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Association of advance care planning with hospital use and costs at the end of life: a population-based retrospective cohort study.

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Complete List of Authors:	Scott, Ian; University of Queensland, School of Clinical Medicine; Princess Alexandra Hospital, Department of Internal Medicine and Clinical Epidemiology Reymond, Liz; Metro South Hospital and Health Service, Statewide Office of Advance Care Planning; Griffith University, School of Medicine Sansome, Xanthe; Queensland University of Technology Carter, Hannah; Queensland University of Technology Faculty of Health, Australian Centre for Health Services Innovation
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Abstract

Objective: To investigate associations between the availability and timing of digitally available advance care planning (ACP) documents and hospital use and costs during the last 6 months of life.

Design: Retrospective population-based cohort study using data linkage.

Setting: 11 public hospitals in Queensland, Australia.

Participants: 5,586 decedents with ACP documents were directly matched 1:2 to 11,172 control decedents based on age category, sex, location, year of death and principal diagnosis code for the last known hospital admission.

Exposure: ACP discussions with documents uploaded to a widely accessible statewide digital platform. Directly matched sub-group analyses investigated differences between decedents with ACP documents available at three different times prior to death: ≥6 months; between 1-6 months; and < 1 month.

Main outcomes and measures: Emergency department (ED) presentations, hospital and intensive care unit (ICU) admissions, and in-hospital deaths, expressed as adjusted odds ratios (aOR). Secondary outcomes were hospital bed-days and costs.

Results: ACP decedents with documents uploaded ≥6 months prior to death, compared to controls, had fewer ED presentations (aOR 0.90, 95%CI 0.81 to 1.00), hospitalisations (aOR 0.83, 95%CI 0.74 to 0.92), ICU admissions (aOR 0.23, 95%CI 0.10 to 0.48), and in-hospital deaths (aOR 0.56, 95% CI 0.51 to 0.63), and lower adjusted mean hospital costs per person over the last 6 months of life ($A2290 less [95% CI -$4116 to -$463]). Conversely, decedents with ACP documents uploaded less than 6 months prior to death showed higher rates of ED presentations and hospital admissions and greater hospital costs relative to controls.

Conclusion: The association between digitally available ACP documents and health service use and cost differed based on the timing of ACP upload, with documents available ≥6 months prior to death being associated with less hospital use and costs.

Strengths and Limitations

- Large multi-site longitudinal analysis of standardised, patient-linked data on consecutive episodes of hospital care for almost 17,000 decedents, providing generalisable estimates of ACP effects on hospital utilisation, costs and place of death.
- Use of a matched cohort design compensated for the logistical difficulties of performing large randomised controlled trials, and where assigning patients to a no-ACP arm may be deemed unethical.
- Observational design precludes confirmation of causal relationships between ACP and measured outcomes.
- Inability to access data to control for potentially important but unmeasured confounders such as clinical status and disease severity, frailty, co-morbidity burden, and levels of psychosocial support.
- Analyses were hospital focussed such that utilisation and costs of non-hospital care were not ascertained.

Key Messages

What is already known on this topic Advance care planning (ACP) is known to decrease anxiety and decisional burden for relatives of patients who die, enhance clinician adherence to patient preferences and avoid unwanted cardiopulmonary resuscitation and life-support treatments. Whether the availability and timing of ACP documentation is associated with reduced hospital use and costs during the last 6 months of life remains unclear.

What this study adds: This study of 16,758 decedents found that those with ACP documents digitally available 6 months or more prior to death experienced fewer emergency department presentations, admissions to intensive care units and in-hospital deaths, and incurred less hospital costs, compared to matched controls with no digitally available documents.

How this study might affect research, practice or policy Findings of this retrospective observational study support ACP discussions being undertaken and documented in digitally accessible formats for all eligible patients in a timely, proactive manner.

Manuscript

INTRODUCTION

Advance care planning (ACP) is the iterative process of defining and documenting a person's values and preferences to guide future healthcare delivery[1]. Evidence shows ACP decreases anxiety, grief, decisional conflict and burden for surviving relatives and surrogates[2,3,4], enhances clinician adherence to patient preferences, increases use of palliative care, improves patient and family satisfaction with care, and avoids unwanted cardiopulmonary resuscitation (CPR) and life-support treatments[5,6,7]. Considerable expenditure on end-of-life care[8,9] may not improve care quality[10], and aggressive treatment may violate patient preferences[11] or prove non-beneficial[12,13].

Whether ACP reduces healthcare use and cost is unclear[14,15], especially when ACP uptake occurs in less than 50% of eligible patients[16] and multiple implementation barriers exist [17], including inaccessibility of ACP documentation when needed, and up to 75% of ACP documents being of poor quality[18]. The findings of economic evaluations of ACP vary according to their definitions of how and who provides ACP (influencing costs), and who the beneficiaries are (influencing outcomes)[19,20]. Studies of the association between ACP and healthcare use have yielded conflicting results depending on the level and fidelity of ACP uptake and documentation, characteristics of the population studied, and the choice of utilisation measures [21,22]. Such ambiguity has led some to question the desirability of investing more resources towards large-scale adoption of ACP[23], while others

assert existing research is methodologically limited and does not adequately account for the nuances and complexity of ACP [24,25].

There is increasing recognition of the need for ACP to be conducted proactively, iteratively and with longer lead time prior to death [26,27]. Advocates have called for system-wide changes to how ACP is conceptualised, moving beyond the one-off completion of advance health directives to an ongoing process to support individuals to better prepare for future decision making [24, 28], including enhancing their understanding of their illness, identifying proxies, and having values-based conversations [28]. The earlier these ACP processes are initiated prior to death, the greater the potential impact on individual treatment choices and care provided during the end-of-life phase. However, the relationship between the timing of ACP and healthcare resource use and cost remains unclear.

The aim of this study was to investigate the association between the time prior to death at which standardised ACP documents became available on an accessible statewide digital platform and hospital use and costs over the last 6 months of life among a large population of decedents..

METHODS

Study Design

This was a retrospective, longitudinal, population-based, matched cohort study comparing public hospital use and costs, in-hospital deaths and terminal admission (i.e. admissions where death occurs in hospital) outcomes over the last 6 months of life between a cohort of decedents with a digitally uploaded ACP document (ACP cohort) and a control cohort with no uploaded ACP documents.

Setting and Population

Eligible decedents were those over 18 years whose deaths were officially registered between 1st August, 2015 and 31st October, 2019, and who had resided in one of five health service regions in south-east Queensland, Australia (Gold Coast, Brisbane North, Brisbane South, Sunshine Coast, West Moreton), serviced by 11 public hospitals. Decedents whose terminal hospital admission and/or registered cause of death was due to acute trauma were excluded, as ACP was aimed at those likely to die an expected death from chronic diseases within 12 months. Due to unavailability of cost data, people dying after June 30th, 2019, were excluded from hospital cost analyses.

Within Queensland, hospitals within a defined geographical catchment area are centrally managed by a local hospital and health service which enables an overarching regional approach to care. All hospitals across the five health services included in this study had equivalent clinical service capabilities in regards to emergency departments, intensive care units, palliative care services, and general medical and surgical inpatient care. All study hospitals also operated under a consistent ACP funding and policy framework. Hence, patients presenting to

different hospitals within the same health service would experience similar approaches to ACP.

The ACP cohort comprised decedents with a complete, valid ACP document uploaded to a statewide digital platform before death. Decedents with only an enduring power of attorney (EPOA) document were excluded as completion of this document may not have involved ACP discussions. All other decedents, with no uploaded document, were eligible to be randomly selected and matched as controls.

Exposure to Advance Care Planning

The Queensland Health (QH) Statewide Office of Advance Care Planning (SOACP) is responsible for supporting a coordinated approach to ACP across all care settings[29]. It provides standardised education for dedicated ACP facilitators who then upskill and assist local clinicians to invite eligible individuals to partake in ACP conversations, having been identified using the "surprise question": would I be surprised if this person died in the next 12 months? [30]. Twelve full-time facilitators are funded and distributed equitably across the five health services according to relative catchment populations and who worked within hospitals, primary care practices and residential aged care facilities (RACFs). The SOACP has developed a values-based, standardised Statement of Choices (SoC) form[31] available as a user-friendly, non-legally binding, easily modified form detailing patients' goals of care and preferences for CPR, life-support interventions and other supportive care (**eAppendix 1 in Supplement**). A legally binding Advance Health Directive (AHD) is also available and considered an appropriate ACP document. In addition, during the study period, QH incentivised hospitals to undertake ACP by providing a one-off

payment of between $A100 and $A200 for each ACP invitation to individual patients.

Copies of ACP documents are sent, via fax, mail or e-mail, to the SOACP where they are audited for legibility and completeness before being uploaded to the person's hospital electronic medical record via an app, 'The ACP Tracker', located within a secure statewide digital platform accessible to all QH clinical staff (**eAppendix 2 in Supplement)**. Forms with incomplete mandatory fields, including missing signatures, are not uploaded until corrected. Queensland Ambulance Service paramedics and authorised primary care practitioners, community nurses and RACF nursing staff also have read-only access to the app through a Health Provider Portal (**eAppendix 3 in Supplement**).

Variables, Data Sources and Matching Process

Data on patient characteristics, episodes of care and outcomes were collected and linked by the QH Statistical Services Branch (SSB) across five datasets: deaths from the Queensland Registry of Births, Deaths and Marriages; International Classification of Disease version 10, Australian modification (ICD-10-AM) coded cause of death from the Australian Bureau of Statistics (ABS); data on ED presentations from the statewide Emergency Department Information System; data on hospital and ICU admissions, including ICD-10-AM primary diagnosis codes, from the Queensland Hospital Admitted Patient Data Collection (QHAPDC); and hospital admission costs (combined direct and overhead costs) from the National Hospital Cost Data Collection. A full list of extracted data items is provided in **eAppendix 4 in Supplement**. Consecutive hospital presentations and admissions at the patient level

were linked by QH SSB using deterministic and probabilistic linkage algorithms (**eAppendix 5 in Supplement**) resulting in 99.7% linkage of available records. All costs are reported in 2021 Australian dollars with costs collected in years 2015–2018 indexed to the most recent reference year using the Australian consumer price[32].

All ACP decedents were randomly matched in a 1:2 ratio with control decedents based on age (with 5-year age brackets applied when direct matches could not be identified), sex, year of death, health service region and ICD-10-AM code for the primary diagnosis of the last-known hospital admission prior to death in the community or in hospital, or of the terminal admission (i.e admission in which the person died in hospital) if no prior admission was recorded. The choice to match on diagnosis of last known hospital admission, rather than on admissions within a specific time period prior to death, reflected our hypothesis that earlier completion of ACP documentation may alter treatment choices which could in turn reduce the likelihood of future admissions. The 1:2 ratio was selected to increase precision and decrease bias in effect estimates, while ensuring feasibility of exact matching within the available data [33].

Outcome Measures

Primary outcome measures were differences between ACP and control cohorts in the odds of decedents, over the last 6 months of life: having one or more presentations to ED, hospital admissions, and ICU admissions; or dying in hospital. Secondary outcome measures were differences between the cohorts in hospital bed-days, ED costs, hospital admission costs, and total hospital costs over the 6 month period. We also assessed associations of an uploaded document prior to a

terminal hospital admission (an admission in which the person died in hospital) with ICU admissions, palliative care classifications (ie admission classified as palliative care if an end-of-life care pathway was initiated and comfort care only was provided), length of stay and cost of that admission.

We followed the Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) guideline in reporting clinical outcomes[34] and the Consolidated Health Economic Evaluation Reporting Standards (CHEERS) checklist in reporting cost outcomes[35].

Statistical Analyses

Adequacy of matching

In addition to comparing cohorts using the matching variables, we also compared both cohorts for ICD-10-AM coded cause of death, this data becoming available after matching had been completed. For decedents with at least one hospital admission during the 6 months prior to death (admitted patient cohorts), we also compared these cohorts for variables unavailable for all decedents. These variables comprised: preferred language, marital status, hospital insurance, indigenous status, residence locality (according to Accessibility/Remoteness Index of Australia [ARIA])[36] and socioeconomic status (according to Socio-Economic Indexes for Areas [SEIFA] quintiles)[37]. For both total and admitted patient cohorts, we calculated standardised mean differences (SMDs) for each variable as a measure of balanced distribution between ACP and control cohorts, with cohorts considered acceptably matched if SMDs were <0.20 [38, 39].

Outcome analyses

The main outcome analysis compared primary and secondary outcomes between the subgroup of ACP decedents who had an ACP document uploaded for 6 months or more prior to death compared to controls directly matched over the same period. Separate pre-specified subgroup analyses compared ACP decedents who had an ACP document uploaded between 1 and 6 months, and less than 1 month, prior to death, with correspondingly matched controls. These subgroup analyses tested our hypothesis that the earlier completed ACP documents became available, the more likely these documents would guide a more person-centred conservative approach to subsequent end-of-life care over a longer period prior to death, resulting in less hospital use and costs and fewer in-hospital deaths. Post-hoc, exploratory analyses assessed differences in hospital costs between ACP subgroups according to the timing of ACP upload.

Regression modelling

Logistic regression models were used in analysing primary outcomes, and linear regression models in analysing secondary outcomes. All regression models adjusted for registered ICD-10 coded underlying cause of death which became known after matching, with effect estimates expressed as an adjusted odds ratio (aOR)[40]. Residual plots of all models were assessed to confirm assumptions of constant variance and normally-distributed error terms were met. Due to the zero-inflated, non-normal distribution of length of stay and costing data, bootstrap resampling was used to produce 10,000 simulated regression models from which adjusted means

were derived and the percentile method used to estimate 95% confidence intervals (CI)[41]. All analyses were performed using R (version 4.0.3) and 2-sided $p < 0.05$ denoted statistical significance.

Ethics Approval

Ethics approval for this multi-site study was granted by Metro South Human Research Ethics Committee (ref: HREC/17/QPAH/36) with administrative ethics approval from Queensland University of Technology Human Research Ethics Committee (approval number: 2000000611) and approval under the Public Health Act to access de-identified decedent data from the Office of the Director General of QH (QH-SSB request ID32140).

Patient and Public Involvement

No patients or members of the public were involved in the design or conduct of this study.

RESULTS

From the initial sample of 14,253 uploaded documents, after excluding those failing participant selection criteria, were duplicates, comprised only EPOA documents, or had an invalid upload date, 5,624 decedents with at least one uploaded ACP document (SoC or AHD) were subject to matching (**Figure 1**). Of these, 38 could not be directly matched as they had no hospital admission in the preceding 5 years, leaving 5,586 in the total ACP cohort matched with 11,172 controls. The admitted patient cohort comprised 4,018 (71.9%) ACP and 7,857 (70.3%) control decedents. For hospital costing analyses, after removing deaths occurring after June 30th, 2019,

and decedents unable to be directly matched, 4,787 (85.7%) and 9,020 (80.7%) decedents comprised ACP and control cost cohorts respectively.

Participant Characteristics

Clinical and demographic characteristics of ACP and control decedents in the total and admitted patient cohorts are listed in **Table 1**, along with SMDs for matching and comparison variables, all of which were <0.16, indicating the cohorts were acceptably matched. Corresponding data for each of the ACP subgroups and the costing cohorts are included in **eAppendix 6.** Mean (standard deviation [SD]) age for both cohorts was 81 (±12) years, 51.7% were females, and among ACP decedents 5,312 (95.1%) had a SoC form, 391 (7.0%) had a AHD, and 117 (2.1%) had both.

Within the ACP cohort, 2,507 (45%) had ACP documents uploaded 6 months or more before death, 1,223 (22%) between one month and less than 6 months, and 1,856 (33%) less than a month before death. (**Figure S1 in Supplement**).

Hospital Use

ACP decedents with documents uploaded ≥6 months prior to death, compared to matched control decedents, demonstrated significantly lower odds of ED presentations (aOR 0.90, 95%CI 0.81 to 1.00; 65.0% vs 68.5%), hospital admissions (aOR 0.83, 95%CI 0.74 to 0.92; 61.9% vs 67.6%), ICU admissions (aOR 0.23, 95%CI 0.10 to 0.48; 0.3% vs 1.3%) and in-hospital deaths (aOR 0.56, 95%CI 0.51 to 0.63; 38.4% vs 53.1%).

For ACP decedents with documents uploaded between 1 and 6 months, or less than 1 month, prior to death, similar reductions were seen in ICU admissions (aOR 0.39; 95%CI 0.20-0.71 and aOR 0.46; 95%CI 0.17-1.04 respectively) and in-hospital deaths (0.58; 95%CI 0.51-0.65 and 0.71; 95%CI 0.61-0.82) compared to controls, although the odds of ED presentations (1.41; 95%CI 1.23-1.61 and 1.74; 95%CI 1.47-2.06) and hospital admissions (1.57; 95%CI 1.36-1.81 and 1.74; 95%CI 1.47-2.08) were higher (**Table 2**).

Hospital bed-days and costs

ACP decedents with a document uploaded ≥6 months prior to death demonstrated an adjusted mean reduction of $2,337 (95%CI -$4,222 to -$452) in total hospital costs with no difference in bed-days compared to matched controls (Table 3). Decedents with an ACP uploaded between 1 and 6 months prior to death, relative to controls, incurred more bed-days (8.9; 95%CI 7.6-10.2) and total hospital costs (+$11,282; 95%CI 8,770-13,793), than ACP decedents with uploads less than 1 month prior to death relative to controls (4.5; 95%CI 3.2-5.9 and +$5628; 95%CI 2700-8557 respectively).

Terminal Admission Outcomes

ACP decedents with documents uploaded prior to the terminal admission had significantly lower odds of ICU admission relative to controls during that admission (aOR 0.13, 95%CI 0.06 to 0.23; 0.7% vs 4.7%), and higher odds of the admission being classified as palliative care (aOR 1.98, 95%CI 1.72 to 2.27; 71.6% vs 57.0%, **Table 4**). While there were no significant differences in length of stay, mean hospital

costs for the ACP cohort were $3,966 less (95%CI -$5,487 to -$2,444) than for controls.

Post-hoc analyses

ACP decedents with documents uploaded ≥6 months prior to death incurred $10,575 (95%CI -$12,458 to -$8691) less total hospital costs than ACP decedents with documents uploaded in the last month of life, but there were no significant difference in costs compared to ACP decedents with documents uploaded between 1 and 6 months. Notably, monthly costs continued to reduce numerically in the months immediately after ACP document upload. (**Figure S2 in Supplement**).

DISCUSSION

Summary of Findings

To our knowledge, this is the first population-level cohort study of the association between audited, standardised and digitally-accessible ACP documents uploaded at varying time intervals prior to death and hospital use and costs over the last 6 months of life.. Having an ACP document available 6 months or more prior to death was associated with fewer ED presentations, admissions to hospital or ICU, and in-hospital deaths, and lower hospital costs compared to having no ACP document available for the same period. In contrast, decedents with an ACP document uploaded <6 months prior to death demonstrated higher rates of hospital use and higher costs than controls, although ICU admissions and in-hospital deaths continued to be lower. While this observational study is unable to demonstrate causality, our findings suggest that more patient benefit and less hospital use and

costs may accrue if ACP documents are completed proactively, with long lead times prior to death, rather than reactively in response to imminent death.

Comparisons with Other Studies

Our findings support those of other observational studies of ACP. In a US study with 1:1 matching (n=325 in each group) and using an adjusted differences-in-differences analysis of hospital use and costs over a 12 month period before ACP and a 12 month period prior to death, ACP patients had fewer admissions (-0.37 per person; 95%CI -0.66 to -0.08), inpatient days (-3.66 days, 95%CI -6.23 to -1.09) and less costs billed to Medicare (-$US9500, 95%CI -$16207 to -$2793), driven primarily by less inpatient utilisation[42]. Another study in Hong Kong of 69 ACP patients matched with 174 controls showed the former had fewer acute hospital admissions (0.78 ± 0.28 vs 1.2 ± 0.8 per person, p=0.037) and shorter length of stay (4.6 ± 1.7 vs 7.5 ± 2.5 days, p=0.023) over the last 3 months of life[43]. In a US population study involving 27,711 patients with one or more chronic diseases and using logistic regression models, patients undergoing ACP >30 days before death had significantly lower odds of hospitalisation and ICU admission in the last month of life, except for patients with only renal disease[22]. In another US study of 237,989 decedent Medicare beneficiaries, patients with at least one billed ACP visit (6.3%, 14,986), after multivariable adjustment, experienced fewer hospitalisations (OR 0.77, 95%CI 0.74 to 0.79), ED visits (OR 0.77, 95%CI 0.75 to 0.80), or ICU stay (OR 0.78, 95%CI 0.74 to 0.81) within a month of death, and were less likely to die in hospital (OR 0.79, 95%CI 0.76 to 0.82), although mean expenditures were not significantly reduced (-$242.50; 95%CI −$103.63 to $588.61)[44]. Finally, among 332 patients with advanced cancer, end-of-life care discussions involving 123 patients were

associated, in the last week of life, with lower rates of ventilation (aOR 0.26, 95% CI 0.08 to 0.83), resuscitation (aOR 0.16, 95% CI 0.03 to 0.80), ICU admission (aOR 0.35, 95% CI 0.14 to 0.90), and earlier hospice enrolment (aOR 1.65, 95% CI 1.04 to 2.63)[7].

However, other observational studies report contrasting results. In a propensity score matched US study of 18,484 seriously ill Medicare patients, a billed ACP encounter which occurred for 864 (4.7%) patients was associated with a higher likelihood of hospitalisation (incidence rate ratio [IRR] 1.37, 95%CI 1.26 to 1.49) and ICU admission (IRR 1.25, 95%CI 1.08 to 1.45) over the subsequent 6 months, and total medical costs were higher (per patient per month difference $US1,635, 95%CI $1,243 - $2,075), largely driven by hospital costs[22]. In another US study of 2,394 selected decedents aged over 65 years, Medicare expenditures in the last 6 months of life had no association with ACP[45]. Critics of ACP also note that randomised trials of ACP have not reported reduced healthcare utilisation[23], but these trials were methodologically limited because of recruitment bias[46], small samples with inadequate power[47], very low uptake and fidelity of ACP interventions[48], fixed default care options in AHDs[49], and primary outcome measures which did not include healthcare use[50].

Implications for Clinical Practice

Several factors specific to the QH setting during this study may explain the observed positive impacts of ACP on hospital use. First, the use of ACP in hospital practice and primary care was supported by whole of community education campaigns, use of skilled ACP facilitators, clinician access to ACP resources and templates,

provision of patient information brochures, and embedment of end-of-life care frameworks that clearly defined clinician roles and responsibilities for ACP discussions[29,51,52]. Second, early patient engagement in ACP discussions was encouraged[53] by proactive identification of ACP-eligible patients using the 'Surprise' question [30] rather than waiting for patients to enter terminal phases. As a primary intent of ACP, this allowed time for iterative refinement of ACP documents which ensured ongoing ACP discussions remained relevant to patient needs and cognisant of important interpersonal relationships[54]. Third, within hospitals, ACP facilitators helped to initiate and progress early discussions with ACP-eligible patients and advised attending clinicians of ACP status and the need to finalise ACP discussions and review, complete and sign documentation. Fourth, a centralised process was in place to ensure valid, high quality ACP documents were widely accessible when needed[55][56]. Finally, as clinical care and patient wishes must align for ACP to represent a high value activity[57], we audited in-hospital care provided to 600 decedents with an uploaded SoC which demonstrated high concordance between preferred and actual place of death (79%) and between practice and preferences for CPR (100%) and life-prolonging treatments (99%) over the last 6 months of life[58]. Similar concordance (79%, 100%, 97% respectively) was seen for care received by 198 patients over a 12-month period following completion of a SoC form[59].

Strengths and Limitations

Study strengths include longitudinal analysis of standardised, patient-linked data on consecutive episodes of hospital care for almost 17,000 decedents. This large multi-site study provides generalisable estimates of ACP effects on hospital utilisation,

costs and place of death using a matched cohort design which compensates for the logistical difficulties of performing large randomised controlled trials, and where assigning patients to a no-ACP arm may be deemed unethical. Analysis of standardised hospital costing data afforded assessment of ACP-mediated hospital cost minimisation. Our SoC form satisfied all relevant documentation quality and accessibility criteria[60] and we described ACP processes and outcomes often missing in evaluation studies[61].

There are also several limitations, in addition to the previously noted inability to establish causality between ACP and hospital use, cost and place of death. While we minimised selection bias by matching ACP and control decedents on available demographic and clinical variables, we could not access data to control for potentially important but unmeasured confounders such as clinical status and disease severity, frailty, co-morbidity burden, and levels of psychosocial support. In addition, underlying differences in individual values and preferences may have influenced decisions by those in the control cohort to elect not to participate in ACP. Data on private hospital presentations were not available, although we suspect very little leakage of patients from the public hospital system. As our analyses were hospital focussed, utilisation and costs of non-hospital care were not ascertained, but other studies suggest hospital costs account for most expenditure[7,22,42]. Finally, some control decedents may have undergone ACP discussions and even completed ACP documents which were not uploaded electronically, but which may still have informed care decisions.

In conclusion, we provide observational evidence that digitally accessible, standardised ACP documentation available prior to death is associated with reduced ICU admissions and in-hospital deaths over the last 6 months of life. Additional reductions in health service use and cost were associated with documents being available 6 months or more prior to death. Large scale pragmatic randomised controlled trials are warranted to confirm causality of these associations.

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Contributorship statement:

Guarantor: Ian Scott accepts full responsibility for the finished work and/or the conduct of the study, had access to the data, and controlled the decision to publish.

Concept and design: Scott, Reymond, Sansome, Carter

Acquisition, analysis, or interpretation of data: Reymond, Sansome, Scott, Carter

Drafting of the manuscript: Scott, Carter

Critical revision of the manuscript for important intellectual content: Reymond, Sansome, Scott, Carter

Statistical analysis: Carter, Scott

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Supervision: Scott, Reymond

Competing interest disclosures

None of the authors have any competing interests to declare.

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Data sharing

Our ethical approvals prevent individual-level data from being shared beyond those named on the ethics application (Authors Reymond, Sansome, Carter). Aggregate-level data may be shared where appropriate. Author Hannah Carter can be contacted if there are any queries related to data or analysis (Hannah.carter@qut.edu.au)

Release of information

The manuscript represents valid work and neither this manuscript nor one with substantially similar content under their authorship has been published or is being considered for publication elsewhere. The manuscript has not been presented in abstract form to any conference or seminar and no information has been issued by press release or mounted on social media.

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Tables

Table 1. Participant Characteristics[a]

	ACP	Control	SMD	p value
Full cohort	**n=5,586**	**n=11,172**		
Age at death: mean (SD) years	80.9 (12.0)	80.8 (11.9)	0.006	0.714
Female sex	2,888 (51.7)	5,776 (51.7)	0.002	0.932
Health service regions: no. (%)			0.085	<0.001
Gold Coast	385 (6.9)	883 (7.9)		
Metro North (Brisbane)	888 (15.9)	1,977 (17.7)		
Metro South (Brisbane)	3,419 (61.2)	6,524 (58.4)		
Sunshine Coast	318 (5.7)	749 (6.7)		
West Moreton	575 (10.3)	1,039 (9.3)		
Year of death: no. (%)			<0.001	1.000
2015	117 (2.1)	235 (2.1)		
2016	609 (10.9)	1,218 (10.9)		
2017	1,369 (24.5)	2,737 (24.5)		
2018	1,916 (34.3)	3,832 (34.3)		
2019	1,570 (28.1)	3,139 (28.1)		
Underlying cause of death: no (%)[b]			0.156	<0.001
Neoplasms	1,799 (32.2)	3,747 (33.5)		
Diseases of the circulatory system	1,398 (25.0)	2,875 (25.7)		
Diseases of the respiratory system	574 (10.3)	1,121 (10.0)		
Mental, behavioural, neurodevelopmental disorders	513 (9.2)	859 (7.7)		
Diseases of the nervous system	446 (8.0)	623 (5.6)		

	ACP	Control	SMD	p value
Endocrine, nutritional metabolic diseases	240 (4.3)	418 (3.7)		
Other	184 (3.3)	420 (3.8)		
Diseases of the digestive system	149 (2.7)	392 (3.5)		
Diseases of the genitourinary system	137 (2.5)	254 (2.5)		
Other	140 (2.5)	444 (4.0)		
Missing	6 (0.1)	19 (0.2)		
Documents available prior to death: no (%)				
SoC only	5,195 (93.0)	-		
AHD only	274 (4.9)	-		
SoC and AHD	117 (2.1)	-		
Admitted patient cohort[c]	**n=4,018**	**n=7,857**		
Preferred language			0.152	<0.001
English	3,845 (95.7)	7,315 (93.1)		
Non-English	157 (3.9)	503 (6.4)		
Not stated/unknown	16 (0.4)	39 (0.5)		
Marital Status			0.069	0.054
Divorced	414 (10.3)	739 (9.4)		
Married (registered and de facto)	1,921 (47.8)	3,803 (48.4)		
Never married	309 (7.7)	668 (8.5)		
Not stated/unknown	125 (3.1)	306 (3.9)		
Separated	112 (2.8)	188 (2.4)		
Widowed	1,137 (28.3)	2,153 (27.4)		
Hospital insurance status			0.105	<0.001
Hospital insurance	498 (12.4)	1,194 (15.2)		
Not insured	3,504 (87.2)	6,592 (83.9)		
Not stated/unknown	16 (0.4)	71 (0.9)		
Indigenous status			0.010	0.875
Indigenous	56 (1.4)	110 (1.4)		
Non-indigenous	3,946 (98.2)	7,716 (98.2)		
Not stated/unknown	16 (0.4)	31 (0.4)		
ARIA classification			0.068	0.014
Inner regional Australia	362 (9.0)	849 (10.8)		
Major cities of Australia	3,608 (89.8)	6,922 (88.1)		
Outer regional Australia	48 (1.2)	86 (1.1)		

	ACP	Control	SMD	p value
SEIFA quintile			0.136	<0.001
1 (lowest socio-economic quintile)	908 (22.6)	1,829 (23.3)		
2	746 (18.6)	1,586 (20.2)		
3	778 (19.4)	1,632 (20.8)		
4	864 (21.5)	1,522 (19.4)		
5 (highest socio-economic quintile)	722 (18.0)	1,288 (16.4)		
Proportion of admitted cohort records in full cohort	71.9%	70.3%		
Proportion of cost cohort records in full cohort	85.7%	80.7%		

[a]Number and percentages are provided unless otherwise indicated.

[b] Queensland Health (QH) Statistical Services Branch (SSB) undertook the matching process on all decedents using age, sex, year of death, health service region and ICD-10-AM code for primary diagnosis of last known hospital admission. Data for the latter variable obtained from the Queensland Hospital Admitted Patient Data Collection were not able to be provided to the authors by QH SSB as a request for this data was not included in the original ethics approval. Subsequent to the matching process, ICD-10-AM coded cause of death data for all decedents were obtained from QH SSB and are included here as a further measure of balance between ACP and control cohorts.

[c] Additional characteristics are available for the cohort that were admitted to hospital within the last six months of life. These characteristics were not included in the matching process and are presented here as descriptive analyses only.

ACP = advance care planning; SD = standard deviation; SMD = standardized mean difference; SoC = statement of choices; AHD = advance health directive; ARIA = Accessibility/Remoteness Index of Australia;
SEIFA = Socio-Economic Indexes for Areas.

Table 2. Hospital use outcomes

Outcomes	Proportion in ACP cohort (%)	Proportion in control cohort (%)	Unadjusted odds ratio	Adjusted odds ratio (95%CI)
ACP document uploaded ≥6 months prior to death (ACP = 2,507; Control = 5,014)				
ED presentation	65.0	68.5	0.85	0.90 (0.81 to 1.00)
Admitted to hospital	61.9	67.6	0.78	0.83 (0.74 to 0.92)
Admitted to ICU	0.3	1.3	0.21	0.23 (0.10 to 0.48)
Death in hospital	38.4	53.1	0.55	0.56 (0.51 to 0.63)
ACP document uploaded between 1 and < 6 months prior to death (ACP = 1,792, Control = 3,584)				
ED presentation	76.3	70.2	2.35	1.41 (1.23 to 1.61)
Admitted to hospital	79.4	72.3	1.47	1.57 (1.36 to 1.81)
Admitted to ICU	0.7	1.8	0.37	0.39 (0.20 to 0.71)
Death in hospital	46.0	58.3	0.61	0.58 (0.51 to 0.65)

ACP document uploaded <1 month prior to death (ACP =1287, Control = 2,574)				
ED presentation	80.7	71.6	1.65	1.74 (1.47 to 2.06)
Admitted to hospital	81.2	72.9	1.61	1.74 (1.47 to 2.08)
Admitted to ICU	0.5	1.3	0.01	0.46 (0.17 to 1.04)
Death in hospital	52.1	71.6	0.72	0.71 (0.61 to 0.82)

ACP = advance care planning; ED = emergency department; CI = confidence interval; LOS = length of stay; ICU = intensive care unit; aOR= adjusted odds ratio

Table 3. Hospital bed day and cost outcomes

Outcomes	Mean ACP	Mean control	Adjusted mean difference (95% CI)
ACP document uploaded ≥6 months prior to death (ACP = 1,906, Control = 3,513)			
Hospital bed days	13.4	10.9	-0.3 (-1.2 to 0.60)
ED cost ($)	1649	1565	115 (14 to 217)
Admissions cost ($)	16062	19203	-2405 (-4188 to -622)
Total costs ($)	17711	20768	-2290 (-4116 to -463)
ACP document uploaded between 1 and < 6 months prior to death (ACP = 1,643, Control = 3,123)			
Hospital bed days	21.86	13.06	8.9 (7.6 to 10.2)
ED cost ($)	2224	1687	549 (428 to 671)
Admissions cost ($)	35311	24380	11282 (8770 to 13793)
Total costs ($)	37535	26067	11831 (9272 to 14391)
ACP document uploaded less than 1 month prior to death (ACP = 1,238, Control = 2,384)			
Hospital bed days	18.05	13.75	4.5 (3.2 to 5.9)
ED cost ($)	2079	1637	420 (292 to 548)
Admissions cost ($)	30798	26331	5208 (2331 to 8085)

Total costs ($)	32877	28010	5628 (2700 to 8557)

ACP = advance care planning; ED = emergency department; CI = confidence interval. All costs in 2021 Australian dollars.

Table 4. Terminal admission outcomes[a]

	Proportion in ACP cohort (%)	Proportion in control cohort (%)	Unadjusted odds ratio	Adjusted odds ratio (95%CI)
Admitted to ICU	0.7	4.7	0.150	0.129 (0.065-0.231)
Palliative care admission	71.6	57.0	1.904	1.979 (1.725-2.274)
	Mean ACP	**Mean control**	**Unadjusted mean difference**	**Adjusted mean difference (95%CI)**
Hospital bed days	6.20	6.51	-0.316	-0.383 (-0.999-0.233)
Admissions cost	9,821	13,572	-3,751	-3,966 (-5487 to -2,444)

[a]ACP cohort (n=1,509) versus control cohort (n=3,823)

ACP = advance care planning; CI = confidence interval; ICU = intensive care unit. All costs in 2021 Australian dollars.

Figure legends

Figure 1. Patient flow diagram

BMJ Open

Association of advance care planning with hospital use and costs at the end of life: a population-based retrospective cohort study.

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Abstract

Objective: To investigate associations between the availability and timing of digitally available advance care planning (ACP) documents and hospital use and costs during the last 6 months of life.

Design: Retrospective population-based cohort study using data linkage.

Setting: 11 public hospitals in Queensland, Australia.

Participants: 5,586 decedents with ACP documents were directly matched 1:2 to 11,172 control decedents based on age category, sex, location, year of death and principal diagnosis code for the last known hospital admission.

Exposure: ACP discussions with documents uploaded to a widely accessible statewide digital platform. Directly matched sub-group analyses investigated differences between decedents with ACP documents available at three different times prior to death: ≥6 months; between 1-6 months; and < 1 month.

Main outcomes and measures: Emergency department (ED) presentations, hospital and intensive care unit (ICU) admissions, and in-hospital deaths, expressed as adjusted odds ratios (aOR). Secondary outcomes were hospital bed-days and costs.

Results: ACP decedents with documents uploaded ≥6 months prior to death, compared to controls, had fewer ED presentations (aOR 0.90, 95%CI 0.81 to 1.00), hospitalisations (aOR 0.83, 95%CI 0.74 to 0.92), ICU admissions (aOR 0.23, 95%CI 0.10 to 0.48), and in-hospital deaths (aOR 0.56, 95% CI 0.51 to 0.63), and lower adjusted mean hospital costs per person over the last 6 months of life ($A2290 less [95% CI -$4116 to -$463]). Conversely, decedents with ACP documents uploaded less than 6 months prior to death showed higher rates of ED presentations and hospital admissions and greater hospital costs relative to controls.

Conclusion: The association between digitally available ACP documents and health service use and cost differed based on the timing of ACP upload, with documents available ≥6 months prior to death being associated with less hospital use and costs.

Strengths and Limitations

- Large multi-site longitudinal analysis of standardised, patient-linked data on consecutive episodes of hospital care for almost 17,000 decedents, providing generalisable estimates of ACP effects on hospital utilisation, costs and place of death.
- Use of a matched cohort design compensated for the logistical difficulties of performing large randomised controlled trials, and where assigning patients to a no-ACP arm may be deemed unethical.
- Observational design precludes confirmation of causal relationships between ACP and measured outcomes.
- Inability to access data to control for potentially important but unmeasured confounders such as clinical status and disease severity, frailty, co-morbidity burden, and levels of psychosocial support.
- Analyses were hospital focussed such that utilisation and costs of non-hospital care were not ascertained.

Key Messages

What is already known on this topic Advance care planning (ACP) is known to decrease anxiety and decisional burden for relatives of patients who die, enhance clinician adherence to patient preferences and avoid unwanted cardiopulmonary resuscitation and life-support treatments. Whether the availability and timing of ACP documentation is associated with reduced hospital use and costs during the last 6 months of life remains unclear.

What this study adds: This study of 16,758 decedents found that those with ACP documents digitally available 6 months or more prior to death experienced fewer emergency department presentations, admissions to intensive care units and in-hospital deaths, and incurred less hospital costs, compared to matched controls with no digitally available documents.

How this study might affect research, practice or policy Findings of this retrospective observational study support ACP discussions being undertaken and documented in digitally accessible formats for all eligible patients in a timely, proactive manner.

Manuscript

INTRODUCTION

Advance care planning (ACP) is the iterative process of defining and documenting a person's values and preferences to guide future healthcare delivery[1]. Evidence shows ACP decreases anxiety, grief, decisional conflict and burden for surviving relatives and surrogates[2,3,4], enhances clinician adherence to patient preferences, increases use of palliative care, improves patient and family satisfaction with care, and avoids unwanted cardiopulmonary resuscitation (CPR) and life-support treatments[5,6,7]. Considerable expenditure on end-of-life care[8,9] may not improve care quality[10], and aggressive treatment may violate patient preferences[11] or prove non-beneficial[12,13].

Whether ACP reduces healthcare use and cost is unclear[14,15], especially when ACP uptake occurs in less than 50% of eligible patients[16] and multiple implementation barriers exist [17], including inaccessibility of ACP documentation when needed, and up to 75% of ACP documents being of poor quality[18]. The findings of economic evaluations of ACP vary according to their definitions of how and who provides ACP (influencing costs), and who the beneficiaries are (influencing outcomes)[19,20]. Studies of the association between ACP and healthcare use have yielded conflicting results depending on the level and fidelity of ACP uptake and documentation, characteristics of the population studied, and the choice of utilisation measures [21,22]. Such ambiguity has led some to question the desirability of investing more resources towards large-scale adoption of ACP[23], while others

assert existing research is methodologically limited and does not adequately account for the nuances and complexity of ACP [24,25].

There is increasing recognition of the need for ACP to be conducted proactively, iteratively and with longer lead time prior to death [26,27]. Advocates have called for system-wide changes to how ACP is conceptualised, moving beyond the one-off completion of advance health directives to an ongoing process to support individuals to better prepare for future decision making [24, 28], including enhancing their understanding of their illness, identifying proxies, and having values-based conversations [28]. The earlier these ACP processes are initiated prior to death, the greater the potential impact on individual treatment choices and care provided during the end-of-life phase. However, the relationship between the timing of ACP and healthcare resource use and cost remains unclear.

The aim of this study was to investigate the association between the time prior to death at which standardised ACP documents became available on an accessible statewide digital platform and hospital use and costs over the last 6 months of life among a large population of decedents..

METHODS

Study Design

This was a retrospective, longitudinal, population-based, matched cohort study comparing public hospital use and costs, in-hospital deaths and terminal admission (i.e. admissions where death occurs in hospital) outcomes over the last 6 months of life between a cohort of decedents with a digitally uploaded ACP document (ACP cohort) and a control cohort with no uploaded ACP documents.

Setting and Population

Eligible decedents were those over 18 years whose deaths were officially registered between 1st August, 2015 and 31st October, 2019, and who had resided in one of five health service regions in south-east Queensland, Australia (Gold Coast, Brisbane North, Brisbane South, Sunshine Coast, West Moreton), serviced by 11 public hospitals. Decedents whose terminal hospital admission and/or registered cause of death was due to acute trauma were excluded, as ACP was aimed at those likely to die an expected death from chronic diseases within 12 months. Due to unavailability of cost data, people dying after June 30th, 2019, were excluded from hospital cost analyses.

Within Queensland, hospitals within a defined geographical catchment area are centrally managed by a local hospital and health service which enables an overarching regional approach to care. All hospitals across the five health services included in this study had equivalent clinical service capabilities in regards to emergency departments, intensive care units, palliative care services, and general medical and surgical inpatient care. All study hospitals also operated under a consistent ACP funding and policy framework. Hence, patients presenting to

different hospitals within the same health service would experience similar approaches to ACP.

The ACP cohort comprised decedents with a complete, valid ACP document uploaded to a statewide digital platform before death. Decedents with only an enduring power of attorney (EPOA) document were excluded as completion of this document may not have involved ACP discussions. All other decedents, with no uploaded document, were eligible to be randomly selected and matched as controls.

Exposure to Advance Care Planning

The Queensland Health (QH) Statewide Office of Advance Care Planning (SOACP) is responsible for supporting a coordinated approach to ACP across all care settings[29]. It provides standardised education for dedicated ACP facilitators who then upskill and assist local clinicians to invite eligible individuals to partake in ACP conversations, having been identified using the "surprise question": would I be surprised if this person died in the next 12 months? [30]. Twelve full-time facilitators are funded and distributed equitably across the five health services according to relative catchment populations and who worked within hospitals, primary care practices and residential aged care facilities (RACFs). The SOACP has developed a values-based, standardised Statement of Choices (SoC) form[31] available as a user-friendly, non-legally binding, easily modified form detailing patients' goals of care and preferences for CPR, life-support interventions and other supportive care (**eAppendix 1 in Supplement**). A legally binding Advance Health Directive (AHD) is also available and considered an appropriate ACP document. In addition, during the

study period, QH incentivised ACP uptake by providing a one-off payment to hospitals of between $A100 and $A200 for each ACP invitation administered .

Copies of ACP documents are sent, via fax, mail or e-mail, to the SOACP where they are audited for legibility and completeness before being uploaded to the person's hospital electronic medical record via an app, 'The ACP Tracker', located within a secure statewide digital platform accessible to all QH clinical staff (**eAppendix 2 in Supplement)**. Forms with incomplete mandatory fields, including missing signatures, are not uploaded until corrected. Queensland Ambulance Service paramedics and authorised primary care practitioners, community nurses and RACF nursing staff also have read-only access to the app through a Health Provider Portal (**eAppendix 3 in Supplement**).

Variables, Data Sources and Matching Process

Data on patient characteristics, episodes of care and outcomes were collected and linked by the QH Statistical Services Branch (SSB) across five datasets: deaths from the Queensland Registry of Births, Deaths and Marriages; International Classification of Disease version 10, Australian modification (ICD-10-AM) coded cause of death from the Australian Bureau of Statistics (ABS); data on ED presentations from the statewide Emergency Department Information System; data on hospital and ICU admissions, including ICD-10-AM primary diagnosis codes, from the Queensland Hospital Admitted Patient Data Collection (QHAPDC); and hospital admission costs (combined direct and overhead costs) from the National Hospital Cost Data Collection. A full list of extracted data items is provided in **eAppendix 4 in Supplement**. Consecutive hospital presentations and admissions at the patient level

were linked by QH SSB using deterministic and probabilistic linkage algorithms (**eAppendix 5 in Supplement**) resulting in 99.7% linkage of available records. All costs are reported in 2021 Australian dollars with costs collected in financial years 2015/2016 to 2018/2019 indexed to the most recent reference year using the Australian consumer price[32].

All ACP decedents were randomly matched in a 1:2 ratio with control decedents based on age (with 5-year age brackets applied when direct matches could not be identified), sex, year of death, health service region and ICD-10-AM code for the primary diagnosis of the last-known hospital admission prior to death in the community or in hospital, or of the terminal admission (i.e admission in which the person died in hospital) if no prior admission was recorded. The choice to match on diagnosis of last known hospital admission, rather than on admissions within a specific time period prior to death, reflected our hypothesis that earlier completion of ACP documentation may alter treatment choices which could in turn reduce the likelihood of future admissions. The 1:2 ratio was selected to increase precision and decrease bias in effect estimates, while ensuring feasibility of exact matching within the available data [33].

Outcome Measures

Primary outcome measures were differences between ACP and control cohorts in the odds of decedents, over the last 6 months of life: having one or more presentations to ED, hospital admissions, and ICU admissions; or dying in hospital. Secondary outcome measures were differences between the cohorts in hospital bed-days, ED costs, hospital admission costs, and total hospital costs over the 6

month period. We also assessed associations of an uploaded document prior to a terminal hospital admission (an admission in which the person died in hospital) with ICU admissions, palliative care classifications (ie admission classified as palliative care if an end-of-life care pathway was initiated and comfort care only was provided), length of stay and cost of that admission.

We followed the Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) guideline in reporting clinical outcomes[34] and the Consolidated Health Economic Evaluation Reporting Standards (CHEERS) checklist in reporting cost outcomes[35].

Statistical Analyses

Adequacy of matching

In addition to comparing cohorts using the matching variables, we also compared both cohorts for ICD-10-AM coded cause of death, this data becoming available after matching had been completed. For decedents with at least one hospital admission during the 6 months prior to death (admitted patient cohorts), we also compared these cohorts for variables unavailable for all decedents. These variables comprised: preferred language, marital status, hospital insurance, indigenous status, residence locality (according to Accessibility/Remoteness Index of Australia [ARIA])[36] and socioeconomic status (according to Socio-Economic Indexes for Areas [SEIFA] quintiles)[37]. For both total and admitted patient cohorts, we calculated standardised mean differences (SMDs) for each variable as a measure of balanced distribution between ACP and control cohorts, with cohorts considered acceptably matched if SMDs were <0.20 [38, 39].

Outcome analyses

The main outcome analysis compared primary and secondary outcomes between the subgroup of ACP decedents who had an ACP document uploaded for 6 months or more prior to death compared to controls directly matched over the same period. Separate pre-specified subgroup analyses compared ACP decedents who had an ACP document uploaded between 1 and 6 months, and less than 1 month, prior to death, with correspondingly matched controls. These subgroup analyses tested our hypothesis that the earlier completed ACP documents became available, the more likely these documents would guide a more person-centred conservative approach to subsequent end-of-life care over a longer period prior to death, resulting in less hospital use and costs and fewer in-hospital deaths. Post-hoc, exploratory analyses assessed differences in hospital costs between ACP subgroups according to the timing of ACP upload. Additional matched sub-group analyses were conducted to test the robustness of results within the two largest cause of death categories: cancer (33% of deaths) and diseases of the circulatory system (25% of deaths).

Regression modelling

Logistic regression models were used in analysing primary outcomes, and linear regression models in analysing secondary outcomes. All regression models adjusted for registered ICD-10 coded underlying cause of death which became known after matching, with effect estimates expressed as an adjusted odds ratio (aOR)[40]. Residual plots of all models were assessed to confirm assumptions of constant

variance and normally-distributed error terms were met. Due to the zero-inflated, non-normal distribution of length of stay and costing data, bootstrap resampling was used to produce 10,000 simulated regression models from which adjusted means were derived and the percentile method used to estimate 95% confidence intervals (CI)[41]. All analyses were performed using R (version 4.0.3) and 2-sided $p < 0.05$ denoted statistical significance.

Ethics Approval

Ethics approval for this multi-site study was granted by Metro South Human Research Ethics Committee (ref: HREC/17/QPAH/36) with administrative ethics approval from Queensland University of Technology Human Research Ethics Committee (approval number: 2000000611) and approval under the Public Health Act to access de-identified decedent data from the Office of the Director General of QH (QH-SSB request ID32140).

Patient and Public Involvement

No patients or members of the public were involved in the design or conduct of this study.

RESULTS

From the initial sample of 14,253 uploaded documents, after excluding those failing participant selection criteria, were duplicates, comprised only EPOA documents, or had an invalid upload date, 5,624 decedents with at least one uploaded ACP document (SoC or AHD) were subject to matching (**Figure 1**). Of these, 38 could not be directly matched as they had no hospital admission in the preceding 5 years,

leaving 5,586 in the total ACP cohort matched with 11,172 controls. The admitted patient cohort comprised 4,018 (71.9%) ACP and 7,857 (70.3%) control decedents. For hospital costing analyses, after removing deaths occurring after June 30th, 2019, and decedents unable to be directly matched, 4,787 (85.7%) and 9,020 (80.7%) decedents comprised ACP and control cost cohorts respectively.

Participant Characteristics

Clinical and demographic characteristics of ACP and control decedents in the total and admitted patient cohorts are listed in **Table 1**, along with SMDs for matching and comparison variables, all of which were <0.16, indicating the cohorts were acceptably matched. Corresponding data for each of the ACP subgroups and the costing cohorts are included in **eAppendix 6.** Mean (standard deviation [SD]) age for both cohorts was 81 (±12) years, 51.7% were females, and among ACP decedents 5,312 (95.1%) had a SoC form, 391 (7.0%) had a AHD, and 117 (2.1%) had both.

Within the ACP cohort, 2,507 (45%) had ACP documents uploaded 6 months or more before death, 1,223 (22%) between one month and less than 6 months, and 1,856 (33%) less than a month before death. (**Figure S1 in Supplement**).

Hospital Use

ACP decedents with documents uploaded ≥6 months prior to death, compared to matched control decedents, demonstrated significantly lower odds of ED presentations (aOR 0.90, 95%CI 0.81 to 1.00; 65.0% vs 68.5%), hospital admissions (aOR 0.83, 95%CI 0.74 to 0.92; 61.9% vs 67.6%), ICU admissions (aOR 0.23,

95%CI 0.10 to 0.48; 0.3% vs 1.3%) and in-hospital deaths (aOR 0.56, 95%CI 0.51 to 0.63; 38.4% vs 53.1%).

For ACP decedents with documents uploaded between 1 and 6 months, or less than 1 month, prior to death, similar reductions were seen in ICU admissions (aOR 0.39; 95%CI 0.20-0.71 and aOR 0.46; 95%CI 0.17-1.04 respectively) and in-hospital deaths (0.58; 95%CI 0.51-0.65 and 0.71; 95%CI 0.61-0.82) compared to controls, although the odds of ED presentations (1.41; 95%CI 1.23-1.61 and 1.74; 95%CI 1.47-2.06) and hospital admissions (1.57; 95%CI 1.36-1.81 and 1.74; 95%CI 1.47-2.08) were higher (**Table 2**).

Hospital bed-days and costs

ACP decedents with a document uploaded ≥6 months prior to death demonstrated an adjusted mean reduction of $2,337 (95%CI -$4,222 to -$452) in total hospital costs with no difference in bed-days compared to matched controls (Table 3). Decedents with an ACP uploaded between 1 and 6 months prior to death, relative to controls, incurred more bed-days (8.9; 95%CI 7.6-10.2) and total hospital costs (+$11,282; 95%CI 8,770-13,793), than ACP decedents with uploads less than 1 month prior to death relative to controls (4.5; 95%CI 3.2-5.9 and +$5628; 95%CI 2700-8557 respectively).

Terminal Admission Outcomes

ACP decedents with documents uploaded prior to the terminal admission had significantly lower odds of ICU admission relative to controls during that admission (aOR 0.13, 95%CI 0.06 to 0.23; 0.7% vs 4.7%), and higher odds of the admission

being classified as palliative care (aOR 1.98, 95%CI 1.72 to 2.27; 71.6% vs 57.0%, **Table 4**). While there were no significant differences in length of stay, mean hospital costs for the ACP cohort were $3,966 less (95%CI -$5,487 to -$2,444) than for controls.

Post-hoc analyses

Hospital outcomes within the subgroup of matched deaths from cancer, as well as the subgroup of matched deaths from diseases of the circulatory system, were consistent with the overall study findings. A full set of outcomes for these two subgroups is presented in eAppendix 7 in Supplement. ACP decedents with documents uploaded ≥6 months prior to death incurred $10,575 (95%CI -$12,458 to -$8691) less total hospital costs than ACP decedents with documents uploaded in the last month of life, but there were no significant difference in costs compared to ACP decedents with documents uploaded between 1 and 6 months. Notably, monthly costs continued to reduce numerically in the months immediately after ACP document upload. (**Figure S2 in Supplement**).

DISCUSSION

Summary of Findings

To our knowledge, this is the first population-level cohort study of the association between audited, standardised and digitally-accessible ACP documents uploaded at varying time intervals prior to death and hospital use and costs over the last 6 months of life. Having an ACP document available 6 months or more prior to death was associated with fewer ED presentations, admissions to hospital or ICU, and in-hospital deaths, and lower hospital costs compared to having no ACP document

available for the same period. In contrast, decedents with an ACP document uploaded <6 months prior to death demonstrated higher rates of hospital use and higher costs than controls, although ICU admissions and in-hospital deaths continued to be lower. While this observational study is unable to demonstrate causality, our findings suggest that more patient benefit and less hospital use and costs may accrue if ACP documents are completed proactively, with long lead times prior to death, rather than reactively in response to more imminent death.

Comparisons with Other Studies

Our findings of less hospital use and fewer in-hospital deaths in patients undertaking ACP more than 6 months prior to death have been replicated in a US study of 650 patients with 1:1 matching and using adjusted differences-in-differences analyses over 12 month periods before ACP (with a matched control corresponding to the same period) and before death. Patients undergoing ACP compared to controls had fewer admissions (-0.37 per person), inpatient days (-3.66 days) and less Medicare costs (-$US9500), driven primarily by less inpatient utilisation[42]. In another US study of 237,989 decedent Medicare beneficiaries subject to multivariable adjustment, patients with at least one billed ACP visit (6.3%, 14,986) which on average occurred 7 months before death, experienced fewer hospitalisations (OR 0.77), ED visits (OR 0.77), or ICU stay (OR 0.78) within a month of death, and fewer died in hospital (OR 0.79), although mean expenditures were unchanged[43]. In contrast, a propensity score matched US study of 18,484 seriously ill Medicare patients revealed a billed ACP encounter for 864 (4.7%) patients was associated with a higher likelihood of hospitalisation (incidence rate ratio [IRR] 1.37) and ICU admission (IRR 1.25) over the subsequent 6 months, and total medical costs were

higher (per patient per month difference $US1,635), largely driven by hospital costs[22]. In another US study of 2,394 selected decedents aged over 65 years, Medicare expenditures in the last 6 months of life had no association with ACP[44]. These discrepancies may relate to variability across jurisdictions in the frequency, intensity and processes of ACP, target populations, availability and cost of non-hospital care, and organisational and public attitudes towards ACP.

Our findings of increased hospital use and costs in patients undergoing ACP less than 6 months prior to death compared to controls is surprising, and not seen in other studies, although the exact timing of ACP prior to death was not reported. In a study in Hong Kong, 69 ACP patients with advanced cancer or end-stage organ failure, compared to 174 matched controls, had significantly fewer acute hospital admissions (0.78 vs 1.2 per person) and shorter length of stay (4.6 vs 7.5 days) over the last 3 months of life[45]. In a US population study involving 27,711 patients with one or more chronic diseases, regression analyses showed patients undergoing ACP >30 days before death, except those with primarily renal disease, had significantly lower odds of hospitalisation and ICU admission in the last month of life[22]. We hypothesise that patients undergoing ACP might have become more aware of their likely clinical trajectory such that, when confronted by symptomatic deterioration or complications, more likely resorted to hospital care than less informed controls who were less sensitised to changes in their health status and who sought less hospital care. Also, patients and treating clinicians motivated to undergo ACP, compared to controls, may have stronger therapeutic relationships and be more aware of care options mutually perceived as being more reliably and quickly accessed by going to hospital.

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Implications for Clinical Practice

Critics of ACP note that randomised trials of ACP have not reported reduced healthcare utilisation[23], but these trials were methodologically limited because of recruitment bias[46], small samples with inadequate power[47], very low uptake and fidelity of ACP interventions[48], fixed default care options in AHDs[49], and primary outcome measures which did not include healthcare use[50].

In our study, several system-level factors specific to the QH setting may explain the observed positive impacts of ACP on hospital use not seen in the randomised trials. First, the use of ACP in hospital practice and primary care was supported by whole of community education campaigns, use of skilled ACP facilitators, clinician access to ACP resources and templates, provision of patient information brochures, and embedment of end-of-life care frameworks that clearly defined clinician roles and responsibilities for ACP discussions[29,51,52]. Second, early patient engagement in ACP discussions was encouraged[53] by proactive identification of ACP-eligible patients using the 'Surprise' question [30] rather than waiting for patients to enter terminal phases. As a primary intent of ACP, this allowed time for iterative refinement of ACP documents which ensured ongoing ACP discussions remained relevant to patient needs and cognisant of important interpersonal relationships[54]. Third, within hospitals, ACP facilitators helped to initiate and progress early discussions with ACP-eligible patients and advised attending clinicians of ACP status and the

need to finalise ACP discussions and review, complete and sign documentation. Fourth, a centralised process was in place to ensure valid, high quality ACP documents were widely accessible when needed[55][56]. Finally, we ensured clinical care and patient wishes were aligned in confirming ACP as a high value activity[57] by auditing in-hospital care provided to patients with an uploaded SoC. One audit of 600 decedents demonstrated high concordance between preferred and actual place of death (79%) and between practice and preferences for CPR (100%) and life-prolonging treatments (99%) over the last 6 months of life[58]. Another showed similar concordance in care (79%, 100%, 97% respectively) for 198 patients over a 12 month period following SoC completion[59].

Most studies of ACP analyse processes at the level of individual patient-clinician interactions. We could find only one other study featuring a standardised, proactive approach to ACP at the system level similar to ours: an 11-hospital US healthcare system which, from late 2019, upgraded system-level capabilities and resources in ACP, revamped inpatient workflows for ACP, engaged outpatients in ACP, used ACP prompts and document uploads embedded in EMR and employed ACP facilitators[60]. Unfortunately, the COVID pandemic disrupted the program and no conclusive before-after results are available.

Strengths and Limitations

Study strengths include longitudinal analysis of standardised, patient-linked data on consecutive episodes of hospital care for almost 17,000 decedents. This large multi-site study provides generalisable estimates of ACP effects on hospital utilisation, costs and place of death using a matched cohort design which compensates for the

logistical difficulties of performing large randomised controlled trials, and where assigning patients to a no-ACP arm may be deemed unethical. Analysis of standardised hospital costing data afforded assessment of ACP-mediated hospital cost minimisation. Our SoC form satisfied all relevant documentation quality and accessibility criteria[60] and we described ACP processes and outcomes often missing in evaluation studies[61].

There are also several limitations, in addition to the previously noted inability to establish causality between ACP and hospital use, cost and place of death. While we minimised selection bias by matching ACP and control decedents on available demographic and clinical variables, we could not access data to control for potentially important but unmeasured confounders such as clinical status and disease severity, frailty, co-morbidity burden, and levels of psychosocial support. In addition, underlying differences in individual values and preferences may have influenced decisions by those in the control cohort to elect not to participate in ACP. Data on private hospital presentations were not available, although we suspect very little leakage of patients from the public hospital system. As our analyses were hospital focussed, utilisation and costs of non-hospital care were not ascertained, but other studies suggest hospital costs account for most expenditure[7,22,42]. Finally, some control decedents may have undergone ACP discussions and even completed ACP documents which were not uploaded electronically, but which may still have informed care decisions.

In conclusion, we provide observational evidence that digitally accessible, standardised ACP documentation available prior to death is associated with reduced

ICU admissions and in-hospital deaths over the last 6 months of life. Additional reductions in health service use and cost were associated with documents being available 6 months or more prior to death. Large scale pragmatic randomised controlled trials are warranted to confirm causality of these associations.

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Contributorship statement:

Guarantor: Ian Scott accepts full responsibility for the finished work and/or the conduct of the study, had access to the data, and controlled the decision to publish.

Concept and design: Scott, Reymond, Sansome, Carter

Acquisition, analysis, or interpretation of data: Reymond, Sansome, Scott, Carter

Drafting of the manuscript: Scott, Carter

Critical revision of the manuscript for important intellectual content: Reymond, Sansome, Scott, Carter

Statistical analysis: Carter, Scott

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Supervision: Scott, Reymond

Competing interest disclosures

None of the authors have any competing interests to declare.

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Data sharing

Our ethical approvals prevent individual-level data from being shared beyond those named on the ethics application (Authors Reymond, Sansome, Carter). Aggregate-level data may be shared where appropriate. Author Hannah Carter can be contacted if there are any queries related to data or analysis (Hannah.carter@qut.edu.au)

Release of information

The manuscript represents valid work and neither this manuscript nor one with substantially similar content under their authorship has been published or is being considered for publication elsewhere. The manuscript has not been presented in abstract form to any conference or seminar and no information has been issued by press release or mounted on social media.

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Tables

Table 1. Participant Characteristics[a]

	ACP	Control	SMD	p value
Full cohort	**n=5,586**	**n=11,172**		
Age at death: mean (SD) years	80.9 (12.0)	80.8 (11.9)	0.006	0.714
Female sex	2,888 (51.7)	5,776 (51.7)	0.002	0.932
Health service regions: no. (%)			0.085	<0.001
Gold Coast	385 (6.9)	883 (7.9)		
Metro North (Brisbane)	888 (15.9)	1,977 (17.7)		
Metro South (Brisbane)	3,419 (61.2)	6,524 (58.4)		
Sunshine Coast	318 (5.7)	749 (6.7)		
West Moreton	575 (10.3)	1,039 (9.3)		
Year of death: no. (%)			<0.001	1.000
2015	117 (2.1)	235 (2.1)		
2016	609 (10.9)	1,218 (10.9)		
2017	1,369 (24.5)	2,737 (24.5)		
2018	1,916 (34.3)	3,832 (34.3)		
2019	1,570 (28.1)	3,139 (28.1)		
Underlying cause of death: no (%)[b]			0.156	<0.001
Neoplasms	1,799 (32.2)	3,747 (33.5)		
Diseases of the circulatory system	1,398 (25.0)	2,875 (25.7)		
Diseases of the respiratory system	574 (10.3)	1,121 (10.0)		
Mental, behavioural, neurodevelopmental disorders	513 (9.2)	859 (7.7)		
Diseases of the nervous system	446 (8.0)	623 (5.6)		
Endocrine, nutritional metabolic diseases	240 (4.3)	418 (3.7)		
Other	184 (3.3)	420 (3.8)		
Diseases of the digestive system	149 (2.7)	392 (3.5)		
Diseases of the genitourinary system	137 (2.5)	254 (2.5)		
Other	140 (2.5)	444 (4.0)		
Missing	6 (0.1)	19 (0.2)		
Documents available prior to death: no (%)				
SoC only	5,195 (93.0)	-		
AHD only	274 (4.9)	-		

	ACP	Control	SMD	p value
SoC and AHD	117 (2.1)	-		
Admitted patient cohort[c]	**n=4,018**	**n=7,857**		
Preferred language			0.152	<0.001
English	3,845 (95.7)	7,315 (93.1)		
Non-English	157 (3.9)	503 (6.4)		
Not stated/unknown	16 (0.4)	39 (0.5)		
Marital Status			0.069	0.054
Divorced	414 (10.3)	739 (9.4)		
Married (registered and de facto)	1,921 (47.8)	3,803 (48.4)		
Never married	309 (7.7)	668 (8.5)		
Not stated/unknown	125 (3.1)	306 (3.9)		
Separated	112 (2.8)	188 (2.4)		
Widowed	1,137 (28.3)	2,153 (27.4)		
Hospital insurance status			0.105	<0.001
Hospital insurance	498 (12.4)	1,194 (15.2)		
Not insured	3,504 (87.2)	6,592 (83.9)		
Not stated/unknown	16 (0.4)	71 (0.9)		
Indigenous status			0.010	0.875
Indigenous	56 (1.4)	110 (1.4)		
Non-indigenous	3,946 (98.2)	7,716 (98.2)		
Not stated/unknown	16 (0.4)	31 (0.4)		
ARIA classification			0.068	0.014
Inner regional Australia	362 (9.0)	849 (10.8)		
Major cities of Australia	3,608 (89.8)	6,922 (88.1)		
Outer regional Australia	48 (1.2)	86 (1.1)		
SEIFA quintile			0.136	<0.001
1 (lowest socio-economic quintile)	908 (22.6)	1,829 (23.3)		
2	746 (18.6)	1,586 (20.2)		
3	778 (19.4)	1,632 (20.8)		
4	864 (21.5)	1,522 (19.4)		
5 (highest socio-economic quintile)	722 (18.0)	1,288 (16.4)		
Proportion of admitted cohort records in full cohort	71.9%	70.3%		
Proportion of cost cohort records in full cohort	85.7%	80.7%		

[a]Number and percentages are provided unless otherwise indicated.

[b] Queensland Health (QH) Statistical Services Branch (SSB) undertook the matching process on all decedents using age, sex, year of death, health service region and ICD-10-AM code for primary diagnosis of last known hospital admission. Data for the latter variable obtained from the Queensland Hospital Admitted Patient Data Collection were not able to be provided to the authors by QH SSB as a request for this data was not included in the original ethics approval. Subsequent to the matching process, ICD-10-AM coded cause of death data for all decedents were obtained from QH SSB and are included here as a further measure of balance between ACP and control cohorts.

[c] Additional characteristics are available for the cohort that were admitted to hospital within the last six months of life. These characteristics were not included in the matching process and are presented here as descriptive analyses only.

ACP = advance care planning; SD = standard deviation; SMD = standardized mean difference; SoC = statement of choices; AHD = advance health directive; ARIA = Accessibility/Remoteness Index of Australia;
SEIFA = Socio-Economic Indexes for Areas.

Table 2. Hospital use outcomes

Outcomes	Proportion in ACP cohort (%)	Proportion in control cohort (%)	Unadjusted odds ratio	Adjusted odds ratio (95%CI)
ACP document uploaded ≥6 months prior to death (ACP = 2,507; Control = 5,014)				
ED presentation	65.0	68.5	0.85	0.90 (0.81 to 1.00)
Admitted to hospital	61.9	67.6	0.78	0.83 (0.74 to 0.92)
Admitted to ICU	0.3	1.3	0.21	0.23 (0.10 to 0.48)
Death in hospital	38.4	53.1	0.55	0.56 (0.51 to 0.63)
ACP document uploaded between 1 and < 6 months prior to death (ACP = 1,792, Control = 3,584)				
ED presentation	76.3	70.2	2.35	1.41 (1.23 to 1.61)
Admitted to hospital	79.4	72.3	1.47	1.57 (1.36 to 1.81)
Admitted to ICU	0.7	1.8	0.37	0.39 (0.20 to 0.71)
Death in hospital	46.0	58.3	0.61	0.58 (0.51 to 0.65)

ACP document uploaded <1 month prior to death (ACP =1287, Control = 2,574)				
ED presentation	80.7	71.6	1.65	1.74 (1.47 to 2.06)
Admitted to hospital	81.2	72.9	1.61	1.74 (1.47 to 2.08)
Admitted to ICU	0.5	1.3	0.01	0.46 (0.17 to 1.04)
Death in hospital	52.1	71.6	0.72	0.71 (0.61 to 0.82)

ACP = advance care planning; ED = emergency department; CI = confidence interval; LOS = length of stay; ICU = intensive care unit; aOR= adjusted odds ratio

Table 3. Hospital bed day and cost outcomes

Outcomes	Mean ACP	Mean control	Adjusted mean difference (95% CI)
ACP document uploaded ≥6 months prior to death (ACP = 1,906, Control = 3,513)			
Hospital bed days	13.4	10.9	-0.3 (-1.2 to 0.60)
ED cost ($)	1649	1565	115 (14 to 217)
Admissions cost ($)	16062	19203	-2405 (-4188 to -622)
Total costs ($)	17711	20768	-2290 (-4116 to -463)
ACP document uploaded between 1 and < 6 months prior to death (ACP = 1,643, Control = 3,123)			
Hospital bed days	21.86	13.06	8.9 (7.6 to 10.2)
ED cost ($)	2224	1687	549 (428 to 671)
Admissions cost ($)	35311	24380	11282 (8770 to 13793)
Total costs ($)	37535	26067	11831 (9272 to 14391)
ACP document uploaded less than 1 month prior to death (ACP = 1,238, Control = 2,384)			
Hospital bed days	18.05	13.75	4.5 (3.2 to 5.9)
ED cost ($)	2079	1637	420 (292 to 548)
Admissions cost ($)	30798	26331	5208 (2331 to 8085)

Total costs ($)	32877	28010	5628 (2700 to 8557)

ACP = advance care planning; ED = emergency department; CI = confidence interval. All costs in 2021 Australian dollars.

Table 4. Terminal admission outcomes[a]

	Proportion in ACP cohort (%)	Proportion in control cohort (%)	Unadjusted odds ratio	Adjusted odds ratio (95%CI)
Admitted to ICU	0.7	4.7	0.150	0.129 (0.065-0.231)
Palliative care admission	71.6	57.0	1.904	1.979 (1.725-2.274)
	Mean ACP	**Mean control**	**Unadjusted mean difference**	**Adjusted mean difference (95%CI)**
Hospital bed days	6.20	6.51	-0.316	-0.383 (-0.999-0.233)
Admissions cost	9,821	13,572	-3,751	-3,966 (-5487 to -2,444)

[a]ACP cohort (n=1,509) versus control cohort (n=3,823)

ACP = advance care planning; CI = confidence interval; ICU = intensive care unit. All costs in 2021 Australian dollars.

Figure legends

Figure 1. Patient flow diagram

On-line supplement

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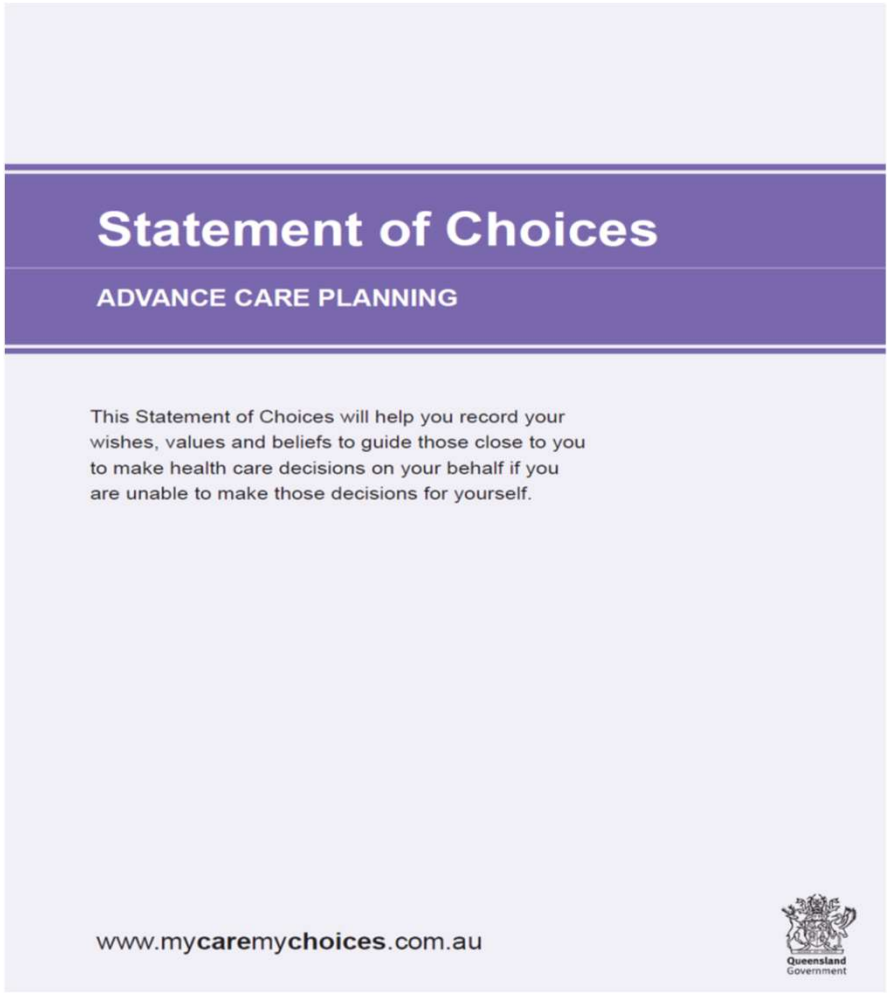
Figure S1. Distribution of ACP document uploads over time prior to death..... 20

Figure S2. Monthly hospital admission costs over last 6 months of life according to timing of ACP document upload..... 21

eAppendix 1. Statement of Choices form



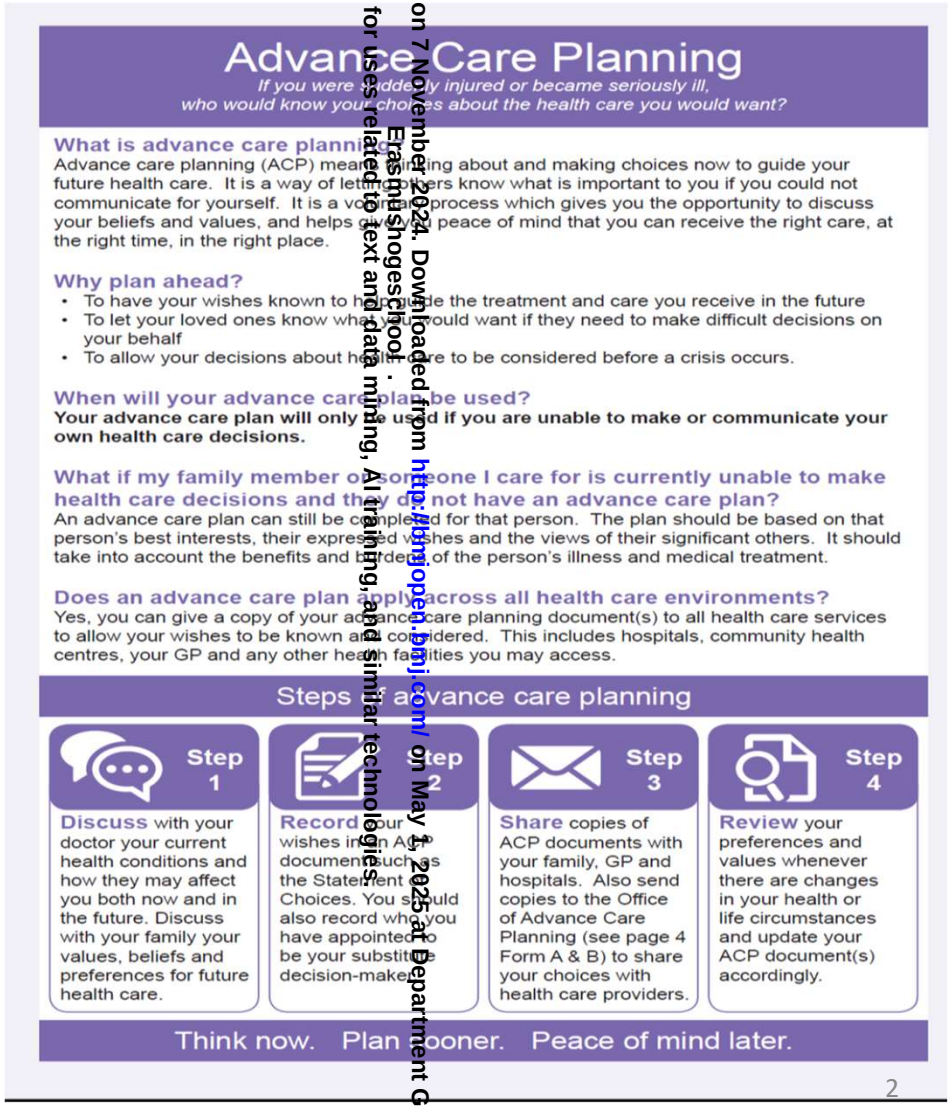
Statement of Choices

ADVANCE CARE PLANNING

This Statement of Choices will help you record your wishes, values and beliefs to guide those close to you to make health care decisions on your behalf if you are unable to make those decisions for yourself.

www.mycaremychoices.com.au

Queensland Government



Advance Care Planning

If you were suddenly injured or became seriously ill, who would know your choices about the health care you would want?

What is advance care planning?

Advance care planning (ACP) means thinking about and making choices now to guide your future health care. It is a way of letting others know what is important to you if you could not communicate for yourself. It is a voluntary process which gives you the opportunity to discuss your beliefs and values, and helps give you peace of mind that you can receive the right care, at the right time, in the right place.

Why plan ahead?

- To have your wishes known to help guide the treatment and care you receive in the future
- To let your loved ones know what you would want if they need to make difficult decisions on your behalf
- To allow your decisions about health care to be considered before a crisis occurs.

When will your advance care plan be used?

Your advance care plan will only be used if you are unable to make or communicate your own health care decisions.

What if my family member or someone I care for is currently unable to make health care decisions and they do not have an advance care plan?

An advance care plan can still be completed for that person. The plan should be based on that person's best interests, their expressed wishes and the views of their significant others. It should take into account the benefits and burdens of the person's illness and medical treatment.

Does an advance care plan apply across all health care environments?

Yes, you can give a copy of your advance care planning document(s) to all health care services to allow your wishes to be known and considered. This includes hospitals, community health centres, your GP and any other health facilities you may access.

Steps in advance care planning

Step 1 — **Discuss** with your doctor your current health conditions and how they may affect you both now and in the future. Discuss with your family your values, beliefs and preferences for future health care.

Step 2 — **Record** your wishes in an ACP document such as the Statement of Choices. You should also record who you have appointed to be your substitute decision-maker.

Step 3 — **Share** copies of ACP documents with your family, GP and hospitals. Also send copies to the Office of Advance Care Planning (see page 4 Form A & B) to share your choices with health care providers.

Step 4 — **Review** your preferences and values whenever there are changes in your health or life circumstances and update your ACP document(s) accordingly.

Think now. Plan sooner. Peace of mind later.

2

eAppendix 1. Statement of Choices form

Statement of Choices

The Statement of Choices is a values-based document that records a person's wishes and choices for their health care into the future. Although the Statement of Choices is not included in Queensland legislation, the content can still have legal effect by guiding substitute decision-makers and clinicians if a person is unable to communicate their choices.

Form A is used by people who **can** make health care decisions for themselves.
Form B is used for people who **cannot** make health care decisions on their own.

Legally-binding ACP documents in Queensland

If you have strong wishes about your future health care you should consider completing these legally-binding documents.

Advance Health Directive (AHD)

This is the legally-binding document that states a person's instructions for health care in specific circumstances. It must be completed with a doctor and signed in front of a qualified witness. It can also be used to appoint your substitute decision-maker for health decisions.

Enduring Power of Attorney (EPOA)

This is a legally-binding document that can appoint one or more person(s) to make personal, health and/or financial decisions on your behalf. It must be signed in front of a qualified witness and you can choose how the responsibility of decision-making is shared.

You can obtain a copy of these documents at: www.mycaremychoices.com.au

Order of substitute decision-making

In Queensland, when a person is unable to make or communicate their own health care decisions, there is an order of priority for substitute decision-making:

Statement of Choices can help guide these decision-makers

1. **Advance Health Directive** — A legally-binding document used to give consent and direct medical management in specific health circumstances.
2. **Tribunal-appointed guardian** — A guardian appointed by the Queensland Civil and Administrative Tribunal (QCAT) to make health care decisions on behalf of a person.
3. **Attorney appointed under an AHD/EPOA** — A person (known as an "attorney") appointed for personal/health decisions in an Advance Health Directive or Enduring Power of Attorney document.
4. **Statutory health attorney** — A relevant person who has authority to make health care decisions in the absence of the above decision-makers. See glossary for details.

Contact information

Office of Advance Care Planning:

PO Box 72
Corinda QLD 4075

Ph: 1300 007 227
Fax: (07) 3710 2291

Email: acp@health.qld.gov.au

www.mycaremychoices.com.au

GLOSSARY OF TERMS

Capacity — Capacity refers to a person's ability to make a specific decision in a particular area of their life. A person has capacity for health care decisions when they can understand the information provided by a doctor about their health and treatment options and are able to make a decision regarding their care. The person also needs to be able to communicate their decision in some way and the decision must also be made of the person's own free will.

Cardiopulmonary Resuscitation (CPR) — Cardiopulmonary resuscitation includes emergency measures to keep the heart pumping (by compressing the chest or using electrical stimulation) and artificial ventilation (mouth-to-mouth or ventilation when a person's breathing and heart have stopped. It is designed to maintain blood circulation whilst waiting for treatment to possibly start the heart beating again on its own. The success of CPR depends on a person's overall medical condition. On average, less than one in four patients who have CPR in hospital survive to be discharged home.[1,2]

Good Medical Practice — Good medical practice requires the doctor responsible for a person's care to adhere to the accepted medical standards, practices and procedures of the medical profession in Australia. All treatment decisions, including those to withhold or withdraw life-sustaining treatment, must be based on reliable clinical evidence and evidence-based practice as well as ethical standards. Good medical practice also requires respecting adults' wishes to the greatest extent possible.

Life Prolonging Treatment — Sometimes after injury or a long illness, the main organs of the body no longer work properly without support. If this is permanent, on-going treatments will be needed to stop a person from dying. These treatments are collectively referred to as life prolonging and can include medical care, procedures or interventions which focus on extending biological life without necessarily considering quality of life. Certain life prolonging treatments acceptable to one person may not be acceptable to another.

Office of the Public Guardian — The Office of the Public Guardian is an independent statutory body that protects the rights and interests of vulnerable Queenslanders, including adults with impaired capacity to make their own decisions.

Organ or Tissue Donation — Donation involves removing organs and tissues from someone who has died (a donor) and transplanting them into a recipient who is on a waiting list. Organs that can be transplanted include the heart, lungs, liver, kidneys, intestine and pancreas. Tissues that can be transplanted include heart valves, bone, skin and eye tissue. Organ and tissue donation can save and significantly improve the lives of many people who are sick or dying. For additional information about donation and to register your wishes visit: www.donatelife.org.au

Statutory Health Attorney — A statutory health attorney is someone with automatic authority to make health care decisions for a person if they become unable to because of illness or incapacity. This attorney is not formally appointed; they act in this role only when the need arises. The statutory health attorney is the first available, culturally appropriate adult from the following, in order: a spouse or de facto partner in a close and continuing relationship; an adult who cares for the person but is not employed to be their carer; or a close friend or relative who is not the person's employed carer. The Public Guardian may, under certain circumstances, become the statutory health attorney of last resort.

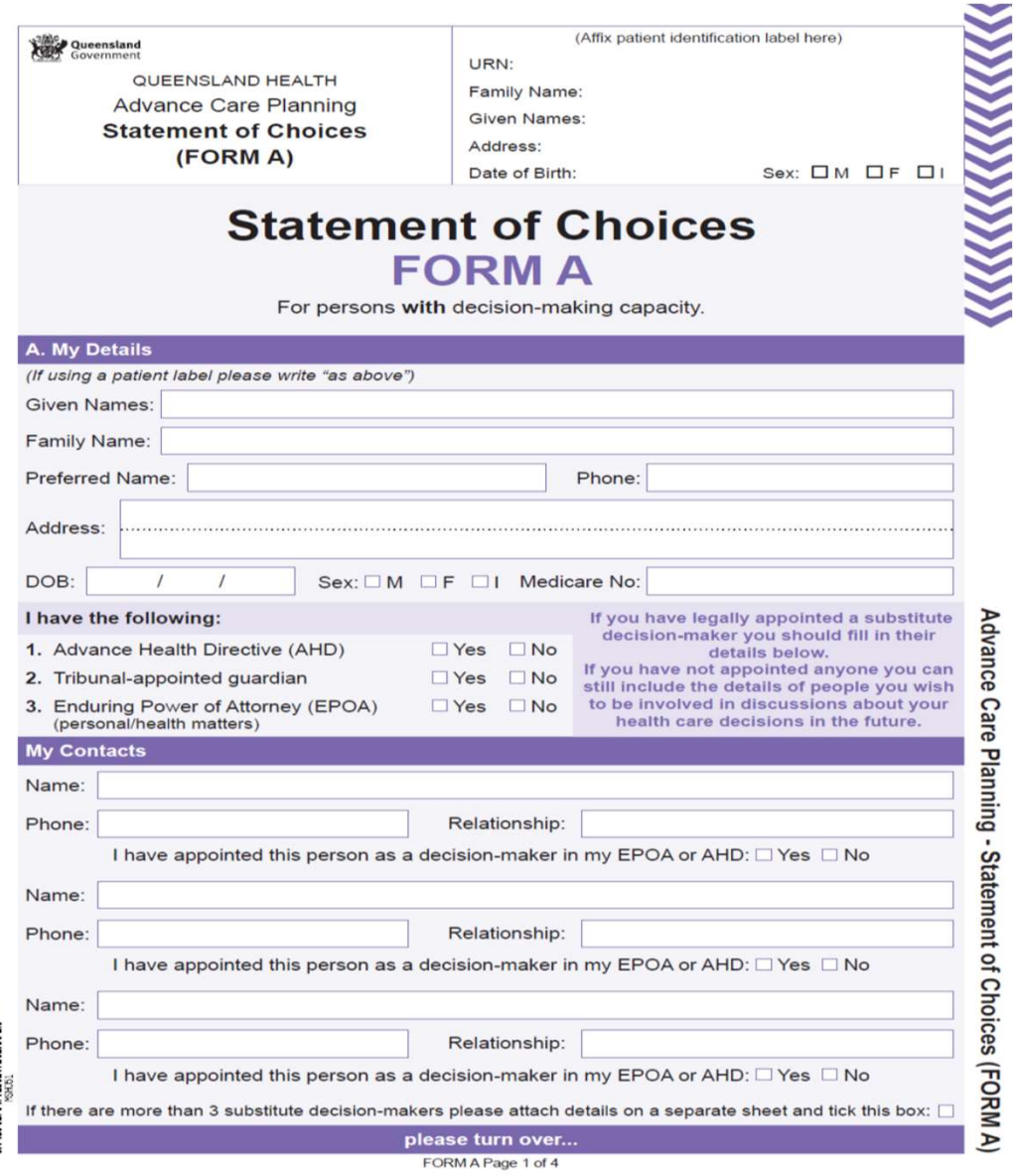
Substitute Decision-maker — Substitute decision-maker is a general term used to describe someone who has legal power to make decisions on behalf of an adult when that person is no longer able to make their own decisions. This may be a person appointed under an Enduring Power of Attorney or Advance Health Directive, a tribunal-appointed guardian or a statutory health attorney.

For more information and resources visit: www.mycaremychoices.com.au

1. Morrison, Laurie J., et al. "Strategies for Improving Survival After In-Hospital Cardiac Arrest in the United States: 2013 Consensus Recommendations A Consensus Statement From the American Heart Association." *Circulation* 127.14 (2013): 1538-1563.

2. Girotra, Saket, et al. "Trends in survival after in-hospital cardiac arrest." New England Journal of Medicine 367.20 (2012): 1912-1920.

eAppendix 1. Statement of Choices form



Queensland Government

QUEENSLAND HEALTH
Advance Care Planning
Statement of Choices
(FORM A)

(Affix patient identification label here)
URN:
Family Name:
Given Names:
Address:
Date of Birth: Sex: ☐ M ☐ F ☐ I

Statement of Choices
FORM A

For persons **with** decision-making capacity.

A. My Details

(If using a patient label please write "as above")

Given Names:
Family Name:
Preferred Name: Phone:
Address:
DOB: / / Sex: ☐ M ☐ F ☐ I Medicare No:

I have the following:

1. Advance Health Directive (AHD) ☐ Yes ☐ No
2. Tribunal-appointed guardian ☐ Yes ☐ No
3. Enduring Power of Attorney (EPOA) (personal/health matters) ☐ Yes ☐ No

If you have legally appointed a substitute decision-maker you should fill in their details below.
If you have not appointed anyone you can still include the details of people you wish to be involved in discussions about your health care decisions in the future.

My Contacts

Name:
Phone: Relationship:
I have appointed this person as a decision-maker in my EPOA or AHD: ☐ Yes ☐ No

Name:
Phone: Relationship:
I have appointed this person as a decision-maker in my EPOA or AHD: ☐ Yes ☐ No

Name:
Phone: Relationship:
I have appointed this person as a decision-maker in my EPOA or AHD: ☐ Yes ☐ No

If there are more than 3 substitute decision-makers please attach details on a separate sheet and tick this box: ☐

please turn over...

FORM A Page 1 of 4

Advance Care Planning - Statement of Choices (FORM A)

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Queensland Government

QUEENSLAND HEALTH
Advance Care Planning
Statement of Choices
(FORM A)

(Affix patient identification label here)
URN:
Family Name:
Given Names:
Address:
Date of Birth: Sex: ☐ M ☐ F ☐ I

My name:

B. Personal Values

Describe what you value or enjoy most in life:
Think about what interests you or gives you the most meaning.

Consider what you would like known about you when health care decisions are being made:
Think about your past experiences, wishes and beliefs or what is important to you.

Describe the health outcomes that you would find unacceptable:
*Think about what you would **not** want, including situations you consider may be worse than death.*

Describe what would be important or comforting to you when you are nearing death:
Think about your personal preferences, special traditions or spiritual support.

The place where you would prefer to die: *(e.g. home, hospital, nursing home)*

Consider how you would want to be cared for after you die:
Think about your spiritual and cultural practices or organ and tissue donation.

proceed to next page...

FORM A Page 2 of 4

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eAppendix 1. Statement of Choices form

Queensland Government

QUEENSLAND HEALTH
Advance Care Planning
Statement of Choices (FORM A)

(Affix patient identification label here)

URN:
Family Name:
Given Names:
Address:
Date of Birth: Sex: ☐ M ☐ F ☐ I

My name:

C. Medical Conditions

My current medical conditions include:

The health impacts of the conditions listed above have been explained to me: *(tick appropriate box)*
☐ Yes ☐ No *If you have answered 'No' please consult a doctor before continuing this form.*

Medical and emergency preferences

Please remember, doctors need to speak with the relevant substitute decision-maker at the time a decision is made. You will always receive relevant care to relieve pain and suffering.

Life Prolonging Treatments

Cardiopulmonary Resuscitation (CPR) *(tick appropriate box)*

☐ **I would want** CPR attempted if it is consistent with good medical practice **OR**
☐ **I would NOT want** CPR attempted under any circumstances **OR**
☐ Other:

Other Life Prolonging Treatments *(tick appropriate box)*

e.g. kidney machine (dialysis), feeding tube, breathing machine (ventilator)

☐ **I would want** other life prolonging treatments if they are consistent with good medical practice **OR**
☐ **I would NOT want** other life prolonging treatments under any circumstances **OR**
☐ Other:

Medical Treatments

If considered to be medically beneficial,	I would want:	I would NOT want:	undecided / no preference:
Major operation (*e.g. under general anaesthetic*)	☐	☐	☐
Intravenous (IV) fluids	☐	☐	☐
Intravenous (IV) antibiotics	☐	☐	☐
Other intravenous (IV) drugs	☐	☐	☐
Blood transfusion	☐	☐	☐

Other:

please turn over...

FORM A Page 3 of 4

Advance Care Planning - Statement of Choices (FORM A)

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QUEENSLAND HEALTH
Advance Care Planning
Statement of Choices (FORM A)

(Affix patient identification label here)

URN:
Family Name:
Given Names:
Address:
Date of Birth: Sex: ☐ M ☐ F ☐ I

My name:

Statement of Choices

This document remains in place until it is changed or withdrawn.
You may indicate a time period when you want to review this document *(optional)*:

☐ 6 monthly ☐ 12 monthly ☐ Other:

My Declaration

I have had this document explained to me and I understand its importance and purpose. This is my true record on this date and I request that my wishes, values and beliefs are respected. I undertand that:

- **This document will only be used if I am unable to make or communicate decisions for myself.**
- My substitute decision-maker(s) and doctors can use this document as a guide when making decisions regarding my medical treatment in the future.
- I may complete all or part of this document and that I can change my mind regarding these choices at any time.
- It is important to discuss my wishes with my doctor and my family, including my substitute decision-maker(s).
- Doctors should only provide treatment that is consistent with good medical practice.
- Regardless of any decisions about cardiopulmonary resuscitation and life prolonging treatments, I will continue to receive all other relevant care, including care to relieve pain and alleviate suffering.

I consent to share the information on this form with persons/services relevant to my health as per the privacy policy and to non-identifiable information being used for quality improvement/research purposes as per the information sheet. The privacy policy and information sheet are available at: www.mycaremychoices.com.au

Signature: Date: / /

Doctor's Review of Plan

I, as a registered medical practitioner, believe that the person completing this form has the capacity necessary to complete this Statement of Choices. I further attest I am not an appointed attorney in this person's Enduring Power of Attorney or Advance Health Directive, a relation or a beneficiary under this person's will.

Doctor's Name:
Doctor's Signature:
Date: / /

Hospital or Practice Stamp

This form was completed with the help of a qualified interpreter or cultural/religious liaison person: ☐ Yes ☐ N/A

IMPORTANT: **To allow this document to be available to health care providers, please send a copy of all four (4) pages of FORM A to:**

Office of Advance Care Planning
Fax: (07) 3710 2291
Email: acp@health.qld.gov.au
Post: PO Box 72, Corinda QLD 4075
For more information phone: 1300 007 227

www.mycaremychoices.com.au

FORM A Page 4 of 4

5

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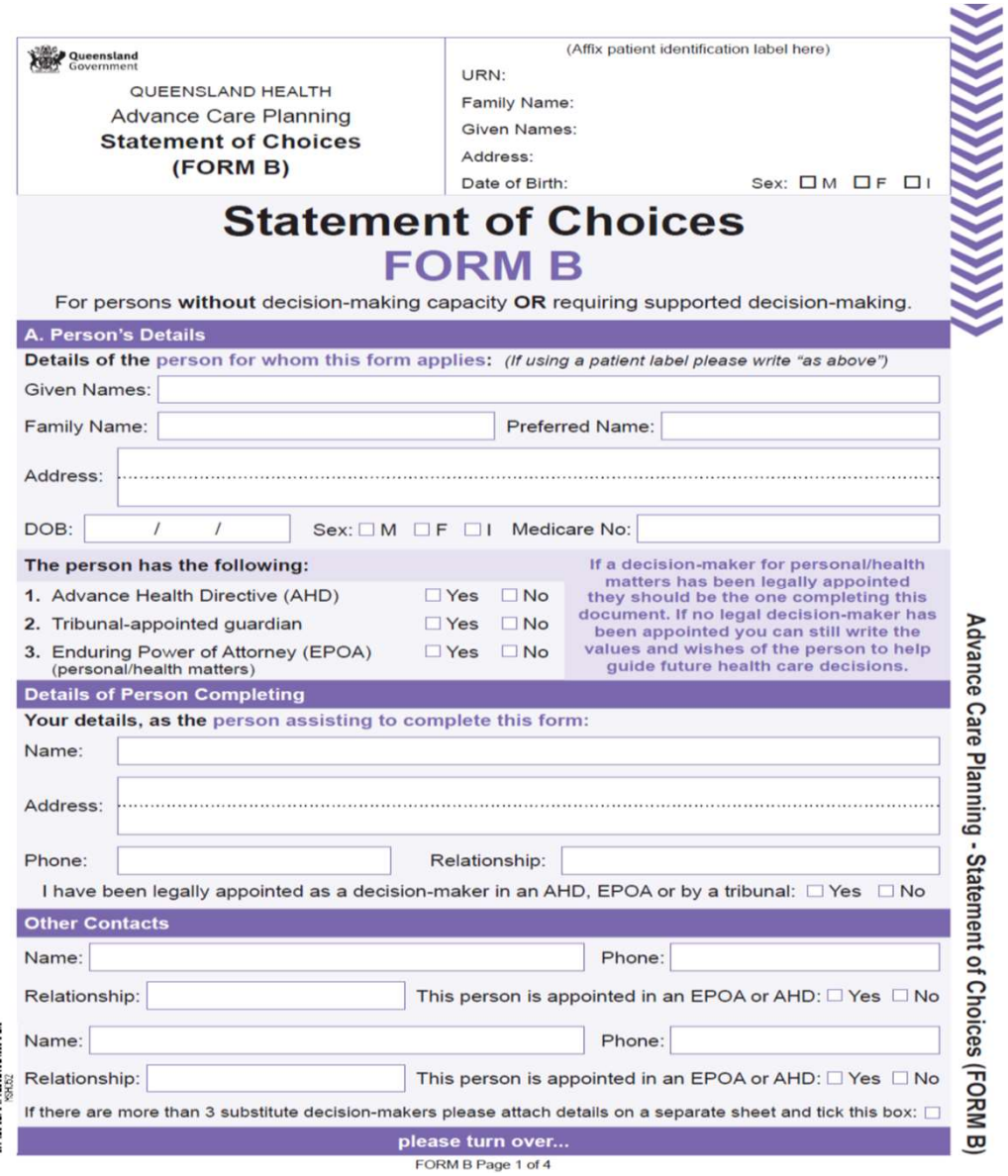
eAppendix 1. Statement of Choices form



Queensland Government

QUEENSLAND HEALTH

Advance Care Planning

Statement of Choices

(FORM B)

(Affix patient identification label here)

URN:

Family Name:

Given Names:

Address:

Date of Birth: Sex: ☐ M ☐ F ☐ I

Statement of Choices

FORM B

For persons **without** decision-making capacity **OR** requiring supported decision-making.

A. Person's Details

Details of the person for whom this form applies: *(If using a patient label please write "as above")*

Given Names:

Family Name: Preferred Name:

Address:

DOB: / / Sex: ☐ M ☐ F ☐ I Medicare No:

The person has the following:

1. Advance Health Directive (AHD) ☐ Yes ☐ No
2. Tribunal-appointed guardian ☐ Yes ☐ No
3. Enduring Power of Attorney (EPOA) (personal/health matters) ☐ Yes ☐ No

If a decision-maker for personal/health matters has been legally appointed they should be the one completing this document. If no legal decision-maker has been appointed you can still write the values and wishes of the person to help guide future health care decisions.

Details of Person Completing

Your details, as the person assisting to complete this form:

Name:

Address:

Phone: Relationship:

I have been legally appointed as a decision-maker in an AHD, EPOA or by a tribunal: ☐ Yes ☐ No

Other Contacts

Name: Phone:

Relationship: This person is appointed in an EPOA or AHD: ☐ Yes ☐ No

Name: Phone:

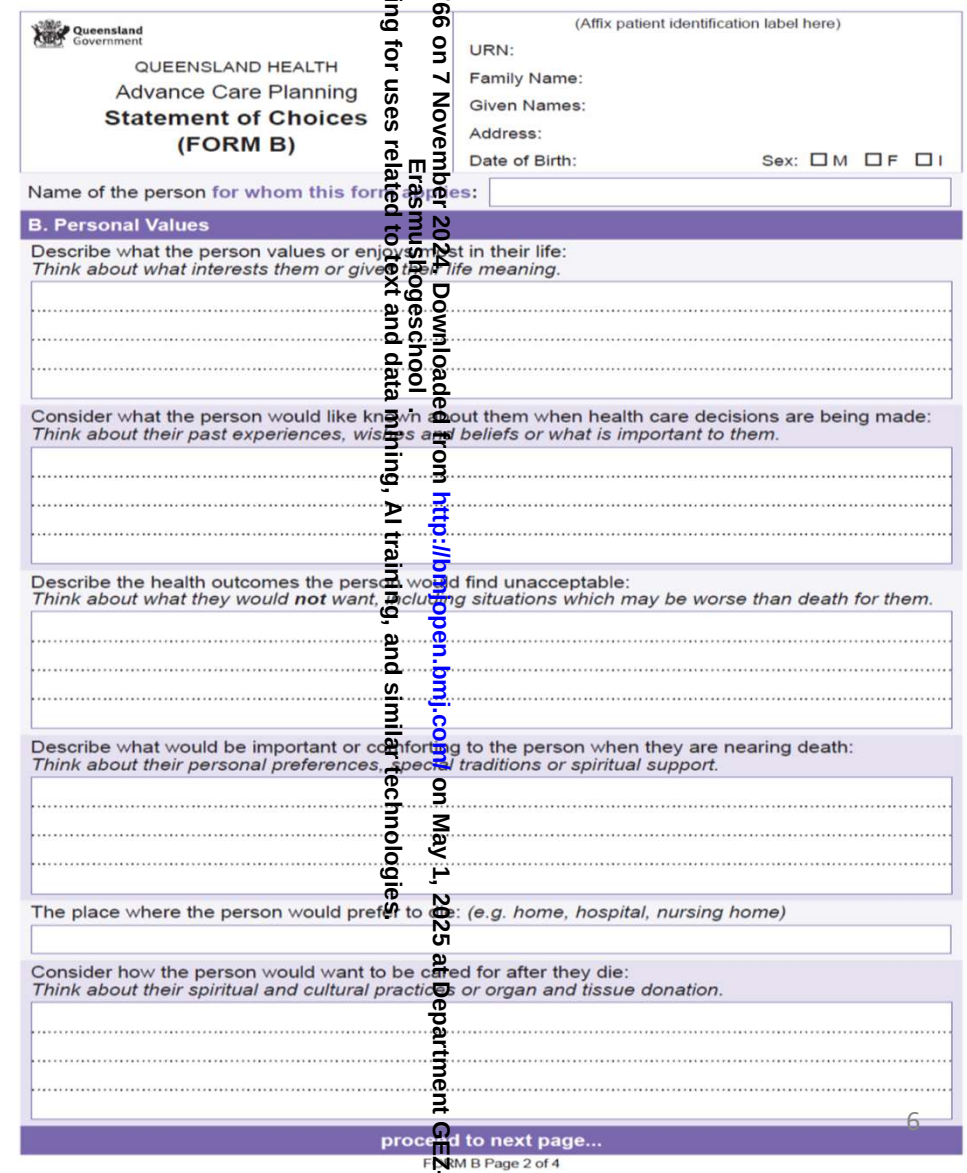
Relationship: This person is appointed in an EPOA or AHD: ☐ Yes ☐ No

If there are more than 3 substitute decision-makers please attach details on a separate sheet and tick this box: ☐

please turn over...

FORM B Page 1 of 4

Advance Care Planning - Statement of Choices (FORM B)



Queensland Government

QUEENSLAND HEALTH

Advance Care Planning

Statement of Choices

(FORM B)

(Affix patient identification label here)

URN:

Family Name:

Given Names:

Address:

Date of Birth: Sex: ☐ M ☐ F ☐ I

Name of the person for whom this form applies:

B. Personal Values

Describe what the person values or enjoys most in their life:
Think about what interests them or gives their life meaning.

Consider what the person would like known about them when health care decisions are being made:
Think about their past experiences, wishes and beliefs or what is important to them.

Describe the health outcomes the person would find unacceptable:
*Think about what they would **not** want, including situations which may be worse than death for them.*

Describe what would be important or comforting to the person when they are nearing death:
Think about their personal preferences, special traditions or spiritual support.

The place where the person would prefer to be: *(e.g. home, hospital, nursing home)*

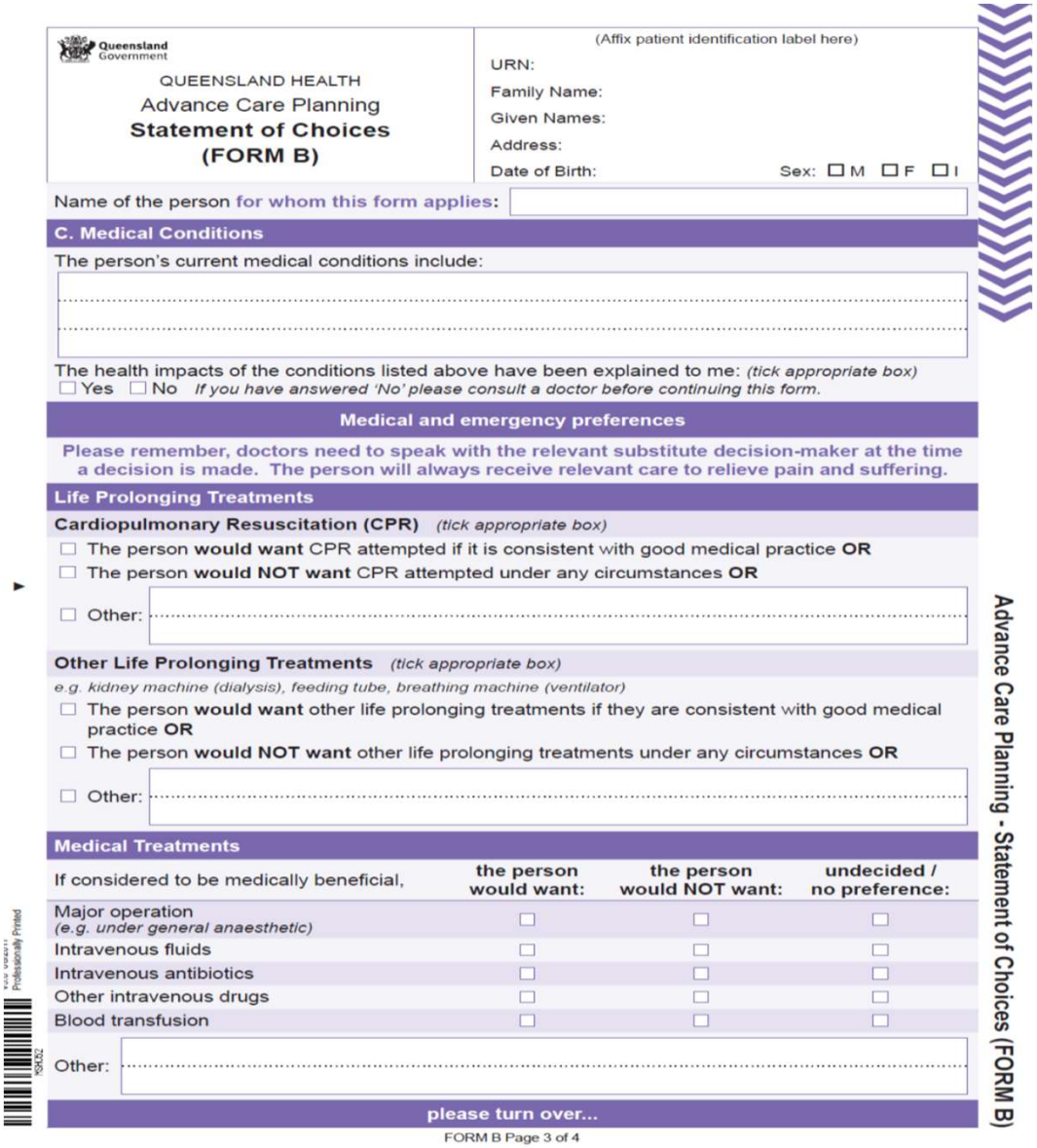
Consider how the person would want to be cared for after they die:
Think about their spiritual and cultural practices or organ and tissue donation.

proceed to next page...

FORM B Page 2 of 4

DO NOT WRITE IN THIS BINDING MARGIN

eAppendix 1. Statement of Choices form



Queensland Government

QUEENSLAND HEALTH
Advance Care Planning
Statement of Choices (FORM B)

(Affix patient identification label here)
URN:
Family Name:
Given Names:
Address:
Date of Birth: Sex: ☐ M ☐ F ☐ I

Name of the person for whom this form applies:

C. Medical Conditions

The person's current medical conditions include:

The health impacts of the conditions listed above have been explained to me: *(tick appropriate box)*
☐ Yes ☐ No *If you have answered 'No' please consult a doctor before continuing this form.*

Medical and emergency preferences

Please remember, doctors need to speak with the relevant substitute decision-maker at the time a decision is made. The person will always receive relevant care to relieve pain and suffering.

Life Prolonging Treatments

Cardiopulmonary Resuscitation (CPR) *(tick appropriate box)*
☐ The person **would want** CPR attempted if it is consistent with good medical practice **OR**
☐ The person **would NOT want** CPR attempted under any circumstances **OR**
☐ Other:

Other Life Prolonging Treatments *(tick appropriate box)*
e.g. kidney machine (dialysis), feeding tube, breathing machine (ventilator)
☐ The person **would want** other life prolonging treatments if they are consistent with good medical practice **OR**
☐ The person **would NOT want** other life prolonging treatments under any circumstances **OR**
☐ Other:

Medical Treatments

If considered to be medically beneficial,	the person would want:	the person would NOT want:	undecided / no preference:
Major operation *(e.g. under general anaesthetic)*	☐	☐	☐
Intravenous fluids	☐	☐	☐
Intravenous antibiotics	☐	☐	☐
Other intravenous drugs	☐	☐	☐
Blood transfusion	☐	☐	☐

Other:

please turn over...

FORM B Page 3 of 4

Advance Care Planning - Statement of Choices (FORM B)

Queensland Government

QUEENSLAND HEALTH
Advance Care Planning
Statement of Choices (FORM B)

(Affix patient identification label here)
URN:
Family Name:
Given Names:
Address:
Date of Birth: Sex: ☐ M ☐ F ☐ I

Name of the person for whom this form applies:

Statement of Choices

This document remains in place until changed or withdrawn.
You may indicate a time period when you want to review this document *(optional)*:
☐ 6 monthly ☐ Yearly ☐ Other:

Declaration

I understand the person for whom this form applies does not have capacity to make independent health care decisions or requires support to make health care decisions. I give my views based on what I believe is in their best interests. I am taking into account their wishes, the views of their significant others and the benefits and burdens of health care treatment as I understand them. I understand the views given in this document are not legally binding but can still have legal effect.

I request the choices recorded in this document are respected by health professionals as part of their application of good medical practice. I also understand that regardless of the choices expressed here the person will continue to receive all relevant care including care to relieve pain and alleviate suffering.

I consent to share the information in this form with persons/services relevant to the health of the person named as per the privacy policy and to non-identifiable information being used for quality improvement/ research purposes as per the information sheet. The privacy policy and information sheet are available at: www.mycaremychoices.com.au

Your Name:
Your Signature: Date: / /

Doctor's Review of Plan

I, as a registered medical practitioner, believe that the person completing this form understands the importance and implications of this document and is acting in the best interests of the person for whom this form applies. I further attest that I am not an appointed attorney in an Enduring Power of Attorney document or Advance Health Directive, a relation or a beneficiary under the will of the person for whom this form applies.

Doctor's Name:
Doctor's Signature:
Date: /

Hospital or Practice Stamp

This form was completed with the help of a qualified interpreter or cultural/religious liaison person: ☐ Yes ☐ N/A

IMPORTANT: **To allow this document to be available to health care providers, please send a copy of all four (4) pages of FORM B to:**

Office of Advance Care Planning
Fax: (07) 3710 2291
Email: acp@health.qld.gov.au
Post: PO Box 72, Corinda QLD 4075

For more information phone: 1300 007 227

www.mycaremychoices.com.au

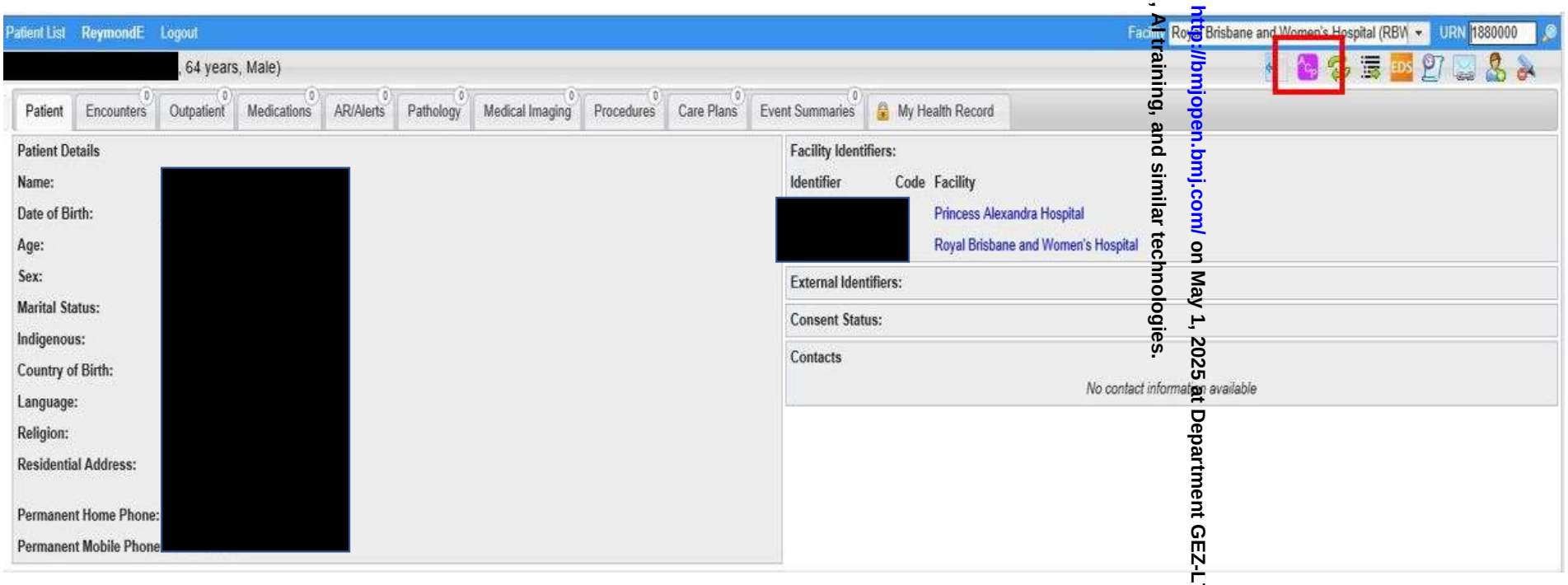
FORM B Page 4 of 4

eAppendix 2. Electronic Advance Care Planning (ACP) Tracker

The *ACP Tracker*, hosted by *The Viewer* digital platform, is an ACP information sharing portal enabling direct and easy access to ACP documents and information across service settings, government and non-government. ACP documents which have been reviewed and uploaded by the Statewide Office of Advance Care Planning are available for viewing within the module and comments regarding ACP approaches can be added by authorised Queensland Health users. Comments entered during a public inpatient admission are included in the person's discharge summary.

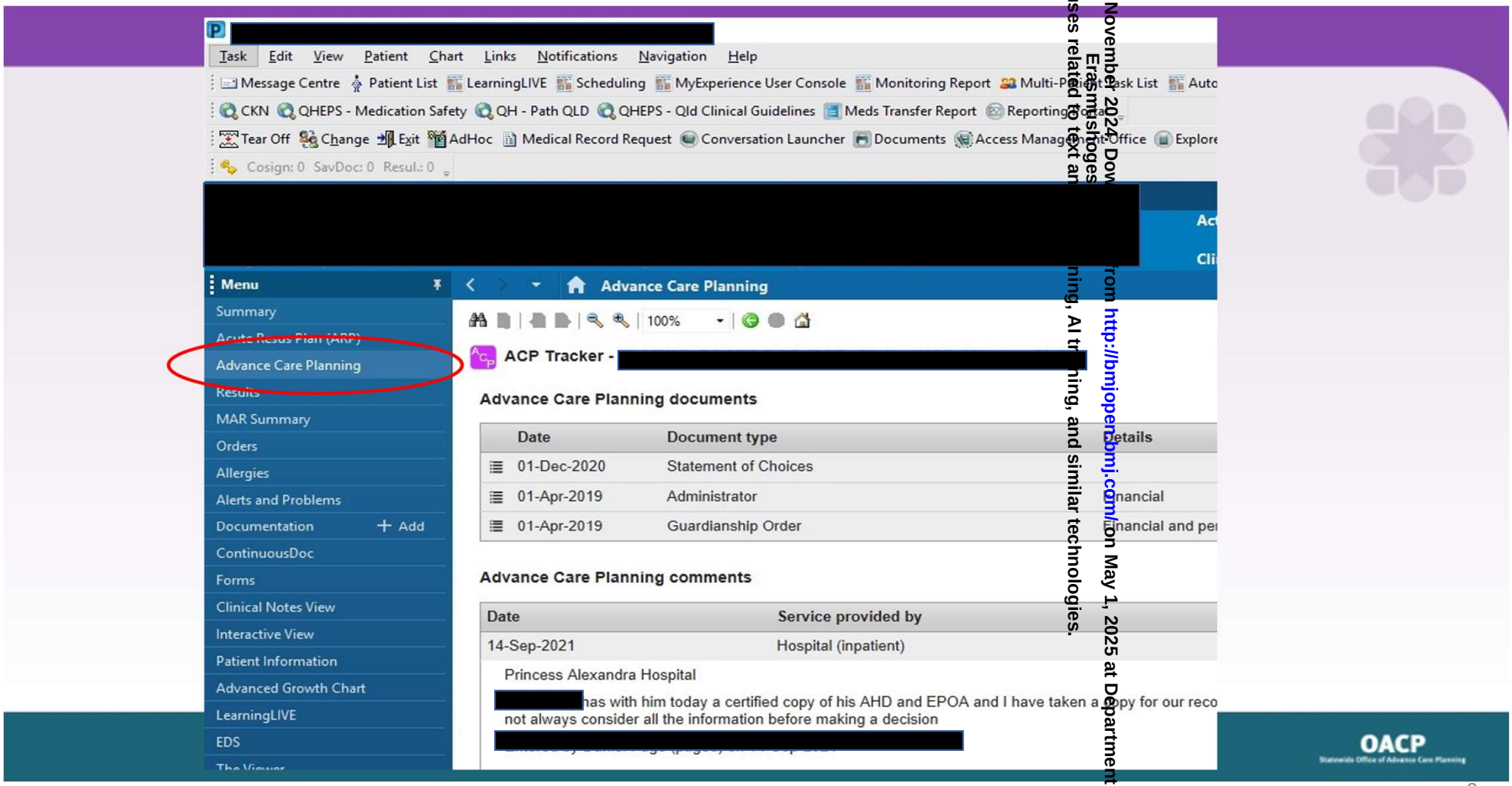
The Viewer is a secure State-wide, web-based application that sources patient data from various enterprise clinical, administrative and speciality systems. It provides a single dashboard view of consolidated clinical and administrative information about a patient. It can be accessed by Hospital and Health Service (HHS) staff, Queensland Ambulance Service staff and authorised Queensland healthcare practitioners (e.g. general practitioners and nurses from residential aged care facilities) via the Health Provider Portal. It is also accessible via mobile devices.

The figure below represents the clinician view of how to access The ACP Tracker (purple button) within the Viewer via the Health Provider Portal.



eAppendix 2. Electronic Advance Care Planning (ACP) Tracker

The following figure (with a hypothetical patient) represents the clinician view of how to access the ACP Tracker from within the patient's electronic medical record, using the Advance Care Planning title in the left-sided menu.



eAppendix 3. Health Provider Portal

Better connecting Queensland's HPs and public hospitals

The Health Provider Portal provides Queensland's *eligible health practitioners (HPs) with secure online access to their patients' Queensland Health (QH) records.

This read-only online access will allow HPs to view public hospital information including appointment records, radiology and laboratory results, treatment and discharge summaries, and demographic and medication details.

This access will bridge the information gap between Queensland's HPs and public hospitals and help ensure patients receive consistent, timely and better coordinated care.

What are the benefits for HPs?

Having secure online access to patients' hospital records will allow HPs:

- to make decisions based on the latest available clinical information
- to spend more time with patients and less time on administration.

Will all patient records be available?

Some patients however may not want HPs to have access to their public hospital records. If a patient is concerned about HPs having access to their public hospital records, please advise them to visit www.health.qld.gov.au/hp-portal.

*Eligible health practitioners can include;

- General Practitioners
- Specialists
- Midwives
- Nurses
- Paramedics

Contact

For more information about *Better connecting Queensland's HPs and public hospitals:*

connectingqld@health.qld.gov.au

visit www.health.qld.gov.au/hp-portal

Please refer to the website for any additional eligible health practitioner updates.

Queensland Health

Better connecting Queensland's HPs and public hospitals

Queensland Government

eAppendix 3. Health Provider Portal

How do I gain online access to my patients' hospital records?

You will need to register for the Health Provider Portal (HPP) to gain read-only online access to your patients' Queensland Health (QH) records.

By registering for the HPP, you will be able to view a wide range of patient hospital information in one place. It's convenient, secure and accessible at any time.

What do I need to do before I register?

For GPs and specialists you, or your practice manager, will need to ensure that details of your Medicare Provider Number and Healthcare Provider Identifier – Individual (HPI-I) are up-to-date and registered with QH's Secure Transfer Service (STS). This allows QH to communicate with you electronically. All other eligible HPs will need to ensure your AHPRA registration is up to date and you have your HPI-I number ready.

How do I register?

Visit www.health.qld.gov.au/hp-portal

How do I gain access to my patients' hospital records?

To register, Queensland HPs will require: 100 points of personal identification

- Australian driver's license*
- Australian passport*/visa/citizenship certificate
- Birth*/marriage/change of name certificate
- Medicare Card

* You must include at least one of these primary documents as part of your 100 points.

Professional identification

- current Australian Health Practitioner Regulation Agency (AHPRA) registration number indicating you are a eligible Health Practitioner
- Medicare Provider Number (GPs and Specialists)
- HPI-I identified as 'Health Practitioner'.

Technical support and more information

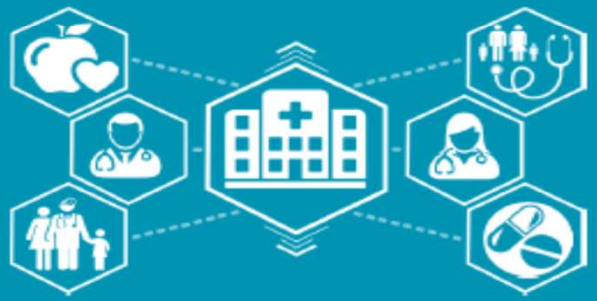
If you experience difficulties in accessing the Health Provider Portal (HPP), please call 1300 478 439 for technical assistance.

Fact sheets and frequently asked questions at www.health.qld.gov.au/hp-portal might also assist you to access the HPP.

Terms and conditions

You must accept the Terms and Conditions when registering for the HPP. Queensland Health will conduct audits to ensure appropriate use of the information is being adhered to.

Penalties apply for inappropriate access and use of the HPP including possible deregistration.



eAppendix 4. List of extracted data items

Data collection	Variables
Death Registrations from the (Qld) Registry of Births, Deaths and Marriages	Patient Study ID Cohort/Control flag Date of death (dd-mm-yyyy) Place of death Age at death Sex Hospital and health service (HHS) of residence
Coded Cause of Death Data (Australian Bureau of Statistics)	Patient Study ID Cohort/Control flag ICD coded cause of death – broad categories
Queensland Hospital Admitted Patient Data Collection (QHAPDC)	Patient Study ID Cohort/Control flag **Episode information:** Facility ID Facility type Episode start date (DDMMYYYY) Episode end date (DDMMYYYY) Length of stay in days Care type Planned same day Mode of separation Elective status Fund source ICU length of stay in hours and minutes (capped at 30+days) Standard ward on admission **Patient demographics:** Age (5 year groupings) Sex Preferred language Marital status Hospital insurance status Indigenous status (Flag indigenous/non-Indigenous) **Clinical information:** Principal diagnosis, ICD code Other diagnoses, ICD codes External causes, ICD codes Morphology, ICD codes Procedures, ACHI codes Block codes DRG (Diagnosis-related Group) MDC (Major Diagnostic Category) **Geographic information:** Facility HHS Patient HHS ARIA+ (Accessibility/Remoteness Index of Australia) SEIFA (Socio-Economic Indexes for Areas)
Emergency Department Information System (EDIS)	Patient Study ID Cohort/Control flag Facility ID Facility HHS Presentation date DDMMYYYY Episode (ED presentation) end date DDMMYYYY Length of presentation in hours and minutes Triage category Mode of arrival Visit type Payment class Episode end status Principal diagnosis Additional diagnoses
State National Hospital Cost Data Collection (NHCDC)	Patient Study ID Cohort/Control flag Direct cost Overhead cost Total costs Average weighted activity unit (WAU) for inpatient episodes

eAppendix 5. Queensland data linkage framework

Data linkage services for Queensland are provided by the Statistical Analysis and Linkage Unit (also known as Data Linkage Queensland, DLQ) in the Statistical Services Branch at Queensland Health.

In Queensland, both deterministic and probabilistic methods of linking records are used. Both methods have their own advantages and their usage is dependent on the information available.

Deterministic linkage involves the linking of data sets using unique identifiers such as a patient/client unique identifier or through comparing fields such as name, street name, Queensland Data Linkage Framework - 6 - year of birth, street number with the requirement that the records agree on all characters. Deterministic linking (sometimes called exact matching) can result in missed matches when there are inconsistencies in the way information is recorded across data sources or introduce false positive matches if limited data are used to merge records. The use of computer programs and partial identifiers such as postcodes can increase the proportion of true matches to alleviate these limitations.

Probabilistic linkage involves the use of statistical models and mathematical formulae (algorithms) to estimate the probability of data from different data sets having commonality (e.g. the same person/event). Matching variables are assigned weighted scores so, for example, rare surnames are given a higher weight than common surnames. Additionally, names are converted to a phonemic code (soundex/NYSIIS) in order to handle spelling discrepancies (e.g. Mcdonald vs. Macdonald, Smyth vs. Smith). Dates of birth that do not match exactly are still given some weight if there is a viable rearrangement or substitution of dates. The main advantage of this method is that data from different sources, and of varying quality, are able to be linked successfully whereas deterministic linkage may fail to identify many true matches due to minor differences. Clerical review is used to manually inspect the 'grey area' of uncertain matches in probabilistic linkage. When pairs are ranked by total weights from linkage, there will be a lower cut-off below which pairs are considered non-matches, and an upper cut-off above which pairs are considered true matches. Between these bounds lie the paired records where there is less certainty about whether or not they are true matches, and human judgement is required to decide whether to link them.

More information is available at: https://www.health.qld.gov.au/__data/assets/pdf_file/0030/150798/qlddatalinkframework.pdf.

36/bmjopen-2023-082766 on 7 November 2024. Downloaded from

eAppendix 6. Subgroup participant characteristics

Table 1: Cohort with ACP uploaded at least 6 months prior to death, compared with matched controls

Characteristics	Control (N=5014)	ACP ≥6 months (N=2507)	p-value	SMD
Age at death (mean (SD))	83.24 (10.64)	83.33 (10.70)	0.736	0.008
Sex = Male (%)	1657 (48.9)	770 (49.6)	0.639	0.015
Residential health service (%)			0.001	0.104
GOLD COAST	428 (8.5)	184 (7.3)		
METRO NORTH	878 (17.5)	386 (15.4)		
METRO SOUTH	2970 (59.2)	1583 (63.1)		
SUNSHINE COAST	314 (6.3)	124 (4.9)		
WEST MORETON	424 (8.5)	230 (9.2)		
Year of death (%)			0.925	<0.001
2015	0 (0.0)	0 (0.0)		
2016	246 (4.9)	123 (4.9)		
2017	978 (19.5)	489 (19.5)		
2018	1640 (32.7)	820 (32.7)		
2019	2150 (42.9)	1075 (42.9)		
Cause of death (%)			<0.001	0.227
Certain infectious and parasitic diseases	72 (1.4)	33 (1.3)		
Diseases of the blood and blood-forming organs	56 (1.1)	28 (1.1)		
Diseases of the circulatory system	1464 (29.2)	725 (28.9)		
Diseases of the digestive system	197 (3.9)	71 (2.8)		
Diseases of the eye or ear	0 (0.0)	0 (0.0)		
Diseases of the genitourinary system	140 (2.8)	66 (2.6)		
Diseases of the musculoskeletal system and connective tissue	52 (1.0)	26 (1.0)		
Diseases of the nervous system	303 (6.0)	250 (10.0)		
Diseases of the respiratory system	583 (11.6)	290 (11.6)		
Diseases of the skin and subcutaneous tissue	18 (0.4)	8 (0.3)		
Endocrine, nutritional and metabolic diseases	204 (4.1)	139 (5.5)		
Mental, behavioral and neurodevelopmental disorders	463 (9.2)	292 (11.6)		
Missing	9 (0.2)	4 (0.2)		
Neoplasms	1228 (24.5)	510 (20.3)		
Other	225 (4.5)	65 (2.6)		
Preferred language (%)			0.002	0.088
English	3170 (63.2)	1487 (59.3)		
Non-English	1826 (36.4)	1015 (40.5)		
Not Stated/Unknown	18 (0.4)	5 (0.2)		
Marital status (%)			0.429	0.069
Divorced	299 (8.8)	138 (8.9)		
Married (Registered And De Facto)	1537 (45.3)	725 (46.7)		
Never Married	251 (7.4)	111 (7.2)		
Not Stated/Unknown	147 (4.3)	51 (3.3)		
Separated	74 (2.2)	42 (2.7)		
Widowed	1082 (31.9)	484 (31.2)		
Hospital insurance status (%)			<0.001	0.181
Hospital Insurance	536 (15.8)	153 (9.9)		
Not Insured	2823 (83.3)	1387 (89.4)		
Not Stated/Unknown	31 (0.9)	11 (0.7)		
Ingidenous status (%)			0.574	0.032
Indigenous	42 (1.2)	25 (1.6)		
Non-indigenous	3331 (98.3)	1518 (97.9)		
Not Stated/Unknown	17 (0.5)	8 (0.5)		
ARIA (%)			0.003	0.095
Inner Regional Australia	365 (10.8)	124 (8.0)		
Major Cities Of Australia	2991 (88.4)	1412 (91.2)		
Outer Regional Australia	29 (0.9)	13 (0.8)		
Remote Australia	0 (0.0)	0 (0.0)		
Very Remote Australia	0 (0.0)	0 (0.0)		
SEIFA (%)			<0.001	0.169
1	727 (14.5)	351 (14.0)		
2	634 (12.6)	351 (14.0)		
3	661 (13.2)	327 (13.0)		
4	736 (14.7)	267 (10.7)		
5	623 (12.4)	253 (10.1)		
Missing	1633 (32.6)	958 (38.2)		

[a]Number and percentages are provided unless otherwise indicated.

ACP = advance care planning; SD = standard deviation; SMD = standardized mean difference; SoC = statement of choices; AHD = advance health directive; ARIA = Accessibility/Remoteness Index of Australia; SEIFA = Socio-Economic Indexes for Areas.

eAppendix 6. Subgroup participant characteristics

Table 2: Cohort with ACP uploaded between 1 to 6 months prior to death, compared with matched controls

Characteristics	Control (N=3584)	ACP <1 month (N=1792)	p-value	SMD
Age at death (mean (SD))	78.83 (12.43)	78.90 (12.54)	0.844	0.006
Sex = Male (%)	1388 (53.6)	742 (52.2)	0.417	0.028
Residential health service (%)			0.359	0.061
GOLD COAST	280 (7.8)	128 (7.1)		
METRO NORTH	658 (18.4)	303 (16.9)		
METRO SOUTH	2001 (55.8)	1033 (57.6)		
SUNSHINE COAST	262 (7.3)	120 (6.7)		
WEST MORETON	383 (10.7)	208 (11.6)		
Year of death (%)			1.000	<0.001
2015	116 (3.2)	58 (3.2)		
2016	538 (15.0)	269 (15.0)		
2017	988 (27.6)	494 (27.6)		
2018	1210 (33.8)	605 (33.8)		
2019	732 (20.4)	366 (20.4)		
Cause of death (%)			0.002	0.176
Certain infectious and parasitic diseases	54 (1.5)	13 (0.7)		
Diseases of the blood and blood-forming organs	32 (0.9)	18 (1.0)		
Diseases of the circulatory system	836 (23.3)	427 (23.8)		
Diseases of the digestive system	99 (2.8)	39 (2.2)		
Diseases of the eye or ear	3 (0.1)	0 (0.0)		
Diseases of the genitourinary system	61 (1.7)	50 (2.8)		
Diseases of the musculoskeletal system and connective tissue	25 (0.7)	10 (0.6)		
Diseases of the nervous system	189 (5.3)	122 (6.8)		
Diseases of the respiratory system	289 (8.1)	153 (8.5)		
Diseases of the skin and subcutaneous tissue	15 (0.4)	12 (0.7)		
Endocrine, nutritional and metabolic diseases	131 (3.7)	58 (3.2)		
Mental, behavioral and neurodevelopmental disorders	230 (6.4)	106 (5.9)		
Missing	8 (0.2)	0 (0.0)		
Neoplasms	1482 (41.4)	742 (41.4)		
Other	130 (3.6)	42 (2.3)		
Preferred language (%)			<0.001	0.202
English	2406 (67.1)	1365 (76.2)		
Non-English	1168 (32.6)	424 (23.7)		
Not Stated/Unknown	10 (0.3)	3 (0.2)		
Marital status (%)			0.127	0.098
Divorced	261 (10.1)	160 (11.3)		
Married (Registered And De Facto)	1283 (49.5)	683 (48.0)		
Never Married	243 (9.4)	122 (8.6)		
Not Stated/Unknown	100 (3.9)	37 (2.6)		
Separated	63 (2.4)	41 (2.9)		
Widowed	641 (24.7)	379 (26.7)		
Hospital insurance status (%)			0.233	0.06
Hospital Insurance	354 (13.7)	192 (13.5)		
Not Insured	2219 (85.6)	1226 (86.2)		
Not Stated/Unknown	18 (0.7)	4 (0.3)		
Ingidenous status (%)			0.579	0.035
Indigenous	41 (1.6)	17 (1.2)		
Non-indigenous	2539 (98.0)	1400 (98.5)		
Not Stated/Unknown	11 (0.4)	5 (0.4)		
ARIA (%)			0.684	0.066
Inner Regional Australia	289 (11.2)	134 (9.4)		
Major Cities Of Australia	2264 (87.5)	1265 (89.0)		
Outer Regional Australia	34 (1.3)	22 (1.5)		
Remote Australia	0 (0.0)	0 (0.0)		
Very Remote Australia	1 (0.0)	0 (0.0)		
SEIFA (%)			<0.001	0.179
1	601 (16.8)	322 (18.0)		
2	489 (13.6)	275 (15.3)		
3	506 (14.1)	314 (17.5)		
4	537 (15.0)	284 (15.8)		
5	451 (12.6)	226 (12.6)		
Missing	1000 (27.9)	371 (20.7)		

[a]Number and percentages are provided unless otherwise indicated.

ACP = advance care planning; SD = standard deviation; SMD = standardized mean difference; SoC = statement of choices; AHD = advance health directive; ARIA = Accessibility/Remoteness Index of Australia; SEIFA = Socio-Economic Indexes for Areas.

eAppendix 6. Subgroup participant characteristics

Table 3: Cohort with ACP uploaded less than 1 month prior to death, compared with matched controls

Characteristics	Control (N=2574)	ACP <1 month (N=1287)	p-value	SMD
Age at death (mean (SD))	78.74 (12.52)	78.78 (12.53)	0.924	0.003
Sex = Male (%)	999 (53.3)	552 (52.8)	0.854	0.009
Residential health service (%)			0.128	0.092
GOLD COAST	174 (6.8)	71 (5.5)		
METRO NORTH	447 (17.4)	200 (15.5)		
METRO SOUTH	1549 (60.2)	804 (62.5)		
SUNSHINE COAST	170 (6.6)	76 (5.9)		
WEST MORETON	234 (9.1)	136 (10.6)		
Year of death (%)			1.000	<0.001
2015	124 (4.8)	62 (4.8)		
2016	434 (16.9)	217 (16.9)		
2017	770 (29.9)	385 (29.9)		
2018	986 (38.3)	493 (38.3)		
2019	260 (10.1)	130 (10.1)		
Cause of death (%)			0.035	0.18
Certain infectious and parasitic diseases	43 (1.7)	14 (1.1)		
Diseases of the blood and blood-forming organs	21 (0.8)	9 (0.7)		
Diseases of the circulatory system	575 (22.3)	246 (19.1)		
Diseases of the digestive system	96 (3.7)	39 (3.0)		
Diseases of the eye or ear	0 (0.0)	0 (0.0)		
Diseases of the genitourinary system	53 (2.1)	21 (1.6)		
Diseases of the musculoskeletal system and connective tissue	19 (0.7)	13 (1.0)		
Diseases of the nervous system	131 (5.1)	74 (5.7)		
Diseases of the respiratory system	249 (9.7)	131 (10.2)		
Diseases of the skin and subcutaneous tissue	10 (0.4)	0 (0.0)		
Endocrine, nutritional and metabolic diseases	83 (3.2)	43 (3.3)		
Mental, behavioral and neurodevelopmental disorders	166 (6.4)	115 (8.9)		
Missing	2 (0.1)	2 (0.2)		
Neoplasms	1037 (40.3)	547 (42.5)		
Other	89 (3.5)	33 (2.6)		
Preferred language (%)			<0.001	0.228
English	1740 (67.6)	994 (77.2)		
Non-English	824 (32.0)	284 (22.1)		
Not Stated/Unknown	10 (0.4)	9 (0.7)		
Marital status (%)			0.095	0.118
Divorced	179 (9.5)	114 (10.9)		
Married (Registered And De Facto)	980 (52.2)	511 (48.9)		
Never Married	172 (9.2)	76 (7.3)		
Not Stated/Unknown	62 (3.3)	40 (3.8)		
Separated	52 (2.8)	28 (2.7)		
Widowed	431 (23.0)	276 (26.4)		
Hospital insurance status (%)			0.002	0.155
Hospital Insurance	308 (16.4)	155 (14.8)		
Not Insured	1548 (82.5)	890 (85.2)		
Not Stated/Unknown	20 (1.1)	0 (0.0)		
Ingidenous status (%)			0.273	0.058
Indigenous	25 (1.3)	13 (1.2)		
Non-indigenous	1847 (98.5)	1026 (98.2)		
Not Stated/Unknown	4 (0.2)	6 (0.6)		
ARIA (%)			0.374	0.051
Inner Regional Australia	195 (10.4)	103 (9.9)		
Major Cities Of Australia	1655 (88.5)	926 (88.7)		
Outer Regional Australia	21 (1.1)	14 (1.3)		
Remote Australia	0 (0.0)	1 (0.1)		
Very Remote Australia	0 (0.0)	0 (0.0)		
SEIFA (%)			<0.001	0.225
1	418 (16.2)	261 (20.3)		
2	328 (12.7)	203 (15.8)		
3	370 (14.4)	205 (15.9)		
4	418 (16.2)	223 (17.3)		
5	335 (13.0)	152 (11.8)		
Missing	705 (27.4)	243 (18.9)		

[a]Number and percentages are provided unless otherwise indicated.

ACP = advance care planning; SD = standard deviation; SMD = standardized mean difference; SoC = statement of choices; AHD = advance health directive; ARIA = Accessibility/Remoteness Index of Australia; SEIFA = Socio-Economic Indexes for Areas.

eAppendix 6. Subgroup participant characteristics

Table 4: Costing cohort

Characteristics	ACP 1 to 6 months (N=4787)	Control (N=9020)	p-value	SMD
Age at death (mean (SD))	83.24 (10.64)	83.33 (10.70)	0.736	0.008
Sex = Male (%)	1657 (48.9)	770 (49.6)	0.639	0.015
Residential health service (%)			0.001	0.104
GOLD COAST	428 (8.5)	184 (7.3)		
METRO NORTH	878 (17.5)	386 (15.4)		
METRO SOUTH	2970 (59.2)	1583 (63.1)		
SUNSHINE COAST	314 (6.3)	124 (4.9)		
WEST MORETON	424 (8.5)	230 (9.2)		
Year of death (%)			NaN	<0.001
2015	0 (0.0)	0 (0.0)		
2016	246 (4.9)	123 (4.9)		
2017	978 (19.5)	489 (19.5)		
2018	1640 (32.7)	820 (32.7)		
2019	2150 (42.9)	1075 (42.9)		
Cause of death (%)			NaN	0.227
Certain infectious and parasitic diseases	72 (1.4)	33 (1.3)		
Diseases of the blood and blood-forming organs	56 (1.1)	28 (1.1)		
Diseases of the circulatory system	1464 (29.2)	725 (28.9)		
Diseases of the digestive system	197 (3.9)	71 (2.8)		
Diseases of the eye or ear	0 (0.0)	0 (0.0)		
Diseases of the genitourinary system	140 (2.8)	66 (2.6)		
Diseases of the musculoskeletal system and connective tissue	52 (1.0)	26 (1.0)		
Diseases of the nervous system	303 (6.0)	250 (10.0)		
Diseases of the respiratory system	583 (11.6)	290 (11.6)		
Diseases of the skin and subcutaneous tissue	18 (0.4)	8 (0.3)		
Endocrine, nutritional and metabolic diseases	204 (4.1)	139 (5.5)		
Mental, behavioral and Neurodevelopmental disorders	463 (9.2)	292 (11.6)		
Missing	9 (0.2)	4 (0.2)		
Neoplasms	1228 (24.5)	510 (20.3)		
Other	225 (4.5)	65 (2.6)		
Preferred language (%)			0.002	0.088
English	3170 (63.2)	1487 (59.3)		
Non-English	1826 (36.4)	1015 (40.5)		
Not Stated/Unknown	18 (0.4)	5 (0.2)		
Marital status (%)			0.429	0.069
Divorced	299 (8.8)	138 (8.9)		
Married (Registered And De Facto)	1537 (45.3)	725 (46.7)		
Never Married	251 (7.4)	111 (7.2)		
Not Stated/Unknown	147 (4.3)	51 (3.3)		
Separated	74 (2.2)	42 (2.7)		
Widowed	1082 (31.9)	484 (31.2)		
Hospital insurance status (%)			<0.001	0.181
Hospital Insurance	536 (15.8)	153 (9.9)		
Not Insured	2823 (83.3)	1387 (89.4)		
Not Stated/Unknown	31 (0.9)	11 (0.7)		
Ingidenous status (%)			0.574	0.032
Indigenous	42 (1.2)	25 (1.6)		
Non-indigenous	3331 (98.3)	1518 (97.9)		
Not Stated/Unknown	17 (0.5)	8 (0.5)		
ARIA (%)			NaN	0.095
Inner Regional Australia	365 (10.8)	124 (8.0)		
Major Cities Of Australia	2991 (88.4)	1412 (91.2)		
Outer Regional Australia	29 (0.9)	13 (0.8)		
Remote Australia	0 (0.0)	0 (0.0)		
Very Remote Australia	0 (0.0)	0 (0.0)		
SEIFA (%)			<0.001	0.169
1	727 (14.5)	351 (14.0)		
2	634 (12.6)	351 (14.0)		
3	661 (13.2)	327 (13.0)		
4	736 (14.7)	267 (10.7)		
5	623 (12.4)	253 (10.1)		
Missing	1633 (32.6)	958 (38.2)		

[a]Number and percentages are provided unless otherwise indicated.

ACP = advance care planning; SD = standard deviation; SMD = standardized mean difference; SoC = statement of choices; AHD = advance health directive; ARIA = Accessibility/Remoteness Index of Australia; SEIFA = Socio-Economic Indexes for Areas.

eAppendix 7 – Subgroup analyses according to cause of death

Table 1: Hospital use outcomes in the subgroup of deaths from cancer

Outcomes	Proportion of decedents in ACP cohort	Proportion of decedents in control cohort	Unadjusted odds ratio	Lower 95% CI of OR	Upper 95% of OR
ACP document uploaded at least 6 months prior to death					
(ACP = 510; Control = 636)					
ED presentation	71.2	78.8	0.67	0.51	0.87
Admitted to hospital	75.9	85.8	0.52	0.38	0.70
Admitted to ICU	0.0	1.3	0.00	NA	NA
Death in hospital	55.3	75.2	0.43	0.33	0.55
ACP document uploaded between 1 and < 6 months prior to death					
(ACP = 742, Control = 1,088)					
ED presentation	77.8	78.6	0.95	0.76	1.20
Admitted to hospital	85.6	88.6	0.76	0.58	1.01
Admitted to ICU	0.94	1.28	0.73	0.28	1.76
Death in hospital	59.2	76.7	0.44	0.36	0.54
ACP document uploaded <1 month prior to death					
(ACP =547, Control = 794)					
ED presentation	80.4	80.9	0.97	0.74	1.28
Admitted to hospital	84.6	88.7	0.70	0.51	0.97
Admitted to ICU	0.73	0.63	1.16	0.29	4.41
Death in hospital	63.6	76.2	0.55	0.43	0.69

eAppendix 7 – Subgroup analyses according to cause of death

Table 2: Hospital use outcomes in the subgroup of deaths from diseases of the circulatory system

Outcomes	Proportion of decedents in ACP cohort	Proportion of decedents in control cohort	Unadjusted odds ratio	Lower 95% CI of OR	Upper 95% CI of OR
ACP document uploaded at least 6 months prior to death					
(ACP = 725; Control = 639)					
ED presentation	58.9	66.4	0.73	0.58	0.91
Admitted to hospital	52.9	64.0	0.63	0.51	0.79
Admitted to ICU	0.28	1.56	0.17	0.03	0.7
Death in hospital	27.4	49.0	0.39	0.31	0.49
ACP document uploaded between 1 and < 6 months prior to death					
(ACP =427, Control = 357)					
ED presentation	72.4	66.7	1.31	0.96	1.78
Admitted to hospital	72.6	62.2	1.61	1.19	2.18
Admitted to ICU	0.23	3.08	0.07	0.00	0.38
Death in hospital	32.8	47.9	0.53	0.40	0.71
ACP document uploaded <1 month prior to death					
(ACP =246; Control = 200)					
ED presentation	76.4	65.6	1.71	1.13	2.59
Admitted to hospital	84.6	88.7	1.90	1.27	2.86
Admitted to ICU	0.73	0.63	0.40	0.02	4.25
Death in hospital	63.6	76.2	0.44	0.30	0.65

Figure S1. Distribution of ACP document uploads over time prior to death

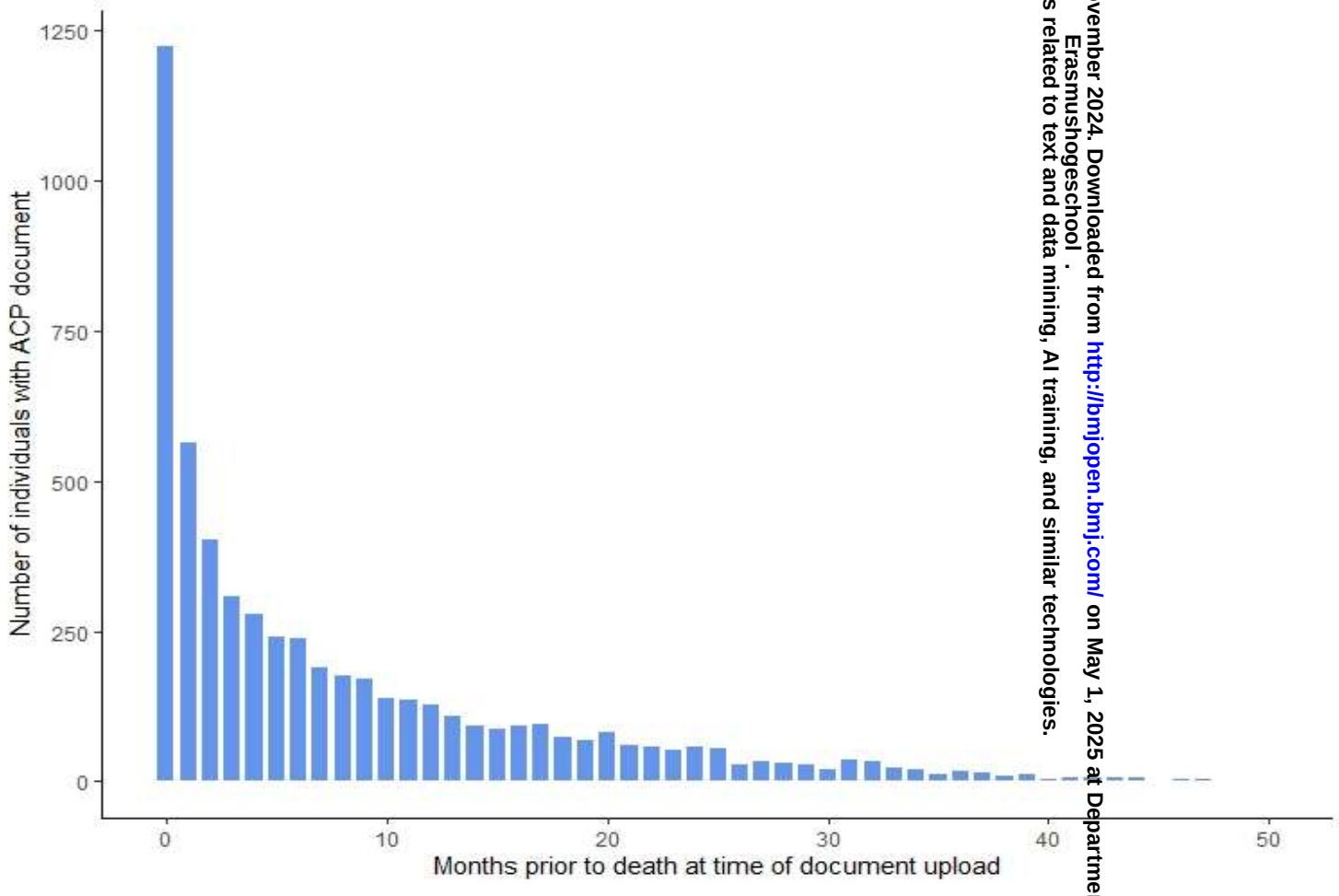


Figure S2. Monthly hospital admission costs over last 6 months of life according to timing of ACP document upload