



Concordance between instructional directions in advance care planning documentation versus medical orders.

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**Advance Care
Planning Australia**

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Our program is focused on improving advance care planning policy and systems, community awareness, understanding and uptake, workforce capability and quality monitoring and evidence. We promote a national collaborative approach to achieving excellence in advance care planning.

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Introduction

This report describes the prevalence and concordance of health records containing at least one *statutory ACD: preferences for care* document or *non-statutory ACD: preferences for care* document outlining preferences for life-sustaining (also known as life-prolonging) medical treatment and at least one medical order containing treatment instructions related to life-sustaining medical treatment. These data are a subset of the *Prevalence of Advance Care Planning Documentation in Australian Health and Residential Aged Care Services study*. This project is an initiative of Advance Care Planning Australia and was funded by the Australian Government, Department of Health (Agreement ID 4-5833ZYN).

Background

When death is near, and quality of life is low, it is difficult for medical professionals to know how far to pursue treatment and at what point treatment may become futile. Futile medical care may prolong suffering and use scarce health resources, and decisions to withhold or provide life-extending therapies can affect patients, their families, health professionals, the health system and the broader community.[1] Two-thirds of Australian deaths occur between the ages of 75 and 95. While most of these deaths are expected, research suggests that the care most Australians receive at the end of life does not often reflect their values, goals or informed choices.[2] As such, it is important to adequately prepare people and medical professionals for the challenges of dying,[3] including encouraging people to document their preferences for care.

Advance care planning (ACP) documentation are widely available tools that uphold autonomy and allow people, in consultation with family members and medical professionals, to make plans and document their preferences for medical treatment, palliative care, and end-of-life care.[4] ACP documentation includes person-completed advance care directives (ACDs), doctor-completed medical orders (e.g. resuscitation plan, goals of care), and doctor or substitute decision-maker-completed advance care plans. Broadly, ACDs are the preferred format for describing future preferences for medical care; however, there may be instances where doctor-completed documents are created on behalf of the person.

ACP activities and ACDs are intended to provide health practitioners and substitute decision-makers (SDMs) with information about the person's preferences for a time when they lose decision-making capacity. [4-7] These documents can be used multiple times and across multiple settings. In contrast, medical orders are doctor-led documents that outline the care preferences and/or treatment intentions for a person for a specific 'treatment episode'. These treatment episodes may span a

single (acute) admission or reflect preferences for care across repeated admissions for a single medical problem, such as renal dialysis. Doctors often prefer using medical orders because the information they contain is clinically relevant. In contrast, the information contained in ACDs may be perceived by doctors as vague, contradictory, or difficult to translate into clinical practice.[8]

There is significant variance in reported ACD prevalence rates globally. In Australia, general ACD prevalence rates have been reported between 14-30% [9, 10]. By sector, Australian ACD prevalence rates vary from 47.7% in RACFs, 15.7% in hospitals, and just 3% in general practices [9]. Research examining the types of instructions contained within ACDs has found that the poorer the individual's prognosis, the more likely the individual will be to reject treatment or state they do not want "heroic end of life measures" (i.e. 'full treatment') to extend their life. Conversely, treatment is more likely to be accepted by individuals where there is a chance of recovery. [11, 12] Likewise, the older the individual, the more likely they are to reject treatments, as are those who had witnessed a terminal illness in a family member.

Medical order prevalence rates, including do not resuscitate or other end of life intervention orders, vary across healthcare settings with estimates between 1.7%-11.9% in hospitals [13-16] and 3.4%-82% in RACFs [17, 18], with limited data describing the prevalence of medical orders in GP settings. Physician treatment document instructions are often categorised as requests for full treatment, limited treatment, or comfort measures only. Research indicates significant variation for the types of instructions included in these documents. Broadly, instructions are more commonly related to limited treatment (36-54%), followed by comfort measures only (16-52%) with the smallest proportion requesting full treatment (11-21%).[14, 17, 19]

Inconsistency between ACDs and medical orders could create confusion for the treating team and potential harm for the patient. In Australia, ACDs are considered to contain legally binding instructions, whereas medical orders are not.[20] As such, instructions in ACDs take legal precedence over the instructions contained in medical orders. However, several international studies have identified a concerning amount of discordance between documents produced by the person being treated and documents created by the health professional. [21-23] For example, in a Canadian study, discrepancies were present between ACD preferences and medical orders in 37% of the included cases, indicating a high risk of medical error in the types of hospital treatments received. Of these, 2% contained medical orders withholding treatment that had been requested in ACDs (i.e. under-treatment specified in medical order), and 35% contained medical orders to receive treatments that had been rejected in a patient's ACD (i.e. overtreatment specified in medical order).

Concordance between doctor-led documentation and ACDs is vital to ensure people receive care that aligns with their preferences. In Australia, more than half of people aged 65 years and older

accessing health and residential aged care services have reported completing ACP documentation. However, only half indicated that their ACP documentation was stored at their current point of care, and of those who believe their ACP documents are stored at their current point of care, a quarter did not have any ACP documentation present in their health record.[24] A lack of accurate and accessible advance care directive documentation, or reluctance of doctors to follow preferences specified in advance care directives, represents an important patient safety issue that could have devastating implications on a person's care and affect medical decision-making. describe a case study of an older man who received life-sustaining treatment that was not according to his preferences. As a result of the treatments received, the patient and his family reported experiencing harm, including complications from treatment, pain, distress, burden, and unnecessary medical costs.

To better understand the likelihood of Australians receiving care that aligns with their preferences, it is important to understand the current healthcare landscape in terms of the prevalence and concordance of person-completed and health practitioner-completed medical orders across three health sectors. This report examines a subset analysis of a larger national prevalence study [26] to:

- describe the prevalence of ACD (person-completed directions) and medical orders (doctor-completed orders) containing details about life-sustaining treatment preferences
- identify the most common treatment preferences by document type
- identify variation in directions between these document types

Methods

Ethics approval for the study was obtained from Austin Health Human Research Ethics Committee, Melbourne, Australia (ref: HREC/18/Austin/109) and site-specific approval was gained where required. ACD and medical order data collection occurred between October 2018 and January 2019 as part of an Australian National ACD Prevalence Study; a multi-centre cross-sectional audit of the health records of eligible adults aged 65 years and over accessing accredited Australian general practices (GPs), public and private hospitals and residential aged care facilities (RACFs). For further details, please refer to the study protocol published elsewhere. [26]

Study sites were recruited through an expression of interest process. Sites provided 2-3 internal staff to undertake audit-specific training (60 minutes duration) and to conduct the audit. All data collectors used a jurisdictional specific audit manual with information to assist with data collection, including classification of documentation. Each site audited between 30 and 50 records of eligible participants within their service.

Health record audit

Eligible audit participants were people aged 65 years or older who were admitted to participating hospitals or residential aged care facilities for at least 48 hours before the audit, or who were attending general practices on the nominated day(s) of the study. In hospitals and residential aged care facilities, health records were randomly selected from all eligible people using a random number generator (www.randomizer.org). In GPs, consecutive eligible patients had their records audited.

The study [26] defined ACDs as documents recognised by statutory legislation (*statutory ACD*) or common law (*non-statutory ACD*) that are completed and signed by a competent adult. Data collectors were trained to categorise ACDs as *statutory ACD-preferences for care*, *statutory ACD-SDM* or *non-statutory ACD*. Non-ACD documents generated by healthcare professionals were classified as either medical orders (e.g., resuscitation plan, goals of care) or “other”. Other documents included advance care plans completed on behalf of the person, ACP discussion records, progress notes and letters.

This report focuses on only health records from the broader prevalence study containing *statutory ACD: preferences for care* documents, *non-statutory ACD: preferences for care* documents or medical orders containing specific details related to life-sustaining medical treatment.

Data screening

Before conducting analyses, data were cleaned to identify records that contained at least one *statutory ACD: preferences for care (statutory ACDs)* or *non-statutory ACD: preferences for care (non-statutory ACDs)* document specifying life-sustaining treatment directions as well as at least one medical order containing specific details related to life-sustaining medical treatment. Data were screened for records containing at least one *statutory or non-statutory ACD: preferences for care* document as well as at least one medical order created by a health professional. Only ACDs containing preferences for medical treatment and medical orders containing details about life-sustaining treatments were included.

Document pairing

After identifying each health record that contained relevant ACDs and medical orders individually, a new variable was created to identify any records that contained both a relevant ACD and a relevant medical order (where 1= both ACD and medical order present, and 0= ACD and medical order not present together). Any records that did not contain both an ACD (statutory or non-statutory) and a medical order detailing life-sustaining medical treatment preferences were not included in the final analysis.

Data analysis

Descriptive statistics were calculated to outline the characteristics and content of *statutory ACDs: preferences for care*, *non-statutory ACDs* and medical orders. Document prevalence by type was calculated by summing all documents by their type (*statutory ACD*, *non-statutory ACD*, or medical order). Prevalence of treatment preferences were then calculated for each document type by summing all documents (by type) that contained details about life-sustaining treatment preferences. Each document type produced three prevalence scores based on the treatment preferences they contained (wants all life-prolonging treatment, wants some life-prolonging treatment, or does not want life-prolonging treatment). After calculating ACD and medical order prevalence by document type, healthcare sector and jurisdiction, prevalence of treatment instructions by type for ACDs and medical orders were calculated by summing all relevant records.

Document age for all included ACDs and medical orders were produced by calculating the total number of months between the date recorded on the document and the end-date of the research period (January 2019), before categorising results into three document age categories: documents produced within the previous 12 months, documents produced between 1 and 2 years ago, and documents 3 or more years old.

Concordance between the person's preferences for care and treatment instructions documented in medical orders was determined by examining the consistency between treatment preferences specified in the person's ACD with treatment limitations outlined in their medical treatment order. Concordance between the age of paired ACDs and medical orders were determined by examining the ages of each document.

Results

In the full sample of 4187 records, 264 contained at least one *statutory ACD: preferences for care* document, 507 contained at least one *non-statutory ACD: preferences for care* document and 1145 contained medical orders created by a health professional. Preferences for medical treatment were present in 236 (89.4%) *statutory ACDs* and 445 (87.8%) *non-statutory ACDs*, and treatment instructions were included in 1095 (95.6% of 1145) of all medical orders. After excluding all documents that did not contain details about life-sustaining treatments, 225 (85.2%) *statutory ACDs*, 422 (83.2%) *non-statutory ACDs*, and 1024 (89.4%) medical orders remained (39.9% of all 4187 records).

After ACD-medical order matching, only 133 (13%) of the 1024 relevant medical orders identified were found in a record that also contained at least one statutory ACD ($n=51$) or non-statutory ACD ($n=82$) outlining preferences for life-sustaining treatments. No records containing both a relevant medical order and a relevant ACD were located in records audited in the GP setting (Table 1).

Similar demographic characteristics were present for records where a medical order was located with either a statutory ACD or a non-statutory ACD containing life-sustaining treatment instructions, except for participant state, where medical orders were most commonly found with a statutory-ACD in SA, but more commonly found with a non-statutory ACD in VIC.

People aged 85 years or over, women, and those born overseas more frequently had both a medical order and ACD outlining life-sustaining treatment instructions in their health record than those aged between 65-74 years and those aged between 74-84 years, men, and those born overseas. Similarly, the presence of both a medical order and ACD containing life-sustaining treatment instructions were more frequently found for individuals not using palliative care than those in palliative care or specialist palliative care.

The presence of a medical order and an ACD describing life-sustaining treatment were also more frequently found for individuals with comorbid medical conditions, ECOG grade 5 scores, severe disability as calculated by the individual's estimated functional status (EFS), or a severe disability as calculated by their combined ECOG and EFS scores as compared to other categories of morbidity, ECOG performance status, EFS and combined ECOG and EFS status (see Table 1).

All relevant document types most frequently included details outlining no life-sustaining treatment measures, with all life-sustaining treatment requested least often. Overall, 63% of medical orders ($n=84$) specified no life-sustaining treatment, with 29% ($n=39$) and 8% ($n=10$) specifying some life-sustaining treatment and all life-sustaining treatment, respectively. For statutory ACDs, 84% ($n=43$)

specified no life-sustaining treatment, with 14% ($n=7$) and 2% ($n=1$) specifying some life-sustaining treatment and all life-sustaining treatment, respectively. For non-statutory ACDs, 49% ($n=40$) specified no life-sustaining treatment, with a further 30% ($n=25$) specifying some life-sustaining treatment, and 21% ($n=17$) specifying all life-sustaining treatment (Table 1).

Table 1. Demographic profile of relevant records by document type

Demographic	Category	Medical order		Statutory ACD		Non-statutory ACD		Total documents
		<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	<i>n</i>
Age group	65-74	19	14%	8	16%	11	13%	38
	75-84	35	26%	14	27%	21	26%	70
	85+	79	59%	29	57%	50	61%	158
Gender	Men	43	32%	17	33%	26	32%	86
	Women	88	66%	34	67%	54	66%	176
	Other	1	1%	0	0%	1	1%	2
	Unknown	1	1%	0	0%	1	1%	2
Birth country	Australia	43	32%	17	33%	26	32%	86
	Overseas	88	66%	34	67%	54	66%	176
Indigenous status	Aboriginal	3	2%	1	2%	2	2%	6
	Torres Strait Islander	0	0%	0	0%	0	0%	0
	Both Aboriginal and Torres Strait Islander	0	0%	0	0%	0	0%	0
	Neither Aboriginal or Torres Strait Islander	125	94%	49	96%	76	93%	250
	Unknown - not available in record	5	4%	1	2%	4	5%	10
Palliative care type	No palliative care used	111	83%	41	80%	70	85%	222
	Palliative care	22	17%	10	20%	12	15%	44
	- Specialist palliative care (subset)	11	8%	10	20%	12	15%	33
	Unknown	0	0%	0	0%	0	0%	0
Morbidity status	No current conditions	7	5%	2	4%	5	6%	14
	Unimorbid	21	16%	8	16%	13	16%	42
	Comorbid	105	79%	41	80%	64	78%	210
Sector	General practice	0	0%	0	0%	0	0%	0
	Hospital	45	34%	21	41%	24	29%	90
	Residential aged care facility	88	66%	30	59%	58	71%	176
State	ACT	2	2%	0	0%	2	2%	4
	NSW	26	20%	0	0%	26	32%	52
	NT	3	2%	3	6%	0	0%	6
	QLD	19	14%	13	25%	6	7%	38
	SA	30	23%	27	53%	3	4%	60
	TAS	0	0%	0	0%	0	0%	0
	VIC	51	38%	6	12%	45	55%	102
	WA	2	2%	2	4%	0	0%	4
Treatment type	All life-sustaining treatment	10	8%	1	2%	17	21%	28
	Some life-sustaining treatment	39	29%	7	14%	25	30%	71
	No life-sustaining treatment	84	63%	43	84%	40	49%	167

Demographic	Category	Medical order		Statutory ACD		Non-statutory ACD		Total documents
		<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	<i>n</i>
ECOG performance status	Grade 0	1	1%	1	2%	0	0%	2
	Grade 1	5	4%	3	6%	2	2%	10
	Grade 2	15	11%	5	10%	10	12%	30
	Grade 3	29	22%	3	6%	26	32%	58
	Grade 4	13	10%	5	10%	8	10%	26
	Grade 5	70	53%	34	67%	36	44%	140
Estimated functional status (EFS)	No disability	1	1%	0	0%	1	1%	2
	Some disability	4	3%	1	2%	3	4%	8
	Moderate disability	14	11%	9	18%	5	6%	28
	Severe disability	36	27%	13	25%	23	28%	72
	Very severe disability	12	9%	8	16%	4	5%	24
	Insufficient information available	3	2%	3	6%	0	0%	6
Combined ECOG and EFS	No disability	2	2%	1	2%	1	1%	4
	Some disability	9	7%	4	8%	5	6%	18
	Moderate disability	29	22%	14	27%	15	18%	58
	Severe disability	65	49%	16	31%	49	60%	130
	Very severe disability	25	19%	13	25%	12	15%	50
	Insufficient information available	3	2%	3	6%	0	0%	6

Most documents were less than 12 months old (Table 2), with non-statutory ACDs most likely to be three or more years old (23%). All but ten medical orders had been produced within the same month ($n=28$, 21%) or had been produced after the date recorded on the matched ACD ($n=95$, 72%) .

Table 2. Document age based on document date

	Category	<i>n</i>	%
Medical orders	Less than 12 months old	74	56%
	1-2 years old	44	33%
	3 or more years old	15	11%
Statutory ACDs	Less than 12 months old	85	64%
	1-2 years old	23	17%
	3 or more years old	25	19%
Structured non-statutory ACDs	Less than 12 months old	79	59%
	1-2 years old	24	18%
	3 or more years old	30	23%
Document age difference	Medical order produced more than 3 years before ACD	0	0%
	Medical order produced 1-2 years before ACD	3	2%
	Medical order produced less than 12 months before ACD	7	5%
	Medical order produced within same month as ACD	28	21%
	Medical order produced within 12 months after ACD	30	23%
	Medical order produced between 1-2 years after ACD	35	26%
	Medical order produced 3 or more years after ACD	30	23%

Almost all medical orders ($n=123$, 92%) outlined preferences for life-sustaining treatment consistent with those documented in the accompanying ACD, see Table 3. Of those that did not align with preferences documented in the accompanying ACD ($n=3$, 2.3%), two medical orders specified under-treatment, one specified overtreatment. For four records, treatment preferences outlined in the medical order were not comparable against treatment preferences outlined in the accompanying ACD. A further three records contained directions for treatment preferences in the medical order that could not clearly be identified as specifying over- or under-treatment when compared against the accompanying ACD.

Table 3. Alignment of medical orders with accompanying ACDs ($n=133$)

Document comparison	Count
Medical orders consistent with ACDs	123
Medical orders not consistent with ACDs	3
Person wants more treatment (under-treatment specified in medical order)	2
Person wants less treatment (over-treatment specified in medical order)	1
Not applicable	4
Unclear	3

Key Findings

Approximately 40% of all ACP documentation identified in the *Prevalence of Advance Care Planning Documentation in Australian Health and Residential Aged Care Services Study* included details about life-sustaining treatments, despite the advanced age, high severity of disease and ECOG status, and high number of participants in RACFs in the sample. Medical orders containing life-sustaining treatment instructions were more frequently found in health records, than an ACD. Only 13% of audited health records contained at least one ACD outlining preferences for life-sustaining treatment and medical order documenting life-sustaining treatment directions.

Instructions for no life-sustaining treatment were more frequent than instructions for limited life-sustaining treatments or all life-sustaining treatments in both ACDs (statutory ACDs $n=43$, 84%; non-statutory ACDs $n=40$, 49%) and medical orders ($n=84$, 63%). Where both an ACD outlining preferences for life-sustaining treatment and medical order were identified in a single health record, the documented treatment preferences were consistent across documents in 92.5% of document pairs. This study indicates concordance between life-sustaining treatment instructions in an ACD and medical order is high where both document types are present in a person's health record. This finding demonstrates greater consistency than previously reported. [21-23] Consistency between ACD and medical order treatment preferences did not appear to be affected by differences in the age of paired documents.

Implications for practice

In this study, older Australians at risk of deterioration and dying had limited documented instructions available for use by treating health professionals, whether instructions in an ACD or a medical order. The availability of an ACD and/or medical order for those receiving health and residential aged care services, is an important element of quality medical treatment, palliative care or end-of-life care.

Health and residential aged care systems should promote advance care planning, palliative care and/or end-of-life care planning. Systems may include robust policy, ACP training and education, health practitioners with ACP and medical order responsibilities, a health record inclusive of ACP documentation, and performance monitoring.

Older Australians should be supported to understand and participate in advance care planning, palliative care and end-of-life care planning, when relevant. ACP may result in the voluntary completion of an ACD for preferences for care and/or appointing a SDM. Early ACP while a person has capacity is important. As care increases or a person becomes at risk of deterioration, people

should be supported to participate in shared medical treatment decision-making and documenting medical orders, regarding life-sustaining treatments.

Accessibility and enactment of this documentation should promote avoidance of over- or under-treatment to a patient concerning life-sustaining treatments. An ACD or medical order should be available in a person's health records at the point of care and the person's electronic My Health Record which is accessible across health and aged care sectors.

Glossary

Term	Definition
Advance Care Directive	<p>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.</p> <p>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.</p> <p>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.</p>
<i>Non-statutory Advance Care Directive (Common Law Advance Care Directive)</i>	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.
<i>Statutory Advance Care Directive</i>	A structured document that focuses on an individual’s values and preferences for future health and medical treatment decisions, completed and signed by a competent person, using a statutory form and/or meets formalities within relevant legislation.
Advance care plan	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)	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.
Advance care planning documentation	The collective term for documentation related to advance care planning completed by the person, a health professional and/or someone else. This includes Advance Care Directives, advance care plans, medical orders, goals of care, statement of choices (competent or non-competent), and other informal advance care planning forms.
<i>Advance care planning documentation by the person</i>	The collective term for statutory Advance Care Directives and non-statutory advance care planning documentation completed by the person.

Term	Definition
<i>Advance care planning documentation by a health professional</i>	The collective term for documentation related to advance care planning completed by a health professional. This may include a medical order, goals of care form, an advance care plan completed on behalf of the person, and advance care planning discussion record, an advance care planning alert, or progress notes.
End of life	The period when a patient is living with, and impaired by, a fatal condition, even if the trajectory is ambiguous or unknown. This period may be years in the case of patients with chronic or malignant disease, or very brief in the case of patients who suffer acute and unexpected illness or events, such as sepsis, stroke or trauma.
Goals of care	A type of medical order that outlines clinical and other goals for a patient's episode of care that are determined in the context of a shared decision-making process.
Health record	Health record includes a record of the patient's medical history, treatment notes, observations, correspondence, investigations, test results, photographs, prescription records and medication charts for an episode of care.
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. Medical orders outline the care preferences and/or treatment intentions for a patient for a specific 'treatment episode'. These treatment episodes may span a single (acute) admission or reflect preferences for care across repeated admissions for a single medical problem, such as renal dialysis.
My Health Record	The secure online summary of a consumer's health information, managed by the System Operator of the national My Health Record system (the Australian Digital Health Agency). Clinicians are able to share health clinical documents to a consumer's My Health Record, according to the consumer's access controls. These may include information on medical history and treatments, diagnoses, medicines and allergies.
Person	Consumers of services provided by hospitals, residential aged care facilities and general practice. Used interchangeably with consumer, resident, patients and clients.

Term	Definition
Substitute decision-maker	Substitute decision-maker is a person appointed or identified by law to make substitute healthcare decision(s) on behalf of a person whose decision-making is impaired. A substitute decision-maker may be appointed by the person, appointed for (on behalf of) the person, or identified as the default decision-maker within legislation. Substitute decision-makers listed in Advance Care Directives are statutory appointments. Substitute decision-makers listed in advance care plans are not legally binding.

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