



# Determining the Effect of Advance Care Planning in Palliative and End-of-Life Care: A Systematic Review of Reviews

A white paper published by the Flinders Research Centre for Palliative Care, Death, and Dying

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## About this White Paper

This publication is a RePaDD White Paper and Research Report. The RePaDD White Paper and Research Report Series provide researchers and policy makers with evidence-based data and recommendations. By organising, summarising and disseminating previous and current studies, the series aim to inform ongoing and future research in palliative care, death, and dying. This White Paper was originally completed as part of the Decision Assist Program, which aimed to help deliver palliative care and advance care planning in residential and community aged care.

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## About the RePaDD

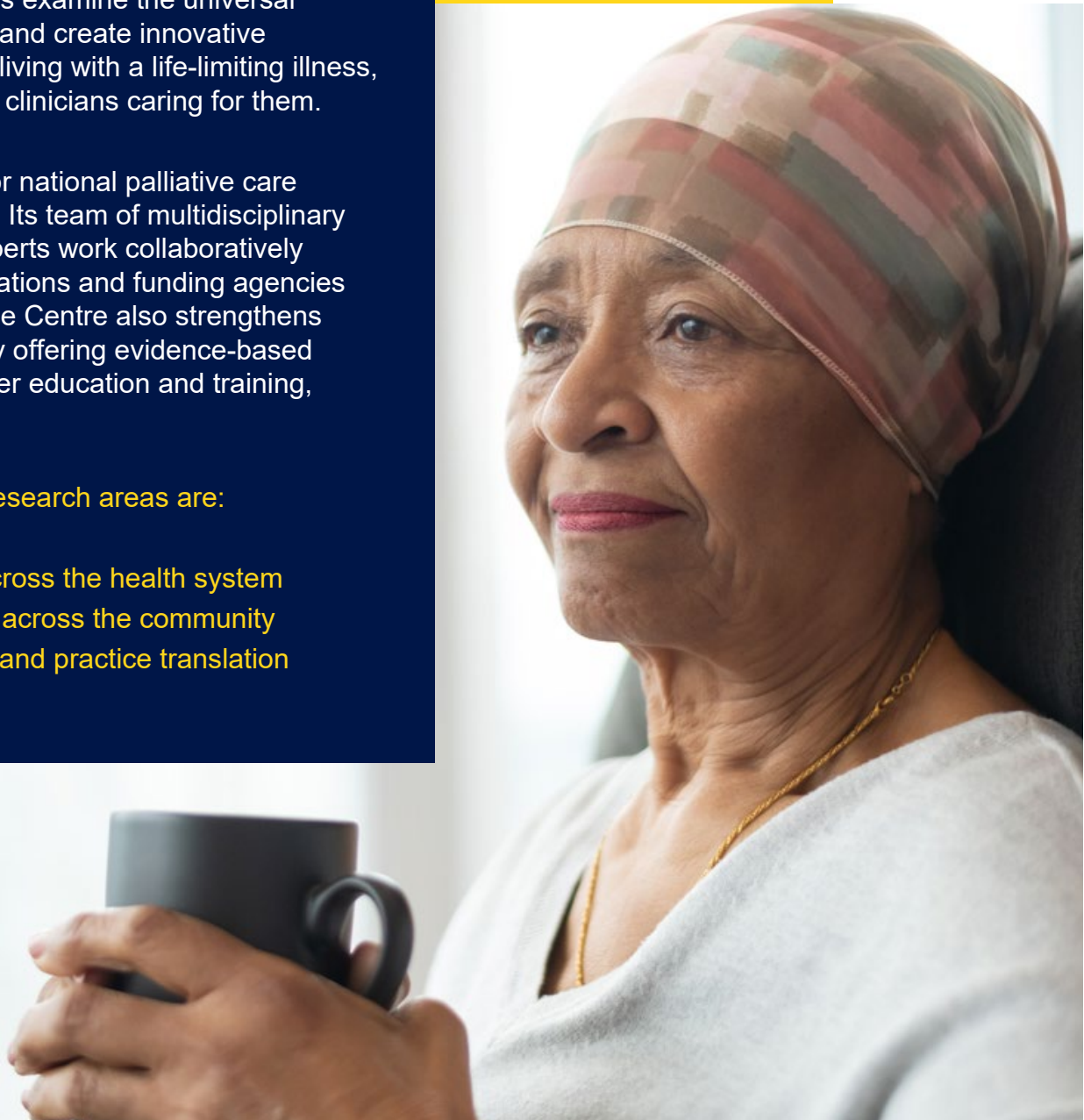
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RePaDD researchers examine the universal experience of dying and create innovative solutions for people living with a life-limiting illness, their carers, and the clinicians caring for them.

RePaDD leads major national palliative care projects in Australia. Its team of multidisciplinary researchers and experts work collaboratively with various organisations and funding agencies to deliver impact. The Centre also strengthens research capacity by offering evidence-based resources, researcher education and training, and scholarships.

RePaDD's current research areas are:

- Palliative care across the health system
- Death and dying across the community
- Online evidence and practice translation



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# Executive Summary

Advance care planning (ACP) plays a critical role in determining a person's values, preferences, and beliefs prior to the point at which that individual may not be able to make or communicate his or her decisions. While ACP has become increasingly important in both policy and practice, a clear, shared understanding of what is meant by advance care planning remains elusive. The consequent variability in meaning and definitional ambiguity in relation to ACP can result in confusion around end-of-life practices and constrain the ability of policy makers, practitioners and others to determine the quality and effectiveness of ACP at different points and in different settings.

This White Paper/Research Report explores the relationship between ACP, palliative, and end-of-life care through a narrative review of systematic reviews. It examines the way in which ACP is envisioned within a palliative care context and whether there are similarities (or contradictions) in how both are used. It also describes the analysis of key literature, specifically looking at what ACP interventions have been used within palliative care, what outcomes have been measured, and the effectiveness of these interventions in meeting the outcome measures defined.

Building on the work of previous overviews of systematic reviews in this area, our research team conducted a systematic electronic search of the MEDLINE, PsycINFO, Embase, CINAHL, Emcare, and PubMed databases. Selected websites were also searched for grey literature. Search results were assessed and potentially relevant studies identified. After exclusions, the total number of full-

text articles meeting the inclusion criteria and addressing the research question was 21. Data was extracted using a purposely created format and findings reported under the following four categories:

- Characteristics of systematic reviews and studies cited in the reviews
- Methodological rigour of the systematic reviews
- ACP information
- Results from the review

This review highlights the need for terminological and definitional clarity to accurately assess the quality and effectiveness of ACP in a variety of different settings. It also provides clearer direction for the timing and promotion of the ACP process within a palliative care space that is evolving and, increasingly, addressing a broader end-of-life agenda.

Our findings show that palliative care practices support the discussion of end-of-life (EOL) matters. While this relates, in part, to the context of palliative care (where death is accepted as an expected event), it also provides an environment that supports ongoing discussion and enables integration of family awareness into this discussion. Our findings also suggest that less is known about how community initiated and consumer directed ACP activity occurring outside of palliative care will affect palliative care practices and care provided at the end of life in other settings. While there is increasing research into ACP, the pathways for systematic, and effective ACP to enable individuals to plan for their end of life are still being established.

# Introduction

Advance care planning (ACP) is a process of planning for future health and personal care whereby the person's values, beliefs and preferences are made known.<sup>1</sup>

Understanding what these values, beliefs and preferences are can guide decision-making at a future time when the person may not be able to make or communicate his or her decisions.<sup>1,2</sup>

ACP has become a significant health policy consideration in Australia and elsewhere.<sup>1,3,4</sup> In the palliative care context, ACP has traditionally been seen as part of an ongoing conversation about current care requirements and future EOL care needs.<sup>2</sup> ACP conversations are meant to provide the ability of patients, family members, and healthcare professionals to clarify the level and type of care the person would prefer within the dictates of the person's self-determining capacity to nominate this care as life-limiting illness progresses to the EOL stage.<sup>2</sup>

A recent study has highlighted some of the complexity in this area by seeking to establish a consensus definition of ACP. In review process various tensions concerning ACP concepts were identified such as whether the definition should focus on conversations vs. written advance directives; patients' values vs. treatment preferences;

current shared decision making vs. future medical decisions; and who should be included in the process.<sup>3</sup> While ACP has become an increasingly important idea within policy and practice, its relationship to activity and to application is not resolved. In particular, while ACP can be conceptualised as an important consumer life review process suitable for both the well and the seriously ill, in reality it is seen to be most valuable in populations where the potential for expression is greatest, namely the terminally ill, older people and those with cognitive impairments including dementia.<sup>5,6</sup>

This review therefore explores the relationship between ACP and palliative care. Is the question of ACP in palliative care about its nature, the best way to implement it, the best measures to determine its effectiveness, or is current ACP a reinvention of a traditional process within palliative care? Exploring these questions may provide clearer direction for timing and promotion of the ACP process within an evolving palliative care space that is increasingly addressing a broader EOL agenda.

# Background

In Australia, the legal context for ACP is complicated by jurisdictional differences in legislation, although common principles apply.<sup>1,7</sup> It is also dynamic with changes in legislation not being uncommon. ACP may be recognised under common law (e.g. New South Wales) or as a statutory advance care directive (ACD) supported by legislative requirements (e.g. South Australian Advance Care Directive Act 2013).<sup>1,8</sup> Legal forms of ACDs that may form a part of ACP include documents such as enduring powers of attorney for health, lifestyle or finance, do-not-resuscitate orders (DNR), do-not-hospitalise orders (DNH), or any other similar directives under legislation.<sup>1</sup> There are also documents which do not have legislative authority but offer the ability for patients, families, and clinicians to discuss and document care requirements nonetheless, for example the Statement of Choices document.<sup>9</sup>

Palliative care has been defined by the World Health Organisation as an approach “that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.”<sup>10</sup> ACP approaches have always been associated with palliative care as part of the ongoing process of clarifying awareness, discussing options, and eliciting care preferences within disease progression.<sup>2</sup> Palliative care can perform this function through ongoing discussions and documentation of the care preferred and required through multiple conversations over a period of time with documentation through legal or other means of those wishes, goals, and values.

So while it is clear, there is a natural connection between ACP and palliative care, ACP has become a broader care

and community context that seeks to support consumer choice and direction, to encourage discussion and forward planning for the well not just the seriously ill, and to capture preferences before decision making incapacity for those with dementia.

Not having a shared understanding of what exactly is meant by ACP, especially in a palliative care context, means that conclusive evidence of its effectiveness and how it is used in this environment is still elusive. To tease out similarities and differences requires understanding how the term ACP is being used. A Delphi study of research experts and those with clinical or policy expertise in ACP conducted by Sudore et al.<sup>3</sup> explored this issue. Their consensus view was that ACP is described as follows: “advance care planning is a process that supports adults at any age or stage of health in understanding and sharing their personal values, life goals, and preferences regarding future medical care. The goal of ACP is to help ensure that people receive medical care that is consistent with their values, goals, and preferences during serious and chronic illness.”<sup>3</sup> In essence, the concept of planning for care at the EOL is moving beyond the confines of palliative care.

The intent of this overview of the systematic review literature on ACP is to understand how ACP is envisioned within a palliative care context and whether there are similarities or contradictions in how both are used. Therefore, the aim of this overview was to synthesise the systematic review literature on ACP in palliative care to identify constructs about the role and purpose of ACP in palliative care.

This review builds on the work of previous overviews of systematic reviews in this area of research, such as those of Street and Ottman<sup>2</sup>; Wilkinson et al.<sup>11</sup>; and Tamayo-Velquez et al.<sup>12</sup> which conducted reviews of the literature for interventions used to



promote ADs and ACP and whether these interventions were effective in generating normal use of these documents across the majority of the population, either well or ill. At the time of Tamayo-Velazquez et al.'s<sup>12</sup> review, there was a resurgence in research on interventions that would better promote and engage people, sick and well, in ADs or ACP. This research effort was spurred on by reports from the SUPPORT group (1995), Fagerlin and Schneider, 2004<sup>11</sup> and, Wilkinson et al. 2007<sup>11</sup> concluded that ADs and ACP were not successful as implements for getting people to put their wishes for future care planning in place ahead of the time when someone else may need to make medical decisions for them. The review by Wilkinson et al.<sup>11</sup> found that although ADs may have been too narrow in scope and execution, there was evidence to suggest that when conducted in conjunction with discussions and conversations about a person's values, goals and wishes, these instruments could provide benefits to patients, families, and healthcare professionals in managing care needs in the way the person and their family would prefer. However, at the time of the Wilkinson et al.<sup>11</sup> review, the evidence in this area was weak due to a "lack of well-developed and meaningful metrics of successful ACP and family-centred care interventions."<sup>11(p50)</sup>

This report assesses whether the literature provides conclusive evidence of the best use of ACP in the palliative care context by looking at the literature from 2000 onwards to see how ACP has been defined in Australia and elsewhere, the types of interventions used, how these are used in the palliative care context, what the outcomes of the interventions were, how these outcomes were measured and whether the outcomes of these interventions support and enhance palliative care practice at the EOL. Demographic information such as authors of studies reviewed within the reviews, countries of review authors, and other elements of the research publication process will also be described. Finally, results of the quality of the reviews as assessed using the SIGN tool (Scottish Intercollegiate Guidelines Network 2015)<sup>14</sup>, a critical analysis tool enabling grading of systematic reviews for rigour and quality will be presented.

## Methods

Although defined as a rapid review due to time constraints, this study follows systematic review processes. A rapid review of is a form of knowledge synthesis in which components of a systematic review process are simplified or omitted to produce information in a timely manner.<sup>15</sup> Although there is no consistent format to conducting rapid reviews, Tricco et al.<sup>15</sup> found in those reviews that assessed the rapid reviews, there was congruence in the conclusions obtained between the rapid review and systematic reviews.

The review protocol was lodged with the PROSPERO International prospective register of systematic reviews. A copy of the Review Protocol can be found in Appendix 1.

## Research objective

The aim of the rapid review is to synthesise constructs around the role and purposes of ACP in relation to palliative care.

## Ethics approval

As this is a bibliometric study of publicly available documents, ethics approval was not needed.

## Study design

This study has been conducted as a narrative review of systematic reviews of the literature on ACP in palliative care. This narrative review describes the analysis of this literature specifically looking at what ACP interventions have been used within palliative care, what outcomes have been measured and the effectiveness of these interventions in meeting the outcome measures defined.

## Inclusion criteria

We included systematic reviews of intervention studies published in peer-reviewed, English-language journals describing the effects of ACP in an EOL context. Figure 1 presents an overview of the inclusion and exclusion criteria.

Because of the propensity for many reviews to combine studies with different patient populations, we chose to include only those systematic reviews where greater than 50% of the studies reviewed within a systematic review contained patient populations where death was anticipated or defined as being in or engaged with palliative care services.

Figure 1: Inclusion/exclusion criteria

### Inclusion Criteria:

1. Must be a systematic review of studies on ACP interventions
2. The focus of the review must be on ACP
3. The care context must be palliative or EOL care and expressed in such a way that there was anticipated death rather than acute death where ACP may not be able to be implemented
4. Studies published in English from January 2000 to present

### Exclusion criteria

1. Reviews on ACP for well people or where 50% or more of the populations in the studies reviewed consisted of well people or those not in an anticipated state of dying
2. Reviews reporting ACP as an outcome measure not an intervention

## Search strategy

A systematic electronic search was conducted in consultation with research librarians employed by CareSearch. The databases MEDLINE, PsycINFO, Embase, CINAHL, Emcare, and PubMed were searched. Only studies that were published in the English language from January 2000 until the present were included as resources did not extend to translation of studies not in English. See Appendix 2 for the full details of the search strategy. As this was a rapid review and time constrained, hand-searching of reference lists, and snow balling was not conducted.

## Grey literature

The following websites were searched for unpublished systematic reviews:

- Google
- OpenDoar
- Eldis
- Trove for theses
- ProQuest Dissertations and Theses
- Global using search terms advance care plan, ACP and systematic review.

Google was searched via Google Advanced and limiting to government and organisational websites, and pdf file types.

## Selection of studies and data extraction

First, two review authors (GT and CT) independently assessed the search results based on titles and abstracts to identify potentially relevant studies. Once this process was completed, another review author (SB) assessed included abstracts for meeting eligibility criteria. Where it was not clear based on title and abstract, a full text of the article was retrieved and reviewed by SB. Any discrepancies or uncertainties were resolved by the involvement of the fourth author (JT) via discussion until consensus was reached.

## Data extraction

Data extraction was conducted using a purposively created format by one author (SB) as this overview was conducted as a rapid review of the literature. Although, we have not used all of the previous formats of rapid review identified by Tricco et al.<sup>15</sup>, we have endeavoured to cover some of the gaps alluded to in this form of review. Specifically, we have tried to generate as much data as possible based on four elements of the research process:

1. Descriptive information about the review design
2. Information about the quality of the systematic review
3. Information about the research question; and
4. Elements of the findings resulting from the systematic review. Individual components of these four elements are described under the following headings:

### 1. Characteristics of the systematic reviews and studies cited in the reviews (descriptive information)

- Author, title, year of publication and journal of systematic review
- Authors and countries of studies cited in the systematic reviews
- Number of studies reviewed within a review

### 2. Methodological rigour of the systematic reviews (Quality)

- SIGN results
- Databases used for search
- Data Extraction Tools used to answer the research question

### 3. ACP information (research question)

- Definition of ACP for each review
- Context of ACP

- Key question or aim
- Search strategy, databases used, any data extraction or specific search strategy tools used
- Author, country characteristics of reviewers, and the studies cited
- Purpose and description of the ACP interventions within the review
- Setting of the ACP interventions
- Timing of ACP interventions
- Illnesses of the participant populations within the studies reviewed
- Outcome measures
- Prevalence rates of ADs or ACPs

#### 4. Results from the review (findings information)

- Findings identified (themes, overall outcomes)
- Strengths of the review

- Limitations of the review
- Practice Recommendations from authors of review
- Future research recommendations from authors of review

Results and findings from the review are reported under these four categories.

If the complete text did not provide all of the information listed, only that information that was found in the text was reported. We did not try to contact the review authors as this overview is based on their systematic review of the original studies available within the context and design of their review. Part of the reason for conducting this overview was to evaluate how the systematic reviews were done in relation to ACP in palliative care rather than assessment of individual studies.

## Search Retrieval Summary

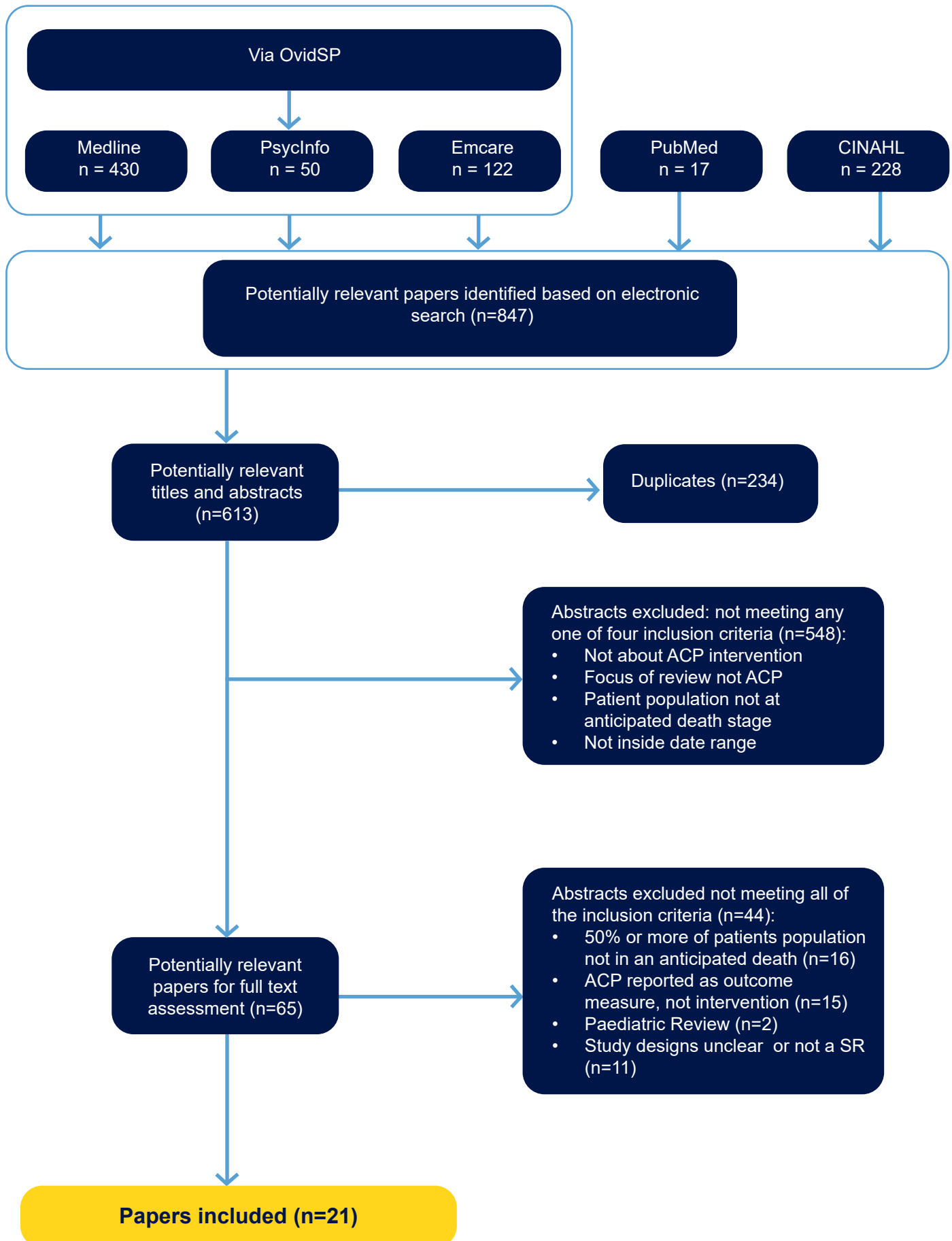
A total of 847 articles were retrieved by the search strategy. After eliminating 234 duplicates, 613 articles remained for analysis. We excluded 548 non-relevant papers from titles or abstracts with the majority excluded based on one of the four eligibility criteria. The remaining 65 papers were assessed based after retrieval of the full text article. As previously described, no reference lists were searched for additional studies. Another 44 full-text articles were excluded for not meeting the full intent of the inclusion criteria, for example, the patient populations in the studies reviewed did not

include more than 50% of participants at anticipated death. After these exclusions, the total number of full-text articles meeting the inclusion criteria and addressing the research question was 21 systematic reviews.

Figure 2 shows the PRISMA diagram of inclusion and exclusion of articles at different phases of the screening process. Reasons for exclusion are also provided.

The 44 excluded full-text studies and reasons for exclusion are listed in Appendix 3.

**Figure 2: PRISMA diagram of included and excluded systematic reviews**



# Findings 1: Characteristics of Systematic Reviews and Studies Cited in the Reviews (Descriptive Information)

## Authors of systematic reviews

Authors from eight countries created the 21 systematic reviews analysed in this overview and their details can be seen in Table 1.

**Table 1. Authors of the 21 systematic reviews included in this overview.**

No.	Author and Year of Publication	Title	Country of Author of SR
1	Austin et al. 2015 <sup>16</sup>	Tools to Promote Shared Decision Making in Serious Illness: A Systematic Review	US
2	Baidoobonso 2014 <sup>17</sup>	Patient Care Planning Discussions for Patients at the End of Life: An evidence-based analysis	Canada
3	Barnes et al. 2012 <sup>18</sup>	Enhancing Patient-Professional Communication about End-of-Life Issues in Life-Limiting Conditions: A critical review of the literature	UK
4	Brinkman-Stoppelenburg et al. 2014 <sup>19</sup>	The Effects of Advance Care Planning on End-of-Life Care: A systematic review	The Netherlands
5	Brooke and Kirk 2014 <sup>20</sup>	Advance Care Planning for People Living with Dementia	UK
6	Cardona-Morrell et al. 2017 <sup>21</sup>	A Systematic Review of Effectiveness of Decision Aids to Assist Older Patients at End of Life	Brazil/Australia
7	Dening et al. 2011 <sup>22</sup>	Advance Care Planning for People with Dementia: A review	UK
8	Dixon et al. 2015 <sup>23</sup>	The Economic Evidence for Advance Care Planning: Systematic review of evidence	UK
9	Durbin et al. 2010 <sup>24</sup>	Systematic Review of Educational Interventions for Improving Advance Directive Completion	US

No.	Author and Year of Publication	Title	Country of Author of SR
10	Flo et al. 2016 <sup>25</sup>	A Review of the Implementation and Research Strategies of Advance Care Planning in Nursing Homes	Norway
11	Houben et al. 2014 <sup>26</sup>	Efficacy of Advance Care Planning: A systematic review and meta-analysis	The Netherlands
12	Khandelwal et al. 2015 <sup>27</sup>	Estimating the Effect of Palliative Care Interventions and Advance Care Planning on ICU Utilization: A systematic review	US
13	Klinger et al. 2016 <sup>28</sup>	Does Facilitated Advance Care Planning Reduce the Costs of Care Near the End of Life? Systematic review and ethical considerations	Germany
14	Lewis et al. 2016 <sup>29</sup>	Evidences Still Insufficient that Advance Care Documentation Leads to Engagement of Healthcare Professionals in End-of-Life Discussions: A systematic review	Australia
15	Lim et al. 2016 <sup>30</sup>	Advance Care Planning for Haemodialysis Patients (review)	Australia
16	Luckett et al. 2014 <sup>31</sup>	Advance Care Planning for Adults with CKD: A systematic integrative review	Australia
17	Martin et al. 2016 <sup>32</sup>	The Effects of Advance Care Planning Interventions on Nursing Home Residents: A systematic review	Australia
18	Murray and Butow 2016 <sup>33</sup>	Advance Care Planning in Motor Neurone Disease: A systematic review	Australia
19	Robinson et al. 2012 <sup>34</sup>	A Systematic Review of the Effectiveness of Advance Care Planning Interventions for People with Cognitive Impairment and Dementia	UK
20	Stephen et al. 2013 <sup>36</sup>	End-of-Life Care Discussions with Non-malignant Respiratory Disease Patients: A systematic review	UK
21	Sumalinog et al. 2017 <sup>37</sup>	Advance Care Planning, Palliative Care, and End-of-Life Care Interventions for Homeless People: A systematic review	Canada

## Characteristics of studies cited in the 21 systematic reviews

There were 325 separate authors cited in the total of 21 systematic reviews with 468 studies analysed. Overall, the majority of studies cited within the 21 systematic reviews were by authors from the US with 220 individual authors from the US cited. There were a number of authors whose studies were cited multiple times and these are listed in Table 2.

**Table 2. Authors who were cited in multiple reviews.**

Author	Number of times cited over the 21 systematic reviews
Kirchoff et al. 2010, 2012	Six times (one or the other or both)
Molloy et al. 2000	Six times
Morrison et al. 2005	Six times
Song et al. 2005, 2008, 2009a, 2009b, 2010, 2012	Six times (one or the other or both)
Caplan et al. 2006	Five times
Engelhardt et al. 2006 and 2009	Four times (one or the other or both)
Gade et al. 2008	Four times
Sulmasy et al. 1996, 2002	Four times
Teno et al. 1997, 2002, 2007, 2011	Four times (one or the other or both)
Cassarett et al. 2001, 2005, 2008	Three times
Chan and Pang 2010	Three times
Clayton et al. 2005, 2007	Three times (one or the other or both)
Detering et al. 2010	Three times
Hickman et al. 2010, 2011, 2014	Three times
Jones et al. 2011	Three times
Lauterette et al. 2007	Three times
SUPPORT 1995	Three times
Zhang et al. 2009	Three times



Studies cited within the 21 systematic reviews were conducted in 29 separate countries as shown in Table 3.

**Table 3. Countries in which studies cited in the systematic reviews were conducted.**

Author	Number of times cited over the 21 systematic reviews
Australia	Saudi Arabia
Australia/Canada	Scotland
Belgium	Singapore
Canada	Spain
Denmark	Sweden
Finland	Taiwan
France	Thailand
Germany	The Netherlands
Holland	United Kingdom
Hong Kong	United Kingdom/Australia
Ireland	United Arab Emirates
Israel	United States
Japan	United States/Canada
Korea	Unknown (too old – early 1990s)
New Zealand	

There were 11 Australian lead authors of studies cited in the 21 systematic reviews. These authors, the number of times their studies were mentioned, and the country of origin for the systematic review in which they were cited can be seen in Table 4.

**Table 4. Authors of the 21 systematic reviews included in this overview**

<p><b>Caplan et al. 2006</b> – used in five different reviews by authors from Australia, Norway, Netherlands, and UK</p> <p><b>Cheung et al. 2010</b> – used in one review by author from US</p> <p><b>Clayton et al. 2005 and 2007</b> – used in three different reviews by authors from Canada, UK and the Netherlands</p> <p><b>Clover 2004</b> – used in one review by author from UK</p> <p><b>Detering et al. 2010</b> – used in three different reviews by authors from Canada, The Netherlands and the US</p> <p><b>Grbich et al. 2006</b> - used in one study by author from UK</p> <p><b>Jeong et al. 2007 and 2010</b> – used in two different reviews by authors from Australia and Norway</p> <p><b>Shanley et al. 2009</b> – used in one review by authors from Norway</p> <p><b>Silvester et al. 2013</b> – used in one review by authors from Norway</p> <p><b>Stirling et al. 2012</b> – used in one review by author from US</p> <p><b>Wilmott et al. 2013</b> – used in one review by author from Australia</p>
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The 21 systematic reviews were published between 2010 and 2017 with 11/21 reviews published between 2015 and 2017; 5/21 published in 2014; and the rest spread out between 2010 and 2013.

The 21 systematic reviews were published in 15 different journals with four of the 21 articles being published in Palliative Medicine and two each being published in the Journal of the American Medical Directors Association (JAMDA) and two in the Journal of Palliative Medicine. Table 5 provides the full listing of journals where the 21 systematic reviews were published.

**Table 5: Journals in which the 21 systematic reviews were published.**

**Age and Ageing**  
**BMC Geriatrics**  
**British Journal of Community Nursing**  
**Cochrane Database of Systematic Reviews**  
**Critical Care Medicine Journal**  
**International Psychogeriatrics Journal**  
**Journal of the American Medical Association (JAMA) Internal Medicine**  
**Journal of the American Medical Directors Association (JAMDA)**  
**Journal of Nursing Scholarship**  
**Journal of Pain and Symptom Management**  
**Journal of Palliative Medicine**  
**Ontario Health Technology Assessment Series**  
**Palliative Medicine**  
**Patient Education and Counselling**  
**Palliative and Supportive Care**

# Findings 2: Methodological Rigour of The Systematic Reviews (Quality)

## Quality assessment

To determine elements of methodological rigour, the Scottish Intercollegiate Guidance Network (2015) Tool for assessing systematic reviews was used.<sup>14</sup> The SIGN Tool measures the following components of a systematic review:

- Relevance of the review to the research question
- Whether the research question was clearly defined and inclusion/exclusion criteria listed
- Whether a comprehensive literature search has been undertaken
- At least two people selected studies and at least two people did the data extraction
- The status of publication and its use was described
- Excluded studies were listed
- Relevant characteristics of the included studies are described
- Scientific quality of the studies was assessed and reported
- Scientific quality was reported appropriately
- Appropriate methods were used to combine individual study findings
- Likelihood of publication bias was assessed
- Conflicts of interest were declared.

Results from the SIGN analysis can be seen in Appendix 4.

Overall, the majority of the reviews yielded high quality methodological rigour for answering their research question with 15/21 reviews received (++) indicating the highest level of methodological integrity. Three reviews (Khandelwal et al. 2015; Robinson et al. 2012 and Barnes et al. 2012)<sup>18, 27, 34</sup> rated (+), an acceptable level of quality while

Durbin et al. 2010<sup>24</sup> received a (-) low quality rating due to many elements of the search and data extraction being unclear or unable to assess. Brooke and Kirk<sup>20</sup> rated a (0) rejection because of the minimally described processes of their search but was included in the overview because of limited information available that directly addresses ACP in a palliative care context.

16 of the 21 reviews included a PRISMA tree<sup>21</sup> showing the exclusion process of articles with all but two reviews (Brooke and Kirk 2014; Durbin et al. 2010)<sup>20, 24</sup> using two or more people to screen articles for inclusion. Nearly half of the reviews did not clearly describe whether two or more people extracted data for the reviews, which is preferred according to SIGN.

In addition to the use of SIGN, an analysis was also made of the different types of databases searched within the systematic reviews as well as any data extraction tools used. This analysis was made as the databases have multiplied over time with publications assessable through specific or multiple databases. Data extraction tools were assessed due to variability and limited transparency in how data was extracted. It was important to understand if there were any data extraction tools being used that could show some consistency in the findings generated.

## Databases searched within the systematic reviews

Databases used within the 21 systematic reviews for searching for studies included those listed in Table 6 with all systematic reviews using PubMed, EMBASE, CINAHL, and/or PsychINFO.

**Table 6. Databases searched in the systematic reviews.**

<b>Systematic review by author</b>	<b>Databases searched for studies assessed in the systematic review</b>
Austin et al. 2015 <sup>16</sup>	PubMed, CINAHL, PsychINFO
Baidoobonso 2014 <sup>17</sup>	Ovid Medline, Ovid Medline in-Process and other non-indexed citations, Ovid EMBASE, CINAHL EBM Reviews
Barnes et al. 2012 <sup>18</sup>	CINAHL, Embase, Medline, ASSIA, Chochrane Reviews, Cochrane clinical trials, Cochrane technology assessments, Cochrane economic evaluations, Citation indexes in web of science, PsychINFO
Brinkman-Stoppelenburg et al. 2014 <sup>19</sup>	PubMed, EMBASE, PsychINFO
Brooke and Kirk 2014 <sup>20</sup>	PubMED, CINAHL, Medline
Cardone-Morrell et al. 2017 <sup>21</sup>	PubMed, Scopus, Ovid Medline, EMBASE, EBM Reviews, CINAHL, PsycINFO
Dening et al. 2011 <sup>22</sup>	PubMed, CINAHL, AMED, PsycINFO, EMBASE, BNI
Dixon et al. 2015 <sup>23</sup>	PubMed, ProQuest, CINAHL Plus with Full text, EconLit, PsycINFO, SocINDEX with Full Text, International Bibliography of the Social Sciences
Durbin et al. 2010 <sup>24</sup>	CINAHL, EBSCO, Medline, Science Direct
Flo et al. 2016 <sup>25</sup>	CINAHL, Medline, PsycINFO, EMBASE, Cochrane libraries
Houben et al. 2014 <sup>26</sup>	Medline/PubMed, Cochrane libraries
Khandelwal et al. 2015 <sup>27</sup>	Medline, EMBASE, Cochrane trials, CINAHL
Klinger et al. 2016 <sup>28</sup>	PubMed, NHS EED, EURONHEED, Cochrane library, EconLit
Lewis et al. 2016 <sup>29</sup>	EMBASE, Medline, EBM Reviews, PsycINFO, CINAHL, Cochrane Library
Lim et al. 2016 <sup>30</sup>	Cochrane Kidney and Transplant Specialised Register (comprised of CENTRAL, Medline Ovid SP, EMBASE), CINAHL, Social Work Abstracts (OvidSP)
Luckett et al. 2014 <sup>31</sup>	Medline, PsycINFO, EMBASE, AMED, CINAHL, Sociological Abstracts
Martin et al. 2016 <sup>32</sup>	EMBASE, Medline, PsychINFO, CINAHL
Murray and Butow 2016 <sup>33</sup>	Medline, CINAHL, EMBASE, Scopus
Robinson et al. 2012 <sup>34</sup>	Cochrane Database of SRs, Database of Abstracts of Reviews of Effectiveness, Central Register of Controlled Trials, NHS Economic Evaluations Database, Medline, EMBASE, CINAHL, PsycINFO, Ageline, Social Science Citation Index (Web of Knowledge), ASSIA, Social Services Abstracts, Sociological Abstracts, ISI conference proceedings, Index to Theses, EThOS, Bandolier, NIHR CRN Portfolio, Current Controlled Trials
Stephen et al. 2013 <sup>36</sup>	PubMed, CINAHL, BNI, ASSIA, PsycINFO, ScienceDirect, Web of Science
Sumalinog et al. 2017 <sup>37</sup>	Medline, EMBASE, PsycINFO, CINAHL, Social Work Abstracts, Cochrane Library, Web of Science, PubMed plus databased of major organisations involved with homelessness

Where the research question of the review indicated specific paradigms, more Social Service databases and those canvassing a broader range of publications were used, such as Web of Science, Web of Knowledge, and the Cochrane Collaboration Cohort of Databases.

## Data extraction tools used

Data extraction tools used by authors of the systematic reviews were almost all self-created for the purpose of the review. Those who did use a specific extraction tool mentioned CONSORT, TREND, a Cochrane Systematic Search Tool, the quality criteria framework of the International Patient Decision Aids Standards, the SCIE Systematic Research Review framework, the criteria by Brinkman-Stoppellenburg et al. (2014)<sup>19</sup>, Qualsyst by Kmet and colleagues (2004)<sup>38</sup>, NICE, Cochrane Effective Practice and Organisation of Care Review Group (EPOC), GRADE, or a framework created by Higginson et al. (2002)<sup>39</sup> as influencing the creation of their own tool.

The fact that many of the reviews used self-created tools to extract data indicates that in order to answer specific questions about the effectiveness of ACP in palliative care, particular elements of studies are required to be assessed with other elements not necessarily being relevant to a review. Thus, begins the journey into the many ways in which ACP in a palliative care context has been identified, described and assessed. The following section attempts to provide more clarity in the review process to identify the specific elements required for measuring the effectiveness of ACP under a range of circumstances and audiences.



# Findings 3: ACP Information (Research Question)

## Definition of ACP from within each of the systematic reviews

From the outset, it is worth considering exactly what is meant by the researchers in their description of ACP and its definition within each of the systematic reviews. Table 7 outlines the ACP definitions within the systematic reviews forming this overview.

For those reviews which provided a definition of ACP, these definitions were based upon 11 different sources with 8 of the 21 reviews providing an indirect or no definition of ACP and 3 of the 21 not providing any reference source at all for their definition of ACP. Reviews described ACP as outputs, e.g. documentation, processes, interventions, or conversations/discussions. These outputs could be between a patient and some other person, but predominantly engaging healthcare professionals. Documentation type ACP included a range of written directives or ADs, while processes were described as leading to treatment decisions, goals of care, care plans, or EOL care. Interventions were many and varied but included decision aids and tools while communication was defined as conversations or discussions.

**Table 7: Definition of ACP within each systematic review**

No.	Author and Year of Publication	Title
1	Austin et al. 2015 <sup>16</sup>	Decision Tools are tools that present treatment options in a balanced and evidence-based manner (Patient Decision Aid Standards Collaboration). The review used tools which did and did not meet this criterion but the focus of the tool had to be to improve decision-making for patients living with serious illness. No definition of ACP given.
2	Baidoobonso 2014 <sup>17</sup>	Describes ACP based on outputs and refers to it as 'patient care planning discussions'. ACP and DNRs are outputs of patient care planning discussions. Palliative care consultations and conferences are associated with increased family satisfaction, improved decision-making, and reduced health care use. ACP interventions associated with increase in ACP documentation, reduction in use of health care services, and increase in hospice use. Patient care planning discussions is an umbrella term used to describe discussions that usually lead to a written medical and nursing care program specifically designed for a particular patient, encompassing ACP or goals of care conversations.
3	Barnes et al. 2012 <sup>18</sup>	No ACP definition given - definition given is just identified as a cancer-style communication model.

No.	Author and Year of Publication	Title
4	Brinkman-Stoppelenburg et al. 2014 <sup>19</sup>	ACP is the process of discussing and recording patient preferences concerning goals of care for patients who may lose capacity or communication ability in the future. It is a means of extending the autonomy of patients to stages in life where they have become incompetent. It can be defined as 'a process of discussion about goals of care and means of setting on record preferences for care of patients who may lose capacity or communicating ability on the future' (Seymour 2010).
5	Brooke and Kirk 2014 <sup>20</sup>	ACP - indirectly defined - requires the provision of information and support to plan care for the end of life during the early stages of (dementia). Early discussions are paramount to avoid situations where capacity to understand these conversations are lost (Livington et al. 2010).
6	Cardona-Morrell et al. 2017 <sup>21</sup>	Decision aids are tools designed to support patient decision-making by presenting information about treatment options relevant to patients and their associated results compared to the existing practice of routine decision processes and/or alternative decision-making interventions. Aim is as a basis for discussions about preference and goals for EOL. No direct definition of ACP.
7	Dening et al. 2011 <sup>22</sup>	ACP is an overarching term that can be understood as a 'process of discussion that usually takes place in anticipation of a future determination of a person's condition between that person and a care worker usually from a healthcare background' (Henry and Seymour 2007).
8	Dixon et al. 2015 <sup>23</sup>	ACP is a process of discussion and review covering future care in the event of losing capacity. It is also often considered as a means of making better use of healthcare resources at EOL. ACP is a voluntary process of discussions and review concerning future care and treatment in the event of losing capacity. ACP conversations need not be documented although usually they are.
9	Durbin et al. 2010 <sup>24</sup>	Completing ADs as a part of ACP is an essential component in EOL care. ADs are a prospective exercise of individual autonomy in the form of written directives about healthcare treatment decisions (Freer, Embanks, Parker, and Hershey 2006).
10	Flo et al. 2016 <sup>25</sup>	ACP is an ongoing communication and decision-making process with patients and relatives, addressing the approaching death and the practical challenges regarding ethics, treatment and care well before the patient reaches a critical state (Henry and Seymour 2007, Detering 2010).
11	Houben et al. 2014 <sup>26</sup>	ACP is the process whereby patients in consultation with healthcare professionals family members and other loved ones make individual decisions about their future healthcare to prepare for future medical treatment decisions (Singer 1996).

No.	Author and Year of Publication	Title
12	Khandelwal et al. 2015 <sup>27</sup>	ACP defined Indirectly: diverse approaches to communication such as ACP, palliative care consultation or ethics consultation (lumped together). Primary reason for implementing palliative care should be to improve quality of care and patient and family outcomes. ACP, PC, and ethics consults lumped together to define overall process as 'focus on communication about goals of care'.
13	Klinger et al. 2016 <sup>28</sup>	ACP is a life-long communication process based on two fundamental aspects: 1) specifically qualified healthcare professionals who assist individual, and their families/friends to develop, articulate and document preferences for future medical care; 2) a systematic regional implementation ensures that the resulting plans are available and honoured reliably across all healthcare institutions in the community (Hammes et al. 1998, in der Schmitzen, 2014).
14	Lewis et al. 2016 <sup>29</sup>	Only defines ACDs as a generic term covering ACDs, living wills or Physician Orders of life sustaining treatment (POLST). ACP not defined.
15	Lim et al. 2016 <sup>30</sup>	ACP traditionally encompasses instructions via living wills concerning patient preferences about interventions such as Cardiopulmonary resuscitation (CPR) and feeding tubes or circumstances around assigning substitute decision-makers (SDMs). ACP involves planning for future healthcare decisions and preferences of the patient in advance while comprehension is intact. (No refs).
16	Luckett et al. 2014 <sup>31</sup>	ACP refers to a process of reflection and discussion between a patient, his or her family and healthcare professionals for the purpose of clarifying values, treatment preferences and goals of EOL care (Davison 2009). It provides a formal means of ensuring that healthcare providers and family members are aware of patient wishes for care if they become unable to speak for themselves (Davison 2011; Davison 2007). ACP is a patient-centred initiative that promotes shared decision making and which may include the patient completing an AD that documents his or her wishes and/or the appointment of an SDM.
17	Martin et al. 2016 <sup>32</sup>	ACP encompasses a process by which people may express and record their wishes and preferences for care and treatment should they lose the capacity to communicate them in the future. No references.
18	Murray and Butow 2016 <sup>33</sup>	ACP is a patient-centred process designed to ensure that healthcare decisions are guided by pre-considered patient preferences (Fried et al. 2009)



No.	Author and Year of Publication	Title
19	Robinson et al. 2012 <sup>34</sup>	ACP - a broader concept that is a multistage process whereby a patient and their carers achieve a shared understanding of their goals and preferences for future care - patients can document their wishes as advance statements to refuse treatments (ADs) and/or nominate a power of attorney to make decisions on their behalf should they lose mental capacity. (No refs).
20	Stephen et al. 2013 <sup>36</sup>	Describes EOL discussion only, does not define EOL discussion. No definition of ACP.
21	Sumalinog et al. 2017 <sup>37</sup>	ACP may occur before the diagnosis of a life-threatening illness (WHO 2004), Palliative Care - occurs in patients diagnosed with a life-threatening illness (WHO 2016).

## Context and Research Question for the Systematic Reviews

Once the definition of ACP was made, this could be seen to influence the context and research questions within the systematic reviews. Table 8 shows the context and research Question used within each of the systematic reviews.

**Table 8: Context and definition of ACP per systematic review.**

No.	Author and Year of Publication	Context	Research Question
1	Austin et al. 2015 <sup>16</sup>	Effectiveness of decision tools used to assist those with serious, life-limiting illnesses to make decisions about their future care	Which tools are relevant to the needs of treatment decision-making by seriously ill patients and their caregivers  How is the quality of evidence for these tools being evaluated?  What is the effect of these tools on patient-centred outcomes?  How accessible are these tools for clinicians?
2	Baidoobonso 2014 <sup>17</sup>	Patient care planning discussions - which approach optimises the quality of EOL care?	What is the effectiveness of patient care planning discussions (PCPDs) in achieving better patient-centred outcomes for people at the end of life?
3	Barnes et al. 2012 <sup>18</sup>	Communication of ACP by healthcare professionals to patients with life-limiting conditions	What are the existing interventions of patient-professional communication developed for life-limiting conditions?  What is the applicability of interventions developed within a cancer framework to other diagnostic groups?
4	Brinkman-Stoppelenburg et al. 2014 <sup>19</sup>	ACP and EOL care	What are the effects of ACP on a variety of outcomes?  What is the effectiveness of different types of ACP on EOL care?
5	Brooke and Kirk 2014 <sup>20</sup>	Barriers to discussion with people who have dementia	What are the barriers that impact on healthcare professionals engagement with ACP for people with dementia and their families?

No.	Author and Year of Publication	Context	Research Question
6	Cardona-Morrell et al. 2017 <sup>21</sup>	Decision aids and their effectiveness for ACP at EOL	What is the range, effectiveness, and acceptability of decision aids available to enable informed choice for older patients at the EOL?
7	Dening et al. 2011 <sup>22</sup>	ACP and dementia	What are the facilitators and inhibitors of ACP for people with dementia?  What are the main themes around this topic?
8	Dixon et al. 2015 <sup>23</sup>	ACP as an economic outcome	What is the economic evidence on ACP?
9	Durbin et al. 2010 <sup>24</sup>	Educational interventions and effectiveness at increasing completed ADs	What is the outcome of and percent of newly completed ADs as a result of an educational intervention?
10	Flo et al. 2016 <sup>25</sup>	Use of ACP in nursing homes	What was the content of ACP interventions?  What ACP implementation strategies were used and how were they described?  What were the main outcomes of ACP interventions in nursing homes?  What study designs and methods were employed?  What were the barriers and promoters of ACP implementation in nursing homes?
11	Houben et al. 2014 <sup>26</sup>	To review the efficacy of ACP interventions in different adult populations	What ACP interventions lead to increased ADs?  Does increased discussion of EOL preferences yield concordance between preferences for EOL care and care delivered?

No.	Author and Year of Publication	Context	Research Question
12	Khandelwal et al. 2015 <sup>27</sup>	ACP in Intensive care unit (ICU)	<p>Do ACP interventions lead to a reduction in ICU admissions for adult patients with life-limiting illnesses when compared to usual care?</p> <p>Do ACP and palliative care interventions reduce ICU length of stay (LOS) in this population when compared to usual care?</p> <p>Is it possible to provide estimates of the magnitude of these effects?</p>
13	Klinger et al. 2016 <sup>28</sup>	Costs implications of ACP programmes	What are the cost implications of comprehensive ACP programmes?
14	Lewis et al. 2016 <sup>29</sup>	ACP and EOL discussions	Does advance care documentation encourage healthcare professionals timely engagement in EOL discussions?
15	Lim et al. 2016 <sup>30</sup>	ACP for Haemodialysis Patients	<p>Does ACP for haemodialysis patients result in fewer hospital admissions or less use of treatments?</p> <p>Were patient's wishes followed at EOL?</p>
16	Luckett et al. 2014 <sup>31</sup>	ACP for patients with Chronic Kidney Disease (CKD)	<p>What are the ACP interventions that have been developed, piloted and evaluated for CKD?</p> <p>Which measures have been used to assess ACP in CKD?</p> <p>What is the evidence of the efficacy of these interventions?</p> <p>What are the barriers and facilitators to implementation?</p> <p>What are the stakeholders' ideal perceptions for ACP?</p>
17	Martin et al. 2016 <sup>32</sup>	ACP and nursing home residents	What are the effects of ACP on nursing home residents?

No.	Author and Year of Publication	Context	Research Question
18	Murray and Butow 2016 <sup>33</sup>	ACP and MND (ALS)	<p>What is the prevalence and predictors of ACP in relation to MND?</p> <p>What is the optimal timing, content and format of discussion and documentation processes?</p> <p>What are the perceived benefits of ACP for patients and caregivers?</p> <p>What is healthcare professionals awareness and acceptance of ACP?</p> <p>What is the evidence of the impact of ACP on key outcomes for this illness?</p>
19	Robinson et al. 2012 <sup>34</sup>	ACP interventions for people with cognitive impairment or dementia	<p>What is the effectiveness of ACP interventions in people with cognitive impairment and dementia?</p> <p>What are the factors influencing implementation of ACP for this population?</p>
20	Stephen et al. 2013 <sup>36</sup>	ACP and non-malignant respiratory disease	<p>What are the key components and challenges for patients and healthcare professionals discussing EOL in non-malignant respiratory disease?</p>
21	Sumalinog et al. 2017 <sup>37</sup>	ACP, palliative care, and EOL interventions for homeless people	<p>What is the existing evidence on ACP, palliative care, and EOLC interventions for homeless people?</p>

Each systematic review targeted specific elements of ACP but not often directly in relation to palliative care, e.g. decision tools or aids for choice in future healthcare treatment were disease specific and may have been for any time along the disease pathway. Effectiveness was a major theme. Effectiveness of ACP programmes was described for investigation for specific disease groups, in relation to meeting patient EOL care goals, and in generating concordance between patient and surrogate or healthcare professionals in relation to goals of care. In addition, a number of reviews queried how different types of ACP interventions were enacted, which ones were most receptive to the audience involved and how ACP affected a specific outcome measure, e.g. prevalence of completed ADs, length of stay in ICU, and costs. More about these elements are described in the sections that follow.

## **Participant Populations within the studies cited in the systematic reviews**

Participant populations in this overview refer to any of the audiences targeted within the studies cited, whether they are patients, healthcare professionals, families, substitute decision-makers or healthcare systems. These participant populations might encompass all of the above in one review or combinations of populations within and between the studies cited. To be able to make some sense for comparative

purposes, we excluded any systematic review where more than 50% of the cited studies had a participant population not in a state of anticipated death. This criterion was established because our overview focuses on the use of ACP within a palliative care context which, until recently, had life-limiting illnesses as its focus with conversations about EOL care as a primary goal.

In total, the number of participants across the cited studies within a particular review varied from 471 (Lim et al., 2016)<sup>30</sup> to over 2.2 million (Brinkman-Stoppelenburg 2014)<sup>19</sup>. The participant groups included patients, families, healthcare professionals (general), doctors, physicians, nurses, proxies, and social workers and included those alive as well as medical records of those deceased. Smaller numbers of participants in a review was usually a reflection of a more targeted question where the research literature was minimal (Lim et al. 2016<sup>30</sup> on hemodialysis patients and ACP). A larger number of participants such seen in the Brinkman-Stoppelenburg et al.<sup>19</sup> review was due to a large and encompassing review of ACP in general. Reviews such as Lim et al.<sup>30</sup> where the ACP investigations are of a specific condition such as End Stage Kidney Disease (ESKD) have become more prominent in the last few years as shown in Table 9.

**Table 9: Illnesses of patient populations within the 21 systematic reviews.**

<b>Systematic Review by Author</b>	<b>Illnesses of patient populations assessed in studies within systematic review</b>
Austin et al. 2015 <sup>16</sup>	ALS, Dementia, NSCLC, COPD, metastatic breast cancer, ICU, advanced cancer (not defined), ovarian cancer, malignant glioma, pancreatic/hepatobiliary cancer, metastatic colorectal cancer, CF
Baidoobonso 2014 <sup>17</sup>	Congestive heart failure, end stage renal disease, COPD, dementia, mix of diseases, cancer, cardiac disease
Barnes et al. 2012 <sup>18</sup>	Cancer, heart failure, and other cardiovascular, renal dialysis, chronic lung conditions, impaired vision/hearing/memory, ambulatory geriatric, not described
Brinkman-Stoppelenburg et al. 2014 <sup>19</sup>	Cognitive impairment or dementia, undergoing emergency surgery, nursing home residents, critically ill medical, surgical and trauma patients, hospice patients, haemodialysis patients, myocardial infarction or other heart failure, mobility impaired, general medical, respiratory infection or pneumonia, intracerebral haemorrhage or stroke, terminally ill in ICU, mechanical ventilation, urinary tract infection, advanced cancer (not defined), frail, end stage disease (not defined), peritoneal dialysis, haematopoietic stem-cell transplantation or malignancies, severe acute renal failure, HIV/AIDS
Brooke and Kirk 2014 <sup>20</sup>	Cancer, dementia, palliative care
Cardona-Morrell et al. 2017 <sup>21</sup>	Cancer, dementia or other cognitive impairment, palliative care, cardiothoracic, COPD and other respiratory, not described
Dening et al. 2011 <sup>22</sup>	Dementia
Dixon et al. 2015 <sup>23</sup>	Nursing home resident (unknown illnesses), dementia, cancer, critical illness requiring ICU, not described
Durbin et al. 2010 <sup>24</sup>	Cardiac, surgery, not described
Flo et al. 2016 <sup>25</sup>	Not described
Houben et al. 2014 <sup>26</sup>	Life-threatening illness, COPD, death, CHF, CRF, cancer, malignant glioma, chronic illness, deceased ICU patients, dementia, HIV, not described
Khandelwal et al. 2015 <sup>27</sup>	Not described
Klinger et al. 2016 <sup>28</sup>	End-stage heart and/or lung disease, COPD, CHF, cancer, diabetes, not described
Lewis et al. 2016 <sup>29</sup>	Not described
Lim et al. 2016 <sup>30</sup>	End stage kidney disease and chronic heart failure
Luckett et al. 2014 <sup>31</sup>	CKD and ESKD
Martin et al. 2016 <sup>32</sup>	Dementia, respiratory illness, not described
Murray and Butow 2016 <sup>33</sup>	Motor Neurone Disease
Robinson et al. 2012 <sup>34</sup>	Not described
Stephen et al. 2013 <sup>36</sup>	COPD, heart disease, advanced cancer (not defined), CHF, non-cancer, AIDS
Sumalinog et al. 2017 <sup>37</sup>	Not described

\*ALS-Amylotropic Lateral Sclerosis; NSCLC-non-small cell lung cancer; COPD-chronic obstructive pulmonary disease; ICU-intensive care unit; CF-cystic fibrosis; CHF-chronic heart failure; CRF-chronic renal failure; HIV-human immunodeficiency virus; AIDS-acquired immune deficiency syndrome; ESKD-end stage kidney disease;

The diseases that dominate ACP investigations include cancer, heart failure or other cardiovascular disease, Chronic obstructive pulmonary disease and dementia. However, motor neurone disease or ALS, and non-malignant chronic illnesses leading to death, such as kidney disease and diabetes are also being researched and reviewed. Where the table lists ‘Not described’ – this means that the patient population was not designated by a particular illness state but may only have been identified for example as ‘nursing home’, ‘palliative’, ‘ICU’, or ‘elderly with serious or life-limiting illness’.

## Setting of studies within the systematic reviews

The setting in which different ACP interventions occurred varied but for the most part focused on nursing homes, inpatient and outpatient hospital settings, hospice, and clinics. A full list of the different settings for interventions can be seen in Table 10.

**Table 10. Setting of ACP interventions in studies cited in systematic reviews.**

Ageing and dementia research centre	Memory Disorder Clinic
Alzheimers Disease Support Group	Medicare or Electronic or Hospital Records
Community setting (general)/community service programs	Men’s shelter
Dialysis clinics	Nursing Home/Long term care facility
Disease Specific rehabilitation clinics	Palliative care retreat/outpatient palliative care services Pre-op or same-day surgery clinics
Hospice	Senior housing units
Hospital, inpatient/outpatient	Specific disease clinics, e.g. MND or COPD
House calls by Geriatrician	Veteran Affair Centres in the US
Intensive Care Unit (ICU)	

Because of the variety of settings in which the ACP interventions may have been applied, this may have affected the timing of the ACP intervention and its effectiveness.

## Timing of ACP interventions

Overall, ACP interventions were timed to be administered at the time of the research study in the first instance but from a participant population perspective this may have occurred upon entry to a nursing home, when admitted to ICU, at the time of an inpatient or outpatient clinic visit, while undergoing dialysis treatment or when attending a GP practice. Table 11 provides a breakdown of the timing of interventions within the studies cited.



**Table 11. Timing of ACP interventions in the studies cited within the systematic reviews.**

<b>Systematic Review by Author</b>	<b>Illnesses of patient populations assessed in studies within systematic review</b>
Austin et al. 2015 <sup>16</sup>	Not Defined
Baidoobonso 2014 <sup>17</sup>	Outpatient clinic Hospital Palliative care unit in hospital Out-patient pall care clinic Nursing home entry Surgery clinic Health insurance network Community setting Veterans Affairs network Outpatient cancer clinic ICU in hospital
Barnes et al. 2012 <sup>18</sup>	Pre-engagement with patients At time of patient illness through focus group or other means Outpatient visit during consultation During rehab programme
Brinkman-Stoppelenburg et al. 2014 <sup>19</sup>	Hospitalisation Admittance to ICU Entry or later into nursing home Seriously ill and released into community When entering hospice When in receipt of emergency team call When undergoing stem cell transplant When attending GP
Brooke and Kirk 2014 <sup>20</sup>	Not defined
Cardona-Morrell et al. 2017 <sup>21</sup>	Not defined
Dening et al. 2011 <sup>22</sup>	Not defined
Dixon et al. 2015 <sup>23</sup>	At risk of dying within year in nursing home Deceased During hospitalisation During GP visit While in ICU During chronic illness treatment Last six months of life via cancer study

<b>Systematic Review by Author</b>	<b>Illnesses of patient populations assessed in studies within systematic review</b>
Durbin et al. 2010 <sup>24</sup>	When in medical practice Pre-operation At home while getting looked after At discharge When entered into geriatric clinic When hospitalised At outpatient clinic
Flo et al. 2016 <sup>25</sup>	Not defined
Houben et al. 2014 <sup>26</sup>	Life-threatening illness diagnosis Deceased Having surgery Admitted to hospital Outpatient clinic In VA Centre In nursing home University When scheduled for elective surgery During community healthcare professional visits During cardiac rehabilitation When admitted to nursing home When discharged from hospital
Khandelwal et al. 2015 <sup>27</sup>	When person in ICU
Klinger et al. 2016 <sup>28</sup>	Unknown During home-based primary care for people with serious chronic illness When at high risk of death In nursing home When entering hospital with serious illness When seeing doctor with advanced cancer
Lewis et al. 2016 <sup>29</sup>	Only at time of sighting patient preference documentation
Lim et al. 2016 <sup>30</sup>	While in clinic Over two - four months' time from entry on to dialysis
Lockett et al. 2014 <sup>31</sup>	Not defined
Martin et al. 2016 <sup>32</sup>	At time of entry When establishing goals of care When initiating action on ACDs

<b>Systematic Review by Author</b>	<b>Illnesses of patient populations assessed in studies within systematic review</b>
Murray and Butow 2016 <sup>33</sup>	Single time at beginning of study Every four months after first signing up Within eight weeks of diagnosis and after three and six months Retrospective chart review After death Baseline and six months
Robinson et al. 2012 <sup>34</sup>	Not defined
Stephen et al. 2013 <sup>36</sup>	Palliative care setting Most studies do not really say
Sumalinog et al. 2017 <sup>37</sup>	When admitted to hospice When using a drop-in centre When participating in a community service program When living at a men's shelter When being provided care by a healthcare professional

As can be seen in Table 11, seven of the 21 reviews did not define when the ACP interventions occurred; however, it seems that when timing was identified, it was often upon entering a particular clinical setting which begs the question that for most of the ACP interventions within these reviews, the person had to be experiencing an illness of some type in order for ACP to be initiated. This contrasts with ACP being promoted for any time of life when healthy or ill.

## **Types of ACP interventions**

So, what were the types of ACP interventions investigated within the systematic reviews? Table 12 describes the different types of ACP interventions by three main categories: Decision Aids or Tools, Documentation, or Communication. For many of the studies cited, these three types may have been combined or overlapped; however, in most of the systematic reviews, the emphasis of the review was placed in one of the three categories. Because all of the systematic reviews encompassed studies that used many of these interventions either singly or in combination, author details for the interventions are not listed.

**Table 12: Type of ACP interventions and formats used within studies cited in the 21 systematic reviews.**

Decision Aids or Tools	Documentation (used or measured)	Communication (for increasing conversations or discussions of ACP or ADs)
Video	Do not resuscitate (DNR)	Education courses - written, verbal, any audience
Audio	Do not hospitalise (DNH)	Prompt lists
Computer based	Advance directives (ADs)	Timing - Identifying appropriate time
Hard copy booklets or other printed materials	Living wills	Workshops
Memory sessions	Power of Attorney	Leaflets
Disease specific exercises or checklists	ACP	Frameworks
Go wish cards	Electronic medical health record documentation (E-MHR)	Models
Let me decide	Chart for choices	Questionnaires
Global deterioration scale and burden inventory	POLST	Surveys
BAN-S Questionnaire	Preferred place of death	Interview schedules
Purposively-designed tools which are disease specific	Proxy reporting of AD	Train the trainer
Gold standard framework	Discussion of EOL preferences	Structure ACP discussions (general or disease specific by various players, e.g. physician, nurse, patient, social worker)
Making health choices programme	Discharge planning	Telephone-based EOL counselling
Liverpool care pathway	Compliance with patient self-determination act (US)	Physician-led EOL discussion

Decision Aids or Tools	Documentation (used or measured)	Communication (for increasing conversations or discussions of ACP or ADs)
<p>Let me talk</p> <p>Project CARE</p> <p>AICCP Programme Course - Social worker ACP</p> <p>Support Intervention</p> <p>PC-ACP interviews</p> <p>Respecting patient choices</p> <p>Reminders- physician or patient or other healthcare professional of any type, e.g. checklist, electronic medical record</p> <p>Palliative care service consultations</p> <p>Ethics consultations</p> <p>Peer-mentoring programmes</p> <p>Sharing patient illness responses to increase trust programme</p> <p>Dementia satisfaction with care scale</p> <p>Family or patient or healthcare professional satisfaction surveys</p>	<p>PAHC (Power of Attorney Healthcare)</p> <p>Andalusian AD form (Spain)</p> <p>Documentation of patient and family preferences (free form)</p> <p>Goals of care</p> <p>Follow-up appointments for continuing conversations</p>	<p>Discussions - any type for any audience on ACP or EOL care</p> <p>Quality improvement programmes</p> <p>Scripts</p> <p>Training of any kind for any audience- may encompass multiple aspects of ACP</p> <p>Establishing goals of care</p> <p>Programs - any type which promotes discussion or conversations about ACP or ADs, e.g. Respecting Patient Choices, Making ACP a Priority</p> <p>Professional home support services</p> <p>Multi-disciplinary meetings</p>

As can be seen in Table 12, the list is wide-ranging and encompasses all currently available formats of interventions created to enhance or promote ACP or ADs by discussion, communication, or interactive engagement. Most of these interventions were designed specifically for the original research study in which they were described. This heterogeneity and cross-over use of multiple interventions at one time makes identifying the most effective interventions nearly impossible at this stage. However, of note was that in five of the systematic reviews the Let Me Decide (Molloy, 2000 – Canada) programme was investigated within the studies cited and in two of the systematic reviews the Let Me Talk (Chan and Pang, 2010 – Hong Kong) programme was cited.

## ACP outcomes and prevalence measured within the studies cited in the systematic reviews

Table 13 shows the outcomes measured within the studies cited in the systematic reviews and those studies which actually explored prevalence rates of different ACP interventions post-implementation. For the most part, outcome measures focused on the following key areas:

- Knowledge and Information exchange – includes knowledge of ACP, attitudes towards ACP, knowledge of disease states and prognosis, patient satisfaction, patient and family knowledge of disease or ACP, different healthcare professional knowledge of the same, knowledge about hospice, and palliative care
- Communication – communication skills, discussions about ACP/EOL care/ treatment choices and decision-making, concordance between patient and proxy or healthcare professional, goals of care, timing of discussions, use of tools to facilitate communication, and who should initiate discussions

- Costs – cost of ACP, hospital admissions, hospice use, ICU use, Medicare services, length of stay, and compliance with ADs
- Document completions – ACP, POLST, ACDs, ADs, Goals of care-type documents, and DNR orders

Only the following reviews had studies cited which looked at ACP in palliative care:

- Austin et al. 2015<sup>16</sup> - Hospice care with ACP
- Baidoobonso 2014<sup>17</sup> - Hospice care with completion of ACP
- Brinkman-Stoppelenburg et al. 2014<sup>19</sup> - Hospice and/or palliative care use
- Flo et al. 2016<sup>25</sup> - The best palliative approach
- Houben et al. 2014<sup>26</sup> - Hospice use
- Klinger et al. 2016<sup>28</sup> - Hospice use in the last week of life
- Martin et al. 2016<sup>32</sup> - palliative care and hospice use
- Stephen et al. 2013<sup>36</sup> - issues important to terminally ill patients getting palliative care
- Sumalinog et al. 2017<sup>37</sup> - palliative care delivery issues for homeless persons.

Prevalence rates are difficult to summarise because those systematic reviews which measured prevalence rates (n=17/21) referred to 139 studies with some studies referred to multiple times (e.g. Molloy 2000) but the majority were single-report studies. Prevalence rates measured:

- Concordance between patients and surrogates
- Choice for comfort care over active treatment
- Completion of different EOL documents after exposure to an ACP intervention
- Prevalence of discussions or communication events after ACP intervention
- Preferred place of death
- Documentation in hospital record of preferences and activities associated with death

- Length of stay, especially in ICU, after ACP intervention
- Satisfaction with ACP knowledge, communication, discussion or information after ACP intervention.

To see specific prevalence rate information from specific studies, please view Appendix 5. Because of the various ways in which prevalence has been measured in the many different studies cited, it is not possible to provide accurate detailed information on the effect of ACP in palliative care from the

perspective of increased documentation, discussion or choice. However, overall, and with the limitations previously mentioned, it seems that ACP interventions can decrease the use of life-sustaining treatment, increase the use of hospice or palliative care and increase the completion of documentation. All other measures, such as ICU use, length of stay and hospital admissions had mixed results. The reasons for this are explained more in the Findings section that follows.



# Findings 4: Results From The Review (Finding Information)

## Themes from the studies

Findings from the twenty one individual systematic reviews can be seen in Appendix 6. The key themes are described below:

### Decision aids

These can improve patient knowledge and preparation for treatment choices;<sup>16</sup> however, there are limitations to the impact of decision aids on EOL care (Brooke and Kirk 2014)<sup>20</sup> because most are targeted towards older people at EOL, are disease-specific, and do not clearly identify benefits, risks, or prognostics of diseases and treatment choices made. Of the type of decision aid most effective with ACP, the research supports video ACP for clinicians to assist in discussions of treatment; and AD documentation available free of charge online.

### Communication:

Baidoobonso (2014)<sup>17</sup> showed that single-provider engagement in patient care plans provided the most benefit for establishing quality of life (QOL), information and understanding in patients and carers. Single-provider engagement was also reported as increasing hospice use and care over multi-provider or team engagement.

### Timing

Almost all of the reviews identified that timing of ACP should be done early, often and continue throughout the patient journey to EOL; however, this also had to be managed with the receptiveness of the patient and family.

## Education

Barnes et al. (2012)<sup>18</sup> and Durbin et al. (2010)<sup>24</sup> found poor levels of evidence led to incomplete findings of the benefits of education interventions to promote ACP. Nevertheless, it appears that verbal education is an essential component regardless of what other mechanism is used to educate.

### Intensive care unit use and length of stay

Khandlewal et al.<sup>27</sup>, Baidoobonso<sup>17</sup> and Brinkman-Stoppelenburg et al.<sup>19</sup> all found that ACP or ACP-like interventions could reduce the use of hospitals, ICU, and LOS depending upon when ACP was introduced and acted upon.

### Barriers to ACP

Barriers from these reviews remain similar to those identified across a number of years. The main barriers being:

- Healthcare professional lack of knowledge, information, confidence in the process and use of ACP as well as support for the process by healthcare systems such as nursing homes and acute hospital care.<sup>25</sup>
- Patient capacity to understand the ACP process and what decisions might mean for the choices made especially if the person has had a diagnosis of cognitive impairment.<sup>20, 22, 25, 34</sup>



## Facilitators to ACP

Again, these echo findings from previous studies with the main facilitators being:

- Time to engage in the discussions over a long period of time<sup>25</sup> with peers or professional facilitators<sup>31</sup>
- Initiation of discussion by healthcare professional<sup>18</sup>
- Allowing time for person to accept the need for ACP and not forcing the issue.<sup>33</sup>

## Costs of ACP

Klinger et al.<sup>28</sup> and Dixon et al.<sup>23</sup> showed inconclusive evidence on the costs associated with ACP interventions due to methodological differences between studies, however Dixon et al.<sup>23</sup> found that ACP did not make things costlier and may lead to healthcare savings.

## Quality of life

There is no clear evidence on the effect of ACP on QOL as this has been measured in many different ways. Baidoobonso<sup>17</sup> found no evidence that QOL improved with the use of Patient Care Plans; Brinkman-Stoppelenburg et al.<sup>19</sup> identified that there was some evidence that ACP positively impacted QOL; Houben et al.<sup>26</sup> did not find any evidence that ACP interventions increased patient satisfaction but family members appeared more satisfied; Martin et al.<sup>32</sup> indicated that in nursing homes, the use of ACP enabled more actions being consistent with the person's wishes while Sumalinog et al.<sup>37</sup> found that there is conflicting evidence as to whether a person's wishes are adhered to because of health system and culture differences in different countries.

In addition, and specific to ACP in palliative care, Stephen et al.<sup>36</sup> identified that for many of the studies they cited, only two of the eight quality domains for EOL care as defined by the National Consensus Project for Quality Palliative Care were measured: structure/

process of care; and, ethical/legal aspects of care. This means that very few studies which looked at the combination of ACP in an EOL context review actually measured quality of life in a consistent fashion or according to a specific framework.

## Strengths of the reviews

The strengths of all of the reviews is that they have highlighted gaps in the knowledge base around ACP interventions and the majority have used very thorough search strategies and systematic processes to answer the specific research question reviewed. The methodological approaches of the majority of the reviews have used PRISMA guidelines or a similar approach to make sure that the literature targeted provides answers to the research question without going wide of the mark.

For some reviews, such as those by Luckett et al.<sup>31</sup>, they are the first to target specific disease information for ACP in palliative care while many of the rest target specific elements of the ACP process, such as Austin et al.<sup>16</sup> on the effectiveness of decision aids in relationship to ACP outcomes.

## Limitations of the reviews as defined by review authors

Limitations of the reviews as defined by the authors of the reviews all come down to one thing: heterogeneity in the methodologies used within all of the studies cited make it very difficult to comprehensively conclude which aspects of ACP are best for different outcome measures or objectives. For example, in relation to measuring the costs associated with ACP and whether ACP is a cost-effective practice, Baidoobonso<sup>17</sup> could not show evidence of its cost-effectiveness in relation to less use of ICU; Dixon et al.<sup>23</sup> found that the evidence of the economics of ACP is limited and equivocal and may

be specific to particular settings, diseases or socio-economic factors, and healthcare systems; Khandelwal et al.<sup>27</sup>, on the other hand, found that ACP interventions reduced the number of ICU admissions for patients at high risk of death; while Klinger et al.<sup>28</sup> found that because the details of the ACP interventions were lacking, there was no way to measure overall costs to a healthcare system with implementation of ACP or the costs accrued to family and friends over time.

In summary, the lack of specific detail of ACP interventions, their costs, the specific outcomes being measured, defining what are the outcomes that should be measured, which of the different parties should be measured for different elements of ACP, e.g. patients, healthcare professionals, healthcare systems, and how all of this actually impacts on quality of life of the patient as opposed to family or healthcare professionals, means that evaluation of ACP as an intervention in palliative care remains inconclusive and ill-defined.

## **Practice recommendations as defined by the authors of the reviews**

Appendix 6 also provides details for each study about practice recommendations based on the individual systematic review findings. In summary, there are several noteworthy areas of practice that the reviews recommend:

1. Begin the process of ACP early and engage in discussions often throughout the patient's palliative care journey using a skilled facilitator who can develop a trusting relationship with the patient and family or carer and do not depend on individual written, online, or other types of ACP interventions to do the job
2. Identify the information needs of the patient and family and when they are willing to accept this information while acknowledging that for the person with a cognitive impairment, sooner is better than later. This means that the facilitator should be skilled in communication strategies as well as being given the support and time to engage in ongoing discussions
3. For documentation of ACP, ADs have a role to play in beginning the conversation but the facilitator should present these documents in a way that is specific to the patient disease and prognosis, including the use of decision aids on dementia and feeding tubes. Documentation should be contained in the patient medical record in a manner that enables constant reflection of the suitability of the document for the current circumstances of the patient and family and to be updated when circumstances change
4. Quality improvement initiatives should include measurement of prevalence rates, cost-effectiveness measures, and identification of patient wishes documented in ACP and ADs and whether these have been followed and, if not, what system failures are preventing this from happening.

# Discussion

These findings suggest that while there is increasing research into ACP, the pathways for a systematic and effective approach to enable individuals to plan for their EOL are still being established. In 2010, Tamayo-Velazquez et al.<sup>12</sup> provided an overview of systematic reviews on interventions to promote ADs specifically. Their conclusion was that passive information material alone without interaction with others would not increase ADs.<sup>12</sup> This review still highlights the need for support to facilitate documentation but highlights the variability in meaning around ACP. ACP activities within the reviews meant many different things and may not have even contain consistent documentation or processes or strictly be for EOL.<sup>28</sup> The role of ACP in EOL as a horizon event in early dementia or chronic kidney disease is important but may be contextually different to the more detailed planning, discussion, and preference elicitation occurring in an expectation of impending death. Preferences also need to be moderated by the capacity to provide the desired care and by medical futility with respect to the appropriateness of providing desired care.

Without a clear definition of ACP, measuring its effectiveness may lead to bias in developing systematic reviews that can provide conclusive evidence (Barnes et al. 2012<sup>18</sup>; Flo et al. 2016<sup>25</sup>; Dixon et al. 2015<sup>23</sup>; Sumalinog et al. 2016<sup>37</sup>) and limit generalisability or applicability in different settings. The issue of defining what we mean when discussing and comparing ACP research has also been highlighted in this review. Across these reviews, ACP included informal and formal discussions, formal documentation, care plans, responses to decision making tools and aids, and expressions of preferences. Sources of definitions of ACP used by reviewers included those by Seymour (2010), Henry & Seymour (2007), Feer et al. (2006),

Livingston et al. (2010), Detering et al. (2010), Singer (1996), Hammes et al. (1998), in der Schmitzen (2014), Davison et al. (2007, 2009, 2011); Fried et al. (2009), World Health Organisation (2004, 2016). With over 14 different sources being used to define ACP within the 21 systematic reviews forming this overview, it is no wonder that consensus on what is being discussed continues to be inconsistent leading to inconsistent research methodologies, outcome measures, and results. While all discussions about EOL are important in developing understanding of the patient's wishes, in reality they may have different value in supporting those choices when needed. As yet a road map that articulates the relationship between awareness, conversation, decision making, sharing of choices, and application at the point of purpose is not fully described which hampers the capacity to allocate and assess effectiveness at different points and in different settings.

It is interesting to note that there are relatively few reviews looking specifically at ACP within palliative care services. This reminds us that ACP approaches are already an integrated part of practice. However, it is worth remembering that palliative care is the health service in which EOL preferences and choices will come into effect. ACP as an ongoing discussion in the context of impending death provides a facility for health professional discussions to occur with patients and families and to be moderated by knowledge about disease progression and the implications of choices. It can also facilitate shared understanding among families and other decision makers. This is an environment in which contexts highlighted in the review including a trusting relationship<sup>18</sup> and the ability to have face to face conversations<sup>19</sup> about the future can occur. Palliative care services and the palliative care discipline may be influential in supporting ACP approaches and strategies

within other health care settings and disciplines and within the community more generally. This may be particularly important in fields relating to ageing and chronic disease where progression to death can be anticipated as a horizon event.

It is also worth noting the diffusion of ACP into other EOL contexts. Several of the studies addressed ACP within a chronic and progressive disease such as kidney disease, heart failure, dementia and Motor Neurone Disease. Settings where EOL is becoming a consideration such as emergency departments and ICU are also becoming more common research sites for ACP. This may be where a community-based approach to ACP will have more the influence on the EOL care received.

It is perhaps pertinent that at this stage it becomes obvious that the term 'ACP' has morphed into other terms such as EOL care, patient care planning and goals of care in determining future care requirements. However, the timepoints for when something is ACP, EOL care planning, requiring goals of care planning, or palliative care planning is less clear in these contexts and has led to most research studies focusing on the early elements of ACP implementation, e.g. measures that increase healthcare professional engagement with patients and ACP or completion of ADs. Although, it is important to provide knowledge, information, and confidence to healthcare professionals to engage in ACP, high staff turnover<sup>25</sup>, individual or healthcare system resistance to ACP, and lack of healthcare professional support (resource and personnel) to pursue these discussions means that patients are often left bereft of the opportunity to have these discussions early and often.

The value of ACP as a process that can enable discussion about the likely future needs to be strengthened. The value needs to be articulated as in many cases, ACPs may not need to be enacted as the person will be sufficiently lucid to provide their own choice or preference but if there is no awareness that death is a possible or likely event such discussions may not have occurred. In this way palliative care remains distinct from ACP as death is a known context for all who are referred.

ADs offer a starting point for initiating ACP processes in and out of palliative care. Although prevalence rates of completed ADs continues to be less than hoped for and evidence of prevalence fluctuates and is inconsistent because it is not regularly measured; nevertheless, engaging a person in consideration of DNR or DNH orders begins the phase of reflection that promotes engagement of ACP. This may be difficult to do in the palliative sense if advance directives are being promoted as being for any timepoint in life for completion, healthy or ill, when palliative care is provided at a time of life-limiting/life-threatening time. Nevertheless, when the life-threatening illness occurs, discussing ADs in the first instance may assist engagement in ACP. Asking if a person has made a previous AD will assist those engaging in ACP communication to better understand the person's long-standing values and wishes.

# Future Research

Future research for ACP as identified within the systematic reviews suggest that larger scale studies conducted over a longer period of time evaluating each individual aspect of the ACP intervention are needed to enable meta-analysis of specific interventions to determine their effectiveness (Appendix 7). These studies should preferably be randomised-controlled trials (RCTs) where blindness of participants to interventions occurs. There is a need for far more RCTs which measure ACP interventions against each other and controls rather than the creation of new models, new outcome measures, and new instruments for measuring outcomes. When comparing ACP interventions, these interventions need to be described in detail in relation to timing, setting, population, number of sessions, and type of facilitation that occurs. If an ACP intervention, such as the Gold Standard Framework, shows some level of consistency across multiple studies then this should be replicated, including in large US studies. When RCTs are not possible to implement, then other types of research such as controlled trials or cohort studies could provide needed information.

ACP studies also need to measure quality of life for specific disease groups, such as dementia and to look at how culture and circumstances affect the ability to address ACP and enact choices and preferences.

Cost analyses need to be specific in relation to areas of cost as well as measuring cost-effectiveness and beneficial QOL elements in palliative care.

Surprisingly, given the public and policy interest in ACP, the consumer voice is still missing in most research. The focus tends to be on rates of uptake or completion. Exploring consumer attitudes to advance care planning and seeking to understand their experience of its application within the health systems is an important area of future research. Without understanding its meaning and value to them, we will continue to design approaches that are not relevant and do not match their needs.

# Conclusion

This rapid review sought to understand how ACP is envisioned within a palliative care context and to explore the role and purposes of ACP in relation to palliative care.

There are suggestions from the literature that palliative care practices may have characteristics that support the discussion of EOL matters. In part this relates to the context of palliative care where death is accepted as an expected event, however it also provides an environment that supports ongoing discussion and enables integration of family awareness into this discussion. Less is known about how community-initiated and consumer-directed ACP activity will affect palliative care practices into the future. Definitional issues around ACP may create some confusion around EOL practices.

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# Appendices

## Appendix 1: Review Protocol

A copy of the Review Protocol can be found [here](#).

## Appendix 2: Search Strategy

### Medline Search

#	Searches	Results
1	advance care planning/ or advance directives/or living wills/ or resuscitation orders/	10555
2	(Advance* adj2 (directive* or plan*)). tw	6181
3	advance* care plan*.kw.	415
4	power of attorney.tw.	360
5	resuscitation order*.tw.	155
6	living will*.tw.	1151
7	(choice* or decision* or discuss* or conversation* or goals of care or care goals or plans or plan or preference*).m_titl.	167469
8	((Withdraw* or withhold* or limit*) adj3 (ventilation or resuscitat* or hydration or lifesupport or life support or treatment)) or end of life).m_titl.	11113
9	7 and 8	1867
10	1 or 2 or 3 or 4 or 5 or 6 or 9	15120
11	limit 10 to yr="1990 -Current"	14231
12	limit 11 to systematic reviews	423

((systematic[sb] AND ( "1990/01/01"[PDat] : "2017/12/31"[PDat] ))) AND  
 ((((((Withdraw\*[ti] or withhold\*[ti] or limit\*[ti]) AND (ventilation[ti] or resuscitat\*[ti] or  
 hydration[ti] or lifesupport[ti] or life support[ti] or treatment[ti])) OR end of life[ti]) AND  
 (choice\*[ti] or decision\*[ti] or discuss\*[ti] or conversation\*[ti] or goals of care[ti] or  
 care goals[ti] or plans[ti] or plan[ti] or preference\*[ti]) OR "Advance\* directive\*" [tiab]  
 OR "advance\* care plan\*" [tiab] OR "living will\*" [tiab] OR "power of attorney" [tiab] OR  
 "resuscitation order") NOT medline[sb]) AND ( "1990/01/01"[PDat] : "2017/12/31"[PDat] ))

### PubMed Search Strategy

#	Searches	Results
1	exp *Advance Directives/	1085
2	(Advance* adj2 (directive* or plan*)).tw.	2311
3	advance* care plan*.kw.	0
4	power of attorney.tw.	174
5	resuscitation order*.tw.	34
6	living will*.tw.	338
7	(choice*or decision*or discuss* or conversation* or goals of care or care goals or plans or plan or preference*).m_titl.	99447
8	(((Withdraw* or withhold* or limit*) adj3 (ventilation or resuscitat* or hydration or lifesupport or life support or treatment)) or end of life).m_titl.	3505
9	7 and 8	685
10	1 or 2 or 3 or 4 or 5 or 6 or 9	3234
11	limit 10 to yr="1990 -Current"	3100
12	limit 11 to systematic reviews	50

## Emcare Search Strategy

#	Searches	Results
1	living will/	3292
2	(Advance* adj2 (directive* or plan*)).tw.	3,592
3	advance* care plan*.kw.	520
4	power of attorney.tw.	164
5	resuscitation order*.tw.	93
6	living will*.tw.	435
7	(choice* or decision* or discuss* or conversation* or goals of care or care goals or plans or plan or preference*).m_titl.	61329
8	((((Withdraw* or withhold* or limit*) adj3 (ventilation or resuscitat* or hydration or lifesupport or life support or treatment)) or end of life).m_titl.	7141
9	7 and 8	1298
10	1 or 2 or 3 or 4 or 5 or 6 or 9	6256
11	limit 10 to yr="1990 -Current"	6254
12	limit 11 to "systematic review"	121

**Medline, CINAHL, Pubmed, PsycInfo, Emcare, and Econlit**

#	Query	Limiters/ Expanders	Results
S1	(MM "Advance Care Planning") OR (MM "Advance Directives+")	Search modes - Boolean/Phrase	4392
S2	TI ( "power of attorney" OR "resuscitation order*" OR "living will*" ) OR AB ( "power of attorney" OR "resuscitation order*" OR "living will*" )	Search modes - Boolean/Phrase	Display
S3	TI ( Advance* N2 (directive* OR plan* ) OR AB ( Advance* N2 (directive* OR plan* ) )	Search modes - Boolean/Phrase	Display
S4	( TI ( ((Withdraw* OR withhold* OR limit*) N3 (ventilation OR resuscitat* OR hydration OR lifesupport OR "life support" OR treatment)) OR "end of life" ) OR AB ( ((Withdraw* OR withhold* OR limit*) N3 (ventilation OR resuscitat* OR hydration OR lifesupport OR "life support" OR treatment)) OR "end of life" ) ) AND ( TI ( choice* OR decision* OR discuss* OR conversation* OR "goals of care" OR "care goals" OR plans OR plan OR preference* ) OR AB ( choice* OR decision* OR discuss* OR conversation* OR "goals of care" OR "care goals" OR plans OR plan OR preference* ) )	Search modes - Boolean/Phrase	Display
S5	S1 OR S2 OR S3 OR S4	Search modes - Boolean/Phrase	10002
S6	S1 OR S2 OR S3 OR S4	Limiters - Published Date: 19900101- 20171231 Search modes - Boolean/Phrase	9910
S7	S1 OR S2 OR S3 OR S4	Limiters - Published Date: 19900101- 20171231; Publication Type: Systematic Review Search modes - Boolean/Phrase	228

## Appendix 3: Excluded Studies

#	Reason
Wallace (2015)	Design and review process not described in full with regard to study particulars
Oczkowski (2016)	Explicitly excluded ACP studies
Wesrenhaver (2010)	Incomplete details of studies reviewed
Jain (2015)	Less than 50% of part population in anticipated death
Field (2014)	Less than 50% of part populations in studies reviewed anticipated death
Bartlow (2005)	Mostly surveys about EOL questions, not an ACP intervention
Lord (2015)	Not ACP intervention
Frost (2011)	Not ACP intervention
Hines (2011)	Not ACP intervention
Johnson (2016)	Not ACP intervention
Societe (2003)	Not available
Stuck (2005)	Not available
Kunz (2003)	Not English
Connolly, Amanda (2012)	Only 25% studies investigated ACP as intervention
Xafis (2015)	Paediatric
Lotz (2013)	Paediatric
Kirolos (2014)	Participant population not anticipated death
Bravo (2008)	Participant population not in anticipated death
Patel (2004)	Participant sample not in anticipated death
Walling (2008)	Systematic review process biased and unclear
Skinner (2014)	Participant population less than 50% anticipated death (we could not really tell)
Van der Steen (2014)	Participant population less than 50% anticipated death (we could not really tell)

#	Reason
Beck (2015)	ACP is not an intervention
Walczak (2016)	Cannot retrieve articles referred to for defining patient populations
Weathers (2016)	More than 50% of participant sample well or not anticipated death
Tamayo (2010)	Not a review of studies, a review of reviews
Jethwa (2015)	Not a Systematic review
Arendts (2010)	Not about ACP
Badrakalimuthu (2014)	Not about ACP
Song (2016)	Not about ACP, more ACP as outcome
Bray (2015)	Not ACP intervention
Sechaud (2010)	Not ACP intervention
Biondo (2016)	Not in palliative care or EOL context with ACP intervention
Kelly, B. (2012)	Only 1/3 anticipated death
Song (2004)	Participants population not anticipated death
LaMantia (2010)	Participants population not anticipated death
Auremma (2014)	Part population were varied – well, chronic, advanced, nursing home – not more than 50% in anticipated death
Thomas (2008)	Part sample less than 50% anticipated death, more than 50% well
Rietze (2015)	Part samples not identified as anticipated death and study does not contained nurses info or link to anticipated death or palliative care
Ramsaroop (2007)	Part samples not identified as being palliative care context
Jezewski (2007)	Participant samples in studies more than 50% are well
Aslakson (2014)	Protocol, not a review
Ostjerr (2016)	Not ACP intervention
Momen (2012)	Not ACP intervention

## Appendix 4: Quality Appraisal Summary

Record	Authors	Relevance	SIGN 1.1	SIGH 1.2	SIGN 1.3	SIGN 1.4	SIGN 1.5	SIGN 1.6	SIGN 1.7	SIGN 1.8	SIGN 1.9	SIGN 1.10	SIGN 1.11	SIGN 1.12	Overall	Pts Applicability
32	Austin, Mohottige, Sudore, Smith, Hanson	Y	Y	Y	Y	Y	Y	Only in PRISMA tree	Not in Full	Y	Y	Y	Y	Y	(++)	Y
659	Brinkman-Stopplelenberg, Rietjens and Van der Heide	Y	Y	Y	Y	Cannot say	Y	Only in PRISMA tree	Y	Y	Y	Y	Y	Y	(++)	Y
37	Barnes, Gott, Chady, Seamark, Halpin	Y	Y	Y	Y	Cannot say	Y	N	Y	Y	N	Y	Y	Y	(+)	Y
458	Brooke and Kirk	Y	Y	N	Cannot say	Cannot say	N	N	Y	N	N	N	N	N	0	Y
34	Baidoobonso	Y	Y	Y	N	N	Y	Only in PRISMA tree	Y	Y	Y	Y	Y	Y	(++)	Y
72	Cardona-Morrell, Benfatti-Olivato, Jansen, Turner, Fajardo-Pulido, Hillman	Y	Y	Y	Y	Cannot say	Y	Only in PRISMA tree	Y	Y	Y	Y	Y	Y	(++)	Y
110	Dening, Jones and Sampson	Y	Y	Y	Y	Cannot say	Y	N	Y	Y	Y	Y	Y	Y	(+++)	Y



Record	Authors	Relevance	SIGN 1.1	SIGH 1.2	SIGN 1.3	SIGN 1.4	SIGN 1.5	SIGN 1.6	SIGN 1.7	SIGN 1.8	SIGN 1.9	SIGN 1.10	SIGN 1.11	SIGN 1.12	Overall	Pts Applicability
132	Flo, Husebo, Bruusgaard, Gjerberg, Thoresen, Lillemoen & Pedersen	Y	Y	Y	Y	Y	Y	Only in PRISMA tree	Y	Y	Y	Y	Y	Y	(++)	Y
113	Dixon, Matosevic and Knapp	Y	Y	Y	Y	Cannot say	Y	Only in PRISMA tree	Y	Y	Y	Y	Y	Y	(++)	Y
115	Durbin, Fish, Bachman, Smith	Y	Y	N	Cannot say	Y	Y	No	Y	N	N	Y	Y	N	(-)	Y
180	Houben, Spruit, Grenen, Wouters, Janssen	Y	Y	N	Y	Y	Y	Only in PRISMA tree	Y	Y	Y	Y	Y	Y	(++)	Y
208	Klingler, der Schmitt, Marckmann	Y	Y	Y	Y	Y	Y	Only in PRISMA tree	Y	Y	Y	Y	Y	Y	(++)	Y
225	Lewis, Cardona-Morell, Ong, Trankle, Hillman	Y	Y	Y	Y	Y	Y	Only in PRISMA tree	Y	Y	Y	Y	Y	Y	(++)	Y
227	Lim, Ng, Cheng, Cigolini, Kwok, Brennan	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	(++)	Y

Record	Authors	Relevance	SIGN 1.1	SIGH 1.2	SIGN 1.3	SIGN 1.4	SIGN 1.5	SIGN 1.6	SIGN 1.7	SIGN 1.8	SIGN 1.9	SIGN 1.10	SIGN 1.11	SIGN 1.12	Overall	Pts Applicability
240	Lockett, Sellars, Tieman, Pollock, Silvester, Butow, Detering, Brennan, Clayton	Y	Y	Y	Y	Y	Y	Only in PRISMA tree	Y	N	N	Y	Y	Y	(++)	Y
248	Martin, Hayes, Gregorevic, Lim	Y	Y	Y	Y	Y	Y	Only in PRISMA tree	Y	Y	Y	Y	Y	N	(++)	Y
276	Murray and Butow	Y	Y	Y	Y	Cannot say	Y	Only in PRISMA tree	Y	Y	Y	Y	Y	N	(++)	Y
364	Stephen, Skirton, Woodward, Prigmore, Endacott	Y	Y	Y	Y	Y	Y	Only in PRISMA tree	Y	Y	Y	Y	Y	Y	(++)	Y
370	Sumalinog, Harrington, Dosani and Wang	Y	Y	Y	Y	Y	Y	Only in PRISMA tree	Y	Y	Y	Y	Y	Y	(++)	Y
328	Robinson, Dickinson, Rousseau, Beyer, Clark, Hughes, Howel and Exley	Y	Y	Y	Y	Y	Y	Only in PRISMA tree	Y	Y	Y	Y	Y	Y	(+)	Y
204	Khandelwal, Kross, Engleberg, Coe, Long, Curtis	Y	Y	Y	Y	Cannot say	N	Only in PRISMA tree	Y	N	N	Y	Y	Y	(+)	Y

## Appendix 5- ACP Outcome Measures and Prevalence in Studies Cited in Systematic Reviews

Systematic review by author	Outcomes measured	Prevalence rates of ACPs where measured
Austin et al. 2015 <sup>16</sup>	<p>Completion of ADs</p> <p>Information on EOL topics</p> <p>Understanding of information on ACP Hospice care</p> <p>Understanding of features of advanced dementia</p> <p>Descriptions of treatment options</p> <p>Description of chronic critical illness for families of patients in ICU</p> <p>Information about mechanical ventilation (MV) in COPD</p> <p>Features of advanced dementia</p> <p>Information on lung cancer treatment</p> <p>Information on palliative care</p> <p>Info on CPR and MV</p> <p>Info on breast cancer</p>	<p>Pearlman (2005) - increased patient report of ACP discussions, increased ACP-related notes written by clinicians</p> <p>Sudore (2007) - improved ease and understanding, including in AD completion over six months</p> <p>Vogel (2013) - no effect on AD completion, no effect on palliative care consultation</p> <p>Volandes (2009) - increased choice for comfort care</p> <p>Volandes (2009) - increased concordance between patients and surrogates</p> <p>Volandes (2011) - increased choice for comfort care, decreased choice of life-prolonging care</p> <p>Clayton (2007) - two - three times more questions asked, more items discussed, more time per visit</p>

Systematic review by author	Outcomes measured	Prevalence rates of ACPs where measured
	<p>Info on diagnoses, prognosis, treatment options for advanced malignant disease</p> <p>Depiction of levels of care for advanced cancer</p> <p>Information on COPD</p> <p>Advance directive document info</p> <p>Information on shared decision-making</p> <p>Communication skills</p> <p>Community services for cancer</p> <p>Disclosure of terminal status</p>	<p>El-Jawahri (2010) - increased choice for comfort care</p> <p>Epstein (2013) - no change in CPR or MV preferences or knowledge, increased ACP documentation at one month</p> <p>Hanson (2011) - decreased decisional conflict, increased frequency of communication with healthcare professionals at three months, increase in use of dysphagia diet at three months</p> <p>Leighl (2011) - no change in chemo choice, no change in decisional conflict or satisfaction, including in knowledge</p> <p>Meropol (2013) - increase in satisfaction with communication, increase in ease of decision-making, no change in decisional conflict</p> <p>Peele (2005) – decrease in choice for therapy</p> <p>Stirling (2012) - no impact, no change in decision conflict, knowledge or treatment preferences</p> <p>Vandemheen (2009) - improved knowledge and expectations, decrease decision conflict, no change in transplant choice</p> <p>Volandes (2012) - increased choice for comfort care</p> <p>Yun (2011) - no change in discussions of terminal prognosis, decrease in decision conflict, decrease in caregiver depression</p>

Systematic review by author	Outcomes measured	Prevalence rates of ACPs where measured
Baidoobonso 2014 <sup>17</sup>	<p>Concordance between patient wishes and care received</p> <p>Concordance between patient and surrogate wishes</p> <p>Completion of ACP documents and processes</p> <p>Informal caregiver QOL</p> <p>Carer and family satisfaction with care</p> <p>Patient satisfaction with care</p> <p>Patient QOL</p> <p>Hospital LOS</p> <p>ICU LOS</p> <p>Hospital care</p> <p>Emergency department visits</p> <p>Home health visits</p> <p>Outpatient services</p>	<p>Completion of ACP Documents and Processes:</p> <p>For single-provider Patient Care Planning Discussion (PCPD) 13% and 77% increase in completion of ACP documents and processes</p> <p>Team-based PCPDs associated with 22% increase in completion of ACP processes and documents</p>

Systematic review by author	Outcomes measured	Prevalence rates of ACPs where measured
	Chemotherapy Hospice care Resuscitation	
Barnes et al. 2012 <sup>18</sup>	Delivery of news Timing of discussion Patient satisfaction with process Number of questions asked Who should initiate discussion? Number of documents completed Confidence in ACP knowledge Type of intervention that is most effective Knowledge and self-efficacy of nurses Effectiveness of Go Wish cards	Increase in delivery of news but not in discussion of patient preferences or specifics Timing of discussion is best initiated after recurrence of a disease Improvement for patients in decision-making, greater satisfaction with process and quality of communication and less decisional conflict Increase in number of questions asked Healthcare professionals should initiate discussion or sometimes wait for patient to initiate More discussions and understanding with more living wills and power of attorneys created but no increase in confidence Leaflet alone is not a reliable method of communicating Need for realistic information

Systematic review by author	Outcomes measured	Prevalence rates of ACPs where measured
	Effectiveness of “Kitchen Table Discussion Tool”	<p>Improvement in knowledge and self-efficacy with nurses showing improvement in confidence in communicating and teaching communication</p> <p>Go Wish cards successful in initiating EOL discussions and preferences</p> <p>“Kitchen Table Discussion Tool” enabled discussions with COPD patients</p>
Brinkman-Stoppelenburg et al. 2014 <sup>19</sup>	<p>CPR</p> <p>Life-sustaining treatment (LST) (including CPR)</p> <p>Hospice and/or palliative care</p> <p>Hospitalisation/LOS</p> <p>ICU admission/LOS</p> <p>QOL/Quality of care/satisfaction</p> <p>Compliance with patient EOL wishes</p> <p>Patient and family symptoms</p>	<p>For DNR orders specifically:</p> <ul style="list-style-type: none"> <li>• 32/56 studies showed a decrease in CPR or LST requests after ACP intervention</li> <li>• 3/56 showed an increase in wanting CPR or LST</li> <li>• 7/56 had mixed results</li> <li>• 13/56 showed no difference in use of CPR or LST after ACP</li> </ul> <p>For combined DNR/DNH/ADs/LW/DPOA or Complex ACPs outcomes were as follows:</p> <ul style="list-style-type: none"> <li>• Hospice or palliative care use - 18/23 studies showed increase in use; 3/23 had mixed results; 2/23 studies showed no difference</li> </ul>

Systematic review by author	Outcomes measured	Prevalence rates of ACPs where measured
		<ul style="list-style-type: none"> <li>• Hospitalisation or LOS - 21/35 studies showed a decrease in these with ACP intervention; 5/35 showed an increase; 1/35 showed mixed results; 8/35 showed no difference</li> <li>• ICU/LOS- 2/8 studies showed decrease in use; 3/8 showed increase in use; 3/8 showed no difference</li> <li>• Quality of life/quality of care/satisfaction - 1/19 studies showed a decrease in this after ACP; 5/19 studies showed an increase; 1/19 studies were mixed; 12/19 studies showed no difference</li> <li>• Compliance with patient EOL wishes - 3/6 studies showed no difference after ACP; 3/6 studies showed increase in compliance</li> <li>• Making a difference to patient or family symptoms - 5/13 studies showed a positive increase in making a difference; 1/13 had mixed results; 7/13 showed no difference.</li> </ul>
Brooke and Kirk 2014 <sup>20</sup>	Barriers to ACP discussions	Prevalence not discussed
Cardona-Morrell et al. 2017 <sup>21</sup>	Change in patient/surrogate knowledge Change in decisional conflict Decision concordance (between patient/surrogate)	Prevalence not discussed



Systematic review by author	Outcomes measured	Prevalence rates of ACPs where measured
Dening et al. 2011 <sup>22</sup>	<p>Complexities and processes that influence EOL decisions</p> <p>Hospitalisation rates and mortality</p> <p>Practice patterns for ACP</p> <p>Psychometric competence assessment</p> <p>LST decisions</p> <p>Sensitivity of MMSE</p> <p>Differences in EOL care preferences</p> <p>Staff attitudes and knowledge</p> <p>Correlation of prevalence and socio-demographics of ACP</p> <p>Influence of spouse</p> <p>Attitudes to EOL decisions</p> <p>Documentation of ACDs</p>	<p>Haydar (2004) showed that due to the ACP, DNRs were created for 62% of CHF patients and 91% of patients with dementia however the CHF patients participated more than patients with dementia in ACP - sample size 142 (so 88/142 for CHF and 129/142 for dementia)</p> <p>Lingler (2008) showed 65% had DPOA and 56% had LW (484/765; 428/765)</p> <p>Triplett (2008) 66% had AD (81/123)</p> <p>Hirschman (2008) 77% of people with dementia had written AD (23/30)</p> <p>Lacey (2006) 123/130 (97%) had AD.</p>

Systematic review by author	Outcomes measured	Prevalence rates of ACPs where measured
	<p>Link between ACP and distress</p> <p>Legal and ethical hierarchy in decision-making</p> <p>Effect of decision-making on decline of person with dementia and caregiver characteristics</p> <p>Facilitators and inhibitors to ACP</p> <p>Use of values clarification in ACP</p>	
Dixon et al. 2015 <sup>23</sup>	<p>Costs for hospital care, nursing home care, ED visits, specialist outpatient clinic, and polyclinic visits</p> <p>Medicare expenditure for people with dementia in/ out of community; Medicare charges for terminal hospitalisations</p> <p>Preferred place of death and association with ACP</p> <p>Total hospital costs</p> <p>Costs of unplanned hospitalisations</p> <p>Medicare expenditure ICU patients</p>	<p>Engagement in ACP</p> <p>Abel et al. (2013) - Preferred place of death - 969/?</p> <p>Engelhardt (2006) - 93/169 55%</p> <p>Baker et al. (2012) - 96/182=50%</p> <p>Teo et al. (2014) 48/247=22%</p> <p>Nicholas et al. (2014) - 3876/?</p> <p>Lukas et al. (2013) - 369/?</p> <p>Kelley et al. (2011) - 2394/?</p>

Systematic review by author	Outcomes measured	Prevalence rates of ACPs where measured
	<p>Cost effectiveness of treatment-limiting ADs vs Medicare expenditure</p> <p>ADs completed before terminal hospitalisation</p> <p>Medicare expenditure in last six months of life</p> <p>Effectiveness of physician discussion of EOL plans</p> <p>Medicare expenditure difference between states and compliance with PSDA</p> <p>Let Me Decide effectiveness in reducing hospitalisation costs</p> <p>Physician charges</p>	<p>Hamlet et al. (2010) - 3112</p> <p>Zhang et al. (2009) - 145/145</p> <p>Gade et al. (2008) - 280/517=54%</p> <p>Molloy et al. (2000) - 636/1292= 49%</p> <p>Teno et al. (1997) - 2632/4784 (55%) 14. Weeks et al. (1994) - 308/?</p> <p>Chambers et al. (1994) - 474/?</p>
Durbin et al. 2010 <sup>24</sup>	Number of documents completed with ACP intervention	<p>Cintron (2006) - 0.9% TG (Treatment Group) vs 1.2% CG (Control Group)</p> <p>Grimaldo (2001) - TG=16%; CG=2%</p> <p>Heffner &amp; Barbierie (2001) - TG =19%; CG=17%</p> <p>High (1993) - TG1 and TG2 = 7%; TG3=3%; TG4=6%; TG5=25%; TG6=5%; CG=6%</p> <p>Reilly (1995) - TG=10%; CG=8%</p>

Systematic review by author	Outcomes measured	Prevalence rates of ACPs where measured
		<p>Sachs (1992) - TG=2%; CG=4%</p> <p>Sulmasy (1996) - TG1 = 0%; TG2=2%; CG=1%</p> <p>Heiman (2004) - TG1=14%; TG2=2%; CG=2%</p> <p>Meier (1996) - TG=36%; CG=0%</p> <p>Pearlman (2005) - TG=48%; CG=23%</p> <p>Richter (1995) - TG=21%; CG=1%</p> <p>Landry (1997) - TG=38%; CG=24%.</p>
Flo et al. 2016 <sup>25</sup>	<p>The best palliative approach</p> <p>Number of deaths in hospital</p> <p>Documentation of DNR and ACP discussions</p> <p>Family satisfaction</p> <p>Staff confidence</p> <p>Types of values and beliefs listed in care plans</p> <p>Stability of treatment preferences</p>	<p>Livingston (2013) 143/176 (49%) residents completed form; 127/176 (65%) had discussions</p> <p>Silvester (2013) 100/203 (49%) had MEPOA; 196/203 (91%) wrote values/beliefs; 158/203 (78%) completed health perspectives</p> <p>Molloy (2000) 311/636 (49%) of residents; 496/636 (78%) relatives</p> <p>Overall:</p> <ul style="list-style-type: none"> <li>Fewer deaths in hospital</li> </ul>

Systematic review by author	Outcomes measured	Prevalence rates of ACPs where measured
	<p>Existential anxiety/distress</p> <p>Concordance between patient and treatment provision</p> <p>Adherence to POLST</p> <p>Participation rates of nurses and doctors in ACP programmes</p> <p>Type and frequency of information to families</p> <p>Measurement of cultural change</p> <p>Number of emergency calls in hospital</p> <p>Hospital costs</p>	<ul style="list-style-type: none"> <li>• Better documentation of DNR orders and ACP discussions</li> <li>• No difference for days spent in hospital</li> <li>• More satisfied relatives</li> <li>• Staff more comfortable with addressing ACP issues</li> <li>• Example of values/belief statements in care plan</li> <li>• Fewer hospital deaths</li> <li>• Stability of treatment preferences</li> <li>• Relieved existential anxiety/distress</li> <li>• Better concordance between patient and treatment provision</li> <li>• Decreased emergency calls in hospital</li> <li>• Reduced hospital costs</li> </ul>
Houben et al. 2014 <sup>26</sup>	<p>Health status</p> <p>Psychological well-being</p> <p>Quality of EOL communication</p>	

Systematic review by author	Outcomes measured	Prevalence rates of ACPs where measured
	<p>Occurrence of Discussions</p> <p>Patient clinical status</p> <p>LST decisions</p> <p>Circumstances of death</p> <p>Patient preferences</p> <p>Proxy predictions</p> <p>Accuracy of preferences</p> <p>Congruence patient-surrogate</p> <p>Decisional conflict</p> <p>Knowledge of ACP</p> <p>Number of patient questions during consultation</p> <p>Number of items discussed during consult</p> <p>Patient satisfaction with healthcare or communication</p>	

Systematic review by author	Outcomes measured	Prevalence rates of ACPs where measured
	Patient anxiety or depression Physician satisfaction Duration of consultation Impact of patient death on relative Family satisfaction Completed AD forms Surrogate experience with healthcare system Symptom control Emotional and spiritual support Health care costs Survival Hospice use Student knowledge	

Systematic review by author	Outcomes measured	Prevalence rates of ACPs where measured
	<p>Student satisfaction</p> <p>Skill and comfort completing AD</p> <p>Knowledge of dementia and CPR</p> <p>CPR preferences</p> <p>Attitudes toward EOL planning</p> <p>Pain assessment</p> <p>Pain treatment</p> <p>Post-Traumatic Stress Disorder</p> <p>Psychosocial measures</p> <p>Subjective wellbeing</p> <p>Death acceptance</p> <p>Physician completion of ADs</p> <p>Reasons for not executing AD</p> <p>Carers making ACP</p>	



Systematic review by author	Outcomes measured	Prevalence rates of ACPs where measured
	Distress Health status Life satisfaction Cognition Health focus of control Comfort with responsibility Life-support attitudes Positive and negative affect Incidence and Timing of DNR orders Physician-patient agreement Days in ICU Hospital resource use Responding to emotions	

Systematic review by author	Outcomes measured	Prevalence rates of ACPs where measured
	<p>Self-assessed confidence</p> <p>Comfort using video-decision tool</p> <p>Goals of care</p> <p>Health literacy</p>	
Khandelwal et al. 2015 <sup>27</sup>	<p>ICU admissions</p> <p>ICU length of stay</p>	<p>Gade et al. (2008) - 5% of PC pts vs 10% non-PC pts ICU admission</p> <p>Penrod et al. 2006 - 33% w PC had ICU vs 68% control</p> <p>Detering et al. (2010) - LOS in ICU was 11 days for control vs five days for ACP group</p> <p>Schneiderman et al. (2003) - four days ICU w Ethics consult vs 13 days control</p> <p>Schneiderman et al. (2007) (2nd paper) - six days for ethics vs eight days for control</p> <p>Andereck et al. (2014) - no difference in LOS</p> <p>Curtis et al. (2011) - no difference in LOS</p> <p>Aherns et al. (2003) - less LOS for intervention six days vs 10 days control</p>

Systematic review by author	Outcomes measured	Prevalence rates of ACPs where measured
		<p>Campbell and Guzman et al.(2003) - less LOS in intervention - four days vs seven days control</p> <p>Dowdy et al. (1998) - 6 day reduction in LOS with Ethics</p> <p>Curtis et al. (2008) - LOS decreased slightly - 3 days vs 4 days control</p> <p>Mosenthal et al. (2008) - decrease in LOS 1 day vs 3 days</p> <p>Lilly et al. (2003) - decrease in LOS 3 days vs 4 days control</p> <p>Norton et al.(2007) - decrease in LOS - nine days for intervention vs 16 days control</p> <p>Shelton et al. (2010) - no difference in LOS</p> <p>Daly et al. (2010) - no difference in LOS.</p>
Klinger et al. 2016 <sup>28</sup>	<p>Total inpatient healthcare charges during last hospitalisation</p> <p>Inpatient and outpatient costs incurred six months before and six months after ACP</p> <p>Inpatient, outpatient, nursing home, inpatient hospice, and 'other' care cost (timeframe unclear)</p>	Prevalence rates not described

Systematic review by author	Outcomes measured	Prevalence rates of ACPs where measured
	<p>All Medicare claims during six months prior to death</p> <p>Hospitalisation, nursing home drugs</p> <p>Hospital charges during hospital stay</p> <p>Hospital and hospice use in last week of life</p> <p>Patient or family satisfaction</p> <p>Incidence and timing of DNR orders</p> <p>Physician awareness of patient preferences</p> <p>Level of pain</p> <p>Days spent in ICU</p> <p>Mechanical ventilation</p> <p>Coma</p> <p>Physical distress</p> <p>LOS in hospice</p>	

Systematic review by author	Outcomes measured	Prevalence rates of ACPs where measured
	<p>LOS in hospital</p> <p>Number of ADs completed</p> <p>Timing of AD completions</p> <p>Survival rates</p>	
<p>Lewis et al. 2016<sup>29</sup></p>	<p>Practices and attitudes regarding ACP</p> <p>Interviews on ACP discussions</p> <p>Timing of discussion</p> <p>Experience of staff with ACP discussions</p> <p>Experience of family with ACP discussions</p> <p>Personal views of palliative care and dementia patients/relatives/volunteers/social workers/legal practices</p> <p>Attitudes toward ADs</p> <p>Examination of beliefs, experience, and practices</p> <p>Knowledge, attitudes and experience of physicians</p> <p>Preferences and influence of having an AD</p>	<p>Said reports within the studies reviewed reported ACD use from 10% in the US to 14% in Australia, 16% in The Netherlands, and up to 25% in Switzerland.</p> <p>Motivations for ACP</p>

Systematic review by author	Outcomes measured	Prevalence rates of ACPs where measured
	<p>Staff perspectives on use of documentation for Mental Capacity Act</p> <p>Presence of chart documentation</p> <p>Patient satisfaction with timing of discussion</p> <p>Written ADs</p> <p>Family perception of QOL care</p> <p>Geriatrician experiences with Living Will</p> <p>Community nurse perspectives</p> <p>Judges' perspectives on dying process</p> <p>Nurse experience with EOL decision-making</p> <p>ADs as an agent for communication</p>	
Lim et al. 2016 <sup>29</sup>	<p>Knowledge about ACP</p> <p>Statement of treatment preferences</p> <p>Quality of patient clinician communication on EOL</p> <p>Concordance of patient preferences and EOL care</p>	<p>Increased percent of surrogates in intervention group knew SDM instructions for patient compared to control group</p> <p>Increased concordance between patient preferences and EOL care with intervention group</p> <p>Peer support yielded higher proportion of parts completing AD or desire to complete</p>

Systematic review by author	Outcomes measured	Prevalence rates of ACPs where measured
	<p>Completion of AD</p> <p>Intent to complete AD</p> <p>Comfort in discussion of AD</p>	<p>Peer support produced greater levels of comfort about discussion of ADs than printed material.</p>
<p>Luckett et al. 2014<sup>30</sup></p>	<p>Measures used were commonly relating to patient or family preferences, attitudes and knowledge and AD completion rates</p> <p>There were also analyses on Socio Economic Status and clinical variables</p> <p>Eight studies measured intervention acceptability</p> <p>No study assessed compliance with patient wishes at EOL, family member satisfaction with patient EOL care, or effect on wellbeing of bereaved family members.</p>	<p>Hopkins et al. (2011) - 93% nurses and patient care techs said education was helpful; 44% felt more confident; 33% sometimes confident; 19% did not feel more confident</p> <p>Singer et al. (1995) - 25% pts chose dialysis with stroke, 19% dementia, 14% coma; 86% wanted LST; 78% mild dementia; 41% terminal illness; 10% permanent coma</p> <p>Tigert (2005) - 47% thought about CPR, 63% MV, 57% withdrawal of dialysis, 70% found pamphlet on AD helpful</p> <p>Weisbord et al. (2003) - 32% had living wills</p> <p>Al-Jahdalia et al. (2009) - all patients did not feel they had enough knowledge to make decisions about CPR or MV; 73% wanted physician to make decisions about CPR</p> <p>Fissell et al. (2005) - US had highest prevalence of DNR orders (8%) and rate of withdrawal from haemodialysis (3.5 per 100 pt-years)</p> <p>Holley et al. (1997) - 35% had completed AD; 67% discussed with family; 14% discussed with physician; 71% completed living will during project</p>

Systematic review by author	Outcomes measured	Prevalence rates of ACPs where measured
		<p>Holley and Hines (1999) - 36% wanted physician in ACP; 91% wanted surrogate; 88% wanted additional family members; 51% had completed AD (29% LW, 22% LW or proxy); 91% with AD notified SDM - 81% with AD or proxy - 55% no AD); 69% had discussed MV; 55% tube feeding; 43% CPR; 31% stopping dialysis</p> <p>Holley (1993) - 33% understood SDM; 58% understood LW; 77% had discussed wishes; 17% had discussed with doctors; 93% agreed doctors should encourage dialysis patients to discuss ADs; 70% agree with dialysis units asking all patients about ADs; 70% agree that dialysis units should conduct education programs about ADs</p> <p>Holley (1993) - No increase in understanding of LWs over time; greater understanding of SDM; less knowledge maintained over follow up</p> <p>Holley (1989) - 96% of renal transplant patients wanted CPR, 76% in dialysis centres, 63% on home dialysis, 82% elderly)</p> <p>Hopkins et al. (2011) - 85% desired knowledge</p> <p>Miura (2001 and 2006) - 42% wanted CPR; 12% if had serious dementia or terminal cancer; more patients who were working wanted to continue dialysis if they had terminal cancer (53%) than those who weren't (37%)</p> <p>Moss et al. (2001) - 87% of patients wanted CPT if cardiac arrest occurred during dialysis</p>



Systematic review by author	Outcomes measured	Prevalence rates of ACPs where measured
		<p>Noble (2006) - 95% pts had documented wish for no CPR; 75% no ICU; 49% withdraw from dialysis prior to death with all wanting family told; only 29% patients were informed; 11% had discussion about hospice or dying at home; 27% were referred to palliative care, 15% made instructions but only 28% of those were carried out; appropriate medication in 78%, non-essential medication stopped in 69%; documented on pain relief in 69%; symptom resolution in 48%</p> <p>Ostermann (2003) - 76% wanted CPR, 7% against CPR, 9% undecided</p> <p>Perry (1995) - 17% had AD</p> <p>Perry (1995) - 80% important to have AD, only 18% had completed one; 52% believed major med decisions should be left to physician</p> <p>Perry (1996) - Social workers discussed ADs less than 50% of time; physicians 38%; LPNs 30%; RNs 25%, Dialysis techs 20%, Dieticians 4%</p> <p>Quintana (1991) - 63% chose CPR, 37% declined</p>

Systematic review by author	Outcomes measured	Prevalence rates of ACPs where measured
		<p>Saltbaek (2012) - 86% of patients and 88% of physicians thought patients should be involved in DNR decisions; 69% wanted CPR in case of cardiac arrest; physicians would attempt to resuscitate in 88% of patients; 30% disagreement bet patients and physician</p> <p>Sanchez-Tomero (2011) - 8% completed AD; 7% expressed wishes in front of witness; 65% thought AD discussions should be offered if asked for; 61% had SDM; 40% made verbal statement of decisions for permanent coma; 65% did not want MV, tube feeding, continued dialysis treatment or resuscitate</p> <p>Sehgal (1996) - Dialysis withdrawn by American nephrologists 5% of time; German 2% of time and Japanese 1% of time. 30% of Americans had AD but these were used in decision making for 3% of patients; only 0.3% of German and Japanese patients had ADs used in decision making 0.09%</p> <p>Sehgal (1992) - 61% of sample granted some leeway in overriding very specific AD if in best interest</p> <p>Song (2012) - 67-69% patients preferred comfort care only, 34% of SDMs congruent</p> <p>Yee (2011) - 82% MSW and 100% doctors felt ACP discussions part of their role, 37% of nurses and 38% of allied health</p>

Systematic review by author	Outcomes measured	Prevalence rates of ACPs where measured
Martin et al. 2016 <sup>32</sup>	Hospitalisation and costs Place of death Mortality QOL/satisfaction Actions consistent with wishes Use of life-sustaining treatments Palliative care and hospice	Prevalence rates not described

Systematic review by author	Outcomes measured	Prevalence rates of ACPs where measured
Murray and Butow 2016 <sup>33</sup>	<p>Satisfaction with ACP</p> <p>Accuracy of ADs reflecting patients wishes of EOL care</p> <p>Documentation of DNR preferences in medical records</p> <p>EOL decisions made during death</p> <p>ADs and circumstances of death</p> <p>Questions about ADs and care preferences</p> <p>Questions about ADs and care preferences</p> <p>Use of ACP tools</p> <p>Experience with preferred priorities of care document</p> <p>Discussions about death and what helped or did not help.</p>	<p>Hossler (2011) - 35% heard a lot and 41% a fair amount about ACP; ADs completed by 67% of ALS patients; 80% had POA</p> <p>Albert (1999) - 28% completed proxy within 12 months of diagnosis; 4% a LW, 11% POA; 4% DNR chart.</p> <p>Astrow (2008) - Ventilator support documented by three months (31%); six months 956%); ANH three months (38%) and six months (56%); DNR three months (25%, six months 41%); 86% had DNR order prior to death</p> <p>Bradley (2001) - 90% completed AD</p> <p>Ganzini (2002) - 88% completed ADs; 86% LWs, 76% healthcare POA</p> <p>Miller (2000) - ADs completed by 70%</p> <p>Moss (1996) - ADs completed by 79% (96% wanted them); 42% made decision to undergo LTMV; 42% consented in emergency situation; 16% no consent</p> <p>Munroe (2007) - 60% chose DNI/DNR orders after discussion; 10% undecided; 5% full ventilator support</p> <p>Mandler (2000) - ADs completed by 89% of patients</p>

Systematic review by author	Outcomes measured	Prevalence rates of ACPs where measured
		<p>Silverstein (1999) - 47% had prior discussion; for scenario of severe pneumonia requiring MV - 58% wanted CPR, 34% did not; for scenario severe pneumonia, irreversible memory loss 22% wanted CPR, 78% did not</p> <p>Burchardi et al. (2005) - 40% completed LW, 27% intended to, 33% did not want to</p> <p>Ray et al. (2010) - 15% completed NFR orders, 15% ACP</p> <p>Dreyer et al. (2011) - no prevalence rates</p> <p>Preston et al (2011) - length of time for preferred priorities of care completion from 2-17 months.</p>

Systematic review by author	Outcomes measured	Prevalence rates of ACPs where measured
Robinson et al. 2012 <sup>34</sup>	<p>Residents' and families' satisfaction with health care</p> <p>Health-care utilisation over 18 months</p> <p>Number of ACP referrals</p> <p>Number of ACP discussions</p> <p>Number of discussions that end in written form</p> <p>Number of documented ACP discussions</p> <p>Completion rates of ADs</p> <p>Chart documentation of ADs</p> <p>Documentation of patient preferences</p>	<p>Caplan et al. (2006) - 3/40 (&lt;1%) completed plan of treatment; 20/40 (50%) had discussions and preferences recorded but no signed document; 10/40 (25%) had discussions but no formal documentation; 6/40 (15%) chose not to discuss ACP; 1/40 (&lt;1%) previously completed</p> <p>Hanson et al. (2005) - documented ACP discussions went from 18/458=4% - 78/458=17%; DNR orders only increased slightly with intervention (265/458=58% to 298/458=65%)</p> <p>Molloy et al. (2000) - 555/1133=49% completed AD overall with 793/1133=70% in intervention completing and 646/1133=57% in control group</p> <p>Morrison et al. (2005) - ACP CPR orders 56/139 =40% in intervention v 29/139=20% in control; ANH 65/139=47% in intervention vs 12/139=9% in control; Antibiotics 61/139=44% intervention vs 12/139=9% control; hospitalisation 68/139=49% intervention vs 22/139=16% control.</p>
Stephen et al. 2013 <sup>36</sup>	<p>Experience of communication and aspects important to different parties</p> <p>Experience of hearing or wanting to hear prognosis</p> <p>Understanding of the part that hope plays in EOL care</p>	<p>Elkington (2011) - 41% of GPs discussed prognosis; 82% of GPs felt they had role in EOL discussions; 72% of GPs felt discussions of prognosis were necessary; 50% of GPs undecided about whether patients wanted to know prognosis; majority of GPs did not discuss EOL with patients</p> <p>Knauff (2005) - 32% of patients reported having EOL discussion with physician</p>

Systematic review by author	Outcomes measured	Prevalence rates of ACPs where measured
	<p>Perceptions of roles of patients, carers and physicians in EOL care</p> <p>What parts of ACP experience by older people and carers can influence future ACP</p> <p>Association of patient race and financial status with discussions about prognosis</p> <p>The types of EOL care provided to patients who died</p> <p>Barriers and facilitators to communication about EOL care</p> <p>Issues important to terminally ill patients getting palliative care</p>	

Systematic review by author	Outcomes measured	Prevalence rates of ACPs where measured
Sumalinog et al. 2017 <sup>37</sup>	<p>Use of services</p> <p>Costs of care</p> <p>Rates of AD completion</p> <p>Changes in knowledge/attitude/behaviour towards</p> <p>EOL issues</p> <p>EOL preferences</p> <p>Participant characteristics associated with AD completion and EOL preferences</p> <p>Analysis of effective EOL care for those with alcohol and/or illicit drug use</p> <p>Support home intervention</p> <p>Palliative care delivery issues for homeless persons</p>	<p>Song (2008 and 2010) - <math>96/321 = 30\%</math></p> <p>Leung et al. (2015) - <math>103/205 = 50\%</math></p>



## Appendix 6: Findings and Practice Recommendations from the Systematic Reviews

Systematic review by author	Outcomes measured	Practice recommendations
Austin et al. 2015 <sup>16</sup>	<ul style="list-style-type: none"> <li>Decision tools improve patient knowledge and preparation for treatment choices, including ACP, palliative care and goals of care communication, feeding options in dementia, lung transplant in cystic fibrosis, and truth telling in terminal cancer.</li> <li>Five of the studies provided evidence of an effect on clinical outcomes, changes in AD documentation, clinical decision making and treatments received.</li> <li>The strongest evidence to promote ACP supports two tools - video ACP to clinicians to assist discussions of treatment preferences for future health states of people with advanced dementia and an AD documentation guide available free on the Internet designed for patients with low health literacy.</li> <li>Only two decision aids (one addressing feeding options in dementia care and one addressing advanced treatment choices in CF) improved knowledge and treatment decisions.</li> </ul>	Healthcare organisations may be more successful at improving shared decision making if they demand decision tools with evidence of effectiveness.

Systematic review by author	Outcomes measured	Practice recommendations
Baidoobonso 2014 <sup>17</sup>	<ul style="list-style-type: none"> <li>• QOL - little to no difference in patient QOL when using Patient Care Plan Documentations (PCPD)</li> <li>• No evidence that PCPDs provided greater QOL for informal caregivers</li> <li>• PCPDs were associated with patient satisfaction with EOL care</li> <li>• Single-provider PCPDs associated with greater satisfaction with EOL care for family members</li> <li>• Single provider PCPDs showed increased concordance between patient wishes and care received when results were pooled</li> <li>• Single-provider PCPDs are associated with greater concordance between patient wishes and family wishes</li> <li>• Both single-provider and team-based PCPDs led to increased completion of ACP documents and processes</li> <li>• Chemotherapy - single-provider PCPDs associated with less likelihood of receiving chemotherapy at EOL especially if 30 days before their death</li> <li>• Resuscitation - single-provider PCPDs less likely to be resuscitated than those who were in control arms</li> </ul>	<p>As an individual healthcare provider, you can improve family satisfaction with EOL care and create a better match between patient and family expectations of care by discussing ACP as soon as possible - this is based on the evidence that single-provider patient care planning discussions led to improved family satisfaction with EOL care, reduced the likelihood of the person receiving unwanted hospital care, reduced the number of days spent in hospital and increased the completion of ACP processes and documents and likelihood of receiving hospice care.</p>

Systematic review by author	Outcomes measured	Practice recommendations
	<ul style="list-style-type: none"> <li>• Hospital care - mixed results with some evidence showing less likely to use with single-provider PCPD and other evidence showing more likely to use depending on timing of PCPD (further away from EOL more likely not to use hospital care)</li> <li>• Emergency Department visits - single-provider PCPDs may have led to less ED but not significant</li> <li>• ICU - No association with single-provider PCPD and receipt of care in ICU however one study showed that if PCPD was received more than 30 days from death, less ICU used</li> <li>• No real evidence that PCPD leads to less days in ICU</li> <li>• Home health visits - no evidence of the effect of PCPD on this</li> <li>• Urgent or Emergency Care Visits and other Outpatient Visits - mixed results with no real evidence on urgent or emergency care but outpatient visits tended to be less with patients receiving team-based PCPD</li> <li>• Hospice care - earlier single-provider PCPD was associated with greater likelihood of receiving hospice care</li> <li>• Overall, the evidence shows that earlier PCPDs lead to better outcomes than having PCPD discussions later</li> </ul>	

Systematic review by author	Outcomes measured	Practice recommendations
Barnes et al.2012 <sup>18</sup>	<p>Three themes: 1. using education to enhance professional communication skills 2. using communication to improve patient understanding 3. using communication skills to facilitate ACP</p> <ul style="list-style-type: none"> <li>• Training courses and workshops assisted healthcare professionals</li> <li>• EOL discussions should take place within caring, trusting, long-term care relationship that allows for repeated conversations</li> <li>• Enabling patients to ask questions can improve understanding such that patients can anticipate what will happen in the future</li> <li>• ACP interviews with a trained facilitator improved patient and physician understanding of EOL preferences and patient knowledge of ACP</li> <li>• Educational workshops had mixed success with questionnaires rather than workshop increasing discussion about advance directives. Information alone via any mechanism, including leaflet is not enough</li> <li>• Timing of ACP sometimes best initiated by patient but if recurrence of disease then responsibility of healthcare professionals to engage patient in discussion</li> <li>• ACP should take place over a number of meetings with a trained professional and focus on goals of care rather than specific treatments</li> <li>• Patients want as much information about their condition as possible but not necessarily with prognostics</li> </ul>	<ul style="list-style-type: none"> <li>• Identify if your patient needs more information about their illness - if so, identify whether they want prognostic information or not - if not, discuss values and other items that may assist the person to engage in the conversation of ACP</li> <li>• It is important to enable patients to lead their training to improve their understanding of their condition - if you do not understand all aspects of their illness, seek information about it so that patients can learn from you more about what they need to know</li> <li>• Be flexible with your conversations around ACP - little and often so that patients can identify how much they want to plan and when</li> <li>• Find ways to fit ACP conversations into your routine practice including time to engage in workshops or online training to improve or enhance communication skills</li> <li>• Practice developing your communication skills with real-life patients and learn from them the best way to deliver bad news or request assistance in understanding their goals of care - this requires flexibility and patience</li> </ul>

Systematic review by author	Outcomes measured	Practice recommendations
Brinkman-Stoppelenburg et al. 2014 <sup>19</sup>	<ul style="list-style-type: none"> <li>• Studies reviewed showed some evidence that ACP positively impacts QOL at EOL</li> <li>• Specifically, DNR orders reduced use of CPR, hospitalisations and increase use of hospice care</li> <li>• Effects of ADs are more diverse but are related to increased frequency of out-of-hospital care and aimed at comfort rather than prolonging life</li> <li>• The evidence suggests that extensive ACP consultations may be more effective than written documents alone however this research is diverse and dilutes any clear association</li> </ul>	<ul style="list-style-type: none"> <li>• When your patient or client is in the EOL stage, engage or continue advance care planning that meets their needs at that specific time and for the time remaining to them</li> <li>• This may include the need to complete a DNR order, Do not hospitalise order, and an examination of any advance directives to determine if the person understands that the situation is now about comfort rather than prolongation of life</li> </ul>
Brooke and Kirk 2014 <sup>20</sup>	<p>Barriers to ACP discussions with people who have dementia</p> <ul style="list-style-type: none"> <li>• Lack of recognition of terminal phase</li> <li>• Patient's lack of awareness of diagnoses</li> <li>• Concern regarding future lack of decision-making capacity</li> </ul>	<ul style="list-style-type: none"> <li>• ACP discussions should be approached with person with dementia and their family over a period of time addressing specific conditions as they arise and should begin as soon as is practicable after first diagnosis - if completing specific advance care documents, these may need to be flexible and not necessarily legally binding in the initial stages</li> </ul>

Systematic review by author	Outcomes measured	Practice recommendations
	<ul style="list-style-type: none"> <li>Healthcare professionals difficulties with ACP - value of ACP, understanding of individual roles and responsibilities within ACP, confusion over documents, understanding which aspects were legally binding, timing of when to initiate ACP with people who have dementia, causing patients anxiety, raising the subject of assisted suicide, difficulty in discussing disease trajectory</li> <li>Person with dementia point of view - lack of knowledge and awareness of ACP, right time for discussion, preference for informal plans over written documentation, constraints on choices for future care, lack of support to make choices about future health decisions</li> </ul>	<ul style="list-style-type: none"> <li>Tell new patients you are working with who have dementia that in the future you will be discussing with them advance care planning. Identify what this is and what it means and that you will go through this process slowly as the person begins to live with their dementia and identifies their needs and preferences</li> <li>Consider using a tool such as the ACP-ED structured questionnaire (Poppe et al. 2013) to assist with the discussion</li> <li>Always include family members in the discussions, if possible, and when the person with dementia has indicated their acceptance of this</li> <li>Upskill training in ACP conversations for the person who has dementia by seeking out appropriate resources that can be distributed at various stages - an information booklet when first diagnosed; later - copies of advance care directive documents</li> <li>Respect people with dementia and their families who choose not to engage in ACP - create discussions around values instead to assist with care provision</li> </ul>

Systematic review by author	Outcomes measured	Practice recommendations
Cardona-Morrell et al. 2017 <sup>21</sup>	<ul style="list-style-type: none"> <li>• Range of decision aids but relatively few for EOL management</li> <li>• Most studies targeted towards older people at EOL</li> <li>• Mostly decision aids are disease-specific participants when tested in multi-format and require additional human or technical resources to be administered</li> <li>• Most common domains investigated were: treatment options; and weighted or unweighted preferences, e.g. stop treatment when..., etc.</li> <li>• Prognostic estimates not often used</li> <li>• Benefits of treatment described in descriptive form rather than in terms of risk probability with some perceived benefits rather than actual - same with harm and risks of harm</li> <li>• Few studies mentioned patient values, did not specify patient values or mention selected values for particular scenarios</li> <li>• Treatment goals defined from the patient less often mentioned as part of the decision aid - rather, goals included decisions about prolonging life, maintaining function or promoting comfort</li> <li>• Most commonly reported measure of effectiveness was change in knowledge or prognosis or nature of illness or change in decisional conflict</li> <li>• Only 5/17 studies reported on decisional concordance</li> <li>• Most studies reported on satisfaction with decision aid process but rarely mentioned testing for statistical significance</li> </ul>	<ul style="list-style-type: none"> <li>• Future decision aids for EOL care need more robust elicitation of values, treatment goals, quant estimates of harms, benefits and prognostic information to be considered holistic and useful</li> <li>• The role of the healthcare professionals in step-by-step guidance and support through the decision-making process is important and suggests that self-administered decision aid should not be used</li> </ul>

Systematic review by author	Outcomes measured	Practice recommendations
Dening et al. 2011 <sup>22</sup>	<ul style="list-style-type: none"> <li>Review identified that ACP is becoming more common in many countries</li> <li>Review highlighted that threshold capacity for person with dementia needs to be understood for ACP to be effective</li> <li>Review found that for healthcare professionals to successfully engage in ACP with people who have dementia and their families, they need to have more education and training in the process of ACP and various prognostic implications of dementia</li> <li>Review highlights that current international evidence for ACP in dementia is limited</li> <li>Mini Mental State Examination score of 18-20 seems to be consistent threshold score for making an ACP: below this threshold, participants tended to opt for life sustaining treatment led by increased caregiver involvement and less patient involvement in decision-making</li> </ul>	<ul style="list-style-type: none"> <li>Understand the threshold capacity in people with dementia to engage meaningfully in ACP - this will usually be early in the disease trajectory (early stage)</li> <li>As the disease progresses, carers may want to become more involved in decision-making without the input of the person - develop strategies to enable both the person with dementia and the caregiver to continue with decision-making that leads to generating agreement rather than one person's preferences over another</li> <li>People need to engage in these discussions with dedicated professional who have the understanding and knowledge of what is to come - do not hesitate to increase your skill level and knowledge in this area</li> </ul>



Systematic review by author	Outcomes measured	Practice recommendations
	<ul style="list-style-type: none"> <li>• Carer attitudes may influence likelihood of people with dementia being exposed to more aggressive treatment at EOL and carer decision-making was influenced by age of person with dementia and level of caregiver 'burden' as well as feelings of guilt and failure when person with dementia was placed in residential aged care facility</li> <li>• Prevalence of ACPs in US were common with white, better educated people more likely to have ACP regardless of diagnosis</li> <li>• Prompts for ACP discussions usually triggered by medical events and changes to financial and living situation of person with dementia (passive avoidance most often)</li> <li>• Professional attitudes influenced use of ADs with relatives finding them important and believing they would be followed while physicians would only follow specific ones</li> <li>• Professional education around ACP could decrease hospital admissions however some professional groups may not have been best placed to conduct ACP conversations (social workers) whilst others required better training and more education</li> </ul>	

Systematic review by author	Outcomes measured	Practice recommendations
Dixon et al. 2015 <sup>23</sup>	<ul style="list-style-type: none"> <li>Evidence on economic implications of ACP is limited and equivocal</li> <li>No evidence that ACP is costlier</li> <li>Several studies found ACP led to healthcare savings especially those in nursing homes, with high support needs, low income, living with dementia in community and living in high-spending healthcare region</li> </ul>	<ul style="list-style-type: none"> <li>Future research needs to be more mixed method to understand the mechanisms linking ACP to healthcare savings and potential for identifying and targeting populations with greatest potential for cost-effectiveness gains</li> <li>Need more research to ensure that design and implementation of ACP interventions in practice are effective (developmental, implementation and process evaluation research)</li> <li>Most studies from the US - need more from other places</li> <li>Need longer term perspective about cost-effectiveness not just cost savings - research should look at the impact on carers, community-based care, and QOL benefits</li> </ul>
Durbin et al. 2010 <sup>24</sup>	<ul style="list-style-type: none"> <li>No RCTs found comparing the effectiveness of a single, written, single verbal or single video educational intervention to controls - therefore inadequate evidence to draw conclusions</li> <li>No RCTs found comparing combined written and video education interventions to controls, combined verbal and video interventions to controls, combined verbal and computer interventions to controls, or combined written/verbal/video interventions to controls</li> <li>Most RCTs consisted of interventions of written material with verbal reinforcement but findings were not consistent</li> <li>Computer reminders to physicians to discuss ADs showed some merit but evidence was inadequate to relate this directly to newly completed ADs</li> </ul>	<ul style="list-style-type: none"> <li>Continue researching the completion of ADs using interventions designed for this purpose and conduct and participate in RCTs which compare against controls</li> <li>Understand whether your patient is best suited to written, verbal, or video communication about ADs</li> </ul>

Systematic review by author	Outcomes measured	Practice recommendations
	<ul style="list-style-type: none"> <li>• Combined written and verbal vs written showed statistically significant differences in increasing ADs</li> <li>• A combined written, verbal and video educational intervention was statistically more significant in increasing ADs over a single written intervention - however there was only one RCT for this so insufficient evidence for overall conclusion</li> <li>• Because of contrary results, insufficient information to form a finding of which intervention is most successful in raising AD completions</li> </ul>	
Flo et al. 2016 <sup>25</sup>	<p>Barriers to ACP discussions:</p> <ul style="list-style-type: none"> <li>• Patients' impaired cognition; lack of time during visit; lack of family involvement</li> <li>• Reluctant personnel; unforeseen medical circumstances; staff cultural beliefs and background; family involvement; lack of GP engagement</li> <li>• Resident unwillingness; staff confidence; nursing home resources; unclear responsibility; extrinsic factors</li> <li>• Legal uncertainties; lack of training; no ACP system</li> <li>• Physicians not following ACP in crises; minority trust; unknown patient; lack of external validity</li> <li>• Form too comprehensive and complicated to complete</li> <li>• Challenging to specific disease groups (dementia, ESRD, Cardiac); reluctance to sign document</li> <li>• Patient illness</li> </ul>	<ul style="list-style-type: none"> <li>• Pay attention to informed and presumed consent.</li> <li>• Physician statements should be reflective and clear especially in regarding who is responsible for what and should invite questions for discussion</li> <li>• Summary of meetings should be documented in patient chart and made available to all personnel with follow-up meetings</li> <li>• Nursing home physician should be initiator and accept lead role in process</li> </ul>

Systematic review by author	Outcomes measured	Practice recommendations
	<ul style="list-style-type: none"> <li>• Unclear effect</li> <li>• Staff turnover/retention/recruitment</li> <li>• Inconsistencies in naming and layout of ACP documentation</li> <li>• Different dementia policies at one time; adaption addressing different cultures in NH</li> </ul> <p>Promoters for ACP Discussions:</p> <ul style="list-style-type: none"> <li>• Staff training - increased awareness, knowledge, confidence</li> <li>• Motivated nursing home management</li> <li>• Being trained in Gold Standard Framework</li> <li>• Low staff turnover</li> <li>• Standards guiding ACP content and documentation; examples of values/belief statements; identification of principles of ACP; knowing principles of ACP</li> <li>• Good, consistent leadership; regular visits from GP; comprehensive palliative care approach</li> <li>• High focus on decision capacity and proxy relative; simple intervention forms; team meetings; feedback by clinicians to social workers</li> <li>• Standardised medical orders throughout the healthcare system</li> <li>• Hotline for info; education</li> <li>• Clarified role of SDM; capacity screening</li> <li>• Allocating dedicated personnel</li> <li>• Standardised location for documentation</li> </ul>	

Systematic review by author	Outcomes measured	Practice recommendations
	<ul style="list-style-type: none"> <li>• Early initiation; family involvement; guidance on how to approach discussion</li> <li>• Country-wide strategy and policy on ACP for whole of system implementation</li> <li>• Involve all stakeholders; systematic approach</li> <li>• Physician signature; SDM; Process rather than decision focus; information in book/video/discussion format; cultural sensitivity</li> </ul>	
Houben et al.2014 <sup>26</sup>	<ul style="list-style-type: none"> <li>• Majority of trials had methodological shortcomings which lowered their quality assessment score (failure to blind patients, therapists and/or outcome assessors)</li> <li>• Trials focused on ADs or communication with a stat significant association between the type of intervention and the period in which the study was conducted, e.g. between 1999-2005 and 2006-2012 emphasis was on communication compared with 1992-1998 where emphasis was on completion rates of ADs</li> <li>• Increased likelihood for completion of ADs with an intervention and was comparable to those focusing on ADs and those focusing on communication</li> <li>• Increased likelihood for occurrence of EOL preference discussions best patients and healthcare professionals following an intervention compared to control and this was comparable across groups focusing on ADs vs communication</li> <li>• Patients had an increased likelihood of receiving preferred care when they received an intervention</li> </ul>	<ul style="list-style-type: none"> <li>• Discussion about ADs can lead to a process of ACP and vice versa so whichever way you wish to begin, it is important to engage in these discussions with patients to ensure their EOL preferences are met</li> <li>• Conducting such conversations in outpatient clinics as part of standardised treatment regimens will not increase anxiety and depression of patients, although this should be considered on an individual case basis</li> <li>• The more patients and healthcare professionals discuss a patient's EOL preferences or goals of care (through ACP), the more satisfaction there will be with family and healthcare professionals when providing such care to the patient in future</li> </ul>

Systematic review by author	Outcomes measured	Practice recommendations
	<ul style="list-style-type: none"> <li>• Inconclusive evidence on knowledge of ACP increasing with intervention (five trials yes, four trials no)</li> <li>• In 6/9 trials where EOL preferences were reported, patients were more likely to prefer comfort care and avoid LST with the intervention</li> <li>• Satisfaction with healthcare - no evidence on interventions increasing patient satisfaction, but family members more likely to be satisfied and to have more discussions</li> <li>• Inconclusive results on decisional conflict</li> <li>• Inconclusive evidence on use of healthcare services</li> <li>• No significant differences reported on symptoms of anxiety, depression, psychological wellbeing, health status or pain</li> <li>• Overall, the meta-analysis showed that ACP can be effective in changing completion of ADs and EOL discussions</li> <li>• Studies reviewed were all conducted in outpatient setting during scheduled visits and all showed positive results for having ACP discussions at this time</li> <li>• Concordance increased in intervention groups when ADs were discussed with ADs being a tool for ACP dialogue BUT need to discuss ADs</li> <li>• No evidence that discussing ADs or ACP will increase patient anxiety or depression</li> </ul>	

Systematic review by author	Outcomes measured	Practice recommendations
	<ul style="list-style-type: none"> <li>Overall, the evidence shows that discussions about ADs and ACP improve patient discussion on EOL care and concordance with care received, however there is no definitive evidence for which aspects of ACP are most effective in doing this</li> </ul>	
Khandelwal et al. 2015 <sup>27</sup>	<ul style="list-style-type: none"> <li>ACP and PC interventions reduce the number of ICU admissions for patients at high risk of death</li> <li>Majority of studies demonstrated reduced ICU LOS with ACP or PC interventions</li> <li>Three studies suggest that targeting interventions directly at patients rather than at the system level will reduce ICU admissions</li> <li>From 16 studies estimating magnitude of effect - 11 showed decrease in LOS and five showed no change - variation probably due to patient characteristics within studies, location of study, and effects measuring differences between patient and system rather than one or the other as well as measuring decedent vs survivors</li> </ul>	<ul style="list-style-type: none"> <li>Using PC and Ethics consults in ICU can reduce ICU LOS</li> <li>Conduct PC and ethics consultations directly with patients to reduce ICU admissions</li> </ul>

Systematic review by author	Outcomes measured	Practice recommendations
Klinger et al. 2016 <sup>28</sup>	<ul style="list-style-type: none"> <li>• ACP interventions varied and were often not described in detail</li> <li>• ACP was used interchangeably to describe ADs, EOL discussions, or EOL counselling</li> <li>• Nurses and social workers did the discussion aspect of EOL care and ADs and were specifically trained for the task</li> <li>• No clear description of content, length and style of conversations with most left open to facilitator</li> <li>• None of the studies assessed overall costs for the healthcare system with implementation of ACP programme</li> <li>• Costs accrued to family and friends not included in calculations</li> <li>• Only three studies included the costs of the intervention in their assessment</li> <li>• Time frames for measuring costs differed widely: one week before death to six and 18 months after implementing intervention</li> <li>• All studies found reduced costs through professionally facilitated discussions about EOL however there was only statistically significant differences in three of the studies</li> <li>• After consideration of different measurements, time, etc. the authors conclude the cost savings may range from 5% - 68% depending on the illness acuity of the patient population</li> </ul>	<ul style="list-style-type: none"> <li>• Observed cost savings of ACP depends on the structure of the healthcare systems and cultural background determining personal preferences and values.</li> </ul>



Systematic review by author	Outcomes measured	Practice recommendations
Lewis et al. 2016 <sup>29</sup>	<ul style="list-style-type: none"> <li>• Lack of appropriate and sufficiently objective evidence suggests that effectiveness of written ADs to trigger EOL conversations is inconclusive; therefore, more high-level evidence is needed</li> <li>• Most of the studies reviewed targeted the views of doctors, then nurses, then patients, or family</li> <li>• Majority of sample sizes were less than 100 participants</li> <li>• Only five studies targeted EOL discussion in relation to ACDs or ACP</li> <li>• Definitions and outcomes predominantly based on opinions, attitudes, beliefs, and person experience rather a standard replicable measure of effectiveness in triggering the discussion</li> <li>• Common qualitative findings were that ACDs act as an icebreaker or tool to initiate opportunities for conversation or discussion with healthcare professionals and that ACDs improve communication between healthcare professionals, medical staff, and patients</li> <li>• Majority of articles showed that healthcare professionals reported positive perceptions of use of ACDs although there was no evidence in the effectiveness of these documents to increase confidence for EOL discussions</li> </ul>	<ul style="list-style-type: none"> <li>• Request to see any documentation about patient preferences for care. This may enable, once sighted, the time and ability to ask patients what this means for their current condition and future EOL care</li> </ul>

Systematic review by author	Outcomes measured	Practice recommendations
Lim et al. 2016 <sup>30</sup>	<ul style="list-style-type: none"> <li>• Only two studies in the literature met the eligibility criteria for the review</li> <li>• Neither study provided evidence of the use of life-prolonging treatments for this cohort</li> <li>• It is uncertain whether ACP can improve health outcomes among ESKD patients</li> </ul>	<ul style="list-style-type: none"> <li>• Discussion regarding ACP with this cohort did not destroy hope or cause unnecessary discomfort or anxiety to patients, therefore these conversations should take place</li> </ul>
Lockett et al. 2014 <sup>31</sup>	<ul style="list-style-type: none"> <li>• ACP studies to date have been largely descriptive and focused on preferences and attitudes toward ACP and medical interventions at the EOL</li> <li>• Findings suggest a disease-specific approach to ACP is warranted for people with CKD</li> <li>• There were only eight trials reported with each focusing on a single aspect of ACP, such as nurse education, patient information, AD completion or patient/surrogate congruence</li> <li>• No intervention took a comprehensive approach to ACP that included patient, caregiver, healthcare professionals and system-related factors</li> <li>• Only one ACP intervention demonstrated effects on patient or family outcomes and showed improvement in wellbeing and reduced anxiety - using peer-mentor facilitated sessions</li> </ul>	<ul style="list-style-type: none"> <li>• Acknowledge the role that family can play (positively and negatively) in ACP</li> <li>• Distinguish between decisions about dialysis therapy withdrawal vs choices about other life-sustaining treatments such as CPR and ventilation</li> <li>• Understand the individuality of preferences for ACP and EOL care</li> <li>• Understand the optimal timing for ACP (early vs readiness) and respect patient wishes not to discuss the topic if they prefer not to</li> </ul>

Systematic review by author	Outcomes measured	Practice recommendations
	<ul style="list-style-type: none"> <li>Peer-mentor facilitated sessions as well as patient/clinician interaction and communication, patient/SDM congruence, and surrogate/nurse confidence as well as AD completions demonstrated an impact on process measures; however, these were limited by incomplete follow-up, poor study design, and difficulty in interpreting due to different measures compared between studies</li> <li>Overall, research on ACP in chronic kidney disease has been descriptive and has focused on people who have chosen to pursue dialysis rather than conservative management</li> </ul>	
Martin et al. 2016 <sup>32</sup>	<ul style="list-style-type: none"> <li>The review showed beneficial effects for ACP interventions in nursing homes but evidence supporting findings was of low quality</li> <li>Interventions were mostly: (a) educational programs and (b) introduction and evaluation of a new ACP approach in facilities</li> <li>Studies using educational programs were shown to be more robust but little evidence to show they are better than initial introduction of ACP into NHs</li> <li>Review showed ACP reduces hospitalisation of NH residents and mortality is not increased by reduced hospitalisation</li> <li>When ACP is completed, actions are consistent with resident wishes</li> <li>Evidence shows those with ACP have greater chance of dying in place</li> </ul>	<ul style="list-style-type: none"> <li>Nursing home residents should have more documented ACP to enable them to remain in place at the time of death and discussions should take place as early as possible</li> </ul>

Systematic review by author	Outcomes measured	Practice recommendations
	<ul style="list-style-type: none"> <li>• Overall, data showed beneficial effects of ACP in nursing homes included: actions being consistent with person's wishes, avoidance of hospitalisation, avoidance of life-sustaining treatments</li> <li>• Although less hospitalisations occur with ACP, there is less evidence about antibiotic use as this may also be given as a "comfort" measure</li> <li>• Unable to say whether reduced hospitalisations yield reduced hospital costs through ACP</li> <li>• Conflicting results in the two studies which investigated the effect of DNR orders on medical treatment</li> </ul>	
Murray and Butow 2016 <sup>33</sup>	<p>Components of communication on EOL for this patient cohort include:</p> <ul style="list-style-type: none"> <li>• how discussion is initiated</li> <li>• patient concerns about EOL</li> <li>• patient info needs</li> <li>• open style of communication</li> <li>• determining patient preferences before starting EOL discussion</li> <li>• balancing realism and hope</li> <li>• selecting most appropriate healthcare professional to discuss with</li> <li>• discussing EOL improves patient functional status, anxiety, depression, and prep for death</li> </ul>	<ul style="list-style-type: none"> <li>• Healthcare professionals should not assume they know what patients want in terms of EOL communication</li> <li>• Preliminary discussions should be initiated by healthcare professionals to determine who should be part of the conversation and when</li> <li>• Style of communication is important such that honesty can be conveyed without denying hope</li> </ul>

Systematic review by author	Outcomes measured	Practice recommendations
	<p>Challenges of communication on EOL for this patient cohort includes:</p> <ul style="list-style-type: none"> <li>• uncertainty about type of care wanted</li> <li>• who will provide that care</li> <li>• patient desire for prognostic info with an healthcare professional prepared to discuss it</li> <li>• power differential bet healthcare professional and patients when making decisions</li> <li>• balancing honest info with hopeful communication</li> <li>• lack of patient centred care impedes EOL communication</li> <li>• discrepancies between healthcare professional and patient reports of discussions</li> </ul>	
Robinson et al. 2012 <sup>34</sup>	<ul style="list-style-type: none"> <li>• Review suggests some evidence to show ACP has potential to reduce inappropriate hospitalisation of the person with dementia but limited evidence about ACP effectively influencing patient preferences for future care</li> <li>• Identified that in most studies, only 1/3 of participants were judged to be able to participate in ACP</li> </ul>	<ul style="list-style-type: none"> <li>• Begin to raise ACP with people who have a recent diagnosis of dementia as soon as possible</li> <li>• If the person with dementia is deemed not to have sufficient capacity to understand ACP, then engage their proxy</li> </ul>

Systematic review by author	Outcomes measured	Practice recommendations
Stephen et al. 2013 <sup>36</sup>	<ul style="list-style-type: none"> <li>• Review demonstrated that homeless people have a greater risk of early mortality due to high prevalence of chronic diseases but face barriers to accessing healthcare at EOL</li> <li>• Review showed that homeless priorities at EOL relate to substance abuse, social and family estrangement and limited finances, but with assistance, homeless are willing to engage in ACDs and ACP issues if there is an opportunity to do so</li> <li>• Of the eight quality domains for end of life care outlined by the National Consensus Project for Quality Palliative Care, the included studies investigated only structure/process of care and ethical/legal aspects of care</li> <li>• For ACP and AD, it was shown that increased discussions about EOL preferences and AD completions could occur if in an intensive, comprehensive and accommodating manner toward their unique situations</li> <li>• For homeless people, they cannot rely on the traditional support structures most terminally ill people could depend upon, e.g. secure housing, supportive family and friends, access to healthcare and social services. ACP needs to understand this and help create plans which can match this situation</li> </ul>	<ul style="list-style-type: none"> <li>• If a person in your care does not have a permanent place to live, discuss ACP with them in context with their current circumstances</li> <li>• These discussions may open up opportunities to provide acute support as well as develop strategies for meeting their EOL needs when that occurs</li> </ul>

Systematic review by author	Outcomes measured	Practice recommendations
Sumalinog et al. 2017 <sup>37</sup>	<ul style="list-style-type: none"> <li>• Prevalence of ACP varied across studies because of different timepoints for data collection</li> <li>• Prevalence figures may have been boosted in some areas due to healthcare policy trends emphasising ACP</li> <li>• Disease progression appears to be strongest catalyst for AD completion. 4. Many patients delay creating ADs until physical deterioration makes it necessary</li> <li>• Earlier instigation of ACP may be beneficial but on the other hand symptom progression may be necessary for patients to accept the seriousness of their condition</li> <li>• ADs frequently associated with feelings of control, relief and peace of mind but there were contrary views where some people linked living wills with death and diminished hope</li> <li>• Efficacy of ADs may be compromised by healthcare professionals lack of awareness, personal/ professional beliefs and/or reluctance to discuss death</li> <li>• Some patients received interventions contrary to their wishes and some met oppositional attitudes to ACP from healthcare professionals</li> <li>• There is conflicting evidence about whether people's wishes are being adhered to and this may be because of health system differences in different countries</li> </ul>	<ul style="list-style-type: none"> <li>• Relentless and rapid functional loss associated with MND compels consideration of optimal timing for ACP</li> <li>• Documented decisions should be periodically reviewed to ensure better consistency over time</li> <li>• Individual preferences should be considered when determining appropriate timing for initiating ACP</li> <li>• Raise awareness of the role and importance of ADs within medical communities</li> <li>• Disease specific decision-aids may facilitate ACP processes and improve decisional accuracy</li> </ul>

## Appendix 7: Future Research suggestions from Authors of Systematic Reviews

Systematic review by author	Future Suggestions
Austin et al. 2015 <sup>16</sup>	<p>Test decision aids for major serious illnesses.</p> <p>Focus future research on outcomes measuring the effect of the change in knowledge on treatment decisions, receipt of care consistent with preferences and satisfaction with care</p> <p>Test how decision aids influence cost of care</p>
Baidoobonso 2014 <sup>17</sup>	<p>Use validated tools for assessing satisfaction with care and QOL</p> <p>Research more fully the different results yielded by single-provider vs team-based PCPD and why since single-provider seems to provide better results</p>
Barnes et al. 2012 <sup>18</sup>	<p>There has not been enough research done on communication interventions for patients with life-limiting conditions especially in primary care settings</p> <p>Need more info on economic cost-saving potential of enhancing communication skills as well as enhanced communication for patients to explore potential for cost savings and decreased resource use</p>
Brinkman-Stoppelenburg et al. 2014 <sup>19</sup>	<p>More studies are needed with experimental design</p> <p>More studies are needed outside the US</p> <p>More studies are needed across different settings, particularly the community</p> <p>Outcome measures for these future studies should be standardised so comparisons can be made</p> <p>Focus of outcomes should be about the patient and family experience</p>
Brooke and Kirk 2014 <sup>20</sup>	<p>Evaluating different tools for assisting healthcare professionals to engage in ACP discussions with people who have dementia</p> <p>Evaluation of people with dementia and their carers in relation to the elements of ACP they wish to discuss and do not want to discuss - when and why</p> <p>Evaluating whether ACP has a place in dementia care and, if so, when is it most effective for those concerned</p>



Systematic review by author	Future Suggestions
Cardona-Morrell et al. 2017 <sup>21</sup>	<p>Decision aids should enable opportunities to change decisions as disease progresses and be measured for effectiveness</p> <p>Future decision aids should cater for various health literacy levels and more research is needed that elicits robust elicitation of values, treatment goals and quantitative estimates of harms, benefits, and prognostic info</p>
Dening et al. 2011 <sup>22</sup>	<p>Need more studies on ACP for people with dementia</p> <p>Need more studies that directly involve the person with dementia</p> <p>More studies needed on threshold of capacity to engage in ACP when person has dementia</p> <p>More research needed on instructions in ACP and relevance to SDM or person with dementia and if there is conflict</p> <p>Need longitudinal evidence to observe influences and changes over time, levels of congruence or divergence between carers and people with dementia to decide if ACP actually improves EOL care in this group</p>
Dixon et al. 2015 <sup>23</sup>	<p>Research into the longer-term economic perspective of ACP is needed with emphasis not just on costs but also cost-effectiveness and efforts made to reflect important QOL benefits</p>
Durbin et al. 2010 <sup>24</sup>	<p>Need more RCTs that compare intervention, singly or combined, to control group and crossover studies</p> <p>Need more diverse samples and RCTs conducted in other countries and settings</p>
Flo et al. 2016 <sup>25</sup>	<p>ACP Tools for people with dementia should be designed with patients with dementia in mind</p> <p>Need for well-powered randomised trials on efficacy of different interventions</p> <p>Need for high quality studies that describe in detail ACP process, implementation strategies and robust primary and secondary outcome measures</p>

<b>Systematic review by author</b>	<b>Future Suggestions</b>
Houben et al. 2014 <sup>26</sup>	<p>Future studies needed to reveal the effective elements of ACP and the best way to implement in standard care</p> <p>Future studies need to overcome methodological limitations (intention to treat, concealed allocation, small sample size)</p> <p>Future studies should use validated instruments</p> <p>More studies needed on outcomes such as quality of communication, knowledge of ACP, EOL care preferences, satisfaction with healthcare, decisional conflict, use of healthcare services, and symptoms</p>
Khandelwal et al. 2015 <sup>27</sup>	<p>Future studies need to provide more accurate assessments of the magnitude of effect on resource utilisation</p> <p>Need to report hospital LOS as well as ICU LOS</p> <p>Observational data and non-RCT study designs may be more pragmatic</p> <p>Need methods to reduce bias such as multivariate regression, propensity score matching, instrumental variable adjustment</p>
Klingler et al. 2016 <sup>28</sup>	<p>Need to understand better which aspects of ACP are most effective as both intervention and for cost reductions (SUPPORT failed primarily due to lack of standard ACP interventions and comparisons)</p> <p>Methodological research needs to incorporate large enough samples to determine whether it is the communication or the EOL care which provides effective cost savings - unclear in the studies reviewed</p> <p>Most studies done in US with varying cost structures and individualistic culture - need to repeat studies in settings where there is more homogeneity in cost and culture</p> <p>Need methodologically robust RCTs which describe all elements of the ACP intervention and assess all elements of costs</p> <p>Reporting of such trials needs to improve with specific information about how costs were calculated, adjustments made, perspective chosen and cost components included in the analysis</p>

Systematic review by author	Future Suggestions
Lewis et al. 2016 <sup>29</sup>	<p>Research should try and replicate US findings from large cohort studies</p> <p>Future research should identify the influence that culture has on the uptake of ADs and subsequently in initiation of EOL communications</p> <p>There is a need to back up health care policy in this area with stronger evidence</p> <p>Overall, studies hint that there is support in written ADs linking to EOL discussions however we need to see the link between these in relation to timeliness once formalised</p> <p>Recommend that effectiveness evaluations go beyond perception, experience and satisfaction to large quant studies using randomised control trials or cohort interventions on measurable effect of ACP documents to generate subsequent EOL conversations</p>
Lim et al. 2016 <sup>30</sup>	<p>Need for more large scale, well designed RCTs involving people with ESKD to determine efficacy and value of ACP for patients</p> <p>Need more consistent methods for reporting outcome measures that are patient-centred and relevant to health services</p> <p>Need for a global, standardised protocol for ACP to facilitate its systematic evaluation</p>
Lockett et al. 2014 <sup>31</sup>	<p>Need to link complex interventions such as ACP to measurement models that link processes to outcomes to understand the mechanism of effect such that this can be replicated or adapted</p> <p>More studies are needed that link concordance with measures of how decisions are informed by knowledge of EOI interventions across different patient populations</p> <p>There were no studies of CKD patients who chose not to have dialysis - this requires future research to see what kind of outcomes this creates</p> <p>More research is needed to identify and implement facilitators to ACP at a systems level in nephrology clinics, educating staff on the benefits of early ACP, ensuring staff have authorisation and time for ACP as core business</p>

Systematic review by author	Future Suggestions
Martin et al. 2016 <sup>32</sup>	<p>Increased need for knowledge and experience of nursing home staff in palliation at EOL in nursing homes. 2. High rates of dementia and decreased capacity in nursing homes residents suggest the opportunity for ACP has been lost in this setting. 3. ACP can be completed by SDMs subverting the autonomy of the resident. 4. Need for more research on earlier commencement of ACP for nursing homes residents prior to dementia or cognitive impairment. 5. Need to understand whether cognitive impairment is enhanced in nursing home setting? 6. Need for randomised controlled trials to help identify most effective ACP interventions for nursing home populations</p>
Murray and Butow 2016 <sup>33</sup>	<p>Address more widespread implementation of training programs in disease-specific palliative care communication and delivery</p> <p>Measure the effect on uptake of palliative care in non-malignant disease</p> <p>Determine how more palliative care resources can be allocated to patients with non-malignant disease by using existing cancer palliative care services for other patient populations</p>
Robinson et al. 2012 <sup>34</sup>	<p>Need for high quality randomised controlled trials on effectiveness of ACP for person with dementia notwithstanding the possible difficulty of doing so</p> <p>Also need to investigate whether ACP is right for people with dementia and their families and, if so, at what point in the trajectory of the disease?</p>
Stephen et al. 2013 <sup>36</sup>	<p>Economic evaluation studies on shelter-based PC should be measured to quantify costs and effectiveness</p> <p>Future studies to explore patient preferences and outcomes in this area</p> <p>Need more controlled study designs with adequate follow-up duration</p> <p>Additional studies on needs of ageing homeless population</p> <p>Studies should be adequately powered with balanced intervention groups</p> <p>Scope of recruitment should be broadened to reflect diversity of services for homeless</p> <p>Need to consider best possible evidence of literature, including introduction of palliative care early and often</p>

<b>Systematic review by author</b>	<b>Future Suggestions</b>
Sumalinog et al. 2017 <sup>37</sup>	<p>More qualitative evidence and examining patients or caregivers experiences of AD completion and impact would be advantageous</p> <p>Stability of patient wishes regarding future treatments is important to gain more knowledge of</p> <p>Larger studies supporting preliminary findings for ACP are required for efficacy</p>

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