Original Article

Concordance Between Self-Reported Completion of Advance Care Planning Documentation and Availability of Documentation in Australian Health and Residential Aged Care Services

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Abstract

Context. Advance care planning (ACP) documentation needs to be available at the point of care to guide and inform medical treatment decision-making.

Objective. To examine concordance between self-reported completion of ACP documentation and self-reported storage of the documentation at the person's current point of care with the availability of the documentation in that person's health record.

Methods. A national multicenter audit of health records and a self-report survey of eligible audit participants in 51 Australian health and residential aged care services. The audit assessed availability of ACP documentation in the health record, whereas the survey assessed self-reported completion and storage of the ACP documentation at the person's current place of care. To ascertain concordance, survey and audit data were cross-tabulated and concordance rates and kappa statistics were calculated overall and by health care sector and ACP documentation type.

Results. The audit included 2285 people, of whom 1082 were eligible for the survey. Of 507 who completed the survey (response rate = 47%), 272 (54%) reported completing ACP documentation, of whom 130 (48%) had documentation identified in the audit. Conversely, 39 of 235 people (17%) who reported *not* completing ACP documentation had documentation identified (concordance rate = 64%; $\kappa = 0.303$, $P < .001$). The concordance rate increased to 79% when self-reported storage of ACP documentation at the person's current point of care was compared with the existence of the document in their health record ($\kappa = 0.510$, $P < .001$). Concordance varied by health care setting and type of ACP documentation.

Conclusion. Discrepancies exist between self-reported completion of ACP documentation and the presence of these documents in the health records of older adults, representing a significant patient safety issue. Public education campaigns and improvements to systems for document storage and accessibility are required to support person-centered medical and end-of-life care. J Pain Symptom Manage 2019;58:264–274.

Key Words

Advance care directive, advance care planning, audit, quality, concordance, documentation accessibility

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Accepted for publication: April 18, 2019.

0885-3924/$ - see front matter
https://doi.org/10.1016/j.jpainsymman.2019.04.026

Introduction

Advance care planning (ACP) is an ongoing process of discussion and planning for future health care, whereby a person's values and preferences are made known so that they can guide decision-making if the person is unable to make or communicate their decisions.[1] Although discussions are central to the process, ACP may also result in written documentation recording a person's values and specific preferences for future care and/or appointment of a substitute decision-maker (SDM).[1–3] The names, types, scope, and legal requirements of ACP documentation vary considerably within Australia and internationally.[4–8] In Australia, ACP documentation includes advance care directives (ACDs), a term encompassing a range of formalized documents recognized by state-based legislation or common law that are completed and signed by a competent adult.[9] A person may also choose to record their ACP preferences in other formats, including personal letters.

Documentation of ACP facilitates the sharing of information and understanding among family and clinicians[10,11] and is linked to improved end-of-life outcomes, including increased likelihood of receiving care consistent with preferences, reduced rates of hospitalization, less aggressive treatment, and greater probability of dying in a preferred setting.[2,12–19]

For the potential benefits of ACP documentation to be realized, it is important that documents are available when needed.[20] This includes being accessible at the point of care if the person is temporarily or permanently unable to participate in decision-making.[3,11,20–22] However, evidence suggests that ACP documents are frequently not accessible at the point of care.[23–28] This represents a significant patient safety issue because health care providers may not have access to relevant information about the person's preferences when treatment decisions are required, potentially resulting in the delivery of care that is inappropriate or inconsistent with the person's documented preferences.[23] These findings are also significant from a policy perspective, as initiatives aimed at increasing ACP uptake and promoting care aligned with the person's preferences will face challenges if documentation is not available to inform medical decision-making.[23,28]

To date, no Australian study has examined the extent to which older peoples' reports of ACP documentation completion matches with actual availability of the documentation in their health record at their current point of care. Australian health services currently use a range of systems to store and retrieve ACP documentation, including service-specific electronic health record systems, scanned medical records, hardcopy files, or a combination.[22] Some services may have mechanisms to elicit existing ACP documentation on admission and/or transfer documents across care settings; however, many rely on the individual to share and store their documentation with relevant providers.[22] Fragmented document storage and retrieval systems within and between health services, together with reliance on the individual to disseminate copies of ACP documentation to relevant parties, may mean that older Australians' efforts to record their ACP preferences are not well reflected in the availability of that documentation in their medical record. This may result in the delivery of unwanted or inappropriate medical treatment, with legal and clinical implications for both the individual and health practitioner. This study therefore aimed to describe the consistency, or level of concordance, between self-reported completion and availability of ACP documentation in Australian health and residential aged care services. These data are critical to better understand current systems and processes for eliciting, storing, and accessing ACP documentation and may inform interventions aimed at increasing accessibility of ACP documentation.

Methods

Design and Setting

This article reports findings from a wider Australian study describing the prevalence of ACP documentation in selected general practices, hospitals, and residential aged care facilities (RACFs). The study included a prospective multicenter audit of health records and a self-report survey of a subset of eligible audit participants. This paper reports on the concordance between self-reported ACP documentation and actual presence of ACP documentation for those participants who completed the survey. The research protocol and prevalence findings have been published elsewhere.[29,30] A summary of the methodology is reported here.

General practices, hospitals, and RACFs from all eight Australian jurisdictions were invited to participate in the study via an expression of interest process, advertised via newsletters, websites, and stakeholder distribution lists. Additional sites were approached by the research team and invited to participate based on the recruitment target of at least two general practices, hospitals, and RACFs from each jurisdiction.[30] Targeted recruitment of general practices was required as typical practice business models do not support research participation. All sites meeting inclusion criteria were accepted to participate in the study.[30] To cover staff costs associated with participating in the study (completing data collection

training; conducting the audit and survey), sites received A$100 per audited health record, to a maximum of A$5000 per site.[30]

The study was approved by Austin Health Human Research Ethics Committee, Melbourne, Australia (ref: HREC/17/Austin/83), and site-specific approval was obtained when required. Survey participants provided written informed consent.

Participants

Participants were eligible for the health record audit if they were 65 years or older (50 years or older for Aboriginal and Torres Strait Islander people) and were 1) admitted to a participating hospital for at least 48 hours before audit, 2) residing in a participating RACF for at least 48 hours before audit, or 3) visiting a participating general practice on the nominated day(s) of the study. A lower age criteria for Aboriginal and Torres Strait Islander people reflected earlier planning for aged care services in this population.[31] In hospitals and RACFs, health records were randomly selected for the audit from a list of eligible people.[30] For feasibility, consecutive eligible records were audited in general practices.

On the day(s) of the study, participants included in the audit were clinically assessed for survey eligibility by an on-site staff member (e.g., nurse or clinician) trained in the study methodology. Eligibility criteria for the survey included being able to speak English, having decision-making capacity (and able to provide written informed consent) and being well enough to complete the survey. Thus, people who were expected to die within 24 hours were ineligible.

Data Collection

Audit. Audit data were collected between September 2017 and January 2018 by trained staff at each site (e.g., nurses or clinicians).[30] Data collectors searched each article and/or electronic health record for ACP documentation for a maximum of 15 minutes. This timeframe was selected as it was felt that if documentation was to influence care in an acute medical situation, it needed to be readily accessible within 15 minutes of opening the record. Demographic and clinical data were also extracted from health records.

Survey. Participants who were eligible for the survey were approached by data collectors on the day of the study and invited to complete the 25-item survey, either on paper or electronically on a tablet or laptop and by themselves or with assistance from the on-site data collector. Survey questions elicited information on demographics and self-reported completion and storage of ACP documentation.

Measures

Audit. ACP documentation was defined as present in a person's health record if an ACD recording preferences for care, an ACD appointing an SDM, or any other documentation written by the person about their preferences for medical care (e.g., personal letters) were located within 15 minutes.[29,30]

Survey. Self-reported completion of ACP documentation was assessed by an affirmative response to either or both of the following questions: 1) *Have you ever written down your goals, values, beliefs, or preferences about specific medical treatment in case you become seriously ill or unable to make your own decisions?* and 2) *Have you ever signed a legal document to appoint someone to make health care decisions on your behalf if you were unable to make your own decisions?* If participants responded yes to either or both questions, they were asked to indicate, via free text response, where their document(s) were stored. Responses were coded as either 1 = *stored at current point of care* or 0 = *not stored at current point of care*, where "current point of care" was the specific site (i.e., a general practice, hospital, or RACF) the person was accessing at the time of the study.

Statistical Analysis

Data were analyzed in SPSS v24.0 (IBM), with alpha set at .05. Survey data were linked to audit data using a de-identified study number. Between-group analyses were conducted to assess differences between survey participants and people included in the audit who were eligible for but did not complete the survey (survey noncompleters). Independent samples t-tests were used for continuous variables and chi-squared tests for independence for categorical variables. Significant between-group differences were examined post hoc using adjusted standardized residuals. Values greater than 3 were taken to indicate cells that significantly deviated from independence.[32]

To assess concordance between the survey and audit data, data were cross-tabulated and concordance rates and Cohen's kappa (κ) were calculated overall and by health care setting and ACP documentation type. Because the traditional κ coefficient is sensitive to systematic differences (bias) between data sources and by the distribution of data across categories (prevalence), the prevalence-adjusted bias-adjusted kappa (PABAK) was also reported for each analysis.[33] A κ or PABAK value of $\leq$0.20 was taken to indicate slight agreement, 0.21−0.40 fair

agreement, 0.41–0.60 moderate agreement, 0.61–0.80 substantial agreement, and 0.81–1.00 almost perfect agreement.[34] Concordance was assessed between the presence of ACP documentation in the audited record and both survey measures (self-reported completion of ACP documentation and self-reported storage of ACP documentation at the current point of care). This enabled a secondary analysis using a multilevel logistic regression model (including a random effect for site) to determine whether self-reported storage of the documentation at the current point of care was a stronger predictor of the ACP documentation being present in the audited record than self-reported completion of documentation alone.

Results

Participating Sites

Participating sites were 13 general practices, 12 hospitals, and 26 RACFs representing six Australian states and territories (no sites were recruited from the

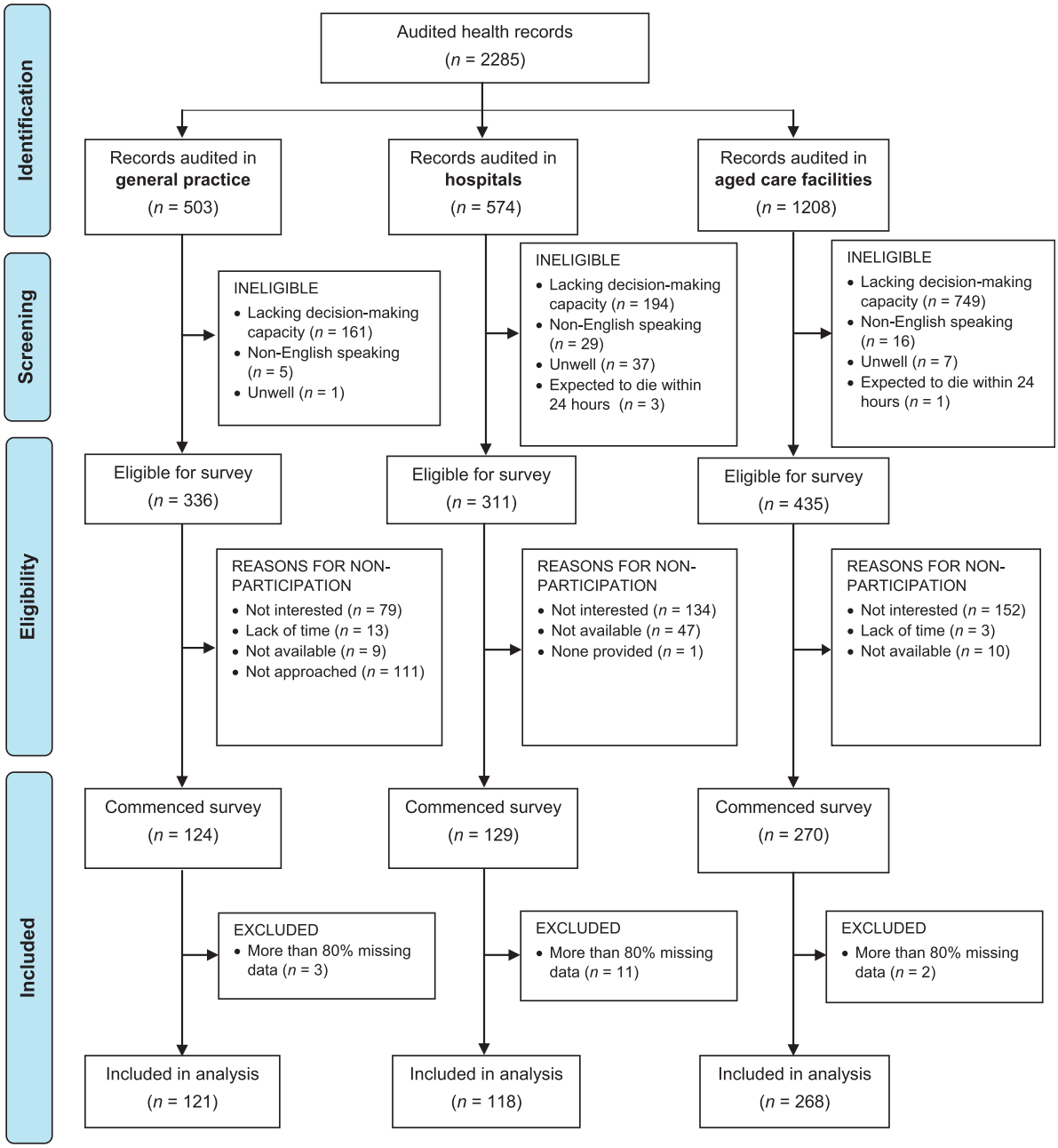

Fig. 1. STROBE flow diagram of participant recruitment according to general practice, hospital, and residential aged care settings.

Northern Territory and Western Australia). Just over half (55%) were located in metropolitan areas with the remainder in regional/remote areas.[29]

Participants

A total of 2285 health records were audited, of whom 1082 were eligible for the survey and 523 provided consent to participate. Of those who began the survey, 16 who completed less than 20% of questions were excluded, leaving a final sample of 507 participants (response rate = 46.9%; see Fig. 1).

Characteristics of survey completers ($n = 507$) and noncompleters ($n = 575$) are presented in Table 1. Survey participants had a median age of 82 years (interquartile range = 17) and were predominantly female (66%), had more than two medical conditions (62%), and resided in an RACF (53%). Almost half of the survey sample (45%) lived in the state of Victoria. Survey completers were comparable to noncompleters with respect to indigenous status and number of medical conditions. However, there were significant differences between the groups in age, gender, health care setting, and presence of ACP documentation in their audited health record. Specifically, survey completers were significantly more likely to be older, female, reside in an RACF and have ACP documentation identified in their health record, and significantly less likely to be in a general practice or hospital than survey noncompleters (see Table 1).

Overall Concordance Between Self-Reported Completion of ACP Documentation and Documentation Present in Health Records

Overall, 272 (54%) participants reported completing ACP documentation. Of these, less than half (48%; 130 of 272) had ACP documentation in

Table 1
Characteristics of Survey Completers ($n = 507$) Compared With Survey Noncompleters ($n = 575$)

Characteristic	Survey Completers, *n* (%)	Survey Noncompleters, *n* (%)	Test Statistic[a]	*P*
Age in yrs	Median = 82; IR = 17	Median = 79; IR = 15	−2.85	0.004
Gender (female)	335 (66.1)	341 (59.3)	6.34	0.012
Health care setting				
General practice	121 (23.9)[b]	215 (37.4)[b]	63.81	<0.001
Hospital	118 (23.3)[b]	193 (33.6)[b]		
Residential aged care facility	268 (52.8)[b]	167 (29.0)[b]		
State/territory[c]				
Australian Capital Territory	26 (5.1)	0 (0.0)	—	—
New South Wales	104 (20.5)	100 (17.4)		
Queensland	66 (13.0)	104 (18.1)		
South Australia	62 (12.2)	68 (11.8)		
Tasmania	21 (4.1)	3 (0.5)		
Victoria	228 (45.0)	300 (52.2)		
Indigenous status				
Indigenous	10 (2.0)	4 (0.7)	5.85	0.054
Nonindigenous	460 (90.7)	513 (89.2)		
Prefer not to say	37 (7.3)	58 (10.1)		
Ethnic diversity[d]				
Little or none	459 (90.5)	—		
Moderate/high	48 (9.5)	—		
Current relationship status				
In a relationship	152 (30.0)	—		
Single	41 (8.1)	—		
Divorced	71 (14.0)	—		
Widowed	243 (47.9)	—		
Education beyond secondary school	136 (26.8)	—		
Religious				
Yes	326 (64.3)	—		
No	156 (30.8)	—		
Prefer not to answer	25 (4.9)	—		
Number of medical conditions				
1	66 (13.0)	92 (16.0)	4.39	0.111
2	125 (24.7)	115 (20.0)		
More than 2	316 (62.3)	368 (64.0)		
ACP documentation identified in audit				
Yes	169 (33.3)[b]	138 (24.0)[b]	11.55	0.001
No	338 (66.7)[b]	437 (76.0)[b]		

IR = interquartile range.
[a] *t* statistic for age (continuous variable); chi-square for other variables.
[b] Adjusted standardized residuals > ±3 (standard errors).
[c] Owing to concerns about sampling bias between the states and territories, inferential statistics are not reported for this factor.
[d] The survey collected a range of measures to assess ethnic diversity including respondent's birthplace, self-reported ethnicity, and language spoken at home. Respondents reporting any combination of two or more indicators were categorized as having moderate/high ethnic diversity.

their audited health record. Conversely, 17% (39 of 235) of participants who claimed they had ***not*** completed ACP documentation had documentation present. The concordance rate between self-reported completion and the presence of documentation in the health record was 64% (fair agreement; $\kappa = 0.303$, PABAK = 0.286; see Table 2).

Twenty-seven percent (136 of 507) of participants stated their ACP documentation was stored *at their current point of care*. Of these, only 74% (100 of 136) had documentation present in their record at that service. Conversely, 19% (69 of 371) of participants who did ***not*** state their ACP documentation was stored at their current point of care did in fact have ACP documentation on file at that service. Despite these discrepancies, the concordance rate increased to 79% (moderate agreement) when self-reported storage of ACP documentation at the current point of care was compared with the presence of documentation in the person's file ($\kappa = 0.510$, PABAK = 0.586; see Table 2).

A multilevel logistic regression model including self-reported *storage* of ACP documentation in the person's current health record was a significant improvement on the model with self-reported *completion* of documentation only. The results of the model with both predictors are summarized in Table 2. It was estimated that the odds of ACP documentation being present in the person's current record were almost seven times higher if the participant reported their ACP documentation was stored in their current record, compared with not reporting their documentation was stored in their current record. The model included a random effect for site, which indicated strong between-site variation (intraclass correlation coefficient = 0.57).

Concordance by Health Care Setting

To assess whether concordance between the self-report and audit data varied by health care setting, self-reported completion of ACP documentation was compared with the presence of ACP documents in the health record separately for people in general practices, hospitals, and RACFs. The concordance rate ranged from 60% in general practices (slight to fair agreement; $\kappa = 0.032$, PABAK = 0.208) to 64% in hospitals (fair agreement; $\kappa = 0.252$, PABAK = 0.288) to 66% in RACFs (fair agreement; $\kappa = 0.301$, PABAK = 0.322; see Table 3). When self-reported storage of ACP documentation at the person's current point of care was compared with the presence of documentation in that record across health care settings, the concordance rate improved in general practices and hospitals but remained relatively stable in RACFs (see Table 3). However, as indicated by the differences between the κ and PABAK values for general practices, caution must be applied in interpreting the findings relating to this sector because of low cell counts.

Concordance by ACP Document Type

To assess whether concordance varied by document type, separate comparisons between the self-report and audit data were conducted for ACP documents expressing preferences for care and ACP documents appointing an SDM.

Of the 272 survey participants who reported completing an ACP document, 50 (18%) completed a document expressing preferences for care, 102 (38%) completed a document appointing an SDM, and 120 (44%) completed both documents.

As demonstrated in Table 4, the concordance rate between self-reported completion of an ACP document and the presence of that type of document in the record was 75% for ACP documents outlining preferences for care (moderate agreement; $\kappa = 0.428$, PABAK = 0.506) and 62% for documents appointing an SDM (slight to fair agreement; $\kappa = 0.150$, PABAK = 0.234).

When self-reported storage of a preferences for care and/or SDM document at the current point of care was compared with the actual presence of that type

Table 2

Concordance Between 1) Self-Reported Completion of ACP Documentation and the Presence of the Documentation in the Health Record and 2) Self-Reported Storage of ACP Documentation at the Current Point of Care and the Presence of the Documentation in That Record, Including the Odds Ratios From a Logistic Regression Model

		ACP Documentation Identified in Health Record, *n* (%)								
		Yes	No	Total	Concordance Rate (%)	κ	PABAK	*P*	OR (95% CI)	*P*
1) Self-reported completion of ACP documentation, *n* (%)	Yes	130 (25.6)	142 (28.0)	272 (53.6)	64.3	0.303	0.286	<0.001	1.87 (0.88, 3.96)	0.103
	No	39 (7.7)	196 (38.7)	235 (46.4)						
	Total	169 (33.3)	338 (66.7)	507 (100.0)						
2) Self-reported storage of ACP documentation at current point of care, *n* (%)	Yes	100 (19.7)	36 (7.1)	136 (26.8)	79.3	0.510	0.586	<0.001	6.83 (2.65, 17.60)	<0.001
	No	69 (13.6)	302 (59.6)	371 (73.2)						
	Total	130 (47.8)	142 (52.2)	507 (100.0)						

ACP = advance care planning; CI = confidence interval; OR = odds ratio; PABAK = prevalence-adjusted bias-adjusted kappa.

of document in the person's file, the concordance rate remained stable for preferences for care documents but increased for SDM documents (see Table 4).

Discussion

This study provides new evidence regarding the availability of ACP documentation across multiple Australian jurisdictions and health sectors. Findings demonstrated that more than half of people aged 65 years and older accessing health and residential aged care services reported completing ACP documentation. However, many of these documents were not present in the person's health record at their current point of care. When participant-reported storage of their ACP documentation at their current point of care was compared with the existence of the actual document in that audited health record, consistency between the self-report and audit data improved. However, a quarter of people who stated their ACP documents were stored at their current point of care still did not have documentation present in that file. Together, these findings indicate that ACP implementation, accessibility, and storage are problematic and may create risk to patient safety and the provision of health care aligned with the person's stated preferences.

Although many participants in this study reported taking the important step of formally completing ACP documentation, only 50% stated their documentation was stored at their current point of care. This suggests that a barrier to document implementation and accessibility may be low public awareness of the importance of sharing documents with all potentially relevant health care services. ACP templates do not typically contain information about appropriate methods of storage or the individuals' responsibilities in making copies accessible to all relevant parties.[35] Community education and clearer instructions on ACP documents for where and how to distribute copies may therefore improve the availability of documentation at the point of care. Furthermore, health professionals could play a greater role in ensuring their patients are informed about adequate document storage and should routinely enquire as to the presence of ACP documentation when a person attends their service.

Concordance between the audit and survey data was found to improve when participants' reports of storing their ACP documentation at their current point of care were compared with the existence of the actual document in their audited file at that point of care. However, a quarter of participants who stated their ACP documentation was stored at their current service

Table 3

Concordance Between 1) Self-Reported Completion of ACP Documentation and the Presence of Documentation in the Health Record and 2) Self-Reported Storage of ACP Documentation at the Current Point of Care and the Presence of the Documentation in That Record

	Health Care Setting	ACP Documentation Present in Health Record, *n* (%)		Total	Concordance Rate (%)	κ	PABAK	*P*
		Yes	No					
1) Self-reported completion of ACP documentation, *n* (%)	GP							
	Yes	2 (1.7)	47 (38.8)	49 (40.5)	60.4	0.032	0.208	0.350
	No	1 (0.8)	71 (58.7)	72 (59.5)				
	Total	3 (2.5)	118 (97.5)	121 (100.0)				
	Hospital							
	Yes	15 (12.7)	40 (33.9)	55 (46.6)	64.4	0.252	0.288	<0.001
	No	2 (1.7)	61 (51.7)	63 (53.4)				
	Total	17 (14.4)	101 (85.6)	118 (100.0)				
	RACF							
	Yes	113 (42.2)	55 (20.5)	168 (62.7)	66.1	0.301	0.322	<0.001
	No	36 (13.4)	64 (23.9)	100 (37.3)				
	Total	149 (55.6)	119 (44.4)	268 (100.0)				
2) Self-reported storage of ACP documentation at current point of care, *n* (%)	GP							
	Yes	0 (0.0)	2 (1.7)	2 (1.7)	95.9	−0.020	0.918	0.820
	No	3 (2.5)	116 (95.9)	119 (98.3)				
	Total	3 (1.7)	118 (97.5)	121 (100.0)				
	Hospital							
	Yes	8 (6.8)	1 (0.8)	9 (7.6)	91.5	0.573	0.830	<0.001
	No	9 (7.6)	100 (84.7)	109 (92.4)				
	Total	17 (14.4)	101 (85.6)	118 (100.0)				
	RACF							
	Yes	92 (34.3)	33 (12.3)	125 (46.6)	66.4	0.333	0.328	<0.001
	No	57 (21.3)	86 (32.1)	143 (53.4)				
	Total	149 (55.6)	119 (44.4)	268 (100.0)				

ACP = advance care planning; GP = general practice; PABAK = prevalence-adjusted bias-adjusted kappa; RACF = residential aged care facility.

Table 4

Concordance Between 1) Self-Reported Completion of ACP Documentation and the Presence of Documentation in the Health Record and 2) Self-Reported Storage of ACP Documentation at the Current Point of Care and the Presence of the Documentation in the Person's Record at That Service[a]

	Document Type	ACP Documentation Present in Health Record, *n* (%)		Total	Concordance Rate (%)	κ	PABAK	*P*
		Yes	No					
1) Self-reported completion of ACP documentation, *n* (%)	Preferences for care							
	Yes	96 (18.9)	74 (14.6)	170 (33.5)	75.3	0.428	0.506	<0.001
	No	51 (10.1)	286 (56.4)	337 (66.5)				
	Total	147 (29.0)	360 (71.0)	507 (100.0)				
	Substitute decision-maker							
	Yes	39 (7.7)	183 (36.1)	222 (43.8)	61.7	0.150	0.234	<0.001
	No	11 (2.2)	274 (54.0)	285 (56.2)				
	Total	50 (9.9)	457 (90.1)	507 (100.0)				
2) Self-reported storage of ACP documentation at current point of care, *n* (%)	Preferences for care							
	Yes	50 (9.9)	68 (13.4)	118 (23.3)	75.4	0.287	0.508	<0.001
	No	57 (11.2)	332 (65.5)	389 (76.7)				
	Total	107 (21.1)	400 (78.9)	507 (100.0)				
	Substitute decision-maker							
	Yes	27 (5.3)	53 (10.5)	80 (15.8)	85.0	0.335	0.700	<0.001
	No	23 (4.5)	404 (79.7)	427 (84.2)				
	Total	50 (9.9)	457 (90.1)	507 (100.0)				

ACP = advance care planning; PABAK = prevalence-adjusted bias-adjusted kappa.
[a]Self-report frequencies may differ from those reported in Tables 2 and 3 because participants may have had more than one type of ACP document.

did not have documentation present in that file, indicating potential issues with systems for storing, transferring, and accessing documents within health care services. This suggests there is a need for organizational improvements to support appropriate document accessibility at the point of care. To illustrate, a recent Australian study demonstrated how a relatively simple intervention involving new clerical processes, minor modifications to the electronic patient administration system and clinician education markedly improved the number, accessibility, and recognition of ACP documents within a regional public health service.[36]

Our findings also suggest there is an opportunity for system-level improvements to support the accessibility of ACP documentation in Australian health services. Given the current variability in systems for storing, retrieving, and accessing ACP documentation in Australia,[22] the use of a centralized e-health record system may improve the availability, transferability, and secure storage of ACP documentation.[21,22,37–39] In the U.S., a study evaluating the effectiveness of a dedicated storage location for ACP documentation in an e-health record found that a standardized location significantly improved rates of ACP documentation and the confidence of health practitioners in accessing documents when required.[40] In Australia, a new centralized e-health system known as "My Health Record" has recently been implemented, which offers online storage of ACP documentation.[41] All Australians are enrolled in this system unless they opt out and records are accessible to all authorized health care providers, including from general practice, hospitals, and RACFs. Although evidence regarding the impact of My Health Record on ACP is limited, this central repository has the potential to improve storage and retrieval processes.[41]

The consistency between self-reported completion of ACP documentation and the presence of documentation in the health record varied by health sector, with highest concordance found in RACFs followed by hospitals and general practices. This is likely to reflect fundamental differences between the care settings, including that people in RACFs reside in the same location as their health records. In addition, RACFs are encouraged through standards and public policy to have systems in place for documentation of ACP outcomes.[9,42] Other reasons for the variation between settings warrant future study but may include differences in support for ACP, local policy, types of documentation used, and processes for sharing documentation between care settings and electronic storage systems. There may also be important differences between sectors in the perceived organizational need for ACP documentation to be accessed as part of routine care.

Despite concordance being strongest in RACFs, many RACF residents who stated they had not completed ACP documentation actually did have documentation present in their file. Considering most residents in aged care have some degree of cognitive impairment,[43,44] it is possible that some

may have previously completed an ACP document with sound understanding of its purpose but subsequently forgotten about its existence. It is also possible that some residents did not understand they had completed ACP documentation. It is increasingly common for ACP documentation to be completed on admission into aged care, often as part of a larger suite of complex documentation. Although admission is an excellent trigger to develop or update ACP documentation, it is important that documents are completed within a broader and ongoing ACP discussion about the person's values, goals, and preferences rather than as a standalone exercise.[45] It may therefore be advisable for ACP documentation to be separated from the wider paperwork needed to enter aged care to avoid a mechanistic "tick box" approach.

The results of this study are consistent with previous international work[23–25,28] demonstrating that older people's reports of completing ACP documentation are not well reflected in the availability of that documentation in their health record. In a study of community-dwelling older adults, 15%–47% of people who reported giving an ACD to their health care provider actually had the document in their medical record.[28] Another study of U.S. veterans accessing an outpatient primary care service found that although 41% reported completing an ACD, only 33% had the document on file.[23] Lack of accessible ACP documentation at the point of care represents an important patient safety issue with potentially devastating impacts.[46] If documentation cannot be quickly accessed by health practitioners when faced with decisions about end-of-life care, life-sustaining treatment may be unlawfully withheld or provided,[47] resulting in legal and clinical risks for both the patient and health practitioner. The results of this study suggest that further research, quality improvement, and education are required to promote a systematized and coordinated approach to the implementation, accessibility, and electronic storage of ACP documentation across Australian health services.

Study strengths include a large sample size, representation from multiple care settings and jurisdictions, and the contemporaneous collection of survey and audit data. However, the self-report nature of the survey may have resulted in misreporting because of lack of knowledge regarding ACP[48] or inaccurate recall. Other limitations were the low number of participants with ACP documentation in general practice, meaning that findings related to this sector should be interpreted with caution, and the survey response rate (47%), which limits the generalizability of findings. For ethical reasons, our survey sample excluded older adults who lacked capacity or were too unwell to participate; however, this will be an important area for future research. Although it would be ideal to examine the availability of ACP documentation among underrepresented subgroups, such as people with indigenous backgrounds, this was beyond the scope of our study. This study did not address possible reasons for discrepancies between the survey and audit data, such as motivating factors for completing or storing ACP documentation or when, where, and with whom the documentation was completed. This audit study examined presence of ACP documentation; it did not investigate whether documentation identified accurately reflected the person's preferences or whether the presence of documentation translated into actual care that was consistent with the person's preferences, the ultimate goal of ACP.[1,49] Finally, owing to the design of this study, we were unable to determine whether ACP documentation was retrievable at locations other than the participant's current point of care. Nevertheless, this study has provided valuable data that can be used to establish benchmarks and inform quality improvement initiatives for storing and accessing ACP documentation at the point of care, not only within the Australian context but also internationally.

Conclusion

This study provides one of the largest multicenter, cross-sector data sets on the concordance between self-reported completion of ACP documentation and the accessibility of that documentation at the point of care among older people in Australia. Despite ACP discussions and documentation being increasingly promoted as a means of ensuring that a person receives care that is aligned with their preferences, our findings suggest that people's recorded preferences are often not accessible or stored in their health record. This represents a significant patient safety risk, whereby clinical decision-making and care delivery may be inappropriate or misaligned with the person's stated preferences.[3,24] Ensuring that people's preferences are documented and easily accessible when medical treatment decisions are required is an important patient safety and quality target to ensure that people's preferences are known and honored. Approaches to improve concordance, accessibility, and storage of ACP documentation include community and health professional education, e-health record systems, and ongoing quality monitoring. Further research is required to determine if e-health record systems can improve accessibility of ACP documentation at the point of care.

Disclosures and Acknowledgments

The authors declare that they have no conflicts of interest.

The authors acknowledge the support and contribution of the National Prevalence Study Advisory Group, Professor Sue Evans' contribution to the study protocol, the Study Coordinator Lead and the data collectors at each participating site, and Dr Sandy Clarke-Errey of the Statistical Consulting Centre, University of Melbourne, for providing statistical expertise.

Funding: This work was supported by the Australian Government Department of Health. The funder had no role in the study design; collection, analysis, and interpretation of data; writing of this article; or the decision to submit the article for publication.

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