

End-of-Life Preferences of the 'Very Old'

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requirements
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Declaration of Originality

I certify that this thesis and the research reported in it are original. It contains no material that has been submitted for the award of any degree in any other university, and that to the best of my knowledge and belief, this thesis contains no copy or paraphrasing of material previously published or written by another person, except where due reference is made in the text of this thesis.

Signed

Xanthe Sansome

Date: 31/08/2021

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Dedication

I dedicate this thesis to the many 'very old' people in our community. I desire for your final years, months, days and hours to be respectful to you and your preferences and to ensure you are honoured for your past and current contributions to the life we enjoy today. I wish to support the many clinical and non-clinical people in your world to know what you want and to enable quality end-of-life care that aligns with your expressed wishes in the place of your choice. May they remember your dying as a beautiful, albeit sad, time because it was peaceful and just as you would have wanted it.

I also dedicate this thesis to advance care planning and palliative care staff across the globe, who are attempting to listen to and honour the wishes of dying patients of all ages. In particular, I dedicate this thesis to Prof. Liz Reymond, who has tirelessly and persistently advocated for improved awareness of the unique preferences of the whole person amidst the dying process and the provision of quality care in the appropriate environment to support these preferences.

In addition, I want to dedicate this thesis to my Mum, who was both diagnosed with a life-limiting illness and died peacefully with palliative care support during the writing of this thesis, even though she was not 'very old'.

Abstract

Background: Despite increasing longevity, growing numbers of people aged 85 years and above (the 'very old') and the inevitability of death, there is a paucity of literature regarding the end-of-life preferences of people within this demographic, especially in the Australian context. This novel study has explored the cardio-pulmonary resuscitation (CPR), life-prolonging treatment (LPT) and place of death (POD) preferences of a large group of 'very old' people in the south-east corner of Queensland, who had a Statement of Choices (SoC) document completed in the six years between 2015 and 2021. In addition, it has explored the hospital use and POD of 'very old' decedents, to determine if the presence of a SoC had an impact on dying.

Methods: The CPR, LPT and POD preferences were extracted from 9555 completed SoC documents to understand aggregated preferences of this cohort. Hospital use and POD data of SoC decedents and matched controls were obtained from Queensland Health Statistical Branch and analysed with IBM-SPSS v26 using chi-squared tests and multinomial regressions with a level of significance of 1%.

Results: A preference to not want CPR or to not want LPTs under any circumstance was indicated by 81.9% and 84.5% of the 'very old' with a completed SoC, respectively (CPR: N=9542; LPT: N=9481). Those with these preferences were significantly ($p < .001$) more likely to be female (CPR: χ^2 (df 2) = 22.2; LPT: χ^2 (df 2) = 24.7), in an older age bracket (within this already 'very old' population) (CPR: χ^2 (df 6) = 71.6; LPT: χ^2 (df 6) = 47.6), residents of residential aged care facilities (RACFs) (CPR: χ^2 (df 6) = 268.1; LPT: χ^2 (df 6) = 142.8) and to have lost decision-making capacity (CPR: χ^2 (df 2) = 85.6; LPT: χ^2 (df 2) = 36.7). Increasing age was the dominant factor contributing to a reduction in odds (0.931) of these collinear characteristics ($p < .001$, OR 0.911-0.952, CI 99%) for those who did not want CPR. A RACF was the most frequently

documented preferred POD (χ^2 (df 12, N=8986) = 2414.1, $p < .001$), influenced by a large RACF representation in the study cohort. Thematic review demonstrated preferences focussed predominantly on maximising quality of life and a comfortable death. All people without a SoC had at least one hospital admission in their last six months of life (median cumulative length of stay (LOS) of 5 days) compared to 60% of people with a SoC (median cumulative LOS of 2 days), with 1.1% and 0.2% of decedents undergoing ICU admission respectively. Sixty percent of 'very old' decedents without a SoC died in hospital, compared to 32% with a SoC (χ^2 (df 1, N=5890) = 436.2, $p < .001$).

Conclusion: While each individual should be respected for their unique preferences, this research has demonstrated that the majority of people aged 85 years and above would prefer to not receive interventions that prolong their life, particularly if they negatively influence quality of life. There is a preference for end-of-life care to be provided in a destination other than hospital, where possible. The presence of a SoC reduces hospital use and hospital death in this 'very old' cohort.

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Abbreviations

ACP	Advance Care Planning
BiPAP	Bilevel Positive Airway Pressure
CPR	Cardiopulmonary resuscitation
ED	Emergency Department
EOL	End of life
GP	General Practitioner
HHS	Hospital and Health Service
ICU	Intensive care unit
K-W	Kruskal-Wallis
K-S	Kolmogorov-Smirnov
LOS	Length of stay
LPT	Life-prolonging treatment
M-W	Mann-Whitney
NIV	Non-invasive ventilation
POD	Place of death
PPOD	Preferred place of death
RACF	Residential aged care facility
SoC	Statement of Choices
χ	Chi

Glossary of Terms

Advance Care Planning (ACP) is an iterative process that involves discussing and possibly documenting one's preferences for future care, particularly end-of-life care. Ideally it should include discussions with the person, their potential decision-makers and health care professionals involved in the person's care so that all are aware of the preferences and plan. Each state and territory in Australia has unique legislation and documentation.

Statement of Choices (SoC) is a values-based document used in Queensland that captures the values, wishes and end-of-life preferences of the person. It is not legally binding but has legal effect as known preferences of the person must be considered in end-of-life decision making. It can be completed by a person with decision-making capacity (Form A) or by nominated or likely health decision makers of someone who has impaired decision-making capacity or requires support with decision making (Form B).

'Very old' is the descriptive term used throughout this thesis for people aged 85 years and above.

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Chapter 1 Introduction

1.1 Overview

Australia is facing a crisis of discordance between celebrated medical advancements that are helping individuals live longer within a death-denying society (Francati, 2017; Kellehear, 1984; Nelson, 2019; Zimmermann, 2007) and a rapidly growing ageing population, with increasing care needs, who are approaching their biologically inevitable end of life. Living longer seems preferable to dying, and for healthy people through to early old age, this is both welcome and appropriate, evidenced by the billions of dollars invested annually into the health and research system (Hunt et al., 2014).

However, there is an approaching tsunami of people living into very (over 85 years) or extreme (over 100 years) old age, with decreasing physical and cognitive function. This cohort is becoming increasingly invisible, powerless, neglected and voiceless (Friedman et al., 2019; Lukosi, 2019; Mansour, 2020; Österlind et al., 2011; Walkner et al., 2018). It is important to explore the preferences of the 'very old' to understand if living-at-any-cost beyond their already advanced years is wanted by the 'very old' themselves, or their significant others.

Understanding the individual's preferences for quality of life, health and personal care, location of care and treatment choices, especially at their inevitable end of life, will enable those aged 85 years and above (the 'very old') to receive truly person-centred care in their final months, weeks and days of life. It is acknowledged death creates immeasurable loss for those intricately connected to the person. However, provision of end-of-life care that aligns with the individual's preferences ensures that the complexity and toll of loss, through unwanted and unnecessary

prolongation of life at all costs, is not amplified for their family, the health and care staff and, indeed, although secondarily, the health system.

This research will explore the end-of-life preferences of a large cohort of 'very old' people and observe if completion of an accessible values-based advance care planning (ACP) document impacts hospital use and POD.

1.2 Background and Rationale

1.2.1 Population

Globally, due to medical advancements and improved living conditions, more people are living longer, resulting in an increasing proportion of the population living over 85 years (the 'very old' or 'oldest old'). In 1990, less than half a percent of the world's population was classified as 'oldest old' (United Nations [UN], 2019). By 2010, this had increased to just under one percent, with a 40 year predicted population increase of 250% (UN, 2019).

In Australia in 2019, two percent of the population were aged 85 years or older and females accounted for approximately 62.5% of these 'very old' (Australian Bureau of Statistics [ABS], 2019a). This population is expected to double by 2042 (ABS, 2018a; ABS, 2018b). The average life expectancy of an 85 year old person in Australia in 2014/15 was 6.2 years for males and 7.3 years for females compared to approximately 20 years for a 65 year old person of either gender at the same time (Australian Government [Older Australia], 2018). Australians aged over 65 years highly value issues of safety, function, independence, security, adequate health care support and having a purpose (Mansour, 2020).

1.2.2 'Burden' of ageing

Increased age is often accompanied by, or results in, an increased likelihood of physical, functional and cognitive decline (Milanović et al., 2013; Murman, 2015) and increased health care needs. Dementia accounts for the largest burden by disease for people over 65 years

(Older Australia, 2018), often requires placement in a residential aged care facility (RACF) and adds to complexity regarding decision-making, including at end of life (Mitchell, 2015; National Institute on Aging, 2017). A third (33%) of 'very old' Australians have dementia and this is expected to double in the next 40 years (Brown et al., 2017), influencing a 17% increase of 'very old' people moving to RACFs in the last ten years (Australian Institute of Health and Welfare [AIHW], 2021d). Seventy-eight percent of 'very old' women and 39% of 'very old' men are widowed (ABS, 2019b) which may contribute to the 64% of women and 47% of men living in RACFs who are 'very old' due to the loss of a life partner and, possibly therefore, in-home carer.

Nearly 70% of Queenslanders aged between 85 and 90 years require assistance for personal tasks such as mobility, self-care or health care. This increases to nearly 97% of the population aged over 90 years (Department of Communities, Disability Services and Seniors [DCDSS], 2019). The ratio of males to females decreases in each five year age bracket after 85 years, starting at 72% in 85-<90 age group to just 38% in centenarians (DCDSS, 2020).

The conflation of increasing numbers and complexity of needs, results in an associated increase in health care use amongst this group (AIHW, 2016b; AIHW, 2018). During 2014/15, people aged over 85 years had up to three times as many GP after-hours call outs than those aged 65-84 years (AIHW, 2016b). Just under five percent (4.7%) of all Emergency Department (ED) presentations were for 'very old' people (AIHW, 2018). Hospitalisations for the 'very old' increased 7% per year from 2003 to 2014 (AIHW, 2016b). During 2019/20, nearly 30% of all 'very old' Australians had at least one hospital admission, 59.5% of which had one, 35.4% had two or three and 4.2% had four or more admissions (ABS, 2020). The average length of stay (LOS) over twelve months (2014/15) for the 'very old' in Australia was 5.3 days, with males admitted for 4.7

days and females for 5.8 days (AIHW, 2016a). Details of ICU use for this particular demographic in Australia is unavailable, however in America, prior to COVID-19, ICU use for respiratory patients aged 85 years or older had increased over the 10 years from 2006-2015 (Laporte et al., 2018).

1.2.3 Interventions for the very old

The outcomes of CPR are poor in elderly populations (Bedell & Fulton, 1986; Cartledge et al., 2018; van Gijn et al., 2014); ICU admissions lead to poor morbidity and high mortality (Duke et al., 2014; Grace et al., 2007) and elderly residents in RACFs are being transferred to hospital and sometimes dying on route or in the ED (Murphy-Jones & Timmons, 2016; Wiseman, 2017) yet people continue to receive treatments that are non-beneficial (Amoroso & Chalela, 2019; Cardona-Morrell et al., 2016; White et al., 2016; Willmott et al., 2016).

Some situations are considered by seriously ill hospitalised patients to be worse than death: dual incontinence (54%), permanent ventilation (53%), being bed-bound (50%) and living in a nursing home (31%) (Rubin et al., 2016). Perhaps for some, therefore, not receiving interventions, even if refusal resulted in death, would be preferable to living with poor quality.

1.2.4 Deaths in the ‘very old’

Increasing age, especially when confounded with increased frailty, increases one’s likelihood of imminent dying (Fompeyrine et al., 2020; García-González et al., 2009) and this is particularly pertinent to the ‘very old’. Over 40% of all deaths in Australia in 2019 occurred in people aged 85 years and above (AIHW, 2021a), with the leading causes of death being coronary heart disease, dementia and Alzheimer’s disease, cerebrovascular disease, chronic obstructive pulmonary disease and influenza (AIHW, 2019; Ritchie & Roser, 2019). Males over 85 years have the highest age-specific suicide rate (Life in Mind, 2020) and an increasing number of older people are choosing suicide or auto-euthanasia, through intentional restriction of food or fluids, in order to end their (poor quality of) life (Chabot & Goedhart, 2009; Simon, 1989).

Ethical discussions regarding rationalisation of limited health care resources have occurred for some time (Warren, 1996), and intensified during the COVID-19 pandemic (Loh & Fleming, 2020; The University of Sydney, 2020) when distributive justice based on age was raised. Discussions about rationalisation of scarce health care resources are likely to continue for years to come, given the predicted population increase and the finite public health resources available. Perhaps the least controversial rationalisation of health care resources involves listening to the wishes of the person and allowing them to forgo treatment if requested and receive care in their environment of choice.

Universally, death, irrespective of patient age, can result in distress for families (Bowlby-West, 1983), doctors and other health professionals (Close et al., 2019; Linklater, 2010; Maffoni et al., 2019; Whippen & Canellos, 1991) and this is heightened if aggressive treatments are used near the end of life (Barclay, 2007). However, documenting preferences about resuscitation has been shown to improve quality of life at the end of life (Garrido et al., 2015).

In 2020, approximately 30% of people over 85 years entering residential care died within one year and 43.6% of all 'very old' deaths occurred between 85 and 90 years (AIHW, Australian Institute of Health and Welfare, 2021a; 2021b), so deaths in this age group are not unexpected and therefore can, and arguably should, be planned for in advance, and include knowledge of preferences for care and treatment.

The Grattan Institute reports that up to 70% of Australian adults want to die at home, but less than 15% achieve this, with hospital and RACF deaths more likely at 54% and 32% respectively (Swerissen & Duckett, 2014). Some of this disconnect may be occurring due to a combined lack of acknowledgement of dying amongst community members (Broom, 2014; Kellehear, 1984; Nelson, 2019; Zimmermann, 2007; Zimmermann & Rodin, 2004), the lack of willingness (Saunders, 2012) or confidence of some clinicians to talk about dying (Scott et al., 2013) resulting in a

lack of ACP even in those likely to die within a year (Mudge et al., 2018). In Australia, 41.5% of deaths in the 'very old' occur in hospital and 50.1% in RACFs. Approximately 30% of deaths in hospital in the 'very old' had used RACF services in the previous month. Only one person in six who died in a RACF received palliative care medicines or a visit by a palliative care specialist (AIHW, 2021c). Males in this age group are more likely to die in hospital than a RACF (47.6:42.1%), whereas the reverse is true for females (37.1:55.8%) (ABS, 2021).

Despite a multitude of data regarding numbers, causes and locations of death of the 'very old' there is a paucity of literature regarding what care 'very old' people would or would not want at their expected and imminent end of life.

This study was undertaken to understand from a large cohort of 'very old' people what they would want for their end-of-life care and what they currently receive which may inform and influence future provision of care in the environment of the person's choice, reduction in unwanted transfers to hospital and treatments that negatively impact quality of life and support dying without added distress burden to the person, their family, health care teams and systems.

1.3 Aims and Objectives of the research

This research aimed to understand the end-of-life preferences of people aged 85 years or above, as determined in advance by themselves or their significant others, for a time when they were unable to speak or decide for themselves. It also aimed to understand the POD and health system utilisation in the last six months of life of a large decedent cohort, with and without ACP documentation.

The principal objectives of this research project were to determine:

- the end-of-life preferences of people aged 85 years or above, including preferences for CPR, other LPTs and preferred POD
- how people aged 85 years or older were currently utilising hospitals in their last six months of life, including where they died
- if preferences and hospital use differed for those requiring support with decision making
- if preferences regarding POD influenced actual POD.

Generalising the preferences of any group of people risks the loss of individualisation but establishes an opportunity to understand the views of a subset of the population, which may differ from the predominant perspective of an entire population. 'Very old' people are deserving of quality health care, however, if this care is being provided from a framework devoid of the person, their quality of life and their preferences, health professionals need to recognise this, comfortably discuss dying and only offer health care that is both appropriate and welcome.

1.4 Thesis structure

This thesis is comprised of six chapters.

Chapter One: Introduction (this chapter) presents an introduction, background and rationale of the research topic and an overview of the research undertaken. It outlines the objectives of this research project and provides an outline of the format of this thesis.

Chapter Two: Scoping review of the Literature provides an overview of current literature and understanding of this topic.

Chapter Three: Methods explains the methodology used for data collection and analyses. Ethics approvals and consents are also explained.

Chapter Four: Results provides summary and statistical outputs of analyses of data of three cohorts and includes statistical significance or descriptive analyses, as appropriate.

Chapter Five: Discussion provides interpretations and explanations of results and compares them with current literature. It also identifies limitations of the research.

Chapter Six: Conclusion and Recommendations provides a summary of the research and recommendations for future research in this area.

Understanding values-based and health-based preferences for care is the central tenement of ACP. Legally-binding documents, available in many Australian states and territories (Advance Care Planning Australia, 2021), provide direction for health care and/or legal-appointment of a health decision maker. Some states have a non-binding advance care plan, to provide information on values and/or preferences for care and outcomes to help guide alternate health decision makers, both medical and family, with decisions when needed. With a decline in cognitive function, options for documentation and decision making are reduced. In Queensland, a non-binding values-based ACP document, the Statement of Choices (SoC) has been developed to capture the wishes of people with capacity (Form A) as well as the known wishes of a person with impaired decision-making capacity (Form B), to be completed by their previously nominated health attorney or their closest relative (preferably spouse or adult child) who has the person's best interest in mind.

Advance care planning is governed by state legislations, so there is no national approach to ACP despite efforts to improve this (Australian Government, 2021). Further details on ACP and decision-making in Queensland are available in Appendix 1.

Chapter 2 Review of the Literature

2.1 Background

While interventions including CPR, intubation and ventilation, chemotherapy and dialysis have increased longevity, many of these interventions have been considered burdensome with limited benefit and high mortality rates for people of advanced age (Ehlenbach et al., 2009; Lannon & O'Keeffe, 2010; Salluh et al., 2015; Vargas et al., 2017).

International studies report people over 80 years are not dying well (Earle et al., 2004; Mitchell et al., 2009; Somogyi-Zalud et al., 2002; Tamura, 2009), with many dying in hospital, some on ventilator support in their final (terminal) admission (Tamura, 2009), others in severe pain in their last three days of life (Somogyi-Zalud et al., 2000), receiving chemotherapy in their last 14 days of life (Earle et al., 2004) and nursing home residents with advanced dementia receiving artificial feeding in their last three months of life (Mitchell et al., 2009).

Location of death has changed over the past 20 years with a decrease in community deaths, a doubling of deaths in hospital and tripling of deaths in care homes in those aged over 85 years (Ahmad & O'Mahony, 2005). Internationally, however there are variations: for example 66% of people aged over 80 years die at home in Botswana (Lazenby & Olshvevski, 2012), 52% of people aged over 85 years die in hospital in the UK (Public Health England, 2010) and 58% of people aged over 95 years die in care homes in the US (Gruneir et al., 2007). A study of centenarians found only 50% died in their usual place of residence (Evans et al., 2014).

The non-beneficence and poor outcomes of invasive treatments in conjunction with the discordance between preferred and actual POD has prompted the implementation of ACP to capture individuals' future health

care wishes. Literature regarding ACP in people over 65 years is increasing and evident in every inhabited continent including Australia (Corke, 2015; Detering et al., 2010).

Advance care planning involves considering, discussing and documenting future health care preferences to ensure medical and lay decision-makers determine goals and delivery of care aligned to the person's preferences. Advance care planning may include quality of life statements; preferred and unacceptable end-of-life (EOL) care, including treatments and/or location of care; and physical, spiritual and cultural aspects of EOL care. Do-not-resuscitate orders may be considered ACP, whether completed by doctors in isolation or in consultation with the person and their family. Most developed countries have formal and informal ACP processes where formal documents appoint a decision-maker and/or provide pre-consent to accept or forgo treatments and informal ACP may include values-based discussions or documentation.

Preferences for future care are as unique as individuals themselves but research reveals factors influencing the EOL preferences of older people include age, marital status, religion and culture (Ohr et al., 2017), cost, chance of survival (Chao et al., 2008), an honest discussion of treatments and expected outcomes (Vargas et al., 2017), impact of disease, past experiences and the presence of carers (Cohen-Mansfield et al., 1992).

Multiple studies indicate most people over 65 years prefer a focus on comfort rather than intervention at their end of life (Fried & Gillick, 1994; Kellogg et al., 1992; Messinger-Rapport & Kamel, 2005; Vargas et al., 2017). Patients would prefer to die than be in a coma (>70%), ventilated (>60%), with a feeding tube (>50%), in pain (>40%), confused (>30%) or in a RACF (>20%) (Somogyi-Zalud et al., 2000). These findings, along with increasing legalisation of euthanasia and older person suicides, raise the question whether quantity or quality of life is more important.

Despite knowledge of improved EOL care secondary to documented care preferences, ACP document completion rate is low and often completed close to death (De Gendt et al., 2013; Jeznach et al., 2015). As acutely ill 'very old' people are often unable to express their EOL preferences (Vargas et al., 2017), the knowledge of an older person's preference in advance may guide the provision of quality, person-centred EOL care.

2.2 Objective

The objective of this review was to scope the quantity and breadth of literature for EOL preferences in people aged over 85 years. As the fastest growing demographic with the greatest probability for death, researching and understanding the care preferences of the 'very old' has the potential to improve an individual's EOL care, impact on their bereaved and improve health system functioning.

2.3 Methods

This scoping review used established medical databases to explore end-of-life preferences of people aged over 85 years. The search was limited to peer-reviewed publications, available online, written in English until 2019. Databases searched include Medline (via Ovid SP), Cinahl (via Ebscohost) and Up to Date.

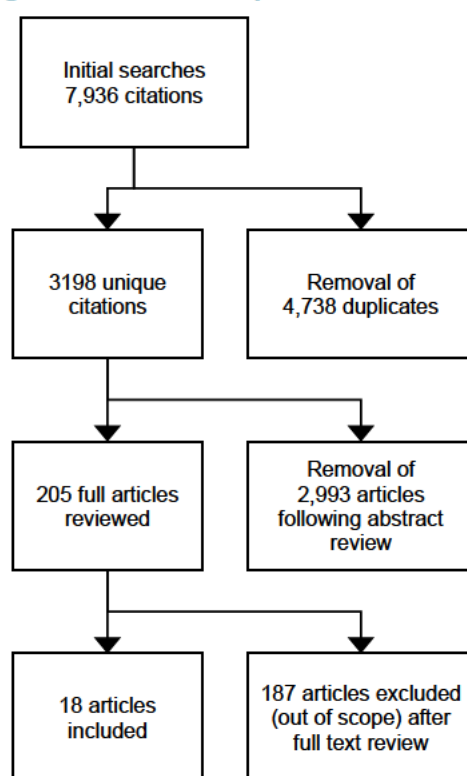
Search parameters included "end-of-life" or "future", and "preferences" or "planning", and "health" or "medical", and "very old", "oldest old", or "over 85 years". Scoping reviews are intended to be a broad overview of literature available on the particular area of interest and do not determine the quality of research or findings. They identify gaps in existing research and opportunities for further research (University of York, 2009). Independent reviews of abstracts and articles were conducted by the Masters' student in completion of this scoping review. Potential personal biases exist with this single reviewer approach but this is one limitation of scoping literature reviews (Arksey & O'Malley, 2005). Full articles were included if they were written in English and included the EOL preferences

of people aged over 85 years (either as a full cohort or subset; using median or mean age or population cohort). Where a mean or median age of over 85 years was used, it is acknowledged this cohort may have contained some members less than 85 years.

2.4 Results

A total of 7936 articles were found. Following removal of 4738 duplicates or triplicates, 2993 articles were removed if their abstracts indicated they did not meet the criteria (e.g. mean age too low). Review of the remaining full articles resulted in inclusion of 18 articles. Figure 1 provides information on the selection process used for inclusion of articles.

Figure 1: Flow diagram of selection process of literature



Due to the increased prevalence of frailty and cognitive issues within this demographic, much research occurred in nursing homes or other care settings, including hospitals and some articles included the preferences from another's perspective – either from post-death audits, interviews with family members or interviews with staff.

Four papers provided perspectives from health care professionals (Abarshi et al., 2010; De Gendt et al., 2013; Gillick et al., 1993; Pivodic et al., 2018) and four involved surveys of proxy carers or family members, because the person had died or had a cognitive impairment (Albert et al., 2016; Bollig et al., 2016; Fleming et al., 2016; Jeznach et al., 2015).

Seven publications were from the USA (Albert et al., 2016; Fried & Gillick, 1994; Gardner & Kramer, 2010; Gillick et al., 1993; Nahm & Resnick, 2001; Somogyi-Zalud et al., 2000; Wu et al., 2008), four from Europe (Abarshi et al., 2010; Bollig et al., 2016; De Gendt et al., 2013; Pivodic et al., 2018), three from the UK (Fleming et al., 2016; Goodman et al., 2013; Hunt et al., 2014), two from Canada (Chochinov et al., 2016; Jeznach et al., 2015) and one each from Japan (Komatsu et al., 2018), Singapore (Ng et al., 2016) and New Zealand (Gott et al., 2017). There were no papers found from Australia, South America or Africa with a 'very old' cohort (ie mean or median age of 85 years or above) identified.

Four papers involved residents of nursing or care homes (Bollig et al., 2016; De Gendt et al., 2013; Goodman et al., 2013; Ng et al., 2016), two specifically related to hospitalised patients (Gillick et al., 1993; Somogyi-Zalud et al., 2000), and the remainder were for individuals living in the community or across a variety of care environments. Sample sizes ranged from 10 for semi-structured interviews (Gardner & Kramer, 2010), to 400 for structured interviews (Gott et al., 2017), to over a thousand for retrospective chart reviews (Albert et al., 2016).

Not surprisingly, females accounted for a greater proportion of participants in all but one study (Gardner & Kramer, 2010) reflecting the predominance of females in the over 85-year-old population, and many were widowed. Proxies were predominantly adult children, and these were also predominantly female (Albert et al., 2016; Bollig et al., 2016; Fleming et al., 2016; Jeznach et al., 2015).

Preferences regarding CPR and/or other life-prolonging interventions were noted in six qualitative reviews (Albert et al., 2016; Bollig et al., 2016; Goodman et al., 2013; Hunt et al., 2014; Nahm & Resnick, 2001; Ng et al., 2016), all post-death chart reviews (De Gendt et al., 2013; Jeznach et al., 2015; Pivodic et al., 2018; Somogyi-Zalud et al., 2000) and discussed in broad terms in all interviews. Preferences of location of death were noted in five studies (Abarshi et al., 2010; Fleming et al., 2016; Gardner & Kramer, 2010; Hunt et al., 2014; Ng et al., 2016). Preferences for non-medical care in the dying process were recorded in seven articles (Bollig et al., 2016; Chochinov et al., 2016; Fleming et al., 2016; Gardner & Kramer, 2010; Goodman et al., 2013; Gott et al., 2017; Komatsu et al., 2018).

Quantitative reviews revealed preferences for CPR ranged from less than 7% (Ng et al., 2016) to nearly 40% (De Gendt et al., 2013). Other LPT preferences such as ventilation ranged from 6% (Ng et al., 2016) to 25% (Nahm & Resnick, 2001). Older people who preferred to receive CPR were most consistently male (Albert et al., 2016; Gott et al., 2017), married and living in their own home (Hunt et al., 2014), African American (Albert et al., 2016) or non-Caucasian (Gott et al., 2017; Ng et al., 2016), Protestant or Catholic and independent with activities of daily living (Albert et al., 2016; Bollig et al., 2016; Ng et al., 2016).

Preferred POD varied. In one study of community-dwelling 'very old', home was the preference in 82% of responses (Hunt et al., 2014). In nursing home residents, the preference for death in the nursing home was reported at 77% (Ng et al., 2016). This may have been influenced by included cohorts and available services. Preferred POD was influenced by gender, religion, current residence and current functional ability (Abarshi et al., 2010; Hunt et al., 2014; Ng et al., 2016). Buddhists and Taos, for example, have beliefs about joining their ancestors if they die at home (Ng et al., 2016).

Non-medical preferences for EOL care included not burdening family, having religious and cultural wishes respected, having everything (e.g. will or funeral) sorted, enjoying little things every day (like flowers blooming), being seen, heard and respected and not dying alone (Bollig et al., 2016; Fleming et al., 2016; Goodman et al., 2013; Komatsu et al., 2018).

The few papers that covered cognitively intact 'very old' people had some insightful, although not surprising, findings. The 'very old' accepted (their) imminent death, wanted to focus on living each day, hoped for a peaceful death, and did not want interventions or transfers. They wanted to be in safe and familiar surroundings, surrounded by the people (both paid and unpaid) who knew them best (Chochinov et al., 2016; Gardner & Kramer, 2010; Komatsu et al., 2018; Nahm & Resnick, 2001; Ng et al., 2016).

A life-threatening situation was viewed as potentially threatening to quality-of-life (Fleming et al., 2016) where the loss of function (e.g. becoming a 'vegetable') was more concerning than the loss of life. Some acknowledged doctors could keep extending life for years (Komatsu et al., 2018), but most did not want this for themselves, expressing "doctors have kept me alive too long already", with a few desiring euthanasia (De Gendt et al., 2013), even where illegal (Fleming et al., 2016). A number mentioned they wanted to have company, or their hand held by family when dying (Bollig et al., 2016; Komatsu et al., 2018).

While not focused on or concerned about death (Komatsu et al., 2018), many were tired of waiting for "it". Most saw death as a release from their current hopelessness or sense of burden on others (Fleming et al., 2016; Gott et al., 2017). Most wanted a peaceful, painless, "natural" death in their sleep (Bollig et al., 2016; Fleming et al., 2016; Gott et al., 2017; Jeznach et al., 2015), in their current residence (Ng et al., 2016), not hospital. Many were fatalistic about death, or trusting that God had a plan (Gott et al., 2017; Komatsu et al., 2018).

Their greatest fear was suffering or pain (Bollig et al., 2016; Gardner & Kramer, 2010), their greatest concern was for those left behind (Komatsu et al., 2018) and their most recurring request (70-100%) was for comfort over prolongation of life.

Some had very concrete wishes related to refusal of treatment, as the outcome of living “more than half dead” would be inhumane (Bollig et al., 2016). Despite this, these ‘very old’ saw little point in documenting preferences at this late stage (over 95 years) trusting their family knew their wishes (Bollig et al., 2016), even though they had not been discussed. They acknowledged either a doctor or family member would be required to make decisions on their behalf (Bollig et al., 2016; Gott et al., 2017; Vargas et al., 2017) but hoped it wouldn’t be required (Bollig et al., 2016). Some thought only doctors would make decisions regarding the withdrawal of treatment (Bollig et al., 2016; Vargas et al., 2017).

Proxies were more likely to over-report symptom burden, based on their observations and knowledge of the person, and under-prefer medical interventions (Albert et al., 2016; Fleming et al., 2016), however they were often representing older patients with dementia or severe functional impairment. Most proxies did not want hospital transfers (Albert et al., 2016), preferred that the person died in a facility providing wholistic care (Abarshi et al., 2010; Albert et al., 2016; Bollig et al., 2016), rather than a hospital, but few chose home. Their highest preference was for no pain, only comfort (Albert et al., 2016; Bollig et al., 2016; Gardner & Kramer, 2010; Gott et al., 2017). They did not want life-sustaining measures and would abhor seeing their relative completely dependent on others for daily tasks (Albert et al., 2016). They were concerned about making decisions – hoping they wouldn’t be asked to make a difficult decision (Bollig et al., 2016). Relatives expressed a desire to be heard and for shared decision making (with a doctor) (Bollig et al., 2016). Proxies were concerned for themselves if they did, or were perceived as doing, anything to assist dying (Albert et al., 2016).

The presence of formal advance directives ranged from 0% to 50% (Albert et al., 2016; Bollig et al., 2016; Hunt et al., 2014; Jeznach et al., 2015). Preferences were less likely to change if the original decision was to decline treatment and if preferences were formalised. Where preferences changed, they were towards less intervention, and occurred over time (with the person getting older) and after hospitalisation.

Health care professionals had very strong opinions about interventions they would accept for themselves when older, especially if they were functionally dependent on others (Abarshi et al., 2010; De Gendt et al., 2013; Gillick et al., 1993; Pivodic et al., 2018). They recognised their patients had not always died well, or in line with their preferences, and commented that quality EOL care, including palliative care, and the honouring of preferences was more likely to occur in people who were well known to them and when care preferences were documented.

Where there had been good communication between patients and their families, there seemed to be better communication between families and clinicians with an increased concordance of EOL preferences (Albert et al., 2016; Gardner & Kramer, 2010; Jeznach et al., 2015).

2.5 Discussion

The purpose of this review was to explore the available knowledge of EOL preferences of the 'very old' to inform person-centred, EOL care in accordance with their wishes. Considering the current and projected population of people living past 85 years, increased likelihood of death in this demographic, and a growing interest in ACP worldwide, there is a surprising paucity of literature of the EOL preferences of this cohort. The absence of literature in Australia is noteworthy. Where literature does exist, numbers of living and cognitively intact participants are low.

The well-researched areas of EOL care preferences of those aged over 65 years suggest a preference for medical care only if it allowed for good

quality of living and this has been echoed in these few studies. High-quality studies were excluded from this scoping review due to low mean age of participants (<85 years), or no mean age documented.

Choice, especially when dependent on others, was important to individuals in this age group, whether in small decisions (what to wear or where to sit), or larger ones (such as euthanasia even though illegal in most countries represented). However, there was an absence of literature related to suicide and euthanasia for this demographic.

Papers reflected the medical and non-medical preferences for care, suggesting these aspects are closely linked and important considerations for further ACP and EOL care research, particularly in countries not reflected in this scoping review, including Australia. Policies in aged care and medical care are increasingly identifying the need for consultation with the patient, in order to centralise the person's voice in care planning.

This review has identified gaps in the available literature, and despite the restricted numbers of articles, there has been no discussion or evaluation of methodology, potential biases, data collection or synthesis of results: another limitation of scoping reviews (Arksey & O'Malley, 2005).

2.6 Conclusion

Despite the inevitability of death, especially in the 'very old', there is a paucity of literature on the EOL preferences of this expanding demographic. Given the implications on demand of scarce healthcare resources, based on population expansion, disease burden, and care needs increasing towards end of life, further research is needed to understand a person's medical and non-medical wishes to optimise delivery of high-value health care that is both fiscally and morally responsible. Discussing, understanding and documenting an individual's unique values, preferred medical treatments, preferred location of EOL care and death may help when difficult decisions are required and may

allow for death to occur as the older person wants. There is a need to understand the medical and non-medical preferences of Australia's 'very old' so that quality EOL care delivery is centred around the unique preference of the person dying and those nearest to them.

3.1 *Introduction*

The aim of this research was to explore the end-of-life preferences of a cohort of people aged greater than or equal to 85 years and, in parallel, what care was provided for people in this age group in their final six months of life, using an exploratory, retrospective cohort design. Given the paucity of literature on this topic, it is hoped this novel and large-scale research project will provide valuable insight into the preferences of the 'very old' and provide information to family members and clinicians involved in the care of the 'very old'.

Each person is unique with an equally unique set of health conditions and health care preferences. This research did not look at these unique preferences, but rather aggregated responses and outcomes to provide a general understanding of what 'very old' people want and receive.

3.2 *Ethics*

Ethics approval was granted by Metro South Health Ethics Committee for compilation of a database of end-of-life preferences (Appendix 2). The Statement of Choices document required signing by the person, or an individual who completed the form on their behalf, and included consent for the person's deidentified data to be used for research purposes.

A protocol amendment, including a waiver of consent, was approved by the Ethics Committee (Appendix 2) to access deidentified decedent data. The waiver of consent was requested given obtaining consent from a deceased person is impossible and obtaining consent from a bereaved family member could, unnecessarily, cause suspicion or concern regarding the death and add distress in their bereavement. A Public Health Act application was required to access deidentified data regarding

deaths from Queensland Registry of Births, Deaths and Marriages (QBDM) and Queensland Health Admitted Patient Data (QHAPDC).

Ethics approval was not required from the University of Sydney Ethics, due to data storage on Queensland Health servers. The Masters student had previously completed Good Clinical Practice modules and had a solid understanding of ethical requirements of research.

3.3 Data collection

Deidentified data were obtained from the Office of ACP, Queensland Health, for people with a completed Statement of Choices, who were 85 years or more at the time of completion and who resided in one of five hospital and health service districts in the south-east corner of Queensland. Data from both SoC forms were utilised and details of data collected are included in Table 1.

Table 1: Description and classification of data items collected from SoC

Data item	Description and classification
SoC Form Type	Form A or Form B
Age at completion	Difference in age between date of birth and date the doctor signed the form - in years, to one decimal place
Location of completion	<ul style="list-style-type: none"> • RACF: if known to be a resident of a RACF • Hospital: if known to be an inpatient at the time or signed by a hospital doctor and not known to be an RACF resident • GP: if signed by a GP and not known to be a RACF resident or an inpatient at the time of signing
HHS of completion	Based on the person's residential postcode within <ul style="list-style-type: none"> • Gold Coast Hospital and Health Service (GCHHS) • Metro North Hospital and Health Service (MNHHS)

Data item	Description and classification
	<ul style="list-style-type: none"> • Metro South Hospital and Health Service (MSHHS) • Sunshine Coast Hospital and Health Service (SCHHS) • West Moreton Hospital and Health Service (WMHHS)
Documented preferences for CPR as per SoC (Appendix 3)	<ul style="list-style-type: none"> • I/the person would wish CPR attempted if it is consistent with good medical practice (classified as Yes) • I/the person would not wish for CPR to be attempted under any circumstances (classified as No) • Other (with space to provide comments)
Documented preferences for LPT as per SoC (Appendix 3)	<ul style="list-style-type: none"> • I/The person would wish for other LPT if consistent with good medical practice (Yes) • I/The person would not wish for other LPTs under any circumstances (No) • Other (with space to provide comments)
Documented preference regarding preferred POD as per SoC (Appendix 3)	<p>Free text box following “Indicate the place you/the person would prefer to die (e.g. home, hospital, nursing home)”, classified by:</p> <ul style="list-style-type: none"> • Home • Hospital • RACF (if “nursing home”, “RACF” or specific RACF name) • Other “Home or hospital”; “Home or RACF” • Undecided / “I don’t know”

Age at completion was bracketed into four groups prior to categorical analysis. These were 85-<90 years, 90-<95 years, 95-<100 years and ≥100 years. Despite a few people having a document completed when they were 107 years old, these brackets were classified as ‘five-year age brackets’ or ‘age brackets’ throughout the thesis.

The second part of the research involved exploring the care that was received by people across the five regions in the final six months of life

utilising hospital admission data obtained by Statistical Services Branch (SSB), and data obtained from QBDM regarding date and POD.

The hospital name and corresponding unique reference numbers of people who had a completed SoC were provided to the SSB in a password-protected spreadsheet to allow them to obtain hospital utilisation and death data. Data for POD and hospital utilisation were obtained from a control group of decedents, matched two-for-one for age (rounded to whole number) at death, HHS, year of death and last known ICD code. Data were returned using a randomly generated study number for all decedents. No identifying information was provided with either the SoC group or the matched control group. Decedent data collected are outlined in Table 2.

Table 2: Description and classification of data items collected for decedents

Data item	Description and classification
Date of death	February 2015 - October 2019
Place of death	<ul style="list-style-type: none"> • Hospital (Public or Private) • Other
HHS of death	<ul style="list-style-type: none"> • GCHHS • MNHHS • MSHHS • SCHHS • WMHHS
Age at death	Age in whole years (i.e. no decimal places)

Age at death was bracketed into four groups prior to categorical analysis. These were 85-<90 years, 90-<95 years, 95-<100 years and ≥ 100 years. As above, these were classified as “five-year age brackets” despite the ≥ 100 years bracket including a few who died aged 105 years or older.

It is important to note that there was a considerable delay in death data being registered and available from QBDM, hence the final date of death

available was 31/10/2019. Place of death defined as “Other” includes deaths out of hospital (e.g. home or RACF) but does not include hospices run by the public hospital system (these were classified as “Public Hospital”).

Hospital admission data were collected from QHAPDC for the period February 2015 to October 2019. Details of data collected are depicted in Table 3.

Table 3: Description and classification of data items collected regarding admissions

Data item	Description and classification
Number of admissions	This included both overnight stays and day therapy admissions. Measured as whole number of admissions.
Cumulative length of stay (LOS)	A sum of length of stay from all admissions, including same day admissions (one day) in last six months of life. Measured as number of whole days in hospital.
Length of stay in intensive care unit (ICU)	A sum of all ICU hours from all admissions in the last six months of life. Measured in hours to two decimal places.

Hospital data collection commenced February 2015, so deaths that occurred before August 2015 were excluded from admissions, LOS and ICU use analyses due to incomplete data for the entire six-month period. This impacted the two-to-one ratio of controls to people with a SoC in this research, however POD was analysed for all 5890 decedents.

Age at death data were provided as a whole year integer so people who died at “85 years” included some with hospital admissions between 84.5 and 85 years of age. These data were still evaluated as (i) these specific

individuals cannot be identified and (ii) the impact of this six months age difference of a few is likely to be minimal in the large dataset.

Days before death of an ICU admission were calculated as the difference between the date of death and the mid date of an admission involving ICU, as exact ICU use dates were not known (i.e. if admission occurred between 1st-15th April, ICU-to-death date was the number of days between date of death and this arbitrarily chosen mid date, 8th of April).

A subset of these decedents also had a SoC, so comparisons of hospital utilisation were made between SoC types and preferred and actual POD. Where there was an ICU admission, the person's corresponding documented preference regarding other LPTs was also analysed. It is acknowledged that ICU does not encapsulate all other LPTs so results will indicate an under-representation of those receiving other LPTs such as dialysis, Bilevel Positive Airway Pressure (BiPAP), non-invasive ventilation (NIV), feeding tubes etc.

The months before death that a SoC was completed were calculated and utilised as a confounding variable in the abovementioned comparisons, recognising a SoC completed less than a month before death has not influenced treatment decisions for the entirety of the last six months of life (i.e. before there was a completed document). Where possible and where results from categorical analyses revealed frequencies less than five, a more detailed descriptive analysis was performed, to understand and rationalise decisions e.g. ICU utilisation. There was no risk to identifying patients as data were deidentified and location was not used in this analysis.

3.4 Data management and analysis

Data were cleaned then aggregated. Deidentified data were stored on password-protected spreadsheets located on a secure government drive. Only Queensland Health staff relevant to this research had data access.

Data collected included a large data set of 9555 people with a SoC and a corresponding dataset of 5890 deaths, of which 2355 had a SoC. The remaining decedents were matched to the SoC decedents as described above. This large sample size could be considered over-powered, so to establish the significance of any differences, it was decided to analyse significance with a level of significance α of 1% in both correlational and regression analyses (Lin et al., 2013). Data were analysed using IBM SPSS Statistics 26 (IBM, 2019) and blank cells were removed from analyses.

Exploratory descriptive statistics, excluding missing values, were used to illustrate the difference in characteristics of people completing a SoC Form A versus those with a SoC Form B completed for them.

Chi-squared analyses were completed for comparisons of categorical fields (e.g. SoC type and preference for CPR/LPT). Integer data were checked for normality using the Kolmogorov-Smirnoff test. General linear models and multinomial regressions were also used to understand the relationship of dependent variables with hypothesised independent variables while controlling for confounders.

Descriptors in “Other” sections of preferences for CPR, LPT and POD were thematically categorised and quoted to provide a more personal insight into what people would like others to know regarding their preferences about CPR, LPTs and their preferred place of death (PPOD).

This chapter reports the analyses of data from 9555 people who had a Statement of Choices (SoC) completed when they were 85 years or older and their preferences for cardio-pulmonary resuscitation (CPR), other life-prolonging treatments (LPTs) and preferred place of death (PPOD). The number of admissions over the final six months of life and associated cumulative length of stay (LOS) and intensive care unit (ICU) hours and actual POD were analysed for 5890 decedents based on their evidence of ACP (i.e. SoC or no SoC). Data from 2335 decedents with a SoC were then analysed for hospital and ICU use, concordance of POD and the impact of time of completion and SoC type (A or B) on these factors.

4.1 Cohort descriptors

The “SoC cohort” included a total of 9555 ‘very old’ people, across five Hospital and Health Services (HHSs) in Queensland. All members had a SoC completed, when they were aged 85 years or above, either by themselves (Form A, N=4051) or by another, if they required support with decision making (Form B, N=5504), during the period from February 2015 to February 2021.

The “Decedent cohort” included a total of 5890 people: 2335 people with a completed SoC and an additional 3555 “controls”, or people without a SoC, all of whom died in Queensland between February 2015 and October 2019.

The “Decedent with SoC cohort” included the 2335 mentioned above who had died with a completed SoC between February 2015 and October 2019. Table 4 outlines the numbers of people included in the SoC (Form A and Form B rows), decedent (deceased column) and decedent with SoC (Form A and B rows AND deceased column) cohorts.

Table 4: Numbers of people included in cohort groups

ACP document type (if any)	LIVING AS AT 31/10/2019	DECEASED BEFORE 31/10/2019
SoC Form A (n=4051)	3124	927
SoC Form B (n=5504)	4096	1408
No SoC (n=3555)		3555

Kolmogorov-Smirnoff tests show age was not normally distributed for any of these subgroups.

4.2 SoC cohort

The 9555 'very old' people in the entire SoC cohort were more likely to be female (65.5%), in the youngest age bracket (85 to <90 years) (49%), people with capacity issues (necessitating another person to complete a SoC (Form B) on their behalf) (57.6%) and living in a RACF (67.6%).

The youngest age bracket (85 to <90 years), representing nearly half (49%) of the entire SoC cohort, had the highest proportion, of all age brackets, of people who were male (38.5%), had decision-making capacity (completing a Form A) (47.1%) and completed their SoC document with their GP (16.6%) from an address that was not a RACF (38.5%).

In comparison, the oldest age bracket (those ≥ 100 years) had the smallest percentage representation (1.7%) and was the age bracket with the highest proportion of people who were female (81.4%), had impaired decision-making capacity resulting in completion of a Form B (69.9%), and had their document completed in the RACF (78.8%) suggesting they were residents of a RACF.

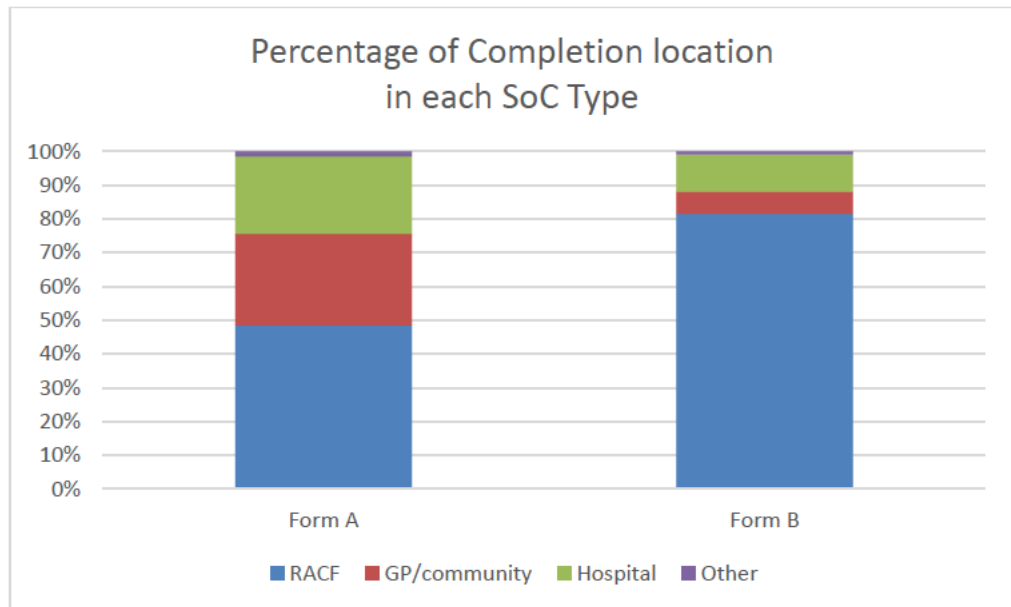
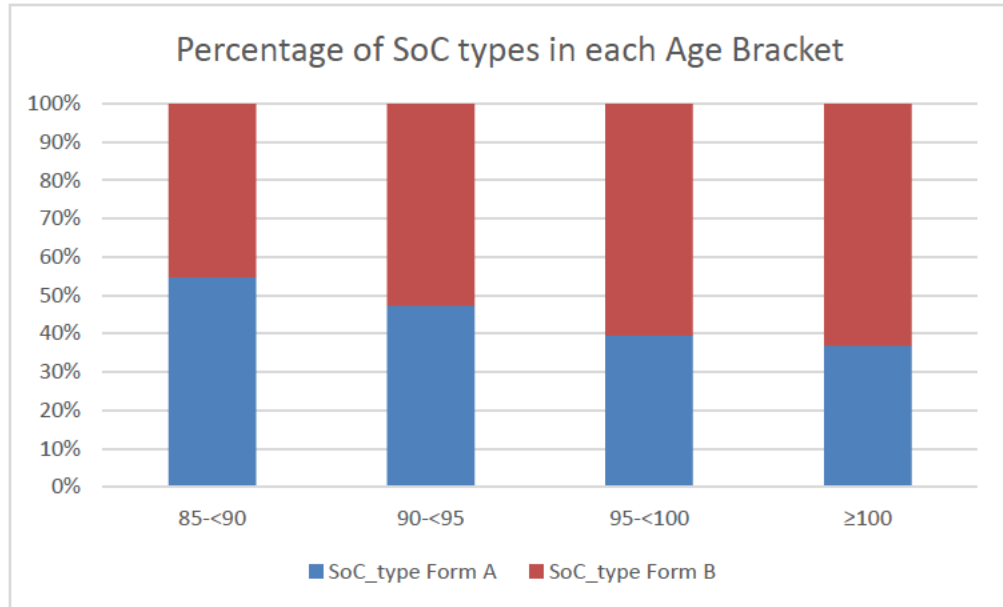
A Mann-Whitney test indicated the age of people with a SoC Form A (median 89.5 years) was significantly different ($p < .001$) to the age of those with a SoC Form B (median age 90.5 years). In addition, they were significantly more likely to be male and living independently, i.e. not in a RACF. Table 5 provides summary descriptive characteristics of those with a completed SoC sorted by different SoC types.

Table 5: Descriptive characteristics of people by SoC document type

Characteristic	SoC Form A n=4051 (%)	SoC Form B n=5504 (%)	Significance n=9555
Median age at completion (years)	89.5	90.5	M-W U = 9742918 $p < .001$
Age range at completion <ul style="list-style-type: none"> • 85-<90 years • 90-<95 years • 95-<100 years • ≥ 100 years 	55.1 34.4 9.4 1.2	45.5 38.2 14.4 2.0	χ^2 (df 3) = 109.8 $p < .001$
Gender <ul style="list-style-type: none"> • Female 	63.3	67.1	χ^2 (df 1) = 14.8 $p < .001$
Location of completion <ul style="list-style-type: none"> • RACF • GP/community • Hospital • Other 	48.4 27.2 23.0 1.4	81.8 6.7 11.0 0.9	χ^2 (df 3) = 1172.2 $p < .001$
HHS of completion <ul style="list-style-type: none"> • GCHHS • MNHHS • MSHHS • SCHHS • WMHHS 	11.9 19.3 52.5 5.9 10.4	18.8 13.0 56.3 6.3 5.7	χ^2 (df 4) = 204.1 $p < .001$

Fifty-five percent of all SoCs were completed in MSHHS. A greater proportion of Form Bs were completed with each increasing age bracket across all HHS (Figure 2(i)). People with a completed Form B were statistically more likely to have completed their document in a RACF, therefore more likely to be residing in a RACF than anywhere else (χ^2 (df 2, N=8813) =1172.2, $p < .001$) (Figure 2(ii)).

Figure 2: (i) Percentage of SoC type completed in each age bracket and (ii) Percentage of completion location per SoC type



4.2.1 Preferences for care

Analyses of the preferences documented on the completed SoCs showed the 'very old' significantly preferred to not receive CPR or other

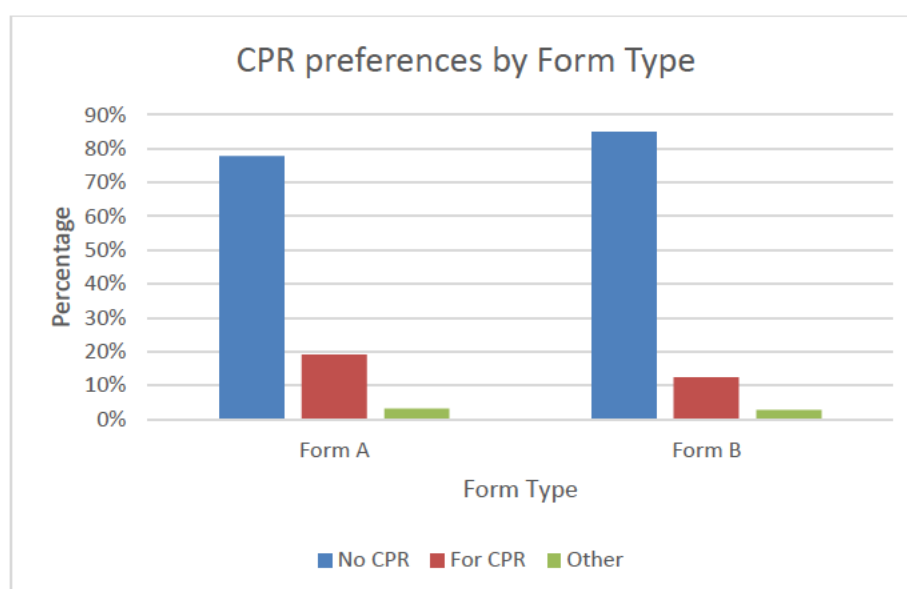
LPTs and to die in their place of residence, irrespective of the SoC Form used.

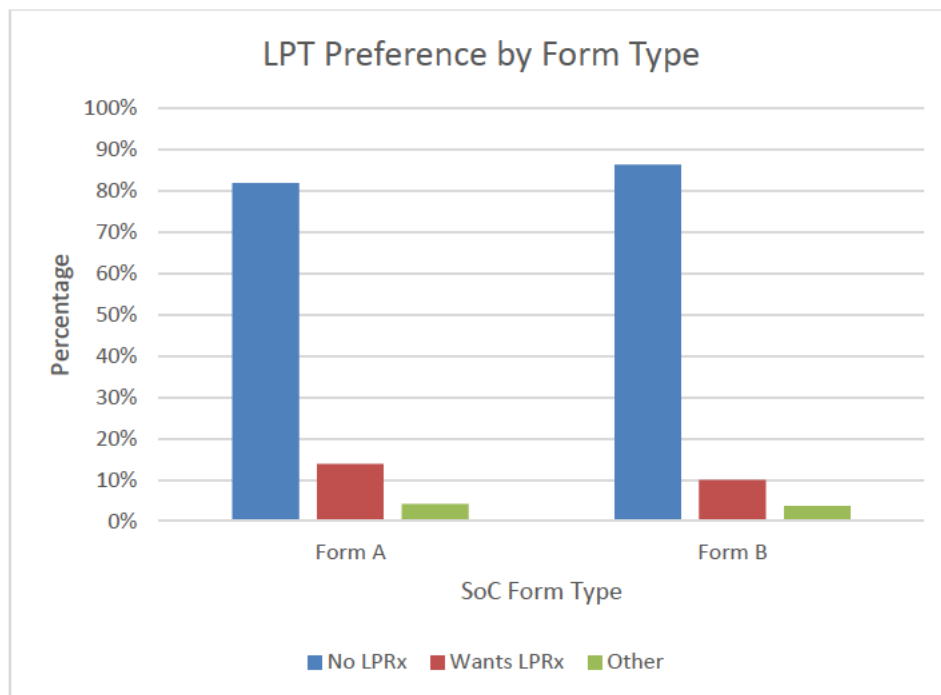
4.2.1.1 CPR and LPT preferences

Of the entire SoC cohort, 81.9% preferred to not receive CPR and 84.5% preferred to not receive LPTs under any circumstance while only 15.2% and 11.6% wished for CPR or LPTs, respectively, if consistent with good medical practice. The remaining 3-4% nominated “Other” as their preference.

The breakdown of CPR and LPT preferences by SoC type is depicted in Figure 3. These graphs demonstrate preferences expressed by either self (Form A) or other (Form B) and show a strong preference to not want to receive CPR or LPTs. Chi-squared analyses demonstrate a significant difference of CPR and LPTs preference within SoC types (CPR: χ^2 (df 2, N=9542) = 85.6, $p < .001$; LPT: (χ^2 (df 2, N=9481) = 36.7, $p < .001$).

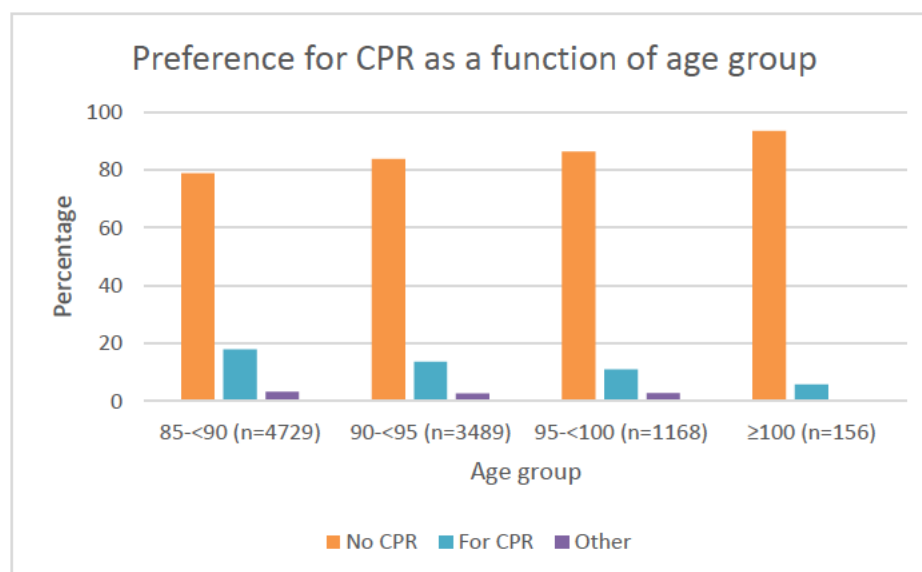
Figure 3: Percentage of (i) CPR and (ii) LPT preferences by SoC type

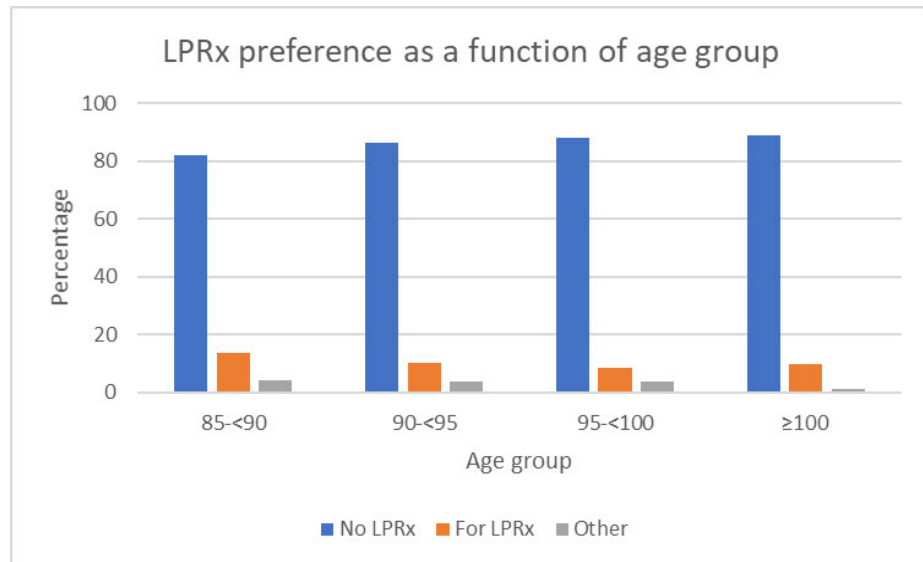




While the youngest age bracket (85 to <90 years) had the highest percentage of those who preferred CPR (17.9%) and LPT (13.7%), the majority of this age bracket had documented preferences to not receive CPR (78.9%) or LPTs (82.1%) under any circumstance. This increased to over 93% and 89% respectively of the oldest age bracket (those ≥ 100 years) (Figure 4).

Figure 4: Percentage of (i) CPR and (ii) LPT preferences across age brackets





Chi-squared tests revealed independent variables of gender, age bracket of completion and known location of completion, including HHS, had statistically significant differences across CPR and LPT preferences ($p < .001$). Table 6 provides a summary of these characteristics and differences.

Table 6: Percentage of Characteristics of people based on their (i) CPR and (ii) LPT preferences

CPR preferences	No CPR n=7815	For CPR n=1452	Other (CPR) n=275	Statistics n=9542
SoC type (%)				
• Form A	77.8	19.1	3.1	χ^2 (df 2) =85.6 $p < .001$
• Form B	84.9	12.4	2.7	
Gender (%)				
• Female	82.8	14	3.1	χ^2 (df 2) = 22.2 $p < .001$
• Male	80.1	17.5	2.4	
Age bracket (%)				
• 85-<90	78.9	17.9	3.2	χ^2 (df 6) = 71.6 $p < .001$
• 90-<95	83.9	13.5	2.6	
• 95-<100	86.5	10.9	2.7	
• ≥ 100	93.6	5.8	0.6	
Median Age (years)	90.2	89.2	89.6	K-W (df 2) = 81.2 $p < .001$
Completion location (%)				
• RACF	81.4	15.7	2.9	χ^2 (df 6) = 268.1 $p < .001$
• Hospital	92.4	5.8	1.9	
• GP	69.3	26.5	4.2	
• Other	90.9	7.1	2	
HHS (%)				
• GCHHS	77.3	20	2.7	χ^2 (df 8) =58.3 $p < .001$
• MNHHS	81.0	15	4	
• MSHHS	83.1	14.4	2.5	
• SCHHS	79.2	16.4	4.4	
• WMHHS	86.7	10.7	2.6	

LPT Preferences	No LPT n=8008	For LPT n=1103	Other (LPT) n=370	Statistics n=9481
SoC type (%) <ul style="list-style-type: none"> Form A Form B 	81.9 86.3	13.9 10	4.2 3.7	χ^2 (df 2) = 36.7 $p < .001$
Gender (%) <ul style="list-style-type: none"> Female Male 	85.6 82.2	10.5 13.9	3.9 3.9	χ^2 (df 2) = 24.7 $p < .001$
Age bracket (%) <ul style="list-style-type: none"> 85-<90 90-<95 95-<100 ≥100 	82.1 86.3 87.9 89.0	13.7 10 8.4 9.7	4.2 3.7 3.6 1.3	χ^2 (df 6) = 47.6 $p < .001$
Median Age (years)	90.2	89.1	89.7	K-W (df 2) = 58.7 $p < .001$
Completion location (%) <ul style="list-style-type: none"> RACF Hospital GP Other 	84.5 91.4 75.4 88.8	12 5.2 18.6 9.2	3.5 3.4 5.9 2	χ^2 (df 6) = 142.8 $p < .001$
HHS (%) <ul style="list-style-type: none"> GCHHS MNHHS MSHHS SCHHS WMHHS 	82.6 83.9 85.1 83.5 86	14.1 11.7 11.4 11 8.8	3.3 4.4 3.6 5.5 5.2	χ^2 (df 8) = 25.0 $p < .01$

Bivariate analyses showed significant differences with each factor contributing independently to CPR or LPT preferences. However, due to strong collinearity between age, gender, completion location and SoC type used, multinomial analyses were required.

Multinomial regressions revealed that the odds of preference for CPR over no CPR were significantly lower (0.788) in females compared to males ($p < .001$, OR 0.670-0.952, CI 99%) and also lower (0.931) with each increasing year of age ($p < .001$, OR 0.911-0.952, CI 99%). In addition, one had significantly reduced odds (0.173) of preferring CPR if their document was completed in a hospital ($p < .001$, OR 0.123-0.242, CI 99%) and similarly (0.713) if completed in a RACF ($p < .001$, OR 0.581-0.874, CI 99%) rather than with the GP but significantly higher odds (1.696) if a Form A was completed ($p < .001$, OR 1.433-2.007, CI 99%).

Similar results were revealed about LPTs. Multinomial regressions showed the odds of choosing LPT over no LPT were significantly reduced (0.735) if the person was female ($p < .001$, OR 0.613-0.881, 99%CI) and also reduced (0.944) with each increasing year of age ($p < .001$, OR 0.921-0.967, 99%CI). Odds were similarly reduced (0.235) if the person's document was completed in a hospital ($p < .01$, OR 0.163-0.339, 99%CI) and also reduced (0.735) if the SoC was completed in a RACF ($p < .001$, OR 0.583-0.928, CI 99%) instead of with the GP but odds increased (1.394) if a Form A was completed ($p < .001$, OR 1.153-1.686, CI 99%) instead of a Form B.

Preferences to not receive CPR changed significantly between 85-<90 and 90-<95 years ($p < .001$) but not significantly after the age of 95 years ($p > 0.05$). However statistically significant differences between preferences to not receive LPTs and age brackets were not detected.

Chi-squared tests of only those who wanted CPR or LPT reveal significant differences between gender and SoC type (CPR: χ^2 (df 1, N=1452) = 19.3, $p < .001$; LPT: χ^2 (df 1, N=1103) = 19.9, $p < .001$).

However, no significant differences were detected between gender and SoC type for those who did not want CPR or LPTs (CPR: χ^2 (df 1, N=7814) = 3.2, p=.72; LPT: χ^2 (df 1, N=8007) = 2.6, p=.108). Given the strong collinearity between gender and age, and SoC type and age, age appeared to be the variable contributing most significantly to a choice to not want CPR or LPTs.

4.2.1.2 Qualitative text

Clarifying or conditional comments were documented for 3-5% of those indicating a preference to receive or refuse CPR and LPTs and 87-94% of those who had nominated "Other", providing necessary clarifications about their conditions.

Comments from those who completed a SoC for themselves (Form A) provided insight into individuals' preferences. A small percentage (3%) of people expressed a preference for extension of existence above all else with words such as "I want life if possible", "do everything possible" and "life is precious". Approximately 16% (16.3%) recognised potential limitations of CPR but would like others to "have a go" or "give it a try" with one person suggesting "only if you are qualified". Over 30% (30.5%) provided complementary conditions starting with "So long as I..." or "Only if I..." and ending with "have good quality of life", "can always clearly communicate", "am in good health prior to my heart stopping", "will not be a burden on my family" or "have a reasonable chance of recovery". The majority (33%), however, provided limiting conditional statements that commenced with "But not if..." and finished with "I have a terminal illness", "I am unlikely to recover", "I am kept alive on machinery", "my illness meant I could no longer be home and independent", "it will prolong dying and cause harm without complimentary benefits", or "my brain is dead". The remaining 17% were clear about no intervention with comments such as "just let me go", "I want to go quickly", "do not undertake CPR if I am at end of life", "just let nature take its course", or "just keep me comfortable".

Comments adjacent to LPT preferences of those with capacity also highlighted the diversity in people's preferences. Opinion was divided, amongst this cohort, regarding specific treatments such as feeding (or nasogastric) tubes, ICU, dialysis and oxygen with similar numbers preferring to receive or refuse each particular intervention. Nearly 20% of those who made a comment specified they wanted "comfort cares" or "to be allowed to die". Life-prolonging treatments were wanted "only for enough time for family to attend", or "only if..." "full cognitive recovery is possible", "quality of life is maintained", "required for my dignity and comfort", "it is a good outcome" or "it will benefit me", but "not if..." "it will just prolong my suffering", "I have lost capacity", or "I am not responding".

Appendix 4 provides details of conditional and clarifying statements regarding CPR and LPTs based on SoC type and CPR or LPT preference. Of note, a number of those who expressed a wish to receive CPR or LPT provided additional clarification suggesting a requirement of a favourable outcome.

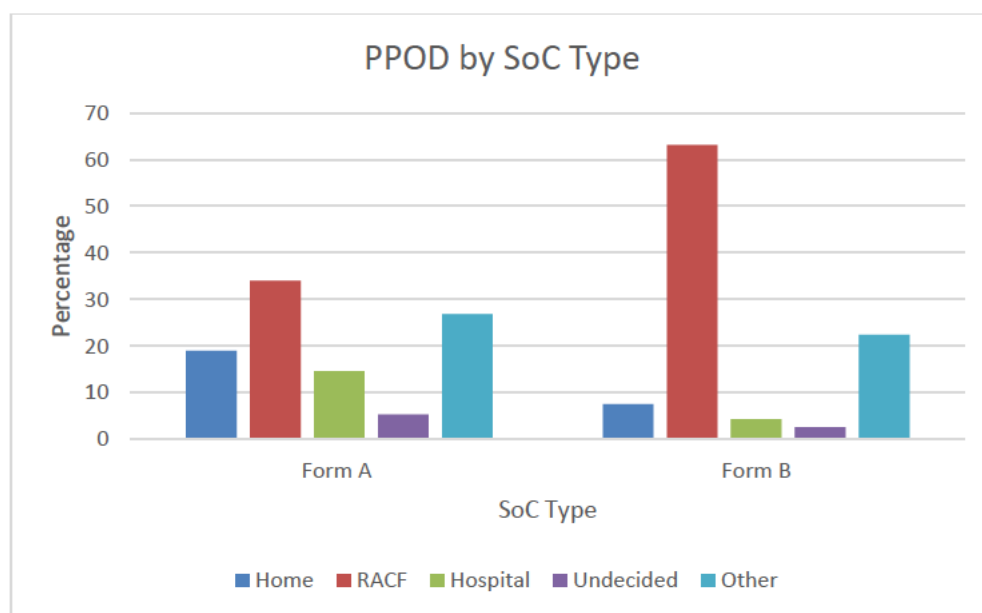
Documented conditional clarifications showed consistent themes which included quality of life, expectation of good outcome or specific details of acceptable treatments.

Comments regarding CPR and other LPTs documented on a Form B (on behalf of the 'very old' person) revealed a similar diversity as those completing a Form A. "Yes (for CPR), if appropriate" or "He has said he wants doctors to give everything a go", with comparable clarifying statements "only if..." "it is within reason", "there is a prospect of reasonable quality of life", "he would be ok afterwards", "there is a reasonable chance of further comfortable living" but "not if..." "it would cause discomfort or distress for them", "outcome would lead to vegetative state", "equipment assistance for life was a permanent outcome" or "she already has a terminal condition, is in a coma or can't communicate with family".

4.2.1.3 Preferences for place of death

Over 50% of people with a SoC had a PPOD documented as RACF. Another 12.5% expressed home as their preference. Less than 9% of people had specified hospital as their sole preference for POD.

Figure 5: Percentage of PPOD by SoC type



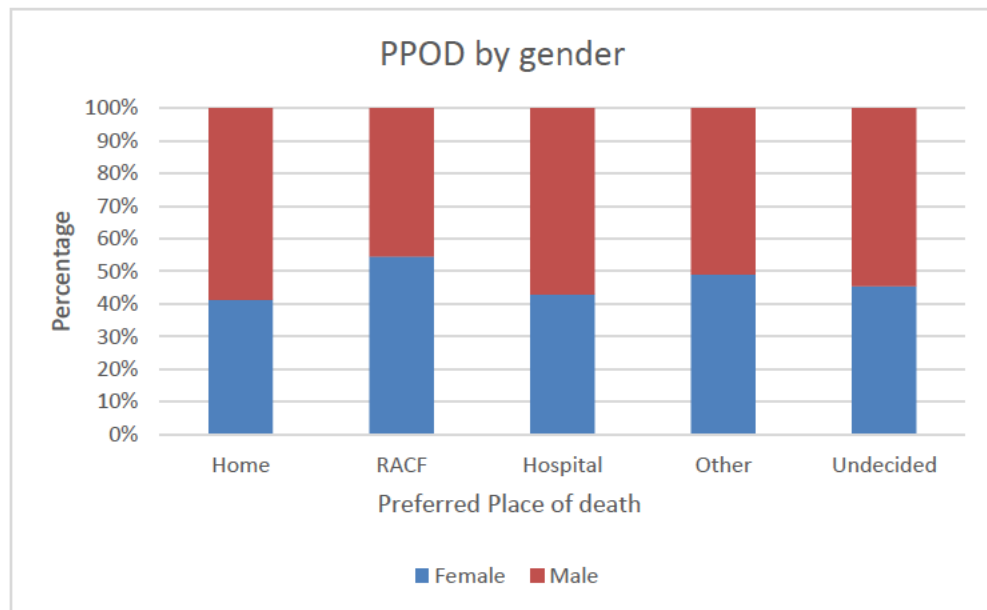
The proportion of people documenting RACF as their PPOD was significantly higher for people with a Form B (Figure 5) and for females, and people with this documented preference also had a significantly higher median age at completion (90.8 years) ($p < .001$). Nearly a quarter of people with a SoC had a preference that included multiple settings (e.g. home or hospital, hospital or RACF) and less than four percent were unsure about where they wanted to die. Table 7 shows a breakdown of characteristics of people for whom a PPOD was documented.

Table 7: Percentage of characteristics for each PPOD

	PPOD home (n=1122)	PPOD RACF (n=4546)	PPOD hospital (n=793)	PPOD undecided (n=335)	PPOD other (>1 option) (n=2190)	Significance n=8986
SoC type (%)						χ^2 (df 4)
• Form A	19	34	14.7	5.3	26.9	= 930.2
• Form B	7.5	63.1	4.4	2.6	22.4	p<.001
Gender (%)						χ^2 (df 4)
• Female	10.9	53.6	7.9	3.5	24	= 83.6
• Male	15.5	44.8	10.5	4.2	25	p<.001
Median Age (years)	89.1	90.8	88.8	89.6	89.7	K-W (df 4) p<.001
Age bracket (%)						
• 85-<90	14.6	44.1	11.2	4	26	χ^2 (df 12)
• 90-<95	11.5	55	6.8	3.3	23.5	= 206.1
• 95-<100	7.1	61.8	5.7	4.1	21.4	p<.001
• ≥100	10.3	66.4	4.8	2.7	15.8	
Completion location (%)						
• RACF	4.8	67.9	4.2	2.3	20.9	χ^2 (df 12)
• Hospital	24.4	21.2	16.7	7.2	30.6	= 2414.1
• GP	33.5	10.3	20.4	5.5	30.2	p<.001
• Other	26.6	25.5	14.9	6.4	26.6	

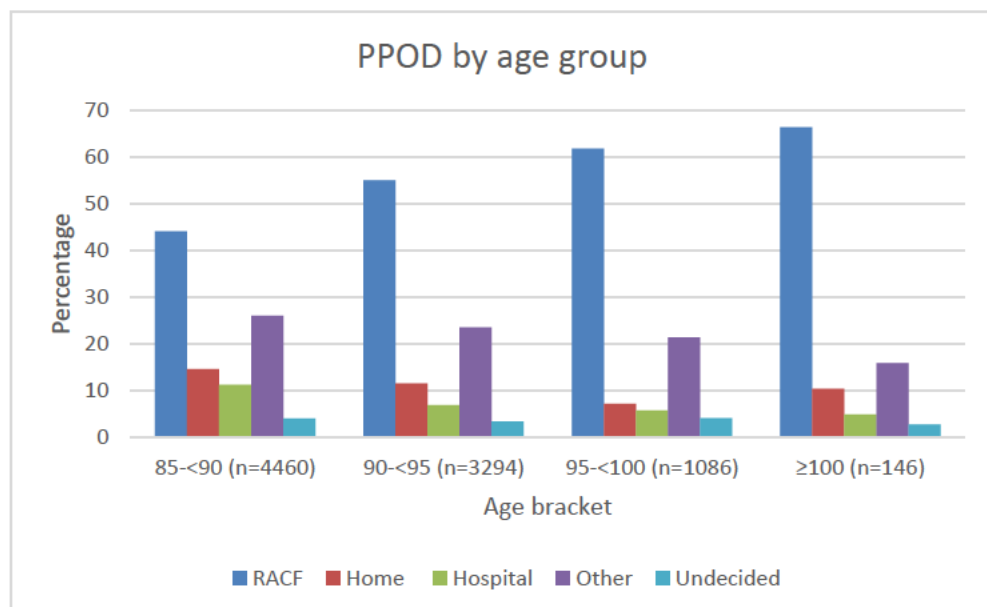
Females were more likely to want to die in a RACF and less likely to want to die either at home or in hospital as per Figure 6.

Figure 6: Proportion of PPOD preference by gender



Nearly 68% of people who were known residents of a RACF had a documented preference to die in their RACF. Those who completed their SoC with a GP had the greatest percentage of people specifying either hospital or home as their PPOD. Preference to die in a RACF increased across ascending age brackets with a corresponding reduction in hospital as documented PPOD. These were both significant to $p < .01$ (Figure 7).

Figure 7: Percentage of each PPOD within age brackets



Of the 2190 who wrote a combination of places that were categorised as “Other”, more than 30% included home as one option, 55% included hospital and nearly 70% included RACF as a possible option. Of note, over 15% mentioned palliative care, or a desire to be comfortable or pain free. Comments reflected a desire for comfort, peace, safety; to be with family or not alone; to die in bed, in room, or at home and many others didn’t mind, recognising it depends on the situation, doctors or others’ ability to manage the increased care needs at end of life. Additional comments around PPOD are outlined in Appendix 5.

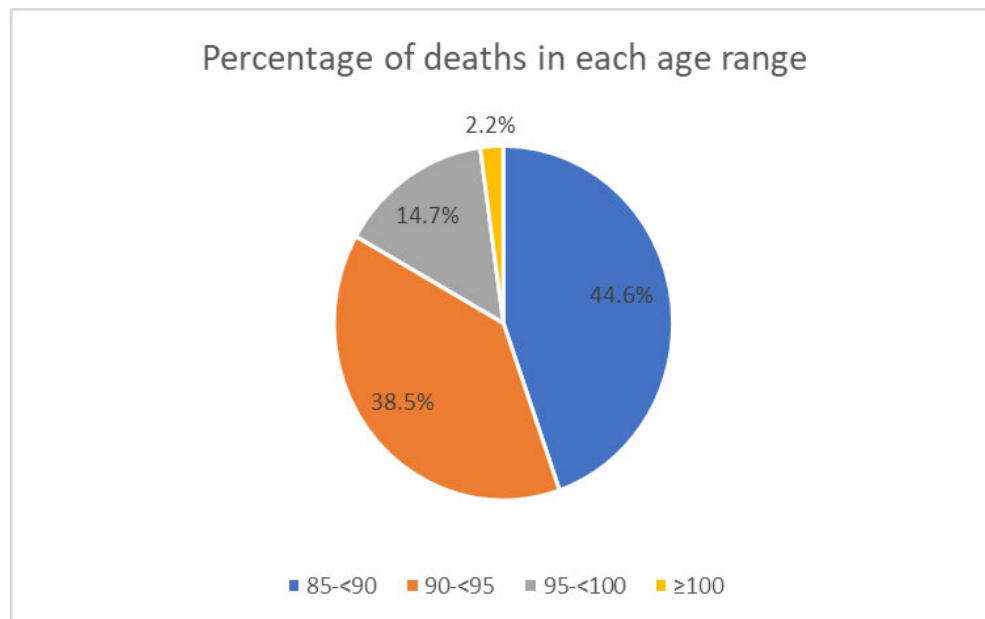
Multinomial regressions revealed males have significantly lower odds (0.672) of a preference to die in a RACF over hospital compared to females ($p < .001$, OR 0.547-0.825, 99%CI) while age bracket at completion did not significantly influence the choice of home over hospital ($p = .087$), despite increasing the odds for preference to all other locations over hospital.

Regression analyses of SoC type and gender on PPOD preferences indicated SoC type impacted PPOD decision for all options over hospital ($p < .01$, OR range from 1.032 to 7.761, 99%CI), with increased odds of preference for a home death or RACF death over a hospital death of 1.339 and 6.227 respectively. Gender significantly impacted the preference for RACF or “Other” as PPOD over hospital with reduced odds for females (0.645 and 0.793) who preferred RACF or ‘other’ as their PPOD. Gender, however, showed no significant change to odds for a home death. General linear multivariate analysis of PPOD using SoC type with age bracket showed both factors continued to hold similar and significant odds ratios (with 99% CI) for all PPOD choices over hospital, with the exception of the preference for a home death over hospital with increasing age brackets ($p = .137$).

4.3 Decedent cohort

A total of 5890 people died in the study cohort across the five Queensland HHS between Feb 2015 and Oct 2019. Two thousand, three hundred and thirty-five people died with a SoC and 3555 died with no SoC. The median age at death was 91 years for females (N=3311) and 89 years for males (N=2579 ($p < .001$)). Median age at death was 91 years for those with a SoC and 90 years for those without a SoC (range for both 85-107 years). An independent samples Kolmogorov-Smirnoff test showed age distribution was not normally distributed and was statistically different, using a Kruskal-Wallis test, between SoC and no SoC ($p < .001$). The number of decedents ranged from 44.6% in the 85 to <90 years age bracket down to 2.2% decedents aged 100 years or more (Figure 8).

Figure 8: Percentage of deaths in each age bracket

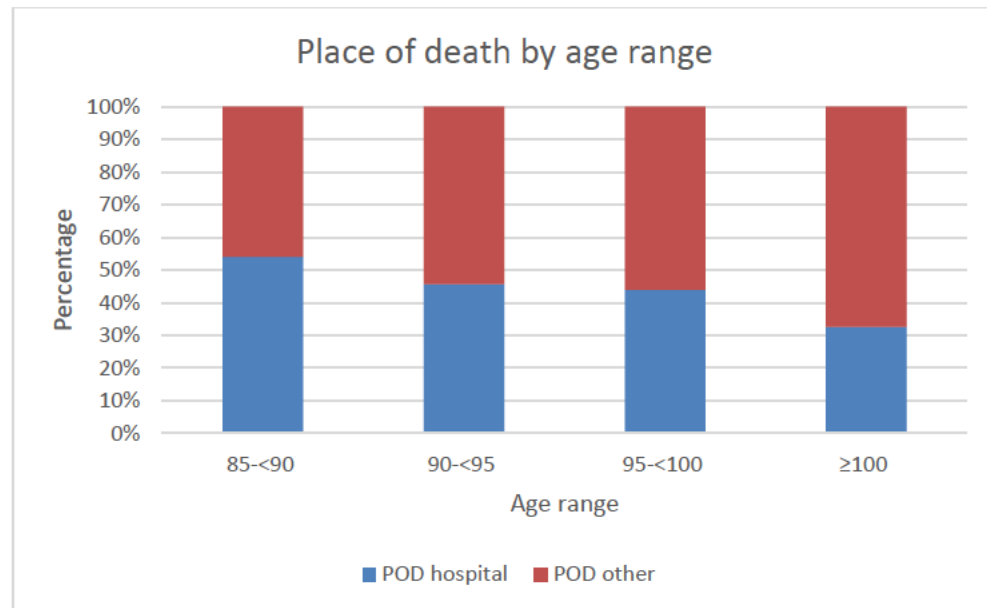


Of these, 2302 decedents with a SoC (98.6%) and 3514 (98.8%) decedents without a SoC had complete data available regarding admissions to hospital in their last six months of life. The remaining 74 decedents (33 and 41 respectively) died between February and August 2015, therefore incomplete hospitalisation data for their last six months of life were available. Place of death, however, was known for all 5890 decedents.

4.3.1 Place of death

The proportion of people in each age bracket who died in hospital decreased from 54.1% of those aged between 85 and <90 years to 45.6%, 43.9% and 32.6% of each successive age bracket (χ^2 (df 3, N=5884) = 60.2, $p < .001$) (Figure 9).

Figure 9: Proportion of each place of death by age range



Chi-squared analysis revealed a statistically significant difference on POD dependent on SoC existence (χ^2 (df 1, N=5890) = 436.2, $p < .001$). Approximately a third (32.1%) of people with a SoC and 59.9% of those without a SoC died in hospital. Males were more likely (54.4%) than females (44.5%) to die in hospital, whether a SoC was completed or not (χ^2 (df 1, N=5890) = 57.1, $p < .001$). The median age of those who died in hospital was one year less than those who died out of hospital (90 compared to 91 years), which was statistically significant (Mann-Whitney U = 3757724.5, $p < .001$). Table 8 reveals the percentage of out of hospital deaths by gender and SoC type.

Table 8: Percentage of “out of hospital” deaths based on gender and SoC completion

Gender	No SoC	With SoC (A or B)	All
Female	43.2%	72.7%	55.5%
Male	36.4%	61.1%	45.6%
All	40.1%	67.9%	N/A

Multinomial regressions analysed in-hospital over out-of-hospital deaths based on age at death, gender and SoC existence and showed all three factors were significant to $p < .001$. As age increased, odds of a hospital death decreased (0.959) significantly ($p < .001$, OR 0.942-0.977, 99%CI), as it did for females (0.715) ($p < .001$, OR 0.619-0.826, 99%CI) however odds of an in-hospital death increased nearly threefold (3.099) for those without a SoC ($p < .001$, OR 2.676-3.589, 99%CI) compared to those with a SoC.

4.3.2 Hospital use

The median number of admissions in the last six months of life was one for those with a SoC and two for people without a SoC. Just over 40% of those with a SoC did not have any hospital admissions, however no one (0%) in the no SoC group avoided hospitalisation in the six-month period before death.

A Mann-Whitney test indicated the cumulative LOS in the last six months of life was significantly less for those with a SoC (median = 2 days) than for those without a SoC (median = 6 days), $U = 2745076$, $p < .001$.

Table 9 shows details of decedent hospital use in the last six months of life.

Table 9: Hospital use and place of death based on SoC completion

	With SoC	No SoC	Statistics
N=	2335	3555	N/A
% Female	59.1	54.4	N/A
POD hospital (%)	32.1	59.9	$\chi^2 = 436.225$ (df 1) p<.001
Median no. of admissions*	1	2	K-W (df 1) = 494.7 p<.001
Range of no. of admissions*	0-76	1-78	N/A
Percentage with no admissions* (%)	40.2	0	N/A
Median cumulative LOS (days)*	2	6	M-W U = 27545076 (p<.001)
Number with an ICU admission*	4	40	N/A
Mean / median ICU hours if >0 hours (hours)*	31.4 / 36.8	67.7 / 40.9	N/A

* Based on 2302 people with a SoC and 3514 people with no SoC with a full six-month hospitalisation data set

There were 931 people who did not spend a day in hospital in their last six months of life (therefore did not die in hospital) and, of these, only 34% were male and 100% had a SoC (median age 92 years). In contrast the 931 people with the longest cumulative LOS of stay were more likely to be male (53%), younger (median age 89 years) and die in hospital (63%) and only 32% of these had a SoC.

Multinomial regressions showed that an increased number of hospital admissions in the last six months of life increased the odds (1.179) of 'very old' people dying in hospital (p<.001, OR 1.120-1.240, 99%CI) and increasing age was protective (0.964) of dying in hospital (p<.001, OR

0.947-0.982, 99%CI). Females had approximately 25% lower odds (0.766) of dying in hospital ($p < .001$, OR 0.665-0.883, 99%CI) than males. No statistical significance ($p = .028$) was detected for increased cumulative LOS in this regression, possibly due to the collinearity between number of admissions and LOS.

Hospital use by age bracket

There was a median of two admissions in the last six months of life for those in the youngest age bracket and all other age brackets had a median of one admission. Median cumulative LOS in the last six months of life were seven, four, two and one day/s within five-year incremental increases of age bracket.

Nearly three percent of the 'very old' decedents in this study spent more than 60 days in hospital, or a third of their final six months of life. Sixty-six percent of these did not have a SoC.

Kruskal Wallis (K-W) tests showed admissions and cumulative lengths of stay differed significantly ($p < .001$, df 3) across age groups (admissions: K-W = 212.7; cumulative LOS: K-W = 227.3) and SoC types (admissions: K-W = 494.7; cumulative LOS: K-W = 488.9).

Forty-four people from this entire group of decedents spent time in ICU; four (0.2%) from the SoC group and 40 (1.1%) from the no SoC group.

Thirty-two of those who spent time in ICU were aged between 85 and <90 years, 11 were aged between 90 and <95 years and one was aged between 95 and <100 years. Table 10 shows summary data of those who were admitted to ICU in their final six months of life.

Table 10: Characteristics of those with ICU admission/s, with and without SoC

Summary statistics of those with ICU admission/s	ICU with SoC n=4	ICU without SoC n=40
Female (%)	25	43
Mean* age at death (years)	87.8	87.9
POD hospital (%)	75	82.5
Mean* no. of hospital admissions in last six months	4.3	6
Mean* total LOS in last six months (days)	44	20.6
Mean* ICU hours last six months (hours)	31.4	67.7
Time from ICU admission to death (days)	74.8	25
Died in hospital with ICU during admission (%)	25	47.5
Mean* age at death if ICU in terminal admission (years)	87	87.7
Mean* ICU hours terminal admission (hours)	6.4	77.1
Female in ICU terminal admission (%)	0	42.1

* Mean used due to low numbers

As numbers are small, only descriptive statistical analyses were performed, however there was a pattern that indicated a person without a SoC may have been more likely than a person with a SoC to spend more hours in ICU, be in ICU closer to death, die in hospital and be in ICU in the terminal admission (an admission that ends with death in hospital). Males represented the higher users of ICU in both groups. Of note, no females with a SoC were admitted to ICU during the terminal admission.

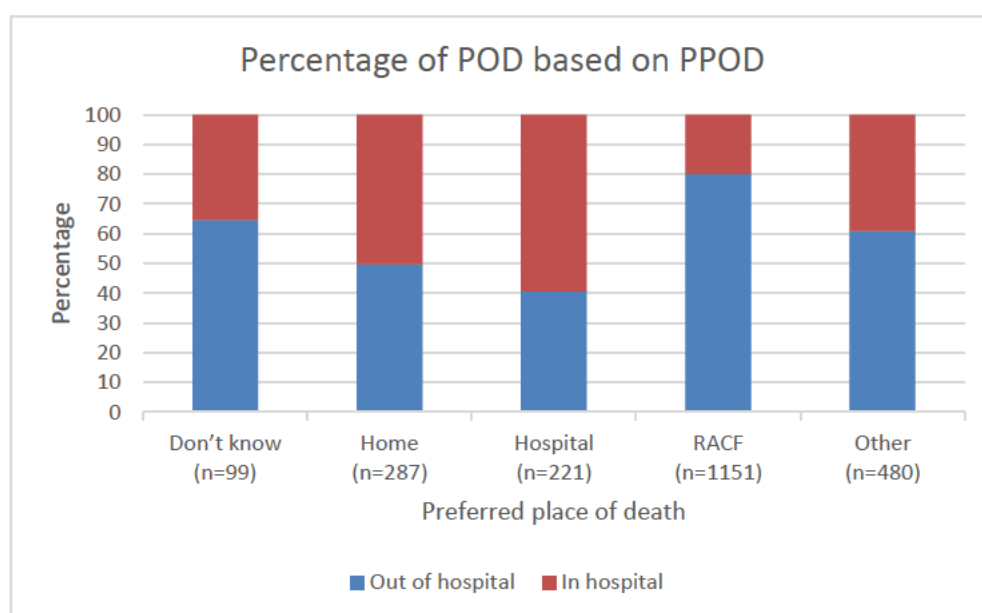
4.4 SoC decedents

A total of 2335 people died with a SoC (927 with a Form A and 1408 with a Form B). Median age at death for those with a Form A was 90 years (range 85-105) and 91 years for Form B (range 85-107). Of all SoC decedents, 59.1% (1379) were female, 60.3% (1408) had a SoC Form B, and 95.8% (2238) had a PPOD recorded.

4.4.1 Place of death

Approximately 46% (46.4%) of people with a Form A died in hospital, compared with 22.7% of those with a Form B. Documentation of PPOD significantly impacted actual POD (χ^2 (df 5, N=2238) = 210.0, $p < .001$). Those who specified hospital as their PPOD had the highest percentage of deaths in hospital (59.3%) while those specifying RACF as their PPOD had the lowest percentage of deaths in hospital (20%). Figure 10 shows where people died (hospital or other) relative to their documented PPOD.

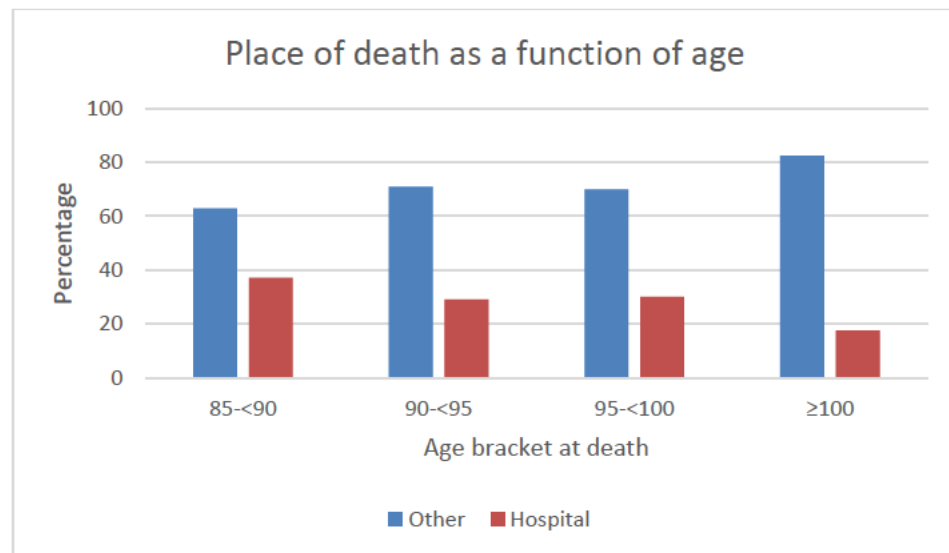
Figure 10: Percentage of actual POD compared to documented PPOD



Chi-squared analysis revealed those with a SoC Form B were significantly less likely to die in hospital than those with a SoC Form A (χ^2 (df 1, N=2335) = 144.5, $p < .001$) and a greater percentage of females with a SoC (72.7%) died out of hospital than males with a SoC (61.1%).

A Mann-Whitney test indicated those who died in hospital were significantly younger (median age 90 years) than those who died out of hospital (median age 91 years) $U = 513383.5, p < .001$). Figure 11 shows an increasing and significant percentage of people died out of hospital with each increasing age bracket ($\chi^2 (df 3, N=2335) = 25.611, p < .001$).

Figure 11: Percentage of place of death by age bracket at death (years)



Multinomial regressions revealed both gender and SoC type influenced odds of a hospital death. Females had lower odds (0.643) than males of dying in hospital ($p < .001$, OR 0.505-0.819, 99% CI) compared to out of hospital and those with a Form A had more than twice the odds (2.861) of dying in hospital than those with a Form B ($p < .001$, OR 2.255-3.631, 99% CI), however odds of a hospital death over out-of-hospital death did not reach significance based on age range at death.

Including singular PPOD locations in the multinomial regression with SoC type and gender revealed more than triple the odds of a hospital death if home (3.16) or hospital (4.17) was documented ($p < .001$, OR (home) 2.171-4.598, OR (hospital) 2.727-6.387, CI 99%) compared to RACF.

Place of death was influenced by the median number of months prior to death that a SoC was completed. People who died in hospital had a SoC

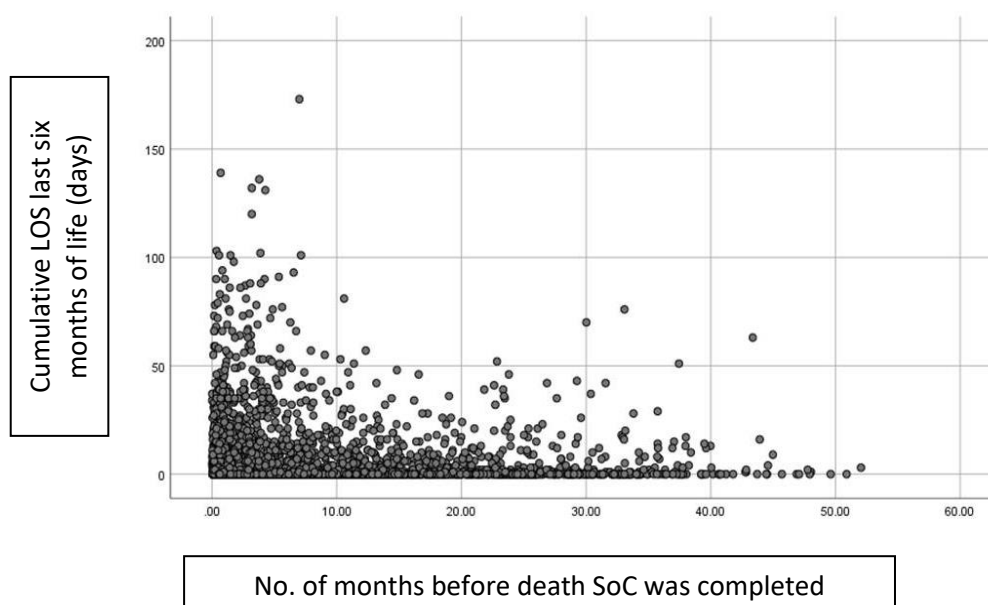
completed 6.3 months before death, while those who died out of hospital had a SoC completed 8 months before they died.

Multinomial regressions revealed decreasing odds of a death in hospital with each extra month prior to death that a SoC was completed (0.976) when controlled for gender and SoC type ($p < .001$, OR 0.964-0.988, 99% CI). Of note, those with a SoC Form A (i.e. with capacity) had approximately triple the odds of dying in hospital (3.073) than those with a SoC Form B ($p < .001$, OR 2.414-3.913, 99% CI).

4.4.2 Hospital use

Median cumulative lengths of stay in the last six months of life were five days (Form A) and one day (Form B). Average hospital utilisation in the last six months of life decreased with each additional month before death that the SoC was completed (Figure 12).

Figure 12: Distribution of cumulative LOS in last six months of life relative to months of SoC completion before death



Those completing the SoC in the last month of life spent the longest median time in hospital with six days in their last six months; those with a SoC completed six or more months before death (and therefore prior to the last six months of life) had a median of one day in hospital; while those with a SoC completed 12 months or more before death had a

median of zero days in hospital in their last six months of life. Table 11 shows the median cumulative LOS range in the last six months of life relative to the number of months before death that a SoC was completed.

Table 11: Median cumulative LOS in days in the last six months of life based on number of months of SoC completion prior to death

Months of SoC completion prior to death*	%	Median length of stay
0 to <1	16.1	6
1 to <2	8.4	5
2 to <3	6.1	5
3 to <4	5.5	5
4 to <5	4.3	6
5 to <6	3.9	2
6 to <9	11.2	1
9 to <12	8.9	0
12 to <24	22.4	1
24 and above	13.2	0

* Note different time increments

Multinomial regression showed increased odds (1.017) of an out of hospital death with each additional month before death that a SoC was completed ($p < .001$, OR 1.005-1.029, CI 99%), while increased age bracket at death did not significantly impact odds of an out of hospital death ($p = .013$) in the same regression.

4.4.3 ICU use

Three of the four decedents who died with a SoC and had an admission to ICU in the last six months of life were aged between 85 and <90 years and one was aged between 90 and <95 years. Three were male and one was female. All had completed a Form A (Table 12).

Two SoCs were completed in a hospital admission prior to the ICU admission, one during the same admission and one following ICU admission. Only one of the two people who completed a document before ICU admission wanted CPR and LPT. No one else wanted CPR and one other person had documented “Other” for LPT but provided no clarifying statement. Preferred place of death was diverse: home, hospital and RACF and one person had no preference documented. Two SoCs were completed in the community, one at a GP practice and one in hospital.

Three people died in the hospital, one less than a day after ICU admission. This person had a preference to die in hospital. The other in-hospital decedents had their ICU admission between three and four months before death. The person who died out of hospital was the only one in the 90-<95 age group. This person also had the longest ICU admission, which was not influenced by the document as their document was completed after their ICU admission.

Table 12: Summary table of four ICU patients (P1-P4) with a SoC

	P1	P2	P3	P4
Age at death (years)	87.3	87.2	90	86.3
Gender	Male	Male	Male	Female
SoC Form	A	A	A	A
CPR preference	No	Yes	No	No
LPT preference	No	Yes	Other	No
PPOD	Home	Hospital	RACF	Blank
Completion location	Other	Other	GP	Hospital
SoC completed before/ after/ during ICU	18 months before	2 months before	3 months after	during
Hours in ICU	36.4	6.4	45.8	37.2
Hospital death	Yes	Yes	No	Yes
Time between ICU admission and death	3 months	< 1 month	4 months	3 months

Chapter 5 Discussion

This study was the first of its kind in Australia to explore the end-of-life preferences of a large cohort (9555) of people aged 85 years and above and provides clinicians with evidence that the predominant preferences of the 'very old' people are to not receive interventions that provide quantity over quality of life and that dying in their place of residence is preferable to dying in hospital.

Completion of a SoC, as the ACP document involved in this research, allows open communication about end-of-life preferences to enable the 'very old' person, their family and health care staff to 'be on the same page' in preparation for the inevitable and imminent death and may improve the quality of dying, by reducing hospitalisations, interventions and deaths in hospital, aligning with their collective wishes. The earlier an ACP document was completed and accessible, the lower the use of the health system. The 'loss' of the person is contained to grief for the family but reduces another type of 'loss' to health care systems and staff.

Many religious, social and legal opinions would argue that life must not be shortened artificially, however the same could be said for extending life artificially. When the inevitable months, weeks and days approach, high-quality palliative care led by the GP or specialist palliative care services may be required to enable the dying person to die in their place of residence, with access to necessary knowledge, skills and medicines to support management of distressing end-of-life symptoms and other concerns. Supporting the person, their loved ones and even paid carers through the dying process, will enable an expected death to be well-managed, ideally with reduced conflict and symptom burden and acknowledgment and support of the losses into bereavement.

This research has analysed data of over 5000 'very old' decedents to determine hospital utilisation and POD in order to provide some initial

insights into locations of care in the last six months of life and the impact of ACP. It is hoped the results emerging from this research will inform and inspire health professionals across many disciplines, specialties, and care environments in their provision of high-quality person-centred care to the 'very old' in their final year of life.

The SoC cohort was defined by those who had a completed SoC on or after their 85th birthday. In 2014/15, Queensland increased its support for ACP with dedicated facilitators in each representative HHS and they prioritised those most vulnerable or imminently dying, including residents of RACFs and this may have resulted in a higher representation of RACF residents (67.6%) than is seen across Australia (39.4%) (ABS, 2019a).

'Very old' individuals, or their supportive relatives who knew the person's preferences, were perhaps more motivated to discuss and complete a document, potentially more so when the wish was to not receive CPR and LPT, in order to prevent a poorer outcome and quality of life.

5.1 CPR and other LPTs

In this study, large cohort sizes have powered robust statistical calculations to provide compelling evidence that over 80% of people in the 'very old' demographic did not wish to receive CPR or LPTs under any circumstance. Age seemed to be the predominant influencing variable in increasing numbers of Form Bs completed, females and preferences to not want CPR and LPTs. Conditional comments alongside CPR and LPT preferences indicate quality of life was most important. It seems apparent, through common sense, literature and this research that quality of life declines with age and conversely, care needs, dependence and even the desire to die (Bollig et al., 2016; De Gendt et al., 2013; Fleming et al., 2016) increases. Death is expected, and according to literature (Komatsu et al., 2018), the 'very old' just want someone to listen to their desires and needs and acceptance of death without further intervention.

Other conditional statements written alongside CPR preferences, such as “only three compressions”, “very gentle”, “only once” or “no intubation or ventilation” demonstrate a lack of understanding of the delivery and sequelae of effective or “successful” CPR, especially in the elderly (Bedell & Fulton, 1986; Cartledge et al., 2018; van Gijn et al., 2014). This apparent lack of knowledge of realistic expectations regarding outcomes of CPR is similar to those observed overseas (Vargas et al., 2017) and highlights the need for honesty in clinician-patient communications to acknowledge and openly discuss dying and whether CPR is appropriate. It could be argued that the documented preferences to not want CPR are under-represented if those indicating a preference for CPR, clarified with these conditional statements and evaluated against realistic outcomes, were included.

Some ‘very old’ with capacity (Form A) appeared to have a reasonable understanding of the limitations of CPR and LPTs in people of their age, health, function and likelihood of recovery and this concurs with Cartledge et al in a population of people over 70 years (2018).

Within the entire SoC cohort of 9555 people, only 1452 (15.2%) and 1103 (11.5%) people had a documented preference to receive CPR or other LPTs, respectively, which supports overseas findings: 7-40% wanting CPR and 6-25% wanting LPTs (De Gendt et al., 2013; Nahm & Resnick, 2001; Ng et al., 2016). The majority of those wishing for CPR or LPT if consistent with good medical practice (58% for both preferences) were in the youngest age bracket. Males represented 34.5% of the entire SoC cohort but accounted for 39.6% and 41.1% of people with a documented preference for CPR and LPTs, respectively. This reported gender imbalance for CPR supports literature overseas (Blewer et al., 2018; Schopen, 2017). Despite the reduced life-expectancy of males universally, historic views (Devin, 2019), predominance of male specialists (Schopen, 2017) and the ‘push’ of a live-in spouse (Pandey, 2019) whom they trust and perhaps feel the need to “protect’ may result

in requests for CPR and other LPTs. A loss of decision-making capacity appeared to impact the documented preference for CPR, with a drop from 32% (Form A) to 15% (Form B). Again, age influenced the decision, with a median age difference of 0.7 years (89.2 to 89.9 years). Australian data suggesting males in this age bracket have the highest age specific suicidality rate (Life in Mind, 2020) may reflect a similar dissatisfaction with living with reduced function and quality.

It is interesting to note that people who had their document completed in hospital were less likely to want CPR or LPT than those who completed the document with their GP. Perhaps those who were sick enough to be hospitalised had more exposure to the impacts of receiving CPR and LPTs or were so sick they were less motivated to live longer or indeed the presence of more doctors may have led to a realistic conversation with doctors who have experienced futile heroic attempts to save lives. Further research in this area would be worthwhile.

The different preferences and comments likely reflect the unique frameworks and motivators behind people's decisions, that are formed by culture, religion, values, family, past experiences, medical condition and health preferences and highlight the need for personalised communication to establish the individual's future health preferences. As one ages, dependence on others for physical and cognitive needs often increases (Milanović et al., 2013; Murman, 2015) and quality of life may consequentially decrease. Given certain aspects of functional decline are considered by some patients as bad as, or worse than, death (Rubin et al., 2016) it is perhaps not surprising that the preference to not want CPR or LPTs under any circumstance was higher in older people who were more likely female, residents of RACFs and those with impaired decision-making capacity. Age is the strongest predictor to not want interventions that attempt to extend existence, namely CPR and LPT.

Consent and decision-making for people with impaired capacity generates a range of clinical, legal and ethical dilemmas, and may cause

existential dilemmas for family members involved. While clinicians formulate their plan based on the person's clinical condition and their preferences, family members presumably balance the contrary emotions of not wanting their loved one to die while not wanting for life to be extended artificially or with suffering at the expense of quality (Albert et al., 2016; Bollig et al., 2016; Gardner & Kramer, 2010; Gott et al., 2017).

Research by Bollig et al. revealed many older people did not want to talk about their preferences believing their offspring would know what they want (Bollig et al., 2016), perhaps an example of a death-denying society (Francati, 2017; Kellehear, 1984; Nelson, 2019; Zimmermann, 2007), while other family members may have discussed these situations specifically ahead of time. Either way, family, based hopefully on their longstanding knowledge of the person, documented a preference that they believed their relative would make based on the combination of contributing physical, psychological, social and cognitive factors. It is preferable that clinical teams support family members through this process to explain appropriateness, or lack of, success, or lack of, and likely impacts of interventions on function and quality of life for the person.

Clarifying statements made for a person with impaired capacity reflected a recognition of the challenges of such a decision, with some reasonably deferring the decision to a medical doctor or "good medical practice". Overseas studies reflect this tendency (Albert et al., 2016; Bollig et al., 2016), especially in proxy decision-makers who, understandably, do not want to make the 'wrong' decision, however that is defined when death is inevitable and imminent. Comments also reflected an awareness of limited lifespan and perhaps a perception of already reduced quality of life alongside a desire to keep their loved one comfortable, pain free and to die naturally when that inevitable period occurs. While diverse across people or one's lifespan, quality of life was the predominant theme in documented comments on the SoC, with a desire from the SoC completer, be that self or other, for the person to regain, or at least maintain, their existing quality of life.

The SoC cohort closely represents the Australian population in both age and gender, although, as mentioned, may over-represent residents of RACFs. While caution is needed in making inferences to all 'very old' people about the strong preference to not want CPR or LPTs, these findings should highlight the imperative to ask for, listen to and understand the basis of a person's preferences. This will enhance good medical practice and perhaps empower a health professional to feel more comfortable when supporting a person or their family in their decision regarding the lack of beneficence or appropriateness of CPR or LPTs.

5.2 Preferred place of death preferences

Asking someone where they would prefer to die may seem an odd question, evidenced by some within the SoC cohort who added comments to the PPOD question on the SoC Form A that included "I have never thought about it" and "I have no idea. That's a question and a half." However, it is a worthwhile question in the context of ACP and person-centred end-of-life care. Given these people are 85 years or older, it again highlights aspects of the dying-denying society that exists (Francati, 2017; Kellehear, 1984; Nelson, 2019; Zimmermann, 2007) even amongst those in the age group most likely to die.

Results from this study are similar to those from overseas (Abarshi et al., 2010; Hunt et al., 2014; Ng et al., 2016) and suggest that where one lives and who is there to provide support most influences a person's decision on PPOD, so a "young" (85 to <90 years), male with capacity was more likely to choose home or hospital, perhaps dependent on supports in the home while a resident of a RACF was most likely to be older, female and choose the RACF as their PPOD, due to its convenience, familiarity as a 'quasi' or new home, and the 24-hour care supports available. The high collective preference for RACF as PPOD supports literature overseas (Ng et al., 2016) and is perhaps not surprising given the strong representation of RACF residents in this study.

Some people commented regarding their PPOD “wherever family is present” which concurs with the literature (Bollig et al., 2016; Komatsu et al., 2018). Preferences for family members’ presence at death requires forethought and communication, as some hospitals do not have rooms large enough to accommodate more than a few family members at once.

Traditions around dying, death and the immediate post-death period vary across religious and cultural groups so discussing these ahead of time in the context of PPOD might be an important factor in enabling these practices to occur. Other comments regarding PPOD included themes such as where comfort and dignity at end of life can be supported to prevent futile attempts at extension of life or prolongation of dying.

Understanding the reason behind, and impacts of, a PPOD decision is important for health professionals. Comments made regarding safety may infer some disquiet with a certain location and hence a preference to die elsewhere. “Safety” is echoed in overseas research (Chochinov et al., 2016; Gardner & Kramer, 2010; Komatsu et al., 2018; Mansour, 2020; Nahm & Resnick, 2001; Ng et al., 2016). Given the vulnerability of a dying person and possible, but unspoken, past trauma the person may have suffered due to race, religion, gender, sexuality or political orientation, the provision of a safe place and safe practices must be reinforced to the dying person and their family. While some may prefer to die in the safety and familiarity of their home, it may not be practical, possible or sustainable for family and friends to provide the 24-hour support necessary to achieve the preferred result.

Community palliative care, provided by generalist or specialist services, may also be required to provide necessary supports for symptom relief, care requirements, equipment, existential distress, emotional well-being and a multitude of other practical factors, however not everyone has access to these services and not every health professional, even if available, can provide optimal palliative care. Early knowledge of a PPOD, perhaps combined with early referral to specialist palliative care

services may provide the time needed to enable necessary supports and skill developments to be arranged.

There is a very small percentage of people (9%) who documented hospital as their only preference for POD which is not dissimilar to other research (Swerissen & Duckett, 2014; Ng et al., 2016). This may be positively impacted by a lack of familiarity of the hospital environment, or a request for a person who lives alone in their own home where no full-time carer is available. It is interesting that a greater percentage of people who completed their document with a GP wanted to die in hospital than those who completed their document in hospital, perhaps supporting the suggestion that those who completed their document in hospital had an awareness of the limitations of space, amount of direct care delivery possible, visiting hours and visitor numbers within a hospital environment and therefore preferred to die elsewhere. Those completing their document in hospital also had the greatest uncertainty about a PPOD.

Choosing more than one preference for location of death may demonstrate a lack of previous thought, as evidenced by the comments quoted above, discussion about options or certainty around timeframe of dying. Those completing the document in a RACF had less uncertainty, and a large percentage of those with one or more locations included RACF as one option. There was a higher mention of hospital in this “Other” category, and this may indicate that if someone is unable to die in their first preference, then hospital is, arguably, the only other option. This may explain the greater uncertainty for hospital completers of the SoC – as there is no “back up plan”.

It is important to recognise that a preference for a POD may indicate a preference for a place of care in the final weeks or days of life rather than the place they want to die (Saunders, 2012). People are generally more relaxed if cared for in their familiar and safe environment, but if a person in their final days required increased care that cannot be managed in their home or RACF, hospital might be a reasonable next best option.

Three of the five HHS represented in this study have small hospices, mostly privately run and hospice was mentioned by some, even in the areas where physical hospices do not exist. Hospices, where available, do provide an alternate option to hospital, if home or RACF is not suitable, and the person has been identified as imminently dying and is stable enough to transfer. Palliative care units are present in some hospitals in all HHS included, and 15% of people expressed a preference for palliative or comfort care. Collectively hospices and palliative care units are primarily focused on providing best-quality end-of-life care to minimise discomfort and suffering at end of life. Some completing the document may have already had positive experience with palliative care for themselves or another family member and recognise its value in, and support during, the dying process. With adequate palliative care resourcing, presence and education and other supports in place, realisation of a home or RACF death is likely to be achievable (Costa et al., 2016; Healy et al., 2018; Quinn et al., 2020).

5.3 Hospital utilisation

Acute health care costs and bed occupancy is reduced if community-based support is provided (McCaffrey et al., 2013), even if the ultimate POD still ends up being hospital. The triple impact of honouring a person's wishes, increasing acute bed capacity in the hospital and saving money, seems to be a sensible/logical course of action with no losers.

It is understood much of the healthcare dollar is spent on elderly people and particularly towards their end of life as care needs increase (Curtis et al., 2012; French et al., 2017). Australian Bureau of Statistics data shows infrequent use of hospitals in the 'very old' (ABS, 2020) and this research of people aged 85 years and above reflects this national data with median number of admissions of up to two and median LOS of less than ten days for decedents, irrespective of SoC completion. It should be noted, however, that ABS data included all people 85 years and above, while this study data included only decedents and health care use often

increases at end of life. In addition, a mean value was calculated from ABS data, which is not the best measure of centrality for a national dataset, and not an accurate comparison to the medium of this study. Less than 60% of people with a SoC spent time in hospital in the last six months of life compared to 100% of people without a SoC. Sixty-six percent of people who spent more than 60 days in hospital in their last six months of life did not have a SoC. These figures suggest completion of an ACP document, which must have included some level of discussion or thought, adds value to the person, if they would rather be anywhere than in hospital, and the health system.

Intensive care use was lower amongst those with a SoC (0.2%) but the percentage use was also low in the no SoC group (1.1%). No one with known impaired capacity (Form B) spent time in ICU in their final six months of life, and this is thought to be appropriate given the intensity of treatment, potential for death, displacement and added confusion for the person and restriction of visitors. Hours in ICU for both groups were less than the national average of 90 hours (ABS ref) inclusive of all adults, which demonstrates some awareness of the poor morbidity and mortality outcomes expected for even 'old' people, aged over 60 years, in ICU (Grace et al., 2007).

It is acknowledged hospitalisation data do not provide a quality-of-care measure, nor has this study analysed preferences for hospital use specifically. Notwithstanding this, it would seem to be morally and fiscally prudent for health executives or researchers to explore care provision of the 'very old', especially those in their final six months of life. Perhaps the first place to start is with hospital deaths of the very old, with an exploration of whether there was provision of ongoing and extended acute care, including intensive care (fixing the unfixable), and whether it was reasonable, beneficial and appropriate, especially if alternate care options were available e.g. RACF. Early identification of dying and ACP discussions will maximise opportunity for care provided to align with

quality, or quantity, of life goals, which may or may not include hospital stays, transfers or treatments.

5.4 Place of death

Exploring location of death for the decedent cohort provided some insight into where the 'very old' are dying. AIHW reports that the likelihood of death in hospital is high if the RACF resident is hospitalised in their final week of life (AIHW,2021c) and this appears to be supported by this research. Hospital death rate was higher in this study than 2019 national (ABS) data, for people without a SoC: nationally, 37% of all 'very old' males' deaths and 31.1% of all 'very old' females' deaths occurred in hospital. In this study, of decedents without a SoC, 63.6% of males and 56.8% of females died in hospital compared to 38.9% of males and 27.3% of females in the SoC group. Presence of an ACP document was associated with the reduced likelihood of an in-hospital death in this study. The gender difference in all cases may be due to increased female occupancy in RACFs, due to increased widowhood and increased age, where end-of-life care can be provided and, potentially, some of the gender bias issues discussed previously.

Decedents without a SoC were in the same regions and died in the same time period as those decedents with a SoC, so had similar, if not equitable, access to the same resources. This increased likelihood of death out of hospital cannot be presumed to be entirely as a result of SoC completion but this process is likely to have had a significant impact as opportunities were available for the health professional, person and family to acknowledge a life-limiting illness, discuss PPOD and commence planning in line with the person's wishes.

It should be noted that a hospital death is not, in isolation, an indicator of poor end-of-life care, as the weeks to days before death may have occurred just as the person would have wanted but carer distress, a lack of skilled generalist palliative care staff, or complex symptom

management or family dynamics may have led to transfer to hospital, including to a palliative care unit in the final days of life.

It is also important to not extrapolate these findings across an entire health system, however literature suggests that early ACP provides improved bed-capacity and fiscal benefits (Dixon et al., 2015; Khandelwal et al., 2015; KPMG, 2020) to the health system. It is believed there are also personal and cost benefits to the person and their family if they can receive care longer in their place of residence as evidenced by the VOICES survey of bereaved carers showing people who died in the home reported they were well supported (Saunders, 2012). Some SoCs were completed in the final few months of life and it was perhaps during, or subsequent to earlier, hospital admissions where an awareness of limited life, clarity on how that limited life should be spent, or family and medical cohesiveness re treatment plans, led to the decision to complete a SoC.

This research has demonstrated that LOS in the last six months of life correlates inversely to the time that a SoC was completed before death: the longer the time before death that a SoC was completed, the shorter the cumulative LOS in the last six months of life. While some documented a preference to not be transferred to hospital, it is not known whether this low hospital utilisation aligned with each person's preference. More research needs to be conducted to determine breadth of concordance, based on both clinical and non-clinical preferences. Again, advance preparations and planning enables wishes to be known and able to be implemented by either family, the community or the health care team.

The over-medicalisation of death (Clark, 2002; Nahm & Resnick, 2001; Schwarz & Benson, 2018) means hospital systems will continue to absorb a multitude of costs that could be dispersed by alternative proactive approaches. Ensuring ACP occurs in advance, as its name suggests, will result in decreased use of precious and expensive acute resources, including hospital beds and ICU, as is suggested by this research. Open and honest communication, revisited regularly as death

approaches, enables concerns to be discussed ahead of the death and facilitate a united approach to care, so that the priority and focus of the clinicians' time is on the dying person, not the unheard concerns of family members. Support provided by community palliative care services, RACF in-reach services or specialist education to upskill RACF and GP staff, allows the realisation of the documented ACP preference to ensure quality care is provided in the right place at the right time in accordance with the person's preferences and best medical practice. This will support the respect and honouring of recurring themes around ensuring quality of life and a pain free and dignified death.

Upskilling staff across multiple health specialties and environments is paramount to increase uptake of ACP in the expanding 'very old' population. In parallel, increasing the understanding of the 'very old' or their representatives that they can and should have a say in THEIR health care is vital and a mammoth task.

5.5 Limitations of study

The shortcomings of exploratory retrospective studies are many and varied and this research had several limitations based on its design (Suchmacher & Geller, 2012).

The people within the SoC cohort were identified by a proactive health professional, family member or indeed themselves, as someone with increasing care needs and approaching their end of life. This may have caused an over-representation of the RACF sub-cohort (67.6%) to above population averages (39.4%) (ABS, 2017). This may limit the generalisability of the findings to the whole 'very old' population.

The research was contained to five HHS in the south-east corner of Queensland so may not accurately capture the views of more regional and rural parts of the state, or Australia in general. Each of the HHS involved had dedicated clinical or project staff that led facilitation of ACP

conversations, processes and education. It is acknowledged the HHS that developed, introduced and promoted the SoC across care environments is the same HHS that hosts the Office of ACP where documents are reviewed and uploaded. These facts combined may have led to an over-representation from this particular HHS and may have biased findings.

Limited demographic data are collected by the Office of ACP so it is recognised more extensive data including marital status, socioeconomic indicators, comorbidities, culture and religion may have enabled a more accurate analysis of factors that contribute to treatment preferences and outcomes. Improved matching of controls would have added rigour to this research and reduce skewed data and limited interpretation.

Broader and deeper research into details of the participants socio-cultural status and value statements on the SoC, hospital care, impacts of dying on person, family and health care staff would have provided more of a whole picture, but this was not possible within the constraints of the study. Further research is needed in the qualitative aspects of ACP and dying.

It is important to not presume causality between SoC completion and care received, despite the decreased hospital and ICU use and reduced in-hospital deaths. Other factors may have also contributed to these reductions.

Determination of place of completion was prioritised under the following categories (i) RACF – based on name of facility or knowledge of RACF addresses (ii) hospital – if the person was not a known resident of a RACF and the person was an inpatient at the time of completion or there was a hospital stamp in the doctor's signature and (iii) GP if the document was signed with doctor's signature and GP practice name or it was sent from a GP fax and (iv) other community services if any of these were not clear. This may have also over-represented the RACF group and underestimated hospital completions. Some conversations and documents

would have commenced in hospital with a request to be reviewed by the GP, and these were included in the GP category.

COVID-19 caused delays in many health processes and this included obtaining deidentified data regarding details of hospitalisation and death data. This was further complicated by availability of death data occurring nine months after the deaths had occurred which required an arbitrary final death date of 31st October 2019. Data from SoCs completed after this date were included in the preference analysis, but further applications for death data were not feasible in the timeframe of this research, perhaps reducing the breadth and power to decedent data analysis.

For convenience and comparability, the research was limited to one ACP document type, which is not the document with the highest legal standing, but it is the document with the highest numbers received by the Office of ACP. There would be value in repeating this research and comparing other document types with similar outcome measures.

Chapter 6 Conclusion & Recommendations

6.1 Conclusion

The world is facing a crisis of near-pandemic proportions as medical advancements and improved health and sanitation mean a greater proportion of the population are predicted to survive into 'very old' age, become more dependent and ultimately near and meet their end of life. Understanding what they want for their end-of-life care will help all involved to respectfully honour their wishes. The paucity of literature on this topic means research is needed and important.

This research has explored the end-of-life preferences of 9555 'very old' Queenslanders with a completed SoC document and indicated that the vast majority of 'very old' people preferred to not receive interventions that prolong their life under any circumstance, and the majority of clarifying statements documented indicated quality of life is paramount and more preferable, for most, than extension of life. Most preferred to die in their current place of residence, be that home or RACF.

Analysis of hospital use and POD of decedents, with and without a SoC, revealed median admission rates and cumulative lengths of stay were statistically lower for people with a SoC, as was the likelihood of a death out of hospital.

Health professionals need to recognise when a 'very old' person is approaching their final twelve months of life, openly and honestly discuss dying and death with the person and their family and ensure only realistic and beneficial interventions are offered, as per good medical practice. Inviting them to express what is important to the person and what they would and would not want allows for a unified and individualised approach to end-of-life care. Documenting preferences and making them accessible allows for these preferences to be known and supported by

health care staff and family alike, assisting in seamless care provision at one's end of life.

It is hoped the results of this study will encourage health professionals to advocate for their patients and guide people and families through this process, primarily based on their unique medical and non-medical needs and preferences but supported with knowledge that the majority of 'very old' people from this cohort do not want interventions to prolong life, especially if quality of living is adversely affected. The earlier these discussions occur, the more time the family can adjust to dying and ask questions, and the more likely that end-of-life care can be provided as the person would want, including specialist or generalist palliative care supports in the home or RACF if required.

Understanding and honouring the end-of-life preferences of the 'very old' person enables the best outcomes throughout dying for this individual, their family, the health care staff and the health system as a whole.

6.2 Recommendations

Further research is needed to understand a broader range of factors that may contribute to the preferences of the 'very old' and where they are dying, including community supports within and outside the home. Analysis of several hundred consecutive "very old" deaths would provide some insights and perhaps determine important contributing factors.

Further work is needed to boost public awareness about death and dying and empower individuals to have their wishes heard and known. This is also important for those without capacity, to ensure they are also heard. Ongoing funding for skilled ACP facilitators to lead discussions and document completion or to train other staff in the complexities and nuances of ACP in their state or territory. Expansion of a national approach to ACP, with scope for document completion on behalf of a person with impaired capacity, would help support the vulnerable.

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Appendices

- Appendix 1: ACP in the Queensland context
- Appendix 2: Ethics approvals
- Appendix 3: Statement of Choices
- Appendix 4: Selection of comments re CPR and LPT
- Appendix 5: Selection of comments regarding PPOD
- Appendix 6: Queensland Advance Health Directive
- Appendix 7: Queensland Enduring Power of Attorney (short)

Appendix 1: ACP in the Queensland context

As consent is needed to withhold or withdraw life-sustaining treatments in Queensland (Queensland Government, 2020b), discussing the preferences of the person and/or their decision-makers in advance can provide some guidance if decisions are required at, or near, end of life.

Dedicated funding was provided to Queensland Health hospitals from 2014/15 to 2019/20 to improve uptake of advance care planning. Many employed dedicated facilitators to develop and implement policy, procedures, strategies and then approaches and completion of ACP discussions and documents with willing patients/family members.

Queensland ACP documents

- (i) an Advance Health Directive (Appendix 6) - a legally-binding document that directs health care decisions and allows for nomination of an attorney for health/personal matters;
- (ii) an Enduring Power of Attorney (Appendix 7) – a legally-binding document that enables a person to nominate their attorney/s for health/personal and/or for financial matters;
- (iii) a Statement of Choices (Appendix 3) – a values-based document that captures the preferences of a person for future health care which is then used to guide treatment decision-making at the time a decision is required.

The Statement of Choices has two distinct forms: Form A for people with decision making capacity and Form B which is completed on behalf of a person without decision making capacity or who requires support with decision-making. The Form B is ideally completed by the nominated attorney for health/personal matters, or if none has been nominated, by an individual who knows the person's wishes best, usually a spouse, adult child, sibling, friend – but not a paid health worker/carer. Both SoC forms require a doctor to determine that the correct form has been completed based on the person's capacity,

declare that they are not the person's nominated health attorney, relative or beneficiary of the person's will and sign and date. Form B also require the doctor to acknowledge the person completing the form is doing so in the person's best interest.


It should be noted that the SoC is not a legal document, so even with documented preferences expressed by, or on behalf of, the person, the decision to withhold or withdraw life-sustaining measures occurs at the time the decision needs to be made. The person who will be required to provide consent is the nominated enduring health attorney or, if none, the statutory health attorney who is very often the spouse, an unpaid carer or a close relative or friend. The highest legally ranked health attorney should be the person completing the SoC Form B. There is value in involving multiple family members in ACP discussions, to reduce potential conflict and to inform a family member who may, due to availability at the time a decision is required, be the substitute decision-maker.

All ACP documents are sent to the Statewide Office of ACP, reviewed and, if complete, uploaded to a statewide digital medical record so they are accessible across all care environments, ensuring a person's directions, nominations or preferences can be known and implemented when appropriate. Clinicians can have confidence that the documents meet minimum legal and administrative requirements, however still have certain obligations and responsibilities at the time a document is used to ensure this is the most recent document and to understand contents and legal standing in order to guide/direct health care decisions.

The hierarchy of decision making in Queensland (Queensland Government, 2020b, 2021) reveals if the person cannot make the decision for themselves, their AHD directs treatment. If there is no AHD and no guardian appointed by a tribunal or the directions in an AHD are unclear or do not align with the emerging medical situation, the nominated health attorney (appointed in an EPOA or AHD if the person

has one) is next in line to make decisions, followed by a statutory health attorney (which can, in order, include a spouse, unpaid regular carer, a close relative or friend or if no one available, the Public Guardian). The SoC Form B expresses that a nominated health attorney should be the person completing this form and outlines that opinions do not constitute consent.

Appendix 2: Ethics approvals

<div data-bbox="399 1467 478 2056" style="text-align: right; padding-right: 20px;">  </div> <div data-bbox="510 1523 582 1747"> <p>Enquiries to: Metro South Human Research Ethics Committee Phone: 07 3441 8000 Fax: 07 3441 8000 Email: HREC@metro.health.qld.gov.au</p> </div> <div data-bbox="590 1892 654 1993"> <p>Prof. L. Reynolds Metro South Health P O Box 77 Cairns QLD 4850</p> </div> <div data-bbox="678 1892 694 1993"> <p>Dear Prof Reynolds</p> </div> <div data-bbox="702 1624 734 1993"> <p>HREC Reference number: HREC/17/014/036 Project Title: Compilation and Evaluation of Statement of Choices documents</p> </div> <div data-bbox="742 1523 782 1993"> <p>Thank you for submitting the above research protocol to the Metro South Human Research Ethics Committee for ethical and scientific review. The protocol was first considered by the Human Research Ethics Committee (HREC) at the meeting held on 7 February 2017.</p> </div> <div data-bbox="790 1523 829 1993"> <p>You are reminded that this letter constitutes ethical approval <i>only</i>. You must not commence the research protocol at a site until separate authorisation from the Metro South Chief Executive is available and you have received written approval from the Metro South Chief Executive of the site.</p> </div> <div data-bbox="837 1523 877 1993"> <p>A copy of this approval must be submitted to the Research Governance Office (RGO) by the relevant Executive or delegate to conduct the research at the Project Alexandra Hospital.</p> </div> <div data-bbox="885 1523 925 1993"> <p>If this study currently involves <i>grant funding</i>, please remember to forward a copy of this approval letter to the relevant Grants Office of the AusLink (granting institution) for the grant.</p> </div> <div data-bbox="933 1523 973 1993"> <p>I am pleased to advise you that the research protocol meets the requirements of the National Statement on Ethical Research Involvement and ethical approval has been granted. The documents reviewed and approved include:</p> </div> <table border="1" data-bbox="981 1523 1157 1993"> <thead> <tr> <th>Document</th> <th>Version</th> <th>Date</th> </tr> </thead> <tbody> <tr> <td>HREC Application</td> <td></td> <td>18 January 2017</td> </tr> <tr> <td>HREC – Submission Code: NUT/17/24/1</td> <td>1</td> <td>18 January 2017</td> </tr> <tr> <td>Statement of Choices – General template (Form A)</td> <td></td> <td>18 January 2017</td> </tr> <tr> <td>Statement of Choices – Choice template (Form B)</td> <td>4.0</td> <td>18 January 2017</td> </tr> <tr> <td>Statement of Choices Activity, as of November 2016</td> <td>n/a</td> <td></td> </tr> <tr> <td>Alert South Australia of SOC preferences when Metro South Health</td> <td>1.1</td> <td>19 January 2017</td> </tr> <tr> <td>Feedback: Upgrading of the Statement of Choices in the Viewer</td> <td>2</td> <td>16 February 2017</td> </tr> <tr> <td>Survey 2: Content of the Statement of Choices report</td> <td>2</td> <td>16 February 2017</td> </tr> <tr> <td>Letter of response to HREC comments</td> <td>2</td> <td>24 February 2017</td> </tr> <tr> <td>Information Sheet</td> <td></td> <td>n/a</td> </tr> </tbody> </table>	Document	Version	Date	HREC Application		18 January 2017	HREC – Submission Code: NUT/17/24/1	1	18 January 2017	Statement of Choices – General template (Form A)		18 January 2017	Statement of Choices – Choice template (Form B)	4.0	18 January 2017	Statement of Choices Activity, as of November 2016	n/a		Alert South Australia of SOC preferences when Metro South Health	1.1	19 January 2017	Feedback: Upgrading of the Statement of Choices in the Viewer	2	16 February 2017	Survey 2: Content of the Statement of Choices report	2	16 February 2017	Letter of response to HREC comments	2	24 February 2017	Information Sheet		n/a
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Enquiries to: Metro South
Human Research Ethics Committee
Phone: 011 443 5046
Metro SAC
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Prof. L. Reymond
Deputy Director
Metro South Health
P O Box 72
Comrad Qld 4075

Dear Prof Reymond

HREC Reference number: HREC/17/OPAM/34

Project Title: Completion and Evaluation of Advanced Care Planning documents

The Office of the Metro South Human Research Ethics Committee notes and approved the following:-

Document	Version	Date
Notification of amendment submitted via Ethical Review Manager (ERM) with respect to the following: - Amendment of evaluation is an economic evaluation of ACP system. Ethics Protocol	1	09/01/2020
	6.0	18/12/2019

The Metro South Hospital and Health Service HREC is constituted and operates in accordance with the National Health and Medical Research Council's National Statement on Ethical Conduct in Human Research (2007) and the CPMP/ICH Note for Guidance on Good Clinical Practice.

This will be ratified by the HREC at its 2nd April 2019 meeting.

Please provide a copy of this approval letter to the Research Governance Office.

It should be noted that all requirements of the original approval still apply. Please continue to provide at least annual progress reports until the study has been completed.

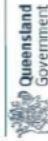
If you have any queries please do not hesitate to contact the Human Research Ethics Committee office on 4111 3443 5046.

Yours sincerely,

Prof Scott Campbell

Chair
Metro South Hospital and Health Service
Human Research Ethics Committee (EC00167)
Metro South Health
Centre for Health Research
1403/2019

C.c. Ms X Sansome, Project Manager



Metro South Health

Research

Metro South Human Research

Ethics Committee

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Dear Prof Reymond

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	6.0	18/12/2019

This amendment will be ratified by the HREC at its 4 February 2020 meeting.

Please provide a copy of this approval letter to the Research Governance Office.

It should be noted that all requirements of the original approval still apply. Please continue to provide at least annual progress reports until the study has been completed.

The Metro South HREC is constituted and operates in accordance with the National Health and Medical Research Council's National Statement on Ethical Conduct in Human Research (2007) updated 2018, NHARC and Universities Australia Association Code for the Responsible Conduct of Research (2018) and the CPMP/ICH Note for Guidance on Good Clinical Practice. The composition of the Metro South HREC, including backgrounds and qualifications, can be found on our website here:

<https://metro.south.health.qld.gov.au/research/about-us/hrec>

If you have any queries please do not hesitate to contact the Human Research Ethics Committee office on 4111 3443 5046.

Yours sincerely,

Prof Scott Campbell

Chair

Metro South Hospital and Health Service

Human Research Ethics Committee (EC00167)

Metro South Health

Centre for Health Research

1403/2019

C.c. Ms X Sansome, Project Manager

Appendix 3: Statement of Choices


Queensland Health

Statement of Choices

ADVANCE CARE PLANNING

This Statement of Choices can 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



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 choices about health care to be considered before a crisis occurs.

When will your advance care plan be used?
 Your advance care plan may 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?
 A Statement of Choices can still be considered for that person. The form 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 of advance care planning

- Step 1** Discuss with your usual doctor your 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 may have already 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.

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 guiding effect by assisting 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 a 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.

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:

- 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 decisions in 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.

Statement of Choices may help guide these decision-makers

Contact information



Office of Advance Care Planning:

P.O. Box 2274

Runcorn QLD 4113

Ph: 1300 007 227
Fax: 1300 008 227
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 ventilator) 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, ongoing treatments will be needed to stop a person from dying. These treatments are collectively referred to as life prolonging and include dialysis, feeding, and breathing support. The quality of life during these treatments is not necessarily of a quality of life that the person would find 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 do so 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 list, 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 in 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, Laurre 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, no. 10 (2013): 1538-1553.

2. Grosse, Saket, et al. "Trends in Survival After In-Hospital Cardiac Arrest." *New England Journal of Medicine* 367, no. 20 (2012): 1912-1920.

DO NOT WRITE IN THIS BINDING MARGIN

 QUEENSLAND HEALTH Advance Care Planning Statement of Choices (FORM A)	(Attach patient identification label here) URN: _____ Family Name: _____ Given Names: _____ Address: _____ Date of Birth: _____ Sex: <input type="checkbox"/> M <input type="checkbox"/> F <input type="checkbox"/> 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:
 If you have a legally appointed substitute decision-maker as per 1, 2 or 3 you should fill in their details below.
 If you have not appointed anyone you can substitute the name of a person or people you wish to be part of decisions in relation to your health care decisions in the future.

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


My Contacts

Name: _____	Relationship: _____
Phone: _____	I have appointed this person as a decision-maker in my EPOA or AHD: <input type="checkbox"/> Yes <input type="checkbox"/> No
Name: _____	Relationship: _____
Phone: _____	I have appointed this person as a decision-maker in my EPOA or AHD: <input type="checkbox"/> Yes <input type="checkbox"/> No
Name: _____	Relationship: _____
Phone: _____	I have appointed this person as a decision-maker in my EPOA or AHD: <input type="checkbox"/> Yes <input type="checkbox"/> 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

DO NOT WRITE IN THIS BINDING MARGIN

 QUEENSLAND HEALTH Advance Care Planning Statement of Choices (FORM A)	(Attach patient identification label here) URN: _____ Family Name: _____ Given Names: _____ Address: _____ Date of Birth: _____ Sex: <input type="checkbox"/> M <input type="checkbox"/> F <input type="checkbox"/> I
--	--

B. Personal Values

Describe what you value or enjoy most in your life.
 Think about what interests you or gives your life 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 involve severe disability.

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

Indicate 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, religious and cultural practices, organ and tissue donation, and any other wishes that you want noted.

Please turn over...
FORM A Page 2 of 4

DO NOT WRITE IN THIS BINDING MARGIN

This resource has been adapted from Austin Health copyrighted publications 2011 by Metro South Health

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

(Atm: 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 updated or withdrawn. You may indicate a time period when you want to review this document (optional):
 6 monthly 12 monthly Other: _____

My Understanding

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 understand that:

- This document may only be used if I am unable to make or communicate decisions for myself.
- My substitute decision-maker(s) and doctors may only 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 for me to discuss my wishes with my usual doctor, my family and 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: _____

Usual Doctor's Statement

As a registered medical practitioner, I believe that the person completing this form has the decision-making capacity necessary to complete this Statement of Choices. 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
 Fac: 1300 008 227
 Email: acp@health.qld.gov.au
 Post: PO Box 2274, Runnymede QLD 4113
 For more information phone: 1300 007 227

www.mycaremychoices.com.au
FORM A Page 4 of 4

DO NOT WRITE IN THIS BINDING MARGIN

151 (2010) Professional Form

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

(Atm: 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, and I understand them:
 Yes No *if you have answered No please consult a doctor before continuing with this form.*

Medical and emergency preferences

Please remember, doctors need to speak with the relevant substitute decision-maker(s) 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 wish CPR attempted if it is consistent with good medical practice OR
 I would NOT wish CPR attempted under any circumstances OR
 Other: _____

Other Life Prolonging Treatments (tick appropriate box)
 e.g. Money machine (dialysis), feeding tube, breathing machine (ventilator)


I would wish for other life prolonging treatments if consistent with good medical practice OR
 I would NOT wish for other life prolonging treatments under any circumstances OR
 Other: _____

Medical Treatments

If considered to be medically beneficial,	I would wish for:	I would NOT wish for:	undecided / no preference:
A major operation (e.g. under general anaesthetic)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Intravenous (IV) fluids	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Intravenous (IV) antibiotics	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other intravenous (IV) drugs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
A blood transfusion	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Please turn over—
FORM A Page 3 of 4

DO NOT WRITE IN THIS BINDING MARGIN

 QUEENSLAND HEALTH Advance Care Planning Statement of Choices (FORM B)	(A/N: patient identification label here) URN: _____ Family Name: _____ Given Names: _____ Address: _____ Date of Birth: _____ Sex: <input type="checkbox"/> M <input type="checkbox"/> F <input type="checkbox"/> I
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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: _____ Preferred Name: _____
 Family Name: _____
 Address: _____
 DOB: _____ Sex: M F I Medicare No: _____

The person has the following:
If a decision-maker for personal/health matters has been legally appointed as per 1, 2 or 3 they should be the one completing this form. 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.

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

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

DO NOT WRITE IN THIS BINDING MARGIN

 QUEENSLAND HEALTH Advance Care Planning Statement of Choices (FORM B)	(A/N: patient identification label here) URN: _____ Family Name: _____ Given Names: _____ Address: _____ Date of Birth: _____ Sex: <input type="checkbox"/> M <input type="checkbox"/> F <input type="checkbox"/> I
--	--

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 involve severe disability 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 die: (e.g. home, hospital, nursing home)

Consider how the person would want to be cared for after they die. Think about their spiritual, religious and cultural practices, organ and tissue donation, and any other wishes that they would want noted.

Please turn over—
FORM B Page 2 of 4

DO NOT WRITE IN THIS BINDING MARGIN

Advance Care Planning - Statement of Choices (FORM B)

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

(Add 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 and I understand them:
 Yes No *if you have answered No please consult a doctor before continuing with this form.*

Medical and emergency preferences

Please remember, doctors need to speak with the relevant substitute decision-maker(s) 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 wish CPR attempted if it is consistent with good medical practice OR

The person would NOT wish CPR attempted under any circumstances OR

Other: _____

Other Life Prolonging Treatments (tick appropriate box)
 e.g. money machine (diagnosis), feeding tube, breathing machine (ventilator)

The person would wish for other life prolonging treatments if consistent with good medical practice OR

The person would NOT wish for other life prolonging treatments under any circumstances OR

Other: _____

Medical Treatments

If considered to be medically beneficial,	the person would wish for:	the person would NOT wish for:	undecided / no preference:
A major operation (e.g. under general anaesthetic)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Intravenous (IV) fluids	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Intravenous (IV) antibiotics	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other intravenous (IV) drugs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
A blood transfusion	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Please turn over—
FORM B Page 3 of 4

DO NOT WRITE IN THIS BINDING MARGIN

Advance Care Planning - Statement of Choices (FORM B)

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

(Add 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 it is updated or withdrawn.
 You may indicate a time period when you want to review this document (optional):
 6 monthly 12 monthly Other: _____

Understanding of the Document

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 as they are known to me and wishes reported to their substitute decision maker. I understand the person for whom this form applies does not understand them. I understand the views given in this document are not legally binding but can still have guiding effect.

I request the choices reported in this document be taken into account by health professionals as part of their decision-making capacity. I understand that the person for whom this form applies does not understand here the person will continue to receive all relevant care including care to relieve pain and alleviate suffering.

I consent to share the information on this form with persons/organisations 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: _____ Date: _____

Your Signature: _____

Usual Doctor's Statement

As a registered medical practitioner, I believe that the person for whom this form applies currently does not have the decision-making capacity necessary to complete a Statement of Choices on their own. I also believe that the person for whom this form applies does not understand them. I am not an appointed attorney in the Enabling Power of Best Interests of the person for whom this form applies. I am not an appointed attorney in the Enabling Power of Attorney document or Advance Health Directive, or a beneficiary under the will of the person for whom this form applies.

Doctor's Name: _____
 Doctor's Signature: _____
 Date: _____
 Yes N/A

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: 1300 008 227
 Email: acp@health.qld.gov.au
 Post: PO Box 2274, Runnymede QLD 4113
 For more information phone: 1300 007 227
www.mycaremychoices.com.au

FORM B Page 4 of 4

Appendix 4: Sample of comments re CPR and LPT

Table 13: Examples of comments added to SoC, by CPR preference and SoC type (labelled by age and gender)

Form Type	CPR pref	N=	Clarifying statement (age and gender of person for whom Form applied)
A	Would not wish for CPR under any circumstance	70	<p>Give me oxygen to keep me comfortable (86, F)</p> <p>I would not want ventilation, intubation, defibrillation, CPR (86, M)</p> <p>I am 87. I don't think it is beneficial to me at all (87, F)</p> <p>Unless able to come back to have quality of life (88, M)</p> <p>If there was no chance of a full recovery, no CPR (89, F)</p> <p>Depending on my general condition (89, F)</p> <p>At my age I would like to go quickly (92, F)</p> <p>Do nothing to keep me alive (92, M)</p> <p>There is no quality of life (92, M)</p> <p>Do not resuscitate me (94, M)</p> <p>Just let nature take its course (95, M)</p> <p>I wish to be made comfortable and pain free (96, F)</p> <p>No resuscitation under any circumstances (102, F)</p>
B		111	<p>Airway maintenance (e.g. clear choking) (85, F)</p> <p>Quality of life to be considered (86, F)</p> <p>For comfort cares only (86, M)</p> <p>He has reached the end of his life, has lost quality of life. No resuscitation (86, M)</p> <p>I don't feel I can make this decision, but his AHD, written before dementia says let nature its course (88, M)</p> <p>Would not wish to go to hospital (90, M)</p> <p>No to CPR but other methods that would make her comfortable OK (90, F)</p> <p>Would like to go quietly and as risks of CPR may lead to suffering, disability, vegetable, don't want CPR (91, M)</p> <p>Any treatment that might obstruct natural dying either not to be initiated or to be stopped (92, F)</p> <p>Given age and multiple illnesses, family feels CPR would not be in the best interests (92, M)</p> <p>You stop breathing, you stop breathing (95, M).</p> <p>At her advanced age and physical condition, CPR would not be beneficial (97, F)</p>

Form Type	CPR pref	N=	Clarifying statement (age and gender of person for whom Form applied)
A	Would want CPR if consistent with good medical practice	75	<p>No CPR in home by family (85, F)</p> <p>Any treatments without reduction of quality of life (85, M)</p> <p>I do not want to live on machines (85, M)</p> <p>As long as I could clearly communicate (85, F)</p> <p>Would not want CPR if there is no chance of recovery to a normal life (86, F)</p> <p>If in a good state of health (i.e. not having a terminal illness) (86, F)</p> <p>If outcome is likely to be confinement (as described in values section), then NO CPR (86, F)</p> <p>I wish CPR to be attempted (87, M)</p> <p>If my quality of life was the same "Have a go" (87, F)</p> <p>But not if I'm too sick (89, M)</p> <p>Do not want ventilator, feeding tube or life support via machines (90, F).</p> <p>Only if it was thought the resuscitation would determine to have a good outcome and I would return to my current level of mobility, cognition and communication (91, F)</p> <p>If in vegetative state, no CPR (92, F)</p> <p>Check with doctor (92, F)</p> <p>Only if a good positive outcome (93, F)</p> <p>Attempt CPR except in advanced stage of terminal illness (93, M)</p> <p>Feeding tube (93, M)</p> <p>I want a good doctor to decide I don't want to decide. No CPR if I will be a vegetable (95, M)</p> <p>I do not want defibrillation or ventilation (95, M)</p> <p>If appropriate for my age (98, M)</p> <p>Breathing assistance if otherwise healthy (100, M)</p>

Form Type	CPR pref	N=	Clarifying statement (age and gender of person for whom Form applied)
B	Would want CPR if consistent with good medical practice	48	<p>If his health condition meant he could no longer be independent, he would not want CPR (85, M)</p> <p>Not if outcome would lead to vegetative state (86, M)</p> <p>CPR only if she would be OK afterwards, otherwise no CPR (86, F)</p> <p>Has said in the past she would want doctors to give everything a go (87, F)</p> <p>At all times we will be guided by the opinions/ recommendations of medical specialists (87, F)</p> <p>Happy to have CPR however do not want her to be a vegetable or unconscious on life support (90, F)</p> <p>As long as he could continue to be healthy and not be a burden on the family (90, M)</p> <p>Not for CPR if in coma, vegetable state or with advanced dementia or irreversible condition (91, M)</p> <p>If outcome means he won't be incapacitated (92, M)</p> <p>You have to try (92, F)</p> <p>If the doctor believes it is in my grandmother's best interest (92, F)</p> <p>If there is no hope of survival or if J will be in pain or suffering, she would not want her suffering to be prolonged (93, F)</p> <p>It all depends on severity of incident (93, F)</p> <p>Need CPR (96, M)</p> <p>Only quality of life (96, F)</p> <p>Only if a good chance of decent recovery (98, M)</p> <p>Not if brain damage is the likely outcome (99, F)</p>
A	Other	104	<p>If condition dire, would prefer no CPR, otherwise CPR to be administered (if stroke, no CPR) (85, F)</p> <p>Family to make decision on advice from doctors (86, F)</p> <p>CPR only if some prospect of return to normal living i.e. in non-vegetative state, non-comatose and reasonably coherent and mobile (86, M)</p> <p>I prefer these treatments only if my quality of life will be improved (87, M)</p> <p>CPR if the outcome is expected to be good, but if I've been unwell for a long time and the outcome is expected to be not good, then no CPR (87, F)</p>

Form Type	CPR pref	N=	Clarifying statement (age and gender of person for whom Form applied)
	Other		<p>Attempt CPR but if not responding then stop (88, M)</p> <p>Do not undertake CPR if at end of life (88, F)</p> <p>If medical issue is allergic response. Defib OK for rhythm disturbance (89, F)</p> <p>After reasonable CPR. No prolonged CPR (89, M)</p> <p>To be determined by my EPOAs at the time (89, F)</p> <p>I would like CPR if the likely outcome is that I will return to normality. I do not want CPR if the likely outcome I that I will not return to normality (90, F)</p> <p>Discuss with daughters if possible (90, F)</p> <p>I want CPR if I have decent quality of life (91, F)</p> <p>Try for short period and only if arrest is witnessed (91, F)</p> <p>Three attempts at CPR only if consistent with good medical practice (92, M)</p> <p>CPR attempted for short time only (5 mins max) (93, M)</p> <p>Please attempt if not serious, but not if could lead to loss of conscious thought and decision making (93, F)</p> <p>Depending on quality of life (discuss with family) (95, F)</p> <p>I want the instructions on my AHD to be followed (97, F)</p> <p>No, I do not want to go to the hospital (100, F)</p>
B		134	<p>He would not wish for CPR if he could die peacefully and there was no chance of quality of life (85, M)</p> <p>Attempt if circumstances would not be terminal or in other words "minor", otherwise do not attempt (85, F)</p> <p>Mum only wants CPR if she is still in good health, she doesn't want CPR if she is very ill or terminal (86, F)</p> <p>They would want CPR if there would be good quality of life (86, M)</p> <p>CPR to be provided always, if and when required (86, F)</p> <p>Only if there will be no brain damage (88, F)</p> <p>They would not want CPR if the inevitable outcome was death (89, F)</p> <p>If my father became unconscious due to cardiac arrest, we would not want CPR. We would want him to be as peaceful as possible (89, M)</p> <p>G is of an age where doctors have advised CPR would likely do more harm than good. I will be guided by</p>

Form Type	CPR pref	N=	Clarifying statement (age and gender of person for whom Form applied)
	Other		<p>attending medical staff with the intention of doing the best for G in the moment (89, M)</p> <p>Attempt CPR if there is no brain injury and she, my wife, is still alive (90, F)</p> <p>Previous medical advice is CPR would be detrimental and of no benefit due to fragility and condition (90, F)</p> <p>D is 90 years of age and is not enjoying life. He would consider there is no point in prolonging life when he is not enjoying it (90, M)</p> <p>Don't keep going if she is not responding to the treatment (91, F)</p> <p>Would not want CPR if likely to be in vegetative state (92, M)</p> <p>CPR to be performed unless there is no good outcome (e.g. significant stroke) (92, F)</p> <p>CPR only when consideration has first been given to his condition or stage of dementia (94, M)</p> <p>Just wants to be let go (94, M)</p> <p>No CPR if it will prolong suffering (95, F)</p> <p>Only treatment if there is hope (96, M)</p> <p>If heart stops as nature intended or if CPR could result in broken ribs or brain deterioration, then NO. (96, M)</p> <p>Immediate life-saving effort only, not prolonged procedure (96, F)</p> <p>Let nature take its course (97, F)</p> <p>Would wish CPR to be done gently if it were to result in broken ribs (99, F)</p>

*Note: some text abbreviated as per body of thesis (eg cardiopulmonary resuscitation to CPR)

Table 14: Examples of comments added to SoC, by LPT preference and SoC type (labelled by gender and age)

Form Type	LPT pref	N=	Clarifying statement (labelled by gender and age of person for whom Form applied)
A	Would not wish for LPT under any circumstance	147	<p>Would still want dialysis (M, 85)</p> <p>If I'm not cognitively able to make my own decisions, I don't want people making decisions for me (M, 85)</p> <p>I would accept bipap / high flow oxygen (F, 86)</p> <p>Do not want ICU, intubation, dialysis (M, 86)</p> <p>Don't want to live as a "vegetable" (F, 86)</p> <p>If dying, allow me to die (M, 86)</p> <p>I want life quality, not life quantity (F, 86)</p> <p>No if terminal or incurable condition (F, 86)</p> <p>No treatment/hospital transfer (M, 87)</p> <p>I will accept IV antibiotics and fluids (F, 87)</p> <p>Only if the outcome may be positive (M, 87)</p> <p>No surgery is to be performed on me (M, 88)</p> <p>I only wanted to be kept comfortable and pain free with wife by my side (M, 89)</p> <p>If I was that bad, I don't think I'd love to live (M, 89)</p> <p>I do not want any machines to prolong life (F, 90)</p> <p>Just let me go (F, 90)</p> <p>Don't put children through any more sorrow (F, 91)</p> <p>Consult EPOA before any decision (F, 92)</p> <p>I would consider feeding tube (M, 93)</p> <p>Unless it is guaranteed to improve my overall condition and return me to normal self (F, 94)</p> <p>Including deactivation of pacemaker if there were no hope of recovery (M, 95)</p> <p>I wouldn't want to bash things out - everyone has to die one day (M, 95)</p> <p>Good comfort care (F, 96)</p> <p>Ventilation or NG tube are not appropriate (F, 96)</p> <p>I am happy for a drip for hydration and pain medicines (F, 101)</p>

Form Type	LPT pref	N=	Clarifying statement (labelled by gender and age of person for whom Form applied)
B	Would not wish for LPT under any circumstance	193	<p>Not when death is imminent (F, 85)</p> <p>I doubt he would want any of the treatments listed at this stage of his life (M, 86)</p> <p>Happy for antibiotics (F, 88)</p> <p>If prolonging life consistent with quality of life (F, 88)</p> <p>Ventilation or NG tube are not appropriate (F, 88)</p> <p>Accept ventilation if having difficulty breathing (F, 89)</p> <p>Blood transfusions only (M, 89)</p> <p>To be kept comfortable, peaceful & pain free (F, 90)</p> <p>At K's age he said no! (M, 90)</p> <p>Pain management/IV fluids for hydration (F, 91)</p> <p>Prioritise comfort and dignity (F, 91)</p> <p>Only to maintain consciousness until close family were informed/arrived - only for a short time (F, 91)</p> <p>Mum clearly stated this in her AHD (F, 92)</p> <p>C has always wanted a natural death (M, 92)</p> <p>Short term intervention only (F, 93)</p> <p>Only if there will be ongoing full quality of life (F, 93)</p> <p>Oxygen (mask) if conscious and short of breath and distressed/agitated, not for prolonging life (F, 93)</p> <p>Not for hospital admission (F, 93)</p> <p>Unless authorised on doctors' advice (M, 94)</p> <p>Would not be worth it (M, 95)</p> <p>Would still want to be consulted, perhaps feeding tube depending on Mum's condition (F, 95)</p> <p>Want mum to be managed in facility (F, 96)</p> <p>D and his (late) wife always promised each other not to prolong death (M, 97)</p> <p>Leave it in God's hands. His time will come (M, 98)</p> <p>For pain management only (F,101)</p>

Form Type	LPT pref	N=	Clarifying statement (labelled by gender and age of person for whom Form applied)
A	Would want LPT if consistent with good medical practice	90	<p>My quality of living is most important. I do not wish to be incapacitated (M, 85)</p> <p>Peace of mind. Living without pain (F, 85)</p> <p>Don't keep going if I am not responding (M, 85)</p> <p>If I could still speak for myself I agree to LPTs; but if I have lost capacity, no LPTs (F, 86)</p> <p>Antibiotics yes - but discuss with me (M, 85)</p> <p>I would want haemodialysis but not intubation or ICU admission (F, 86)</p> <p>Not for dialysis or feeding tube (M, 86)</p> <p>Do not prolong life if quality is poor (M, 86)</p> <p>Only if wife feels it would benefit me (M, 86)</p> <p>Only if quality of life remained. Have a go (F, 87)</p> <p>Not if I am in a coma or nearing end of life (F, 87)</p> <p>I am happy to receive LPT that can still improve my quality of life (M, 87)</p> <p>Not if I'm in a bad way & only if it was thought I could return to a good quality of life (F, 89)</p> <p>I want to be pain free, comfortable, let nature take its course in my death. I don't want to be a vegetable with no quality of life (M, 89)</p> <p>Probably don't want a ventilator (M, 89)</p> <p>Only if chance of good outcome, not reliant on them to support me (F, 89)</p> <p>Only to allow time for family to attend (M, 90)</p> <p>Only if there was a hope of recovery to my current state - living at home, walking and talking (M, 90)</p> <p>Only if there is a chance of full recovery (F, 92)</p> <p>If there is a realistic possibility of recovery of my independence (F, 95)</p> <p>I don't like machines, but let the doctor decide. Sons don't want me to have feeding tube (M, 95)</p> <p>Only if it will improve my health not if it will just prolong my suffering (F, 98)</p>

Form Type	LPT pref	N=	Clarifying statement (labelled by gender and age of person for whom Form applied)
B	Would want LPT if consistent with good medical practice	56	<p>If his condition mean he could no longer walk or be independent he would not want LPTs (M, 85)</p> <p>If the treatments are minimal and do not result in her being kept alive by machines (F, 86)</p> <p>No cancer surgery or treatments (M, 86)</p> <p>G often says that if I (his wife) should pre-decease him he would no longer wish to be around (M, 86)</p> <p>No feeding tube (F, 87)</p> <p>If possible, keep alive until family can visit (F, 88)</p> <p>Send to hospital if condition deteriorates (F, 88)</p> <p>Would wish for other LPT except dialysis (F, 88)</p> <p>Provided high likelihood of full recovery (F, 90)</p> <p>You have to try (F, 92)</p> <p>Would not choose LPT if they kept Mum in pain or fully incapacitated (F, 92)</p> <p>Dad to be treated & transferred to hospital (M, 93)</p> <p>Does not wish to have oral antibiotics unless it is for relief of pain (M, 95)</p> <p>Only focus on quality of life (F, 95)</p> <p>Oxygen should be supplied if it sustains life (F, 96)</p>
A	Other	155	<p>Only if underlying condition can be treated (M, 85)</p> <p>With least intervention but pain removal OK (F, 85)</p> <p>Only if subsequent health is expected without machine help (M, 85)</p> <p>Comfort only, pain free, maintain dignity (F, 86)</p> <p>Short term only and if I could return to my current state (walking, talking, independence) (F, 87)</p> <p>Leave to doctor's discretion (M, 87)</p> <p>Only if full cognitive recovery possible (F, 87)</p> <p>Not dialysis - I would like intensive care and would be happy for ventilation also feeding tube (F, 89)</p> <p>I would not wish for any treatment (M, 89)</p> <p>Only for immediate post-operative recovery (F, 89)</p> <p>I would consider hi-flow oxygen and Bipap temporarily, if quality outcomes are assured (F, 90)</p> <p>Only if necessary to reduce pain and suffering, otherwise allow me to die (F, 91)</p>

Form Type	LPT pref	N=	Clarifying statement (labelled by gender and age of person for whom Form applied)
	Other		<p>If it is for a short period only (2 days) (F, 91)</p> <p>If I can recover to think clearly and be active with a good quality of life (F, 91)</p> <p>If death was inevitable then I wouldn't wish for this treatment or to prolong life (M, 91)</p> <p>Don't want breathing machine / feeding tube (M, 92)</p> <p>Only if it would 'better the situation' - doctors will advise. I don't think it's nice to be kept alive, if it was futile (F, 92)</p> <p>I can't see my quality of life improving now. If I needed dialysis or ventilation for extended time, my GP would assist in decision making (M, 93)</p> <p>I wish only for kidney dialysis (machine) (F, 94)</p> <p>Let my son decide (M, 95)</p> <p>No such treatment if it would leave me totally reliant on others, or on the machinery involved (M, 95)</p> <p>If I am so seriously ill that there is no likelihood of recovery then I do not wish to be subjected to medical intervention (F, 97)</p>
B		191	<p>If quality of life (defined by values / enjoyments / ability to interact with family and friends) was to continue as a result of treatment (F, 85)</p> <p>Ventilator if it keeps her calm and settled (F, 85)</p> <p>Family consultation and decision considering circumstances at the time (F, 86)</p> <p>If appropriate - do what can. If he cannot manage then let him go peacefully and naturally (M, 87)</p> <p>No to try and prolong life long term, but yes to improving quality of life that remains (F, 87)</p> <p>Short term ventilator only not long term (F, 88)</p> <p>Oxygen as comfort, not life support (F, 88)</p> <p>No kidney machine, no feeding tube, but ventilator if no brain damage (M, 90)</p> <p>Depending on the length of time the treatments were needed, the condition being treated and the possible outcome (F, 90)</p> <p>If the doctor thinks a ventilator will give him quality of life, no feeding tube (M, 91)</p>

Form Type	LPT pref	N=	Clarifying statement (labelled by gender and age of person for whom Form applied)
	Other		<p>Only provide oxygen and other treatments, if conscious (F, 91)</p> <p>If it gives time for family members time to be at her bedside (F, 91)</p> <p>Dad does not want dialysis (M, 91)</p> <p>Would not want to be on machines - it is unlikely to get off them (M, 92)</p> <p>Only provide these treatments if his quality of life will be improved or maintained (M, 92)</p> <p>Would wish if good medical practice for person of S's age (M, 95)</p> <p>Dad values life, but not under all conditions. He considers dignity and quality of life to be more important than mere existence. He would want this to be considered and the would want to be given sufficient medication to control his pain, even if it hastened his death (M, 95)</p> <p>Would prefer palliative care rather than LPT, except where antibiotics are appropriate (F, 96)</p>

*Note: some text abbreviated as per body of thesis (eg life prolonging treatment to LPT)

Appendix 5: Sample of comments regarding PPOD

Additional comments around place of death (age, gender, SoC type):

- To die in my sleep but I need to be safe and secure, so probably hospital (85, F, A)
- Wherever God takes her (85, F, B)
- Where it is the safest (85, M, B)
- Where dignity and comfort can be provided (85, F, B)
- At home or in hospital, he has not really said (85, M, B)
- In my sleep, in my own bed (86, M, A)
- Wherever my body is lying, preferably in my bed (86, M, A)
- With family around (multiple)
- I think it might be better in hospital as no family around (86, F, A)
- I would go for a swim and keep swimming and I know exactly where I will go (86, F, A)
- Flexible dependent on circumstances (87, F, A)
- At home, not at hospital (87, F, B)
- Ideally home, been in nursing home for several years (87, F, B)
- Hospital better for family (87, F, B)
- Wherever I am at the time (multiple)
- Doesn't worry me, when I'm dead I'm dead (88, F, A)
- Refer to my power of attorney (88, F, A)
- Pass naturally, at his new home, the nursing home (89, M, B)
- Comfortably and not alone (89, F, A)
- Hospital – important for his dignity and beliefs (91, M, B)
- I have never thought about it (91, M, A)
- Want to die at home or in my garden (92, M, A)
- Whatever is easiest for the family (93, M, A)
- No preference (multiple)
- It doesn't matter much to me (96, F, A)
- No preference, hospice was nice (97, M, A)
- Wherever I happen to be (98, F, A)
- Has fear of hospital so home or nursing home (104, F, B)

Appendix 6: Queensland Advance Health Directive

Note: AHD explanatory guide available (Queensland Government, 2020a)

What is an advance health directive?

At some point in the future, you may be unable to make decisions about your health care, even temporarily.

Your advance health directive is a legal document that allows you to give **directions about your future health care and special health care**.

- **Health care** includes most medical treatments, procedures and services to treat both physical and mental conditions. When nearing the end of your life, the definition of health care also includes **life-sustaining treatment**.
- **Special health care** includes special procedures such as participation in special medical research.

Your advance health directive also allows your wishes to be known and gives health professionals direction about the treatment you want.

As the person who is making this advance health directive, you are referred to as the **'principal'**. Any directions you give in this advance health directive will only **operate if you do not have capacity** to make decisions about your health care.

Appointing an attorney (decision-maker)

You can also use this form to appoint someone that you trust to make decisions about your health care if there is a time when **you do not have capacity to make decisions about your health care**. The person you appoint is called your **'attorney'**.

Important information about your advance health directive

- This form can only be completed by an adult who has capacity to make an advance health directive. This means you must be able to understand the nature and consequences of the signing. You must be making this document freely and voluntarily, not due to pressure from someone else to make it.
- **A doctor must sign section 5 'doctor certificate' of this form.**
- **You must sign this form in the presence of an eligible witness** (a justice of the peace (JP), commissioner for declarations, lawyer or notary public).
- If an interpreter is required to interpret or translate this document, they should complete [Form 7 – Interpreter's/Translator's statement](#).
- You are not required to register this advance health directive anywhere.

What to do with this advance health directive once complete:

- give a certified copy to your attorney(s) (if appointed), lawyer, doctor or health provider(s)
- notify your close family and friends that you have made an advance health directive and where to find the document.

Page 2 | **ADVANCE HEALTH DIRECTIVE** | Version 5, approved for use from 30 November 2020.

Form 4

Powers of Attorney Act 1998 (Qld) section 44(2)
Version 5, approved for use from 30 November 2020.

For patient record purposes, health services can affix identification label here

Advance health directive (Queensland)

Use this form to give directions about your future health care and special health care. You can also use this form to appoint an attorney(s) for health matters.

To help you complete this form, please read [Form 10 – A advance health directive explanatory guide](#) first.

You should then talk to people who are important to you and can help inform your healthcare choices including your doctor, family and friends.

Forms and explanatory guides are available at www.qld.gov.au/queenship-planahead

Page 1

Queensland Government

ADVANCE HEALTH DIRECTIVE | Version 5, approved for use from 30 November 2020.

SECTION 1: YOUR PERSONAL DETAILS

You must fill in your full name, date of birth and address.

Refer to section 1, page 5 of Form 10—Advance Health Directive Explanatory Guide.

Full name			
Date of birth			
Address		State	Postcode
Suburb			
Phone number			
Email			

SECTION 2: YOUR HEALTH CONDITIONS AND CONCERNS

My major health conditions and concerns are:

Refer to section 2, page 5 of Form 10—Advance Health Directive Explanatory Guide.

Cross out this section if you do not want to complete it. If you do complete this section cross out any space in the box that you do not use.

SECTION 3: YOUR VIEWS, WISHES AND PREFERENCES

This section lets your health provider, family and friends know what is important to you now and into the future.

You are not giving directions about your health care (section 4 allows you to do this). You should discuss this section with your doctor before completing it.

Refer to section 3, pages 5–6 of Form 10—Advance Health Directive Explanatory Guide.

Cross out this section if you do not want to complete it. If you do complete this section cross out any space in the boxes that you do not use.

(b) These things worry me about my future: (e.g. being unable to live at home, being unable to communicate)

(c) These are the cultural, religious or spiritual values, rituals or beliefs I would like considered in my health care:

(d) When I am nearing death, the following would be important to me and would comfort me: (e.g. you may prefer to die at home or you may like a certain type of music played)

(e) I would prefer these people to be involved in discussions about my health care:

(f) I would prefer these people not be involved in discussions about my health care:

SECTION 4: YOUR DIRECTIONS

Before completing section 4, it is recommended that you discuss your proposed directions with your doctor.

DIRECTIONS ABOUT LIFE-SUSTAINING TREATMENT

This part allows you to give directions about life-sustaining treatment when you are nearing the end of your life. For directions about health care other than life-sustaining treatments, complete the part 'Directions about other health care' on page 7.

Life-sustaining treatments are aimed at sustaining or prolonging your life (i.e. keeping you alive or delaying your death). Examples could include CPR (cardiopulmonary resuscitation) and assisted ventilation (e.g. the use of a breathing machine).

Your directions about life-sustaining treatment that you provide below will only apply if you are unlikely to regain capacity to make your own decisions about health care and one of the following applies:

- » you are so unwell due to a terminal illness or condition that, in the opinion of two doctors, you are reasonably likely to die in the next 12 months
- » you are so unwell due to an injury or illness that there is no reasonable prospect that you will recover to the extent that you can live without life-sustaining treatment
- » you are permanently unconscious (with no reasonable prospect of regaining consciousness)
- » you are in a persistent vegetative state (involving severe and irreversible brain damage).

A health provider does not have to follow directions in an advance health directive that are not consistent with good medical practice or will not benefit you. A health provider also does not have to follow directions that are uncertain or where circumstances, including advances in medicine, have changed to the point that your directions are no longer appropriate. **Before completing this section, it is recommended that you discuss your proposed directions with your doctor.**

I give the following directions about life-sustaining treatment:

(Please choose only one of the following four options)

Option 1

I consent to all treatments aimed at sustaining or prolonging my life.

OR

Option 2

I refuse any treatments aimed at sustaining or prolonging my life.

OR

Option 3

I cannot decide at this point. I want my attorney(s) to make the decisions about life-sustaining treatment on my behalf at the time the decision needs to be made using the information in this advance health directive and in consultation with my health providers and the people I have listed in section 3.

OR

See next page for option 4.

You can only choose one option.

Read all four options (see next page for option 4) before you make a decision.

Refer to section 4, pages 7–8 of Form 10—Advance health directive & explanatory guide.

Option 4

I give the following specific directions about life-sustaining treatments:

(Pick one box per row in the table below)

Life-sustaining treatment	(a) I consent to this treatment in all circumstances	(b) I refuse this treatment in all circumstances	(c) I consent to this treatment in the following circumstances (see next page for more information)
CPR (For greater detail, specify circumstances here)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Assisted ventilation (For greater detail, specify circumstances here) Use of a device which assists your breathing through a face mask or a breathing tube	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Artificial nutrition (e.g. a feeding tube through the nose or stomach) (For greater detail, specify circumstances here)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Artificial hydration (e.g. intravenous (IV) fluids) (For greater detail, specify circumstances here)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Antibiotics (For greater detail, specify circumstances here)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other life-sustaining treatment (State the treatment, e.g. kidney dialysis) (For greater detail, specify circumstances here)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

I need more space.

Attach any additional pages to this form and indicate the box in which the extra pages are attached.

Page 6 | **ADVANCE HEALTH DIRECTIVE** | Version 5, approved for use from 10 November 2020.

Page 5 | **ADVANCE HEALTH DIRECTIVE** | Version 5, approved for use from 10 November 2020.

DIRECTIONS ABOUT OTHER HEALTH CARE

I give the following directions about my health care:

Health condition (if relevant) Directions about my health care

This part allows you to give directions about health care, other than life-sustaining treatment. You can use this part to give directions to consent to or refuse health care. You do not need to specify a health condition but your directions need to be clear. Refer to section 4, page 9 of Form 10 – Advance health directive explanatory guide.

I need more space.

Attach any additional pages to this form and include them in the envelope.

DIRECTIONS ABOUT BLOOD TRANSFUSIONS

I give the following direction about blood transfusions:

(Please use one only)

I consent to a blood transfusion

OR

I do not consent to a blood transfusion

OR

other: _____

(If you select one, you must specify the circumstances or types of transfusions that you consent to or refuse, e.g. I consent to a transfusion of blood products but not blood.)

SECTION 5: DOCTOR CERTIFICATE

A doctor must complete, sign and date this section.

DOCTOR

- By signing below, I certify that:
- I am a doctor.
 - I have discussed the contents of this advance health directive with the principal.
 - At the time of making this advance health directive the principal appeared to me to have the capacity to make this advance health directive. The principal appeared to:
 - understand the nature and effect of this advance health directive
 - be capable of making this advance health directive freely and voluntarily.
 - I am not:
 - the person witnessing this advance health directive
 - the person signing this advance health directive for the principal
 - an attorney of the principal
 - a relation of the principal or relation of an attorney of the principal
 - a beneficiary under the principal's will.

INFORMATION FOR THE DOCTOR
Refer to section 5, pages 9–10 of Form 10 – Advance health directive explanatory guide and the Queensland Capacity Assessment Guidelines.

Doctor's name	
Name of facility or practice	
Address of facility or practice	
Suburb	State
Phone number	Postcode
Doctor's signature: _____ Date: _____	

SECTION 6: APPOINTING AN ATTORNEY(S) FOR HEALTH MATTERS

This section allows you to appoint one or more attorneys to make decisions about health care for you. You can choose how your attorney(s) can make decisions (e.g. jointly, severally, by a majority, successively or alternatively). You can also set terms on your attorney(s)' decision-making power or provide instructions on how your attorney(s) exercise their power.

WHO ARE YOU APPOINTING AS YOUR ATTORNEY(S) FOR HEALTH MATTERS?

Your attorney(s) must:

- have capacity to make decisions for the matter they are being appointed for
- be 18 years or older
- not be a service provider for a residential service if you are a resident there
- not be your paid carer in the previous three years or your health provider.

Note: a paid carer is someone who is paid a fee or wage to care for a person but not someone receiving a carer's pension or benefit.

Your attorney(s) cannot make decisions that are inconsistent with your instructions or if these instructions are clear and can be followed by your health providers.

Refer to section 6, pages 10–11 of Form 10 – [Advance health directive explanatory guide](#).

Fill out this part if you do not want to complete it.

Full name			
Address	Suburb	State	Postcode
Phone number			
Email			
Full name			
Address	Suburb	State	Postcode
Phone number			
Email			
Full name			
Address	Suburb	State	Postcode
Phone number			
Email			

I am appointing an additional attorney(s) and need more space. Attach any additional pages to this form and tick the box to indicate that extra pages are attached.

HOW MUST YOUR ATTORNEYS MAKE DECISIONS?

If you do not complete this part your attorneys must make decisions jointly.

I authorise my attorneys to make decisions:

(Please tick only)

jointly (all of my attorneys must agree on all decisions)

OR

severally (any one of my attorneys may decide)

OR

by a majority (more than half of my attorneys must agree on all decisions)

OR

other: (e.g. jointly and severally, or appointing a successive or alternative attorney) *(If you choose 'other', please specify how you want your attorneys to make decisions)*

TERMS AND INSTRUCTIONS FOR YOUR ATTORNEY(S)

Write the terms and instructions for your attorney(s) here.

Only complete this part if you do not want terms on the exercise of power by your attorney(s) or provide instructions to your attorney(s) about the exercise of their powers.

Refer to section 6, page 13 of Form 10 – [Advance health directive explanatory guide](#).

Fill out this part if you do not want to complete it. If you do complete this part cross out any space in the box that you do not use.

I need more space to write my terms and instructions.

Attach any additional pages to this form and tick the box to indicate that extra pages are attached.

SECTION 7: DECLARATIONS AND SIGNATURES

PRINCIPAL'S SIGNATURE

By signing this document, I confirm that:

- » I am making this advance health directive freely and voluntarily.
- AND**
- » I understand the nature and effect of this advance health directive including:
 - » the nature and likely effects of each direction in this advance health directive
 - » that a direction operates only while I do not have capacity for the health matter covered by the direction
 - » that I may revoke a direction at any time I have the capacity to make a decision about the health matter covered by the direction
 - » that at any time I do not have capacity to revoke a direction, I will be unable to effectively oversee the implementation of the direction.

AND

- » I understand that if I am appointing an attorney(s) for health matters that:
 - » I may specify or limit my attorney(s)' power and instruct my attorney(s) about the exercise of the power
 - » the power given to my attorney(s) begins when I lose capacity to make decisions for health matters
 - » once my attorney(s)' power begins, my attorney(s) will have full control over, and power to make decisions about, health matters subject to any terms or information included in this advance health directive
 - » I may revoke the power given to my attorney(s) in this advance health directive at any time I am capable of making an advance health directive giving the same power
 - » the power I am giving to my attorney(s) continues even if I do not have capacity to make decisions about health matters
 - » If I am not capable of revoking this advance health directive, I will not be able to oversee the use of the power given to my attorney(s) for health matters.

ONLY SIGN THIS PART IN FRONT OF AN ELIGIBLE WITNESS

Principal's signature: _____ Date: _____
 Witness's signature: _____ Date: _____
(Witness must also sign Page 12)

Person signing for the principal

By signing this document, I confirm that:

- » the principal instructed me to sign this document
- » I am 18 years or older
- » I am not an attorney of the principal.

Name		
Address		
Suburb	State	Postcode

ONLY SIGN THIS PART IN FRONT OF THE PRINCIPAL AND AN ELIGIBLE WITNESS

Person signing for the principal signs here: _____ Date: _____
 Witness's signature: _____ Date: _____

WITNESS CERTIFICATE

This part must be filled in and signed by the eligible witness at the same time that you sign the advance health directive.

By signing this document, I certify that: *(Tick one box only)*

the principal signed this advance health directive in my presence

OR

in my presence, the principal instructed another person to sign this advance health directive for the principal, and that person signed it in my presence and in the presence of the principal.

INFORMATION FOR THE WITNESS

As a witness you are not simply witnessing the principal's signature. You must also be satisfied that the principal appears to have capacity to make the advance health directive.

Refer to section 7, page 14-15 of Form 10—Advance health directive explanatory guide and the *Questions and Capacity Assessment Guidelines 2020*.

- AND**
- » I am a: *(Tick one box only)*
 - justice of the peace (JP)
 - commissioner for declarations
 - lawyer
 - notary public.
 - » I am not:
 - » the person signing the document for the principal
 - » an attorney of the principal
 - » a relation of the principal or relation of an attorney of the principal
 - » a paid carer or health provider of the principal
 - » a beneficiary under the principal's will.

I have verified that section 5 of this advance health directive has been signed and dated by a doctor.

At the time of making this advance health directive the principal appears to have the capacity to make this advance health directive. The principal appears to:

- » understand the nature and effect of this advance health directive
- » be capable of making the advance health directive freely and voluntarily.

This document (including any additional pages) has _____ pages.

Witness's signature: _____ Date: _____
 Witness's name: _____
(Witness must also sign page 11)

SECTION 8: ATTORNEY(S)' ACCEPTANCE

If you have appointed an attorney(s) under section 6 of the *Advance Care Planning Act 2012*, you must sign this section.

It does not matter which order your attorney(s) sign this section.

Your attorney(s) must sign this section of the original form after you and the witness have signed section 7.

INFORMATION FOR ATTORNEYS

An attorney has important duties and obligations.

Refer to section 8, page 17 and pages 22–24 of *Form 10 – Advance Care Planning* for further information about the duties and obligations of an attorney.

Note: a paid carer is someone who is paid a fee or wage to care for a person but not someone receiving a carer's pension or benefit.

In signing this advance health directive I accept the appointment in accordance with the terms of this advance health directive and confirm that:

- I have read this advance health directive and understand that I must make decisions and exercise power in accordance with this advance health directive, the *Powers of Attorney Act 1996* and the *Guardianship and Administration Act 2000*.

I understand:

- in exercising my powers I must apply the general principles and if exercise powers for health care matters, the general care principles under the *Powers of Attorney Act 1996* and the *Guardianship and Administration Act 2000*.

the obligations of an attorney and the consequences of failing to comply with those obligations.

I declare that:

- I have capacity for the matter that I am appointed for
- I am 18 years or older
- I am not a paid carer for the principal
- I am not a health provider for the principal
- I am not a service provider for a residential service where the principal is a resident.

Signature: _____ Date: _____

Full name: _____ Date: _____

Signature: _____ Date: _____

Full name: _____ Date: _____

Signature: _____ Date: _____

Full name: _____ Date: _____

Signature: _____ Date: _____

Full name: _____ Date: _____

I have appointed an additional attorney(s) and need more space for my attorney(s) to sign. Attach any additional pages to this form and tick the box to indicate extra pages are attached.

SECTION 9: WHAT TO DO WITH YOUR COMPLETED ADVANCE HEALTH DIRECTIVE

You should:

- keep the original in a safe place
- give a certified copy to your attorney(s) (if appointed), doctor, other health provider(s), bank or lawyer
- notify your close family and friends that you have made an advance health directive and where to find the document
- review your advance health directive at least every two years or if your health changes significantly.

Refer to 'Further information' on pages 18–19 of *Form 10 – Advance Care Planning* for information on how to make a certified copy and how your advance health directive may be revoked.

My Health Record

If you wish your document to be in My Health Record you can upload it via the My Health Record website at www.myhealthrecord.gov.au. Your document will be valid regardless of whether it is uploaded.

Office of Advance Care Planning

You are able to have your advance health directive uploaded to your Queensland Health electronic record. To do this, send a copy of your document to the Office of Advance Care Planning. This way it will be easily available to authorised clinicians involved in your care when it is required. A copy of your document can be sent to the Office of Advance Care Planning at acp@health.qld.gov.au, PO Box 2274, Runnymede, Queensland 4113 or fax 1300 008 227.

What about registering as an organ donor?

If you are interested in donating your organs after death, visit the Australian Organ Donor Register at donorregister.gov.au

Appendix 7: Queensland Enduring Power of Attorney (short)

Note: EPOA explanatory guide available (Government, 2020)

Form 2
Powers of Attorney Act 1995 (section 44(1))
Version 4 - approved for use from 30 November 2020.

For patient record purposes, health services can affix identification label here

Enduring power of attorney –short form (Queensland)


This form allows you to appoint someone you trust (an "attorney") to make decisions for you during your lifetime. Use this form to appoint:

- » attorney(s) for personal (including health) matters only
- » attorney(s) for financial matters only
- » the same attorney (s) for both personal (including health) matters and financial matters.

Before you complete this form, read [Form 9 – Enduring power of attorney explanatory guide](#), consider who you want to appoint and talk to them.

This is a **legal document** that can significantly affect your legal rights. It is recommended that you seek independent legal advice before completing this form.

Forms and explanatory guides are available at www.qld.gov.au/queenslandship-plainhead



ENDURING POWER OF ATTORNEY – SHORT FORM | Version 4 - approved for use from 30 November 2020.

Is this the right form for you?

- » Use [Form 2 – Enduring power of attorney – short form](#) (this form) to appoint:
 - » attorney(s) for personal (including health) matters only
 - » the same attorney(s) for both personal (including health) matters and financial matters.
- » Use [Form 3 – Enduring power of attorney – long form](#) to appoint **different attorneys for personal (including health) matters and for financial matters.**

What is an enduring power of attorney?

Your enduring power of attorney allows you to appoint someone you trust to make decisions for you during your lifetime. The person you appoint is called your **attorney**. Your attorney does not have to be a lawyer. As the person who is making this enduring power of attorney, you are referred to as the **principal**.

What types of decisions can your attorney make for you?

Your attorney can make decisions about:

- » **personal (including health) matters** – decisions about lifestyle decisions. This includes decisions about support services, where and with whom you live, health care and legal matters that do not relate to your financial or property matters.
- » **financial matters** – Financial matters relate to your financial or property affairs including paying expenses, making investments, selling property or carrying on a business.

Important information about your enduring power of attorney

- » You can decide when your attorney(s) power to make decisions for **financial matters** begins. Your attorney(s) power to make decisions for **personal matters** operates during times when you do not have capacity to make decisions about those matters.
- » During those times your attorney(s) will have full powers to make decisions unless you set terms or provide instructions in this form.
- » This form can only be completed by an adult who has capacity to make an enduring power of attorney. This means you must fully understand the nature and effect of this document and the powers it gives. You must be making this document freely and voluntarily, not due to pressure from someone else.
- » **You must sign this form in the presence of an eligible witness** (a justice of the peace (JP), commissioner for declarations, lawyer or notary public).
- » If an interpreter is required to interpret or translate this document, they should complete [Form 7 – Interpreters/translators statement](#).

What to do with this enduring power of attorney once complete:

- » Keep the original in a safe place.
- » Give a certified copy to your attorney(s), doctor, other health providers(s), bank or lawyer
- » Notify your close family and friends that you have made an enduring power of attorney, and where to find this document.
- » If your attorney(s) wish to deal with land in Queensland on your behalf, your enduring power of attorney must first be registered with the Queensland Titles Registry by lodging a [Form 16 – Request to register power of attorney](#), together with a single-sided certified copy of the enduring power of attorney.

Page 2 | ENDURING POWER OF ATTORNEY – SHORT FORM | Version 4 - approved for use from 30 November 2020.

SECTION 1: YOUR PERSONAL DETAILS

You must fill in your full name and address. Refer to section 1, page 6 of form 9 – Enduring Power of Attorney explanatory guide.

Full name			
Address		State	Postcode
Suburb			
Phone number		Email	

SECTION 2: YOUR VIEWS, WISHES AND PREFERENCES

This is what I want my attorney(s) to know about me when making decisions for me: (e.g. your views about where you would prefer to live, your healthcare preferences and any other views, wishes and preferences you would like your attorney(s) to know)

Your attorney(s) must consider your views, wishes and preferences when making decisions for you but these are not instructions to your attorney(s). Section 2 allows you to provide information about yourself, including what is most important to you in life now and into the future. Refer to section 2, page 6 of form 9 – Enduring Power of Attorney explanatory guide. **Cross out this section if you do not want to complete it. If you do complete this section cross out any space in the box that you do not use.**

SECTION 3: YOUR ATTORNEY(S)

This section allows you to appoint one or more attorneys to make decisions for you. You can also choose the types of decisions your attorney(s) can make and how they make these decisions (e.g. jointly, severally or by a majority). There is no limit on the number of attorneys you can appoint, except that you can only appoint a maximum of four joint attorneys for a matter (i.e. you can only appoint a maximum of four people who must agree on all decisions). You can set terms on their decision-making powers or provide instructions on how they exercise their powers.

WHO ARE YOU APPOINTING AS YOUR ATTORNEY(S)?

You must fill in the details of each of your attorney(s). I appoint the person(s) listed below as my attorney(s): (in no particular order)

Full name			
Address		State	Postcode
Suburb			
Phone number		Email	
Full name			
Address		State	Postcode
Suburb			
Phone number		Email	
Full name			
Address		State	Postcode
Suburb			
Phone number		Email	
Full name			
Address		State	Postcode
Suburb			
Phone number		Email	

Your attorney(s) must:

- have capacity to make decisions for the matter they are being appointed for
 - be 18 years or older
 - not be a service provider for a residential service if you are a resident there
 - for a financial matter, not be taking advantage of the laws of bankruptcy
 - not be your paid carer in the previous three years or your health care provider
- Notes: a carer is someone who is paid a fee or wage to care for a person but not someone receiving a pension or benefit.

Refer to section 3, pages 7–8 of form 9 – Enduring Power of Attorney explanatory guide.

I am appointing additional attorney(s) and need more space.

Attach any additional pages to this form and tick the box to indicate the extra pages are attached.

WHAT DECISIONS CAN YOUR ATTORNEY(S) MAKE?

You must complete this part. Use Form 2 – Enduring power of attorney – short form (this form) to appoint:

- I authorise my attorney(s) to exercise power for:**
 - personal (including health) matters only**
Personal matters relate to personal or lifestyle decisions. This includes decisions about support services, where and with whom you live, health care and legal matters that do not relate to your financial or property matters.
- OR
- financial matters only**
Financial matters relate to your financial or property affairs including paying expenses, making investments, selling property or carrying on a business.
- OR
- personal (including health) matters and financial matters.**

To appoint an attorney(s) for personal (including health) matters and a different attorney(s) for financial matters you should use Form 3 – Enduring power of attorney – long form.

Refer to section 3, page 9 of Form 2 – Enduring power of attorney explanatory guide.

WHEN DOES YOUR ATTORNEY(S)' POWER BEGIN FOR FINANCIAL MATTERS?

Your attorney(s)' power to make decisions for personal matters begins if and when you do not have capacity to make decisions.

If a person is unsure whether they have capacity, they can seek a practitioner or a declaration from the Queensland Civil and Administrative Tribunal (QCAT) or the Supreme Court.

- Refer to page 4 of Form 2 – Enduring power of attorney explanatory guide and the Queensland Civil and Administrative Tribunal Act 2004 (QCAT Act 2004) for information about capacity to make a decision for a matter.
- Refer to section 3, page 9 of Form 2 – Enduring power of attorney explanatory guide for information about when your attorney(s)' power for financial matters will begin.
- I authorise my attorney(s) to exercise power for financial matters:**
 - when I do not have capacity to make decisions for financial matters
 - OR
 - immediately
 - OR
 - at this time, or in this circumstance, or on this occasion:
(You must specify the time, circumstance or occasion)

HOW MUST YOUR ATTORNEYS MAKE DECISIONS?

If you do not complete this part, your attorneys must make decisions jointly. I authorise my attorneys to make decisions:

- jointly (all of my attorneys must agree on all decisions)
(Tick one box only)
- OR
- severally (any one of my attorneys may decide)
- OR
- by a majority (more than half of my attorneys must agree on all decisions)
- OR
- other: (e.g. jointly and severally, or appointing a successor or alternative attorney) (If you choose 'other', please specify how you want your attorneys to make decisions)

TERMS AND INSTRUCTIONS FOR YOUR ATTORNEY(S)

This part allows you to provide terms and instructions for your attorney(s). You can provide:

- general terms and instructions
- terms and instructions about who your attorney(s) must notify when exercising a power for personal (including health) matters
- terms and instructions about who your attorney(s) must notify when exercising a power for financial matters.

Terms and instructions (general terms and instructions)

Only complete this part if you want to set terms on the exercise of powers by your attorney(s) or provide instructions to your attorney(s) about the exercise of their powers.

Refer to section 3, page 12 of Form 2 – Enduring power of attorney explanatory guide about terms and instructions (general terms and instructions).

Refer to page 12 of Form 2 – Enduring power of attorney explanatory guide about conflict transactions (e.g. if you are appointing your spouse as your attorney).

Cross out this part if you do not want to complete it. If you do complete this part, you must provide space in the box that you do not use.

- I need more space to write my terms and instructions. Attach any additional pages to this form and tick the bar to indicate that extra pages are attached.

WHAT DECISIONS CAN YOUR ATTORNEY(S) MAKE?

You must complete this part. Use Form 2 – Enduring power of attorney – short form (this form) to appoint:

- I authorise my attorney(s) to exercise power for:**
 - personal (including health) matters only**
Personal matters relate to personal or lifestyle decisions. This includes decisions about support services, where and with whom you live, health care and legal matters that do not relate to your financial or property matters.
- OR
- financial matters only**
Financial matters relate to your financial or property affairs including paying expenses, making investments, selling property or carrying on a business.
- OR
- personal (including health) matters and financial matters.**

To appoint an attorney(s) for personal (including health) matters and a different attorney(s) for financial matters you should use Form 3 – Enduring power of attorney – long form.

Refer to section 3, page 9 of Form 2 – Enduring power of attorney explanatory guide.

WHEN DOES YOUR ATTORNEY(S)' POWER BEGIN FOR FINANCIAL MATTERS?

Your attorney(s)' power to make decisions for personal matters begins if and when you do not have capacity to make decisions.

If a person is unsure whether they have capacity, they can seek a practitioner or a declaration from the Queensland Civil and Administrative Tribunal (QCAT) or the Supreme Court.

- Refer to page 4 of Form 2 – Enduring power of attorney explanatory guide and the Queensland Civil and Administrative Tribunal Act 2004 (QCAT Act 2004) for information about capacity to make a decision for a matter.
- Refer to section 3, page 9 of Form 2 – Enduring power of attorney explanatory guide for information about when your attorney(s)' power for financial matters will begin.
- I authorise my attorney(s) to exercise power for financial matters:**
 - when I do not have capacity to make decisions for financial matters
 - OR
 - immediately
 - OR
 - at this time, or in this circumstance, or on this occasion:
(You must specify the time, circumstance or occasion)

HOW MUST YOUR ATTORNEYS MAKE DECISIONS?

If you do not complete this part, your attorneys must make decisions jointly. I authorise my attorneys to make decisions:

- jointly (all of my attorneys must agree on all decisions)
(Tick one box only)
- OR
- severally (any one of my attorneys may decide)
- OR
- by a majority (more than half of my attorneys must agree on all decisions)
- OR
- other: (e.g. jointly and severally, or appointing a successor or alternative attorney) (If you choose 'other', please specify how you want your attorneys to make decisions)

TERMS AND INSTRUCTIONS FOR YOUR ATTORNEY(S)

This part allows you to provide terms and instructions for your attorney(s). You can provide:

- general terms and instructions
- terms and instructions about who your attorney(s) must notify when exercising a power for personal (including health) matters
- terms and instructions about who your attorney(s) must notify when exercising a power for financial matters.

Terms and instructions (general terms and instructions)

Only complete this part if you want to set terms on the exercise of powers by your attorney(s) or provide instructions to your attorney(s) about the exercise of their powers.

Refer to section 3, page 12 of Form 2 – Enduring power of attorney explanatory guide about terms and instructions (general terms and instructions).

Refer to page 12 of Form 2 – Enduring power of attorney explanatory guide about conflict transactions (e.g. if you are appointing your spouse as your attorney).

Cross out this part if you do not want to complete it. If you do complete this part, you must provide space in the box that you do not use.

- I need more space to write my terms and instructions. Attach any additional pages to this form and tick the bar to indicate that extra pages are attached.

Terms and instructions (notifications for personal (including health) matters)

Who to notify

My attorney(s) for personal (including health) matters must notify the following person(s) when exercising power for financial matters in writing:

me (the principal)

my other current attorney(s)

the nominated person below

Full name			
Address	Suburb	State	Postcode
Phone number			
Email			

I need more space to include additional nominated person(s).
Attach any additional pages to this form and tick the box to indicate that extra pages are attached.

What to notify

My attorney(s) for personal (including health) matters must provide the following to the person(s) nominated above:

written notice that my attorney(s) intend to begin exercising power for a personal matter (including a health matter) under this enduring power of attorney before exercising the power for the first time

other information; provide details about the information that must be provided including how often your attorney(s) must provide the information

When to notify

My attorney(s) must give the information:
(Tick one or more of the boxes below)

on request at any time by the nominated person

on a regular timeframe: (State the timeframe, e.g. annually on 1 July of each year or quarterly starting on 1 July) _____

other: (Provide details)

Terms and instructions (notifications for financial matters)

Who to notify

My attorney(s) for financial matters must notify the following person(s) when exercising power for financial matters in writing:

me (the principal)

my other current attorney(s)

the nominated person below

Full name			
Address	Suburb	State	Postcode
Phone number			
Email			

I need more space to include additional nominated person(s).
Attach any additional pages to this form and tick the box to indicate that extra pages are attached.

What to notify

My attorney(s) for financial matters must provide the following to the person(s) nominated above:

written notice that my attorney(s) intend to begin exercising power for financial matters under this enduring power of attorney before exercising the power for the first time

all financial records and accounts

records relating to transactions above a nominated amount: \$ _____
(You must specify an amount here if you select this option)

records and accounts for all assets including property, investments and vehicles

summaries of income, expenditure and assets

copies of financial management plans and financial advice obtained

other: (Provide details)

When to notify

My attorney(s) must give the information:
(Tick one or more of the boxes below)

on request at any time by the nominated person

on a regular timeframe: (State the timeframe, e.g. annually on 1 July of each year or quarterly starting on 1 July) _____

other: (Provide details)

SECTION 4: DECLARATIONS AND SIGNATURES

PRINCIPAL'S SIGNATURE

As the principal, you must sign this part in front of an eligible witness.

Refer to section 4, pages 15–16 of [Form 9](#), [Attorney's Guide to Enduring Power of Attorney](#), and the [Attorney's Guide to Enduring Power of Attorney](#) (2020).

- AND**
- I understand the nature and effect of this enduring power of attorney, including:
 - that I may specify or limit my attorney(s)' power and instruct my attorney(s) about the exercise of the power
 - when the power given to my attorney(s) begins
 - that once the power for a matter begins, my attorney(s) will have full control and power to make decisions about the matter, subject to any terms or information included in this enduring power of attorney
 - that I may revoke this enduring power of attorney at any time if I am capable of making another enduring power of attorney giving the same power
 - that the power I am giving to my attorney(s) continues even if I do not have capacity to make decisions about the matter
 - that I am not capable of exercising the enduring power of attorney. I am unable to effectively exercise the use of the power given to my attorney(s) by this document.

ONLY SIGN THIS PART IN FRONT OF AN ELIGIBLE WITNESS

Principal's signature: _____ **Date:** _____
Witness's signature: _____ **Date:** _____
 (Witness must also sign page 10)

Person signing for the principal

If you are physically unable to sign this form, another person who is eligible must sign the form for you.

- Refer to section 4, page 16 of [Form 9 – Enduring Power of Attorney](#), [Attorney's Guide](#).
- By signing this document, I confirm that:**
- the principal instructed me to sign this document
 - I am 18 years or older
 - I am not a witness for this enduring power of attorney
 - I am not an attorney of the principal.

Name of person signing for the principal	_____		
Address	_____		
Phone number	Suburb	State	Postcode
Email	_____		

ONLY SIGN THIS PART IN FRONT OF THE PRINCIPAL AND AN ELIGIBLE WITNESS

Person signing for the principal signs here: _____ **Date:** _____
Witness's signature: _____ **Date:** _____
 (Witness must also sign page 10)

WITNESS CERTIFICATE

This part must be filled in and signed by an eligible witness at the same time that you sign the enduring power of attorney.

By signing this document, I certify that:

- the principal signed this enduring power of attorney in my presence
- OR**
- in my presence, the principal instructed another person to sign this enduring power of attorney for the principal, and that person signed it in my presence and in the presence of the principal.

INFORMATION FOR THE WITNESS

You must also be satisfied that the person appears to have capacity to make the enduring power of attorney.

- AND**
- I am a:
 - (Tick one box only)
 - justice of the peace (JP)
 - commissioner for declarations
 - lawyer
 - notary public.
 - I am not:
 - the person signing the document for the principal
 - an attorney of the principal
 - a relation of the principal or relation of an attorney of the principal
 - if this enduring power of attorney appoints an attorney for personal (including health) matters, a paid carer or health provider of the principal.
 - At the time of making this enduring power of attorney the principal appears to me to have the capacity to make the enduring power of attorney. The principal appears to:
 - understand the nature and effect of this enduring power of attorney
 - be capable of making the enduring power of attorney freely and voluntarily.

This document (including any additional pages) has _____ pages.

Witness's signature: _____ **Date:** _____
 (Witness must also sign page 9)

Witness's name: _____

If an interpreter assisted in the preparation of this document or if an interpreter is present when this document is witnessed, complete Form 7 – [Interpreter's Statement](#) at [www.publications.qld.gov.au](#)

SECTION 5: ATTORNEY(S)' ACCEPTANCE

Your attorney(s) must sign this section of the original form after you and the witness have signed Section 4.

It does not matter which order your attorney(s) sign this section.

INFORMATION FOR ATTORNEYS

An attorney has important duties and obligations.

Refer to pages 21–24 of the explanatory guide for information for attorneys. Form 9, Enduring Power of Attorney explanatory guide.

Note: a paid carer is someone who is paid a fee or wage to care for a person but not someone receiving a carer's pension or benefit.

I have read this enduring power of attorney and I understand that I must make decisions and exercise power in accordance with this enduring power of attorney, the *POWERS OF ATTORNEY ACT 1992* and the *Guardianship and Administration Act 2000*.

- I understand:
 - in exercising my powers I must apply the general principles and if I exercise powers for health care matters, the health care principles under the *Powers of Attorney Act 1992* and the *Guardianship and Administration Act 2000*
 - the obligations of an attorney under an enduring power of attorney and the consequences of failing to comply with those obligations.

- I declare that:
 - I have capacity for the matter that I am appointed for
 - I am 18 years or older
 - I am not a paid carer for the principal and have not been a paid carer for the principal within the previous three (3) years
 - I am not a health provider for the principal
 - I am not a service provider for a residential service where the principal is a resident
 - if I am appointed for financial matters, I am not bankrupt or taking advantage of the laws of bankruptcy as a debtor under the *Bankruptcy Act 1966* (Cth) or a similar law of a foreign jurisdiction.

Signature: _____ Date: _____
Full name: _____

Signature: _____ Date: _____
Full name: _____

Signature: _____ Date: _____
Full name: _____

Signature: _____ Date: _____
Full name: _____

I have appointed an additional attorney(s) and need more space for my attorney(s) to sign. Attach any additional pages to this form and tick the box to indicate that extra pages are attached.

SECTION 6: WHAT TO DO WITH YOUR COMPLETED ENDURING POWER OF ATTORNEY

You are not required to register this enduring power of attorney anywhere.

- keep the original in a safe place
 - give a certified copy to your attorney(s), doctor, other health provider(s), bank or lawyer
 - if your attorney(s) wish to deal with land in Queensland on your behalf, register your enduring power of attorney with the Queensland Titles Registry by lodging Form 16 – Request to register power of attorney, together with a single-sided certified copy of the enduring power of attorney
 - notify your close family and friends that you have made an enduring power of attorney and where to find the document
 - review your enduring power of attorney if your personal circumstances change.
- Refer to 'Further information' on pages 16–19 of Form 9 – Enduring power of attorney explanatory guide for how to make a certified copy.

My Health Record

If you wish your document to be in My Health Record you can upload it via the My Health Record website at www.myhealthrecord.gov.au. Your document will be valid regardless of whether it is uploaded.

Office of Advance Care Planning

You are able to have your enduring power of attorney uploaded to your Queensland health electronic record. To do this, send a copy of your document to the Office of Advance Care Planning. This way it will be easily available to authorised clinicians involved in your care when it is required. A copy of your documents can be sent to the Office of Advance Care Planning at acp@health.qld.gov.au, PO Box 2274, Runcorn, Queensland 4113 or fax 1300 008 222.