (4.0)
Sector	General practice	15 (15.0)
	Hospital	27 (27.0)
	Residential aged care facility	58 (58.0)
Location	Metropolitan	46 (46.0)
	Regional	39 (39.0)
	Rural or remote	15 (15.0)
Type	Government	35 (35.0)
	Not-for-profit	33 (33.0)
	Private	18 (18.0)
	Combination	14 (14.0)
Access to My Health Record	Yes	32 (32.0)
	No / unsure	68 (68.0)

The majority of sites had a formal advance care planning program (81%). Most provided advance care planning resources to clients (90%), had mechanisms to record advance care planning activities (98%) and provided advance care planning training to staff (71%). Just over 60% had an advance care planning policy or guideline available, while 71% used template advance care directives. However, nearly 60% reported that no funding was provided to support advance care planning practices within the site.

Health record audit participants

Of 4188 audited records, one fell outside of specified age criteria and was excluded, leaving a total cohort of 4187 participants. Participant characteristics are summarised in Table 5.

Table 5. Sample characteristics* (*n* = 4187)

Characteristic		*n* (%)
Age (years)	Median (interquartile range)	82 (14)
Sex	Female	2525 (60.3)
	Male	1647 (39.3)
	Other	10 (0.2)
	Unknown	5 (0.1)
Country of birth	Australia	2688 (64.2)
	Other	1152 (27.5)
	Unknown	347 (8.3)
Speaks English	Yes	3750 (89.6)
	Interpreter required	277 (6.6)
	Unknown	160 (3.8)
Current relationship status	Married/de facto	1452 (34.7)
	Divorced/separated	387 (9.2)
	Widowed	1612 (38.5)
	Single	408 (9.7)
	Unknown	328 (7.8)
Medical condition(s) †	Cancer (malignant)	628 (15.0)
	Dementia	1388 (33.2)
	Heart condition	2194 (52.4)
	Respiratory condition	998 (23.8)
	Chronic kidney condition	445 (10.6)
	Endocrine/metabolic/nutritional	1343 (32.1)
	Gastrointestinal condition	1043 (24.9)
	Neurological condition	959 (22.9)
	Urinary or reproductive condition	884 (21.1)
	Mental health condition	1370 (32.9)
	Musculoskeletal/connective tissue	2250 (53.7)
	Other	516 (12.3)
Number of medical conditions (morbidity)	No current conditions	73 (1.7)
	One condition	608 (14.5)
	Two conditions	766 (18.3)
	More than two conditions	2740 (65.4)

Table 5 (cont.). Sample characteristics* (*n* = 4187)

Characteristic		*n* (%)
Palliative care	Yes	327 (7.8)
	No	3561 (85.0)
	Unknown	299 (7.1)
Functional status [⁎]	No disability	440 (10.5)
	Some disability	451 (10.8)
	Moderate disability	914 (21.8)
	Severe disability	1506 (36.0)
	Very severe disability	676 (16.1)
	Insufficient information to determine	200 (4.8)

Note: *Reported as median and interquartile range for continuous variables and as frequency (percentage) for categorical variables. [†] Participant may have more than one medical condition. [⁎]Assessed using ECOG performance status where available and estimated based on information in the health record where ECOG not available.

Advance care directives completed by the person

Overall prevalence of advance care directives completed by the person

Prevalence rates for advance care directives completed by the person are presented in Table 6. The overall prevalence of having at least one advance care directive was 25.3%. Statutory advance care directive: substitute decision-maker were the most frequently identified documents (12.2%) followed by non-statutory advance care directives (11.5%) and statutory advance care directive: preferences for care (5.9%); see Table 6.

The majority of advance care directives (80%-89%) were identified within 5 minutes. Statutory advance care directives: substitute decision-maker were most likely to be identified in paper-based records (47.7%) followed by electronic records (34.4%) and both paper and electronic records (17.8%). Statutory advance care directives: preferences for care were equally likely to be identified in either paper (38.2%) or electronic records (38.2%) followed by both paper and electronic records (23.7%). Non-statutory advance care directives were most commonly located in paper records (36.5%) followed by electronic records (31.7%) and both paper and electronic records (30.8%). Approximately 72% of statutory advance care directives: preferences for care, 72% of non-statutory advance care directives and 32% of statutory advance care directives: substitute decision-maker were located in a specified advance care planning section of the patient health record.

Sixteen advance care directives were identified in the person's My Health Record; 15 of these were non-statutory advance care directives and one was a statutory advance care directive: substitute decision-maker. Only 32 of the 100 sites and only two of the 58 residential aged care facilities were linked to My Health Record.

The prevalence of advance care directives varied across health care settings, as shown in Table 6. People in residential aged care facilities had the highest percentage of having at least one advance care directive on file (37.7%) compared to people in hospitals (11.1%) and general practices (5.5%). Prevalence also varied greatly across sites (0%-100%), as shown in Figure 2.

By jurisdiction, overall prevalence rates were highest in South Australia (40.0%) followed by Queensland (32.6%), New South Wales (25.7%) and Victoria (24.2%); see Table 6. However, caution is necessary in interpreting these differences, given that not all jurisdictions had representation from the three health sectors, and only one site was included from Tasmania.

Table 6. Prevalence of advance care directives overall, and by health sector and jurisdiction (*n* = 4187).

		Individual type of ACD† (*n*, %)		
	At least one ACD overall	Statutory ACD: preferences for care	Statutory ACD: SDM	Non-statutory ACD
Total sample (*n* = 4187)	**1061 (25.3)**	**249 (5.9)**	**511 (12.2)**	**480 (11.5)**
Healthcare sector				
General practice (*n* = 676)	37 (5.5)	6 (0.9)	22 (3.3)	21 (3.1)
Hospital (*n* = 1122)	124 (11.1)	36 (3.2)	93 (8.3)	30 (2.7)
RACF (*n* = 2389)	900 (37.7)	207 (8.7)	396 (16.6)	429 (18.0)
Jurisdiction				
Australian Capital Territory (*n* = 127)	**17 (13.4)**	**1 (0.8)**	**9 (7.1)**	**9 (7.1)**
General practice	-	-	-	-
Hospital	9 (11.0)	1 (1.2)	8 (9.8)	2 (2.4)
Residential aged care facility	8 (17.8)	0 (0.0)	1 (2.2)	7 (15.6)
New South Wales (*n* = 1187)	**305 (25.7)**	**1 (0.1) ⁎**	**129 (10.9)**	**196 (16.5)**
General practice	7 (23.3)	0 (0.0)	0 (0.0)	7 (23.3)
Hospital	6 (1.8)	0 (0.0)	3 (0.9)	4 (1.2)
Residential aged care facility	292 (35.6)	1 (0.1) ⁎	126 (15.4)	185 (22.6)
Northern Territory (*n* = 290)	**15 (5.2)**	**11 (3.8)**	**15 (5.2)**	**0 (0.0)**
General practice	3 (1.3)	2 (0.8)	3 (1.3)	0 (0.0)
Hospital	12 (24.0)	9 (18.0)	12 (24.0)	0 (0.0)
Residential aged care facility	-	-	-	-
Queensland (*n* = 850)	**277 (32.6)**	**111 (13.1)**	**149 (17.5)**	**52 (6.1)**
General practice	4 (8.0)	2 (4.0)	2 (4.0)	3 (6.0)
Hospital	51 (19.2)	17 (6.4)	36 (13.6)	7 (2.6)
Residential aged care facility	222 (41.5)	92 (17.2)	111 (20.7)	42 (7.9)
South Australia (*n* = 420)	**168 (40.0)**	**87 (20.7)**	**89 (21.2)**	**27 (6.4)**
General practice	9 (8.9)	0 (0.0)	9 (8.9)	0 (0.0)
Hospital	-	-	-	-
Residential aged care facility	159 (49.8)	87 (27.3)	80 (25.1)	27 (8.5)
Tasmania (*n* = 50)	**5 (10.0)**	N/A	**0 (0.0)**	**5 (10.0)**
General practice	5 (10.0)	N/A	0 (0.0)	5 (10.0)
Hospital	-	N/A	-	-
Residential aged care facility	-	N/A	-	-
Victoria (*n* = 1118)	**270 (24.2)**	**35 (3.1)**	**120 (10.7)**	**190 (17.0)**
General practice	9 (5.1)	2 (1.1)	8 (4.6)	6 (3.4)
Hospital	44 (13.5)	7 (2.1)	34 (10.4)	17 (5.2)
Residential aged care facility	217 (35.2)	26 (4.2)	78 (12.7)	167 (27.1)
Western Australia (*n* = 145)	**4 (2.8)**	**3 (2.1)**	**0 (0.0)**	**1 (0.7)**
General practice	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)
Hospital	2 (3.3)	2 (3.3)	0 (0.0)	0 (0.0)
Residential aged care facility	2 (3.7)	1 (1.9)	0 (0.0)	1 (1.9)

Note: A dash [-] indicates a sector/jurisdiction that was not represented in the study. N/A indicates a document that is not available in a particular jurisdiction. † Participants may have had more than one type of advance care directive. ⁎ Statutory ACDs: preferences for care are not available in NSW; however, one NSW participant had an interstate (Queensland) ACD. This ACD has been included in the prevalence rate for NSW as it would be subject to NSW legislation. ACD = advance care directive; SDM = substitute decision-maker.

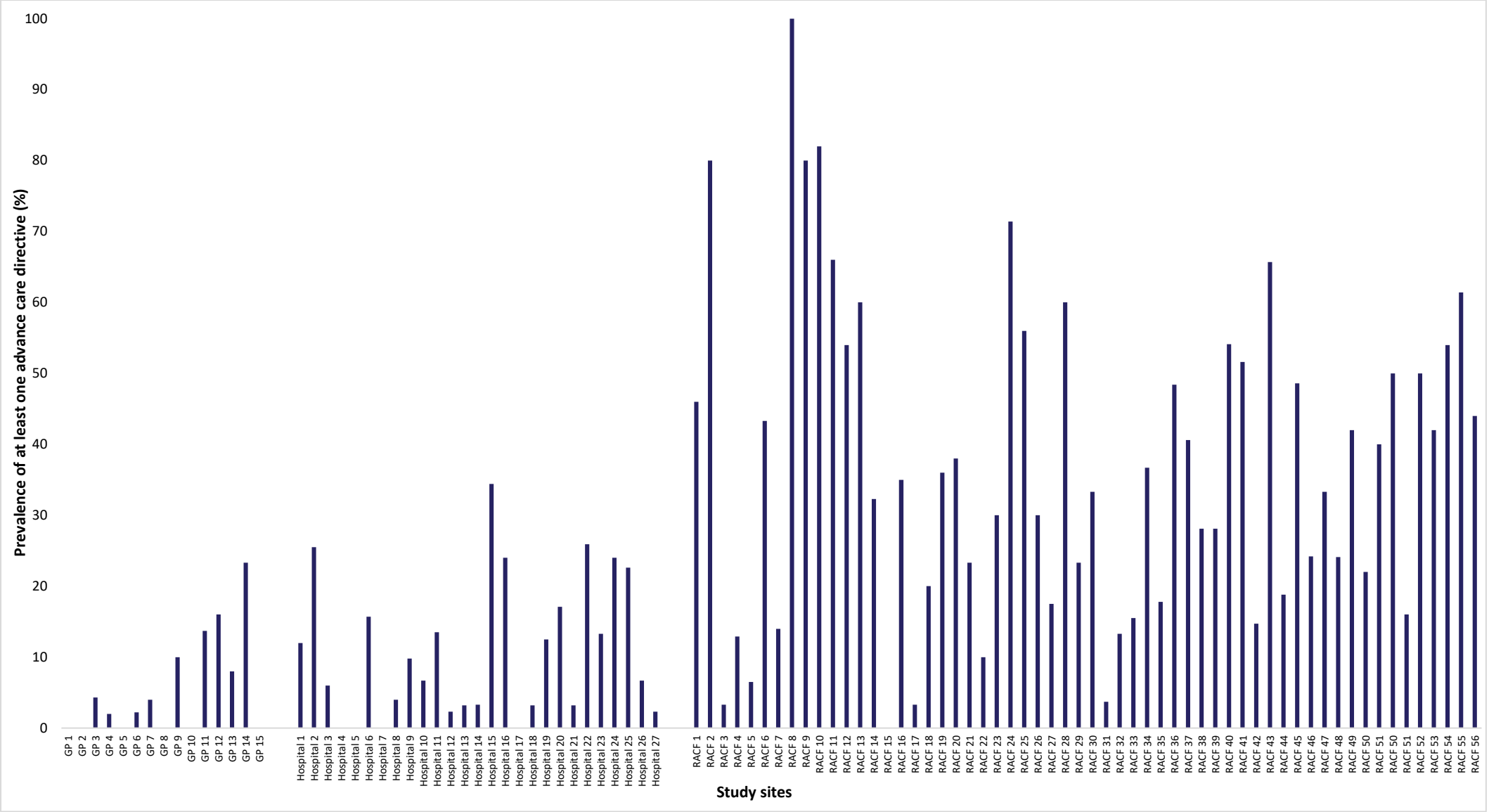

Figure 2. Prevalence of advance care directives by participating site (*n* = 100).

Prevalence of advance care directives by participant demographic characteristics

Prevalence rates of advance care directives according to participant demographic characteristics are presented in Table 7. Prevalence rates were higher among people who were older, female, widowed, born in Australia and/or spoke English. People of indigenous background were less likely to have at least one advance care directive than non-indigenous people. However, the small number of indigenous participants prompts cautious interpretation of these findings.

Table 7. Prevalence of advance care directives by demographic characteristics (*n* = 4187).

			Individual type of ACD (*n*, %)		
	n	At least one ACD overall n (%)	Statutory ACD: preferences for care	Statutory ACD: SDM	Non-statutory ACD
Age					
65-69	467	42 (9.0)	10 (2.1)	21 (4.5)	21 (4.5)
70-79	1177	190 (16.1)	42 (3.6)	89 (7.6)	95 (8.1)
80-89	1564	474 (30.3)	116 (7.4)	230 (14.7)	203 (13.0)
90-99	949	344 (36.2)	79 (8.3)	164 (17.3)	156 (16.4)
>100	30	11 (36.7)	2 (6.7)	7 (23.3)	5 (16.7)
Gender					
Male	1647	325 (19.7)	70 (4.3)	158 (9.6)	153 (9.3)
Female	2525	731 (29.0)	179 (7.1)	352 (13.9)	322 (12.8)
Other	10	4 (40.0)	0 (0.0)	0 (0.0)	4 (40.0)
Unknown	5	1 (20.0)	0 (0.0)	1 (20.0)	1 (20.0)
Country of birth					
Australia	2688	777 (28.9)	203 (7.6)	372 (13.8)	335 (12.5)
Other	1152	252 (21.9)	40 (3.5)	122 (10.6)	129 (11.2)
Unknown	347	32 (9.2)	6 (1.7)	17 (4.9)	16 (4.6)
Current relationship status					
Married/de facto	1452	263 (18.1)	67 (4.6)	142 (9.8)	98 (6.7)
Divorced/separated	387	94 (24.3)	16 (4.1)	43 (11.1)	48 (12.4)
Widowed	1612	529 (32.8)	139 (8.6)	255 (15.8)	220 (13.6)
Single	408	95 (23.3)	10 (2.5)	35 (8.6)	60 (14.7)
Unknown	328	80 (24.4)	17 (5.2)	36 (11.0)	54 (16.5)
English language status					
Speaks English	3750	998 (26.6)	240 (6.4)	480 (12.8)	443 (11.8)
Interpreter required	277	41 (14.8)	4 (1.4)	22 (7.9)	23 (8.3)
Unknown	160	22 (13.8)	5 (3.1)	9 (5.6)	14 (8.8)

Note: ACD = advance care directive; SDM = substitute decision-maker.

Prevalence of advance care directives by participant clinical characteristics

Prevalence rates of advance care directives completed by the person according to participant clinical characteristics are presented in Table 8. Highest overall prevalence was found among people with mental illness (34.0%), followed by people with a urinary/excretory and reproductive condition (32.6%) or neurological condition (32.6%). The prevalence of having at least one advance care directive among people with dementia (*n* = 1388) was 31.6%. Only 7% of people with dementia had documented their preferences for care in a statutory advance care directive, and only 17% had a statutory advance care directive appointing a substitute decision-maker.

The prevalence of having at least one advance care directive for persons with malignant cancer (*n* = 628) was 26.8% (see Table 8). However, only 7.6% had a statutory advance care directive outlining their preferences for care and 14.2% had a statutory advance care directive appointing a substitute decision-maker.

Prevalence rates overall and for each type of advance care directive increased according to number of medical conditions (morbidity). Only 4% of people with no current/active medical conditions had an advance care directive in their record, compared to 8% of people with one current condition, 21 % of people with two current conditions and 31% of people with more than two current medical conditions.

The prevalence of having at least one advance care directive was higher among people with lower functional status (see Table 8). Participants who were rated as having no disability that impacted functioning had a low prevalence of advance care directives (3.0%). Prevalence rates increased to 13.7% for people with some disability and increased again to 23.5% for people with moderate disability. People with severe disability had the highest overall prevalence of 37.2%. Only 26.9% of those rated as having very severe disability had at least one advance care directive.

People receiving palliative care (*n* = 327) were less likely than those not receiving palliative care (*n* = 3561) to have at least one advance care directive (24.2% and 26.8%, respectively).

Table 8. Prevalence of advance care directives by clinical characteristics (*n* = 4187).

			Individual type of ACD (*n*, %)		
	n	At least one ACD overall n (%)	Statutory ACD: preferences for care	Statutory ACD: SDM	Non-statutory ACD
Medical condition †					
Heart condition	2194	656 (29.9)	154 (7.0)	302 (13.8)	306 (13.9)
Musculoskeletal/connective tissue	2250	724 (32.2)	177 (7.9)	337 (15.0)	335 (14.9)
Urinary/excretory/reproductive	884	288 (32.6)	61 (6.9)	138 (15.6)	142 (16.1)
Dementia	1388	438 (31.6)	97 (7.0)	240 (17.3)	168 (12.1)
Endocrine/metabolic disorders	1343	343 (25.5)	64 (4.8)	176 (13.1)	166 (12.4)
Neurological system	959	313 (32.6)	69 (7.2)	165 (17.2)	145 (15.1)
Gastrointestinal system	1043	304 (29.1)	69 (6.6)	152 (14.6)	141 (13.5)
Respiratory system	998	270 (27.1)	68 (6.8)	117 (11.7)	134 (13.4)
Mental illness	1379	469 (34.0)	101 (7.3)	212 (15.4)	224 (16.2)
Cancer (malignant)	628	168 (26.8)	48 (7.6)	89 (14.2)	66 (10.5)
Chronic kidney condition	445	123 (27.6)	24 (5.4)	48 (10.8)	68 (15.3)
Other	516	146 (28.3)	21 (4.1)	77 (14.9)	72 (14.0)
Number of medical conditions					
None	73	3 (4.1)	1 (1.4)	3 (4.1)	0 (0.0)
One (unimorbid)	608	50 (8.2)	13 (2.1)	29 (4.8)	17 (2.8)
Two (comorbid)	766	160 (20.9)	32 (4.2)	76 (9.9)	86 (11.2)
More than two (multimorbid)	2740	848 (30.9)	203 (7.4)	403 (14.7)	377 (13.8)
Functional status⁎					
No disability	440	13 (3.0)	1 (0.2)	7 (1.6)	5 (1.1)
Some disability	451	62 (13.7)	17 (3.8)	23 (5.1)	34 (7.5)
Moderate disability	914	215 (23.5)	63 (6.9)	70 (7.7)	103 (11.3)
Severe disability	1506	560 (37.2)	114 (7.6)	284 (18.9)	254 (16.9)
Very severe disability	676	182 (26.9)	41 (6.1)	102 (15.1)	77 (11.4)
Unknown	200	29 (14.5)	13 (6.5)	25 (12.5)	7 (3.5)
Receiving palliative care					
Yes	327	79 (24.2)	23 (7.0)	49 (15.0)	24 (7.3)
No	3561	955 (26.8)	218 (6.1)	444 (12.5)	441 (12.4)
Unknown	299	27 (9.0)	8 (2.7)	18 (6.0)	15 (5.0)

Note: † Participants may have multiple comorbidities. ⁎ Assessed using ECOG performance status where available and estimated based on information in the health record where ECOG not available. ACD = advance care directive; SDM = substitute decision-maker.

Quality of advance care directives completed by the person

Most advance care directives were completed three or more years prior to the audit. Almost half of statutory advance care directives appointing a substitute decision-maker were greater than five years old. While most advance care directives contained the person's full name, many did not contain the person's date of birth or address (see Table 9). Approximately 15% of all non-statutory advance care directives were not signed by the person. Only a quarter of statutory advance care directives appointing a substitute decision-maker contained instructions for the substitute decision-maker.

Table 9. Quality of advance care directives.

Characteristic	Type of ACD (*n*, %)[†]		
	Statutory ACD: preferences for care (*n* = 249)	Statutory ACD: SDM (*n* = 511)	Non-statutory ACD (*n* = 480)
Dated	240 (96.4)	505 (98.8)	429 (89.4)
Age of document			
0-6 months	33 (13.3)	32 (6.3)	105 (21.9)
7-11 months	21 (8.4)	26 (5.1)	57 (11.9)
1-2 years	37 (14.9)	52 (10.2)	91 (19.0)
3-5 years	77 (30.9)	145 (28.4)	131 (27.3)
>5 years	70 (28.1)	249 (48.7)	45 (9.4)
Missing	11 (4.4)	7 (1.4)	51 (10.6)
Contains person's full name	239 (96.0)	501 (98.0)	400 (83.3)
No, only part of their name	9 (3.6)	8 (1.6)	45 (9.4)
No, name not present	1 (0.4)	0 (0.0)	0 (0.0)
Missing	0 (0.0)	1 (0.2)	35 (7.3)
Contains person's date of birth	222 (89.2)	136 (26.6)	341 (71.0)
No	27 (10.8)	374 (73.2)	104 (21.7)
Missing	0 (0.0)	1 (0.2)	35 (7.3)
Contains person's address	194 (77.9)	483 (94.5)	308 (64.2)
No	55 (22.1)	27 (5.3)	137 (28.5)
Missing	0 (0.0)	1 (0.2)	35 (7.3)
Signed by person	237 (95.2)	495 (96.9)	377 (78.5)
No	12 (4.8)	15 (2.9)	68 (14.2)
Missing	0 (0.0)	1 (0.2)	35 (7.3)
Witnessed/signed by someone else	235 (94.4)	497 (97.3)	374 (77.9)
Doctor	88 (35.3)	34 (6.7)	185 (38.5)
Other health professional	23 (9.2)	33 (6.5)	120 (25.0)
Legal practitioner/judge	48 (19.3)	300 (58.7)	13 (2.7)
JOP/public notary	112 (45.0)	125 (24.5)	7 (1.5)
Substitute decision-maker	24 (9.6)	5 (1.0)	128 (26.7)
Unable to determine	11 (4.4)	25 (4.9)	42 (8.8)
Other	17 (6.8)	12 (2.3)	39 (8.1)
SDM signed to accept their appointment	NA	417 (81.6)	NA
No		58 (11.4)	
Not required		33 (6.5)	
Missing		3 (0.6)	
Form contains instructions for SDM	NA	139 (27.2)	NA
Person designated additional SDMs	NA	321 (62.8)	NA
Contains information on how the SDMs should make decisions	NA	259 (50.7)	NA

Note: [†] Some advance care directives were not located within patient records; therefore, denominators are not necessarily the same as overall frequencies for each type of document. ACD = advance care directive; SDM = substitute decision-maker.

Content of advance care directives completed by the person

Among participants with a **statutory advance care directive: preferences for care**, approximately 95% specified their preferences within the document (see Table 10). The majority of participants (63.9%) did not want life-prolonging treatment. Approximately 10% of participants recorded their preferred location for medical care, 7% specified their preferred place of death, 8% recorded instructions for funeral arrangements and 16% specified their preferences regarding organ donation. Almost half of participants specified their values, beliefs or goals within their statutory advance care directive: preferences for care document.

Table 10. Preferences for care specified in **statutory** advance care directives: preferences for care (*n* = 249)

Characteristic	GP *n* (%) (*n* = 6)	Hospitals *n* (%) (*n* = 36)	RACF *n* (%) (*n* = 207)	Overall *n* (%) (*n* = 249)
Treatment preferences specified in ACD	**5 (83.3)**	**34 (94.4)**	**197 (95.2)**	**236 (94.8)**
Wants all LPT	1 (16.7)	4 (11.1)	13 (6.3)	18 (7.2)
Wants some LPT	0 (0.0)	6 (16.7)	37 (17.9)	43 (17.3)
Doesn't want LPT (symptom management/comfort care only)	3 (50.0)	21 (58.3)	135 (65.2)	159 (63.9)
Wants to delegate care decisions to another person	0 (0.0)	0 (0.0)	4 (1.9)	4 (1.6)
Unable to determine	0 (0.0)	2 (5.6)	3 (1.4)	5 (2.0)
Other	1 (16.7)	1 (2.8)	5 (2.4)	7 (2.8)
Missing	1 (16.7)	2 (5.6)	10 (4.8)	13 (5.2)
Other preferences				
None	2 (33.3)	11 (30.6)	100 (48.3)	113 (45.4)
Preferred place of care	1 (16.7)	3 (8.3)	22 (10.6)	26 (10.4)
Preferred place of death	1 (16.7)	2 (5.6)	15 (7.2)	18 (7.2)
Funeral arrangements	1 (16.7)	4 (11.1)	14 (6.8)	19 (7.6)
Organ donation	2 (33.3)	8 (22.2)	29 (14.0)	39 (15.7)
Other preferences	2 (33.3)	13 (36.1)	55 (26.6)	70 (28.1)
Values, beliefs or goals specified in ACD	3 (50.0)	17 (47.2)	93 (44.9)	113 (45.4)

Note: ACD = advance care directive; GP = general practice; LPT = life prolonging treatment; RACF = residential aged care facility.

Among participants with a **non-statutory advance care directive**, approximately 91% specified their treatment preferences within the document (see Table 11). The majority of people did not want life-prolonging treatment (47.9%). Approximately 27% of participants recorded their preferred location for medical care, 25% specified their preferred place of death, 15% recorded instructions for funeral arrangements and 7% specified their preferences regarding organ donation. 64% of participants specified their values, beliefs or goals within their non-statutory advance care directive.

Table 11. Preferences for care specified in **non-statutory** advance care directives (*n* = 480)

Characteristic	GP *n* (%) (*n* = 21)	Hospitals *n* (%) (*n* = 30)	RACF *n* (%) (*n* = 429)	Overall *n* (%) (*n* = 480)
Treatment preferences specified in ACD	**20 (95.2)**	**30 (100.0)**	**388 (90.4)**	**438 (91.3)**
Wants all LPT	1 (4.8)	8 (26.7)	65 (15.2)	74 (15.4)
Wants some LPT	7 (33.3)	8 (26.7)	79 (18.4)	94 (19.6)
Doesn't want LPT (symptom management/comfort care only)	12 (57.1)	12 (40.0)	206 (48.0)	230 (47.9)
Wants to delegate care decisions to another person	0 (0.0)	0 (0.0)	15 (3.5)	15 (3.1)
Unable to determine	0 (0.0)	0 (0.0)	1 (0.2)	1 (0.2)
Other	0 (0.0)	2 (6.7)	22 (5.1)	24 (5.0)
Missing	1 (4.8)	0 (0.0)	41 (9.6)	42 (8.8)
Other preferences				
None	6 (28.6)	12 (40.0)	130 (30.3)	148 (30.8)
Preferred place of care	2 (9.5)	7 (23.3)	121 (28.2)	130 (27.1)
Preferred place of death	4 (19.0)	11 (36.7)	103 (24.0)	118 (24.6)
Funeral arrangements	2 (9.5)	3 (10.0)	71 (16.6)	76 (15.8)
Organ donation	11 (52.4)	3 (10.0)	17 (4.0)	31 (6.5)
Other preferences	4 (19.0)	7 (23.3)	99 (23.1)	110 (22.9)
Values, beliefs or goals specified in ACD	16 (76.2)	25 (83.3)	266 (62.0)	307 (64.0)

Note: ACD = advance care directive; GP = general practice; LPT = life prolonging treatment; RACF = residential aged care facility.

Documentation completed by a health professional

Medical orders

The overall prevalence of medical orders across all sites was 27.3%. Prevalence varied across health care settings from 25.1% in residential aged care facilities, to 48.6% in hospitals files, to 0.1% in general practices.

The most common treatment instruction listed in medical orders overall was for treatment aimed at symptom management/comfort care (49.0%); see Table 12. This was also the most common treatment instruction in residential aged care facilities (60.1%). In hospitals, 36.7% of people wanted treatment aimed at comfort care, while 42.0% of people wanted some treatment aimed at prolonging life, see Table 12.

Table 12. Treatment instructions specified within medical orders (*n* = 1145).

Medical order treatment instructions	Hospitals *n* (%) (*n* = 545)	RACF *n* (%) (*n* = 599)	GP *n* (%) (*n* = 1)	Overall *n* (%) (*n* = 1145)
All treatment aimed at prolonging life	86 (15.8)	57 (9.5)	0 (0.0)	143 (12.5)
Some treatment aimed at prolonging life	229 (42.0)	91 (15.2)	0 (0.0)	320 (27.9)
Treatment aimed at symptom management/comfort care	200 (36.7)	360 (60.1)	1 (100.0)	561 (49.0)
Other	25 (4.6)	37 (6.2)	0 (0.0)	62 (5.4)
Unable to determine	5 (0.9)	4 (0.7)	0 (0.0)	9 (0.8)
Missing	0 (0.0)	50 (8.3)	0 (0.0)	50 (4.4)

As presented in Table 13, 324 participants had both a medical order and an advance care directive. Of these, 60.5% of medical orders were assessed as being consistent with the person's advance care directive, 18.5% were of unclear consistency, and six (1.9%) were assessed as being inconsistent. The remainder were assessed as being not applicable (6.5%) or data was not available (12.7%). Of the six medical orders that were inconsistent with the person's advance care directive, two specified less treatment than the person wanted, three specified more treatment and one was unclear; see Table 13.

Table 13. Consistency between the person's advance care planning preferences and medical order/clinical care plan (*n* = 324).

Medical order consistent with person's preferences in their advance care directive	Overall (*n* = 324) *n* (%)
Yes	196 (60.5)
No	6 (1.9)
Person wanted more treatment than specified in medical order	2 (0.6)
Person wanted less treatment than specified in medical order	3 (0.9)
Unclear	1 (0.3)
Unclear	60 (18.5)
Not applicable	21 (6.5)
Missing	41 (12.7)

Prevalence of advance care planning documentation by a health professional

The prevalence of advance care planning documentation by a health professional was 11.7%. This documentation included advance care plans completed on behalf of the person (43.4%), advance care planning discussion records (39.3%), progress notes (29.1%), letters (3.3%) and other (6.3%). The majority of documents were completed by a nurse (62.5%). Approximately half acknowledged discussion with the person.

Documentation completed by someone else

The overall prevalence of advance care planning documentation by someone else (e.g. family, carer, substitute decision-maker) was 18.1%. By health care sector, prevalence was much higher in residential aged care facilities (30.4%) compared to hospitals (2.6%) and general practices (0.3%).

Almost 90% of identified documents were advance care plans completed on behalf of the person, while 10% were notes regarding advance care planning. Most documents were completed by a family member (70.9%) followed by the substitute decision-maker (37.9%), other (9.0%) or carer (2.6%). Only 25% of documents acknowledged discussion with the person. Approximately 77% of documentation completed by someone else specified treatment instructions (see Table 14). The most common treatment instruction listed was for treatment aimed at symptom management/comfort care (67.7%).

Table 14. Preferences for care specified in **documentation completed by someone else** (*n* = 757)

Characteristic	Overall *n* (%) (*n* = 757)
Treatment preferences specified in documentation	**586 (77.4)**
Wants all LPT	54 (9.2)
Wants some LPT	96 (16.4)
Doesn't want LPT (symptom management/comfort care only)	397 (67.7)
Wants to delegate care decisions to another person	16 (2.1)
Unable to determine	21 (2.8)
Other	2 (0.3)
Other preferences	
Preferred place of care	239 (31.6)
Preferred place of death	159 (21.0)
Funeral arrangements	115 (15.2)
Organ donation	32 (4.2)
Other preferences	47 (6.2)
Values, beliefs or goals specified in documentation	428 (56.5)

Note: LPT = life prolonging treatment.

Miscellaneous documentation

The prevalence of miscellaneous advance care planning documentation was 8.0%. Of these, 26.1% were classified as an information sheet/brochure/pamphlet, 9.9% an advance care planning alert, 9.3% an advance care planning invitation and 61.6% other types of documentation.

Discussion

This report describes comprehensive data and information on the prevalence, characteristics and quality of advance care directives completed by the person in selected Australian health and residential aged care services. The study also examined the prevalence and characteristics of advance care planning documentation completed by a health professional (medical treatment orders or advance care plans) and by someone else.

Key findings

- In Australia, advance care planning documentation is being completed by the person, health professionals or someone else. The overall prevalence of advance care planning documentation that is completed by the person, health professionals or someone else is approximately 41% across all sectors and approximately 65% in residential aged care.
- Advance care planning legislation allows for a competent person to document and sign an advance care directive. Therefore, the overall prevalence of quality advance care planning documentation, completed by the person according to law, is low at approximately 25%. The majority of these were statutory advance care directives: appointing a substitute decision-maker at 12% and non-statutory advance care directives at 12%. The prevalence of statutory advance care directives: preferences for care was 6%. An older Australian's ability to achieve choice and control over medical treatment decisions and end-of-life care appears limited.
- Sites reported systems to support advance care planning, including having advance care planning programs (81%), staff training (71%), and policy or guideline (62%). However, 59% indicated no additional funding was provided to support advance care planning implementation or practice.
- Advance care planning documentation completed by the person, prevalence is low across all sectors. Residents of aged care facilities were more likely to have an advance care directive (38%) than people in hospitals (11%) and those attending general practice (5.5%).
- Advance care planning documentation prevalence is low and varies across jurisdictions. People living in South Australia, Queensland, and New South Wales were more likely to have an advance care directive than people living in other states and territories.

- Advance care planning documentation prevalence is low and varies across medical conditions. People living with dementia were no more likely to have advance care directives than people with other medical conditions. Overall, only 32% of people with dementia had at least one advance care directive and only 17% of people had formally appointed a substitute decision-maker.
- People born outside of Australia (22% compared with 29% born in Australia) and those requiring an interpreter (15% compared to 27% who speak English) had a lower prevalence of advance care planning documentation.
- People living with moderate, severe and/or very severe disability were more likely to have an advance care directives than those with no or some level of disability.
- Advance care planning documentation may be at risk of not being legally and/or clinically valid if legislated formalities and/or person identification requirements are not met. Non-statutory advance care directives were least likely to comply with formalities with 22% having no date of birth, 22% not being witnessed, 14% being unsigned, and 11% being undated.
- Advance care planning legislation does not allow for documentation of binding instructions on behalf of a non-competent person. Approximately 18% of older Australians have an advance care directive completed by someone else. Approximately 30% of older people in aged care have advance care planning documentation completed by someone else, most commonly a family member (71%) or substitute decision-maker (38%). Approximately 77% of documentation contained treatment instructions, with most (68%) being treatment limitations. Therefore, nearly half of the advance care planning documentation in aged care are possibly invalid (30% documented by someone else, compared to 38% documented by a competent person).
- The prevalence of advance care planning documents in aged care (65%) completed by the person, health professionals or someone is high and demonstrates significant resources and commitment in having these documents available. However, as nearly half of the documentation is being completed by someone else. Without a legal or policy framework there are risks to the resident, health professionals and services. Resources need to be redirected to the completion of advance care directives earlier and according to the law or within a policy framework.
- Advance care directives completed by the person frequently specified limitation of treatment instructions (64% specified no life prolonging treatment, 17% specified some life prolonging treatment) and only 7% requested all treatment to sustain life.

- Medical orders completed by doctors, outlining the plan of care in relation to emergency treatment or severe clinical deterioration such as resuscitation or transfer to acute care status remains low. The prevalence of medical orders was low across all sectors: hospitals (49%), residential aged care facilities (25%) and general practice (0.1%). Most medical orders contained limitation of treatment instructions, with only 13% indicating all available treatments.
- The availability of existing advance care directives within My Health Record is extremely low (1%), limiting transferability between sectors and accessibility at the point of care. Only a third of participating sites and two of 58 residential aged care facilities were connected to My Health Record. These results indicate advance care directives may not be accessible at the point of care or transferable between sectors.

Policy implications

The *2018 Prevalence of Advance Care Planning Documentation in Australian Health and Residential Aged Care Services Study* identified low prevalence of advance care planning documentation completed by the person. It also identified low prevalence of medical order, low uptake within My Health Record and issues with document quality and validity.

The willingness of sites to participate in this study and provide the necessary data and information demonstrates a strong commitment to improving advance care planning within Australian health and aged care services. This work promotes person choice and control of their future health care decisions. However, nearly half of the advance care planning documentation in aged care have been completed by someone else and not according to the law.

Advance Care Planning Australia is funded by the Australian Government to provide national advance care planning leadership, engagement, advisory services, a resource hub, curriculum and education resources and research. A comprehensive range of advance care planning resources, education modules and legal resources can be found via www.advancecareplanning.org.au. These resources should be utilized by consumers, the health and aged care workforce and services.

Advance Care Planning Australia advocates for changes in legislation, policy, systems and resources to support improved awareness and uptake of advance care planning and end-of-life care. Recommendations include but are not limited to the importance of having an ongoing advance care planning national authority; robust policy including the update of the National Framework for Advance Care Directives;[4] increased consistency in legislation terminology, scope, formalities, obligations and recognition; improved requirements and obligations within national quality standards; enhanced integration with supported decision-making; increased uptake of existing information resources, workforce education and guidelines; an ongoing community awareness campaign; earlier advance care planning when people have decision-making capacity; and increased storage, transferability and accessibility via My Health record. The ongoing monitoring of a national advance care planning prevalence dataset and clinical indicator reporting is a key priority.

Advance Care Planning Australia, in collaboration with research partners, will conduct further analyses and reporting of these important findings with academic publications.

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