National Institute for Health and Care Excellence

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Consultation

Chapter 15 Advance care planning

Emergency and acute medical care in over 16s: service delivery and organisation

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Chapter 15 Advance care planning

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15 Advance care planning

15.1 Introduction

Advance care planning is established as part of best practice as an integral part of the management of people with multiple chronic conditions, particularly as they approach the limits of their treatment and end of life.

Advance care planning has been defined as a process of formal decision making that aims to help people establish decisions about future care that take effect when they lose the capacity[41] to make informed decisions. In many cases that will lead to decisions about the extent of treatment, location of treatment and cardiopulmonary resuscitation. Some people may also instruct their families and friends and/or delegate power of attorney for such decisions.

This is incorporated in government strategy "End of life care strategy: promoting high quality care for adults at the end of their life" (2008) and supported by GM guidance "treatment and care towards the end of life: good practice in decision making" (2010). Patient and care advice is also available[73].

These people are likely to also present with acute medical emergencies and advance care plans have the potential to improve their care, including the treatment in the environment of their choice. Therefore, we asked the question "Does advance care planning improve outcomes compared with usual care?"

15.2 Review question: Does advance care planning improve outcomes compared with usual care?

For full details see review protocol in Appendix A.

Table 1: PICO characteristics of review question

Population	Adults and young people (16 years and over) with a suspected or confirmed or at risk of an AME
Intervention	Advance care planning • Patients who receive advance care planning and go on to make an advance care directive (ACP/AD+) • Patients who receive advance care planning and do not go on to make an advance care directive (ACP/AD-) • Patients who receive advance care planning but it is not reported whether they make an advance care directive (ACP)
Comparison	Usual care (no advance care planning) • Patients who do not receive advance care planning but make an advance care directive (No ACP/AD+) • Patients who do not receive advance care planning and do not make an advance care directive (No ACP/AD-) • Patients who do not receive advance care planning and it is not reported whether they make an advance care directive (No ACP)
Outcomes	Avoidable adverse events (CRITICAL) Quality of life (CRITICAL) Patient and/or carer satisfaction (CRITICAL) Length of hospital stay/Hospital-free days/Super spell days (IMPORTANT) Number of presentations to Emergency Department (CRITICAL)

	Number of admissions to hospital (CRITICAL) Number of GP presentations (IMPORTANT) Readmission up to 30 days (IMPORTANT) Place of death (CRITICAL)
Study design	Systematic reviews (SRs) of RCTs, RCTs, observational studies only to be included if no relevant SRs or RCTs are identified.

15.3 Clinical evidence

Three studies were included in the review[30,34,35]. These are summarised in Table 2 below. Evidence from these studies is summarised in the GRADE clinical evidence summary below (Table 3). See also the study selection flow chart in Appendix B, study evidence tables in Appendix D, forest plots in Appendix C, GRADE tables in Appendix F and excluded studies list in Appendix G.

We searched for randomised trials comparing the impact of advance care planning or usual care (no advance care planning) on the outcomes outlined in Table 1.

Three randomised controlled trials were identified in which patients were randomised to receive facilitated advance care planning or usual care.

Table 2: Summary of studies included in the review

Study	Intervention and comparison	Population	Outcomes	comments
Detering, 2010[30] RCT	Facilitated advance care planning versus usual care	Legally competent medical inpatients aged 80 or above. n=309 Setting: A University hospital in Melbourne, Australia	Patient and/or carer satisfaction; Family satisfaction	Single centre study
Engelhardt 2006[34] RCT	Advanced illness co-ordinated care program including end of life care versus usual care (69.4% created advance directives in intervention group versus 48.4% in the usual care group)	Patients from Veterans Affairs Medical Centres, a home care organisation and 2 managed care organisations. n=275 Setting: Three Department of Veterans Affairs Medical centres, a home care organisation and 2 managed care organisations in New York, USA	Patient and/or carer satisfaction, family satisfaction	Limited generalisability of the findings to populations with different demographic characteristics (for example, female, non-white), to those with less serious medical problems (for example, outpatients), and to those with other diagnoses is limited.
Engelhardt 2009[35] RCT	Advanced illness co-ordinated care programme including end of life care versus usual care (47.0% created advance directives in intervention group versus 21.1% in the usual care group)	Patients with advanced illnesses. n=532 Setting: New York, USA	Inpatient admissions, ED visits, quality of life	Limited generalisability-study included a homogeneous population (87.9% white)

Table 3: Clinical evidence profile: advance care planning versus usual care, RCT evidence

Outcomes	No of Participants (studies) Follow up	Quality of the evidence (GRADE)	Relative effect (95% CI)	Anticipated absolute effects	
				Risk with Control	Risk difference with Advance care planning (95% CI)
Patient and/or carer satisfaction	272 (1 study)	⊕⊕⊕⊖ MODERATE[a] due to risk of bias	RR 1.05 (1 to 1.09)	Moderate	
				942 per 1000	47 more per 1000 (from 0 more to 85 more)
Family satisfaction	56 (1 study)	⊕⊕⊖⊖ LOW[a,b] due to risk of bias, imprecision	RR 1.15 (0.91 to 1.46)	Moderate	
				778 per 1000	117 more per 1000 (from 70 fewer to 358 more)
Patient and/or carer satisfaction	186 (1 study)	⊕⊕⊖⊖ LOW[a] due to risk of bias	-	-	The mean patient and/or carer satisfaction in the intervention groups was 0.09 higher (0.1 lower to 0.28 higher)
Family satisfaction (problems reported)	143 (1 study)	⊕⊕⊖⊖ LOW[a] due to risk of bias	-	-	The mean family satisfaction (problems reported) in the intervention groups was 0.12 lower (0.22 to 0.02 lower)
QOL: SF-12 Physical standardised score	403 (1 study)	⊕⊕⊖⊖ LOW[a,b] due to risk of bias, imprecision	-	-	The mean QOL: SF-12 physical standardised score in the intervention groups was 1.66 lower (3.71 lower to 0.39 higher)
QOL: SF-12 Mental standardised score	403 (1 study)	⊕⊖⊖⊖ VERY LOW[a,b] due to risk of bias, imprecision	-	-	The mean QOL: SF-12 mental standardised score in the intervention groups was 1.1 higher (1.08 lower to 3.28 higher)
McGill QOL questionnaire	403 (1 study)	⊕⊕⊖⊖ LOW[a] due to risk of bias	-	-	The mean McGill QOL questionnaire in the intervention groups was 0.14 higher (0.06 lower to 0.34 higher)

Outcomes	No of Participants (studies) Follow up	Quality of the evidence (GRADE)	Relative effect (95% CI)	Anticipated absolute effects	
				Risk with Control	Risk difference with Advance care planning (95% CI)
ED visits	403 (1 study)	⨁⨁⊖⊖ LOW[a] due to risk of bias, imprecision	-	-	The mean number of ED visits in the intervention groups was 1.66 lower (3.62 lower to 0.3 higher)
Inpatient admissions	403 (1 study)	⨁⨁⊖⊖ LOW[a] due to risk of bias, imprecision	-	-	The mean number of inpatient admissions in the intervention groups was 1.89 lower (4.23 lower to 0.45 higher)

(a) Downgraded by 1 increment if the majority of the evidence was at high risk of bias, and downgraded by 2 increments if the majority of the evidence was at very high risk of bias.
(b) Downgraded by 1 increment if the confidence interval crossed 1 MID or by 2 increments if the confidence interval crossed both MIDs.

Outcomes which could not be analysed in Revman:

In 1 study [30] 133/154 patients (or family members if patients died before discharge) in the intervention group and 139/155 patients (or family members if patients died before discharge) in the usual care group completed a discharge questionnaire. Overall patient level of satisfaction with hospital stay was 93% very satisfied, 5% satisfied and 2% not satisfied in the intervention group and 65% very satisfied, 29% satisfied and 6% not satisfied in the usual care group. Family satisfaction with the quality of death was 83% very satisfied, 7% satisfied and 10% not satisfied in the intervention group and 48% very satisfied, 30% satisfied and 22% not satisfied in the usual care group.

15.4 Economic evidence

Published literature

No relevant economic evaluations were identified.

The economic article selection protocol and flow chart for the whole guideline can found in the guideline's Appendix 41A and Appendix 41B.

Unit costs

Table 4: Unit costs of end of life admissions

	Mean cost
Hospital admission ending in death	£2,506 to £3,587[(a)]

(a) Source: NHS Improving Quality 2013.[97] The lower value is based on NICE QIPP calculations while the higher value is based on the NHS Improving Quality study

The Centre for Reviews and Dissemination produced a briefing for Bristol CCG to support decisions regarding the delivery of advance care planning.[23] This briefing highlighted the lack of evidence on the cost-effectiveness of advance care planning. However, it cited an independent data analysis from South West England that was used in an economic evaluation of transferring people to an Electronic Palliative Care Co-ordination system (EPaCCS) that supports the co-ordination of care, including support for conversations about end of life care wishes[97]. This data analysis showed that deaths in hospital in the area relating to people transferred to EPaCCs were below 10% (compared to a national average of 54.5%). They estimated the support required for death in usual place of residence was £2107, and therefore there would be a saving of £399 to £1480 per death in usual place of residence compared with the lower and upper values of the cost of a hospital admission ending in death (see Table 4).

15.5 Evidence statements

Clinical

Three studies comprising 1116 patients evaluated advance care planning for improving outcomes, in adults and young people at risk of an AME, or with a suspected or confirmed AME. The evidence suggested that compared with usual care, advance care planning may provide a benefit for reduced number of ED visits and inpatient admissions (1 study, low quality), and family satisfaction (1study, low quality). However, the evidence suggested there was no difference to patient and/or carer satisfaction (1 study, moderate quality), family satisfaction problems reported (1 study, low quality), quality of life SF-12 physical standardised score (1 study, low quality) and quality of life SF-12 mental standardised score (1 study, very low quality).

Economic

No relevant economic evaluations were identified.

15.6 Recommendations and link to evidence

Recommendations	**9. Offer advance care planning to people who are approaching the end of life and are at risk of a medical emergency[a] . Ensure that there is close collaboration between the person, their families and carers, and the professionals involved in their care.**
Research recommendation	**-**
Relative values of different outcomes	The guideline committee considered quality of life, place of death, total number of admissions to hospital, avoidable adverse events, and presentations to ED and patient and/or carer satisfaction as critical outcomes for their decision-making. The outcomes considered to be important were: readmission, length of hospital stay and number of presentations to the GP.
Trade-off between benefits and harms	There was evidence from 3 randomised controlled trials comparing advance care planning (ACP) with usual care. The evidence suggested that compared to usual care, advance care planning may provide a benefit for reduced number of ED visits and inpatient admissions and family satisfaction. However, the evidence suggested there were no differences to patient and/or carer satisfaction, family satisfaction, problems reported and quality of life (using several scales), but the estimates of effect generally favoured advance care planning. No evidence was found for the following outcomes: length of hospital stay, avoidable adverse events, number of GP presentations, place of death and readmission. The committee felt that given the benefit in terms of reduced ED visits and inpatient admission and the trend towards a positive benefit for other outcomes, a recommendation could be developed to support the use of advance care plans. The committee made a strong recommendation for ACP, even though the evidence was not of high quality. This was because providing ACP did not seem to have any obvious negative effects. In addition, it is in line with public surveys in which the majority express a wish to die at home. It was felt that ACP would help to preserve dignity; enable patient choice and does not involve a significant burden in terms of costs. While recognising that the prediction of life expectancy was not an exact science, the committee members were content to use the General Medical Council's definition[38] of 'approaching the end of life' as meaning that death was likely within 12 months. The NICE quality standard guidance on End of life care for adults[72] refers to end of life care as being provided by the NHS in England for people who are likely to die within the next 12 months. Choosing the best time for such sensitive discussions needed to take into account individual's particular circumstances. There are useful tools that are available to help identify and care for patients in this phase of their life (for example, The Gold Standards Framework[1]).
Trade-off between net effects and costs	No economic evidence was identified and therefore, unit costs were presented to the committee. The committee felt that for many patients it would be less resource intensive to die at home. ACP reduces hospital admission and emergency department visits which might be translated into cost savings. The committee also noted that none of the studies assessed hospital length of stay as an outcome. Additionally, evidence considered in the review of community palliative care

a NICE is developing a guideline on end of life care for adults in the last year of life.

Recommendations	**9. Offer advance care planning to people who are approaching the end of life and are at risk of a medical emergency[a] . Ensure that there is close collaboration between the person, their families and carers, and the professionals involved in their care.**
Research recommendation	-
	(Chapter 14) suggests that this service was cost saving. Based on their collective experience, the committee believed that caring for terminally ill people at home can release hospital beds for other patients and this would allow the hospital to use its available resources more efficiently.
Quality of evidence	The evidence for the outcomes: family satisfaction, ED attendance and inpatient admissions were of low GRADE quality due to risk of bias and imprecision. The evidence for patient and/or carer satisfaction was of moderate to low GRADE quality, due to risk of bias. The evidence for quality of life (physical and mental components) was low to very low GRADE quality respectively, due to imprecision and risk of bias. Evidence reporting quality of life through the McGill pain questionnaire was of low GRADE quality due to risk of bias.
Other considerations	The committee noted that in order to implement ACP (also known as advance statement of wishes) it is crucial that information can be accessed by all relevant parties, such as the GP, hospital staff, paramedics and nursing home staff. Without this information staff may attempt to resuscitate patients who had DNAR orders as part of their advance decision or paramedics may transport patients to hospital against the person's wishes, particularly if they are unable to express this. The committee noted that in London, senior paramedics have access to the "Coordinate my care" database which alerts them if a person has an advance care directive. This helps the paramedics to make an informed decision about how to manage the patient. It is also important the next of kin and relevant family members are aware of advanced directives to ensure that they do not countermand the wishes of an informed and capacitous person. The committee also considered by whom, how and when advance care planning conversations should be held. It was felt that it was probably best done by the healthcare professional with the closest relationship with the patient, while involving others with specific expertise (for example, in terms of the benefits and burdens of particular medical interventions and technologies, such as intensive care medicine). The GP, care home staff or hospital doctors all had a role in initiating the discussion, which should include the family and carers, and spiritual leaders where appropriate. There was an agreement that an acute medical emergency was not an ideal context for these discussions, but that if the patient's wishes had not been determined beforehand then it was still better to attempt to do so in the acute situation rather than embarking on a potentially burdensome treatment pathway. The opportunity to broach these sensitive discussions shortly after resolution of an AME should also not be neglected. Advance care directives should be reviewed at regular intervals to permit changes in patients' wishes to be respected. Mental capacity when discussing ACP must be considered and the appropriate measures should be put in place if needed for example, enduring power of attorney. The current use of ACP within the NHS is variable. Greater emphasis on ACP is required, especially with an increasing elderly population with multiple co-morbidities which limit the efficacy of life-sustaining therapies. The committee noted that for ACP to be implemented it is crucial that staff are

Recommendations	**9. Offer advance care planning to people who are approaching the end of life and are at risk of a medical emergency[a] . Ensure that there is close collaboration between the person, their families and carers, and the professionals involved in their care.**
Research recommendation	**-**
	appropriately trained, with regular updates and readily accessible supporting information. Training should include when and how to implement discussions, and should include background information on the natural history and management of chronic diseases in patients in the community. Identifying that people are progressing towards the end of their lives requires knowledge of the person as well as an understanding of disease and the exclusion of reversible but undiagnosed acute, chronic, or acute-on-chronic illness. Public education is a key component but currently not well-addressed. Initiatives to promote advance care planning should focus on public understanding of the limits of medical technology, and optimising informed decision-making between communities, primary and secondary care. Improvements are required in IT infrastructure to bridge the communication gaps between primary, secondary and social care. An example is provided by the NHS programme 'Coordinate my care' (http://coordinatemycare.co.uk/) which permits information-sharing about treatment preferences and limits, and links to NHS 111 and some ambulance services. NICE has developed guidance on Care of dying adults in the last days of life.[71] NICE is developing a guideline on End of life Care for adults in last year of life' due to publish 2018 (see NICE website for further details).

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Appendices

Appendix A: Review protocol

Table 5: Review protocol: Advance care planning

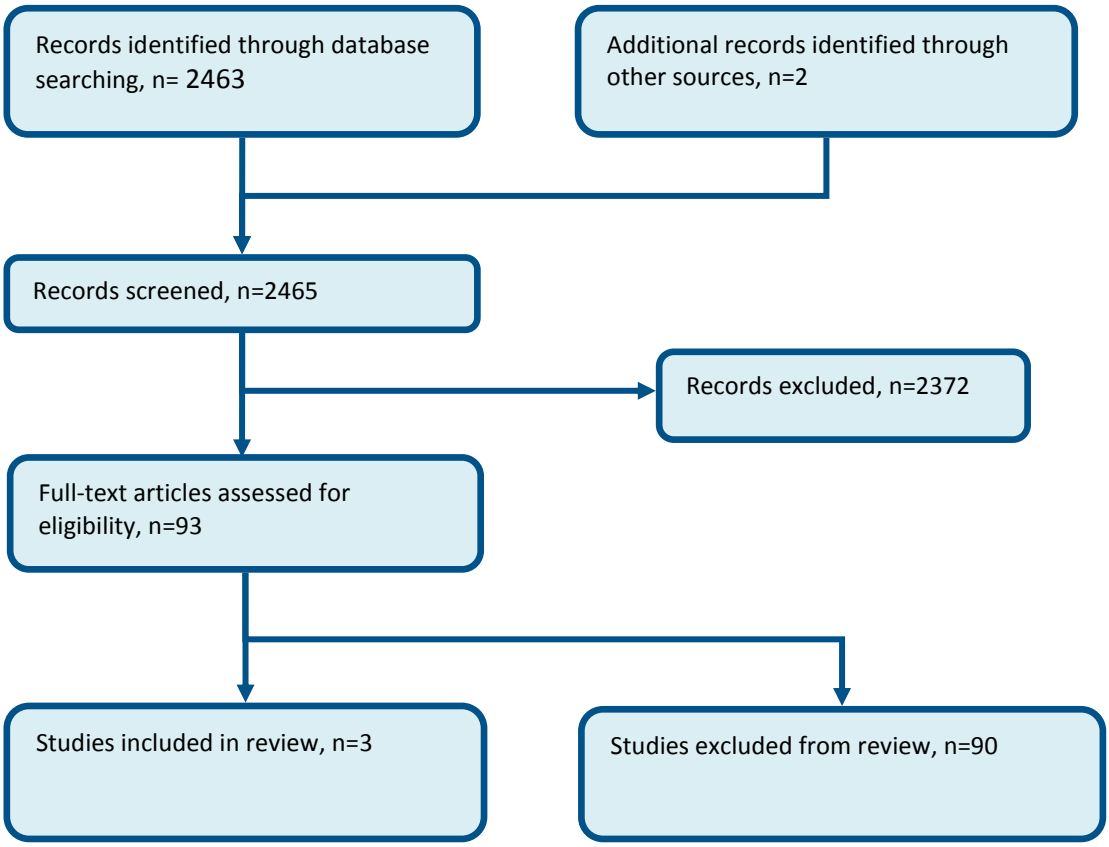
Review question	Does advance care planning improve outcomes compared with usual care?
Guideline condition and its definition	Acute medical emergencies. Definition: A medical emergency can arise in anyone, for example, in people: without a previously diagnosed medical condition, with an acute exacerbation of underlying chronic illness, after surgery, after trauma
Objectives	To determine if the provision of advance care planning, with or without advance directives improves outcomes.
Review population	Adults and young people (16 years and over) with a suspected or confirmed AME or at risk of an AME
	Adults
	Line of therapy not an inclusion criterion
Interventions and comparators: generic/class; specific/drug (All interventions will be compared with each other, unless otherwise stated)	Advance care planning; Patients who receive advance care planning and go on to make an advance care directive (ACP/AD+) Advance care planning; Patients who receive advance care planning and do not go on to make an advance care directive (ACP/AD-) Advance care planning; Patients who receive advance care planning but it is not reported whether they make an advance care directive (ACP) No advance care planning; Patients who do not receive advance care planning but make an advance care directive (No ACP/AD+) No advance care planning; Patients who do not receive advance care planning and do not make an advance care directive (No ACP/AD-) No advance care planning; Patients who do not receive advance care planning and it is not reported whether they make an advance care directive (No ACP)
Outcomes	- Quality of life at end of follow-up (Continuous) CRITICAL - Place of death- hospital/home at end of follow-up (Dichotomous) CRITICAL - Number of admissions to hospital at end of follow-up (Dichotomous) CRITICAL - Readmission up to 30 days at end of follow-up (Dichotomous) IMPORTANT - Number of presentations to Emergency Department during study period at end of follow-up (Dichotomous) CRITICAL - Patient and/or carer satisfaction at end of follow-up (Dichotomous) CRITICAL - Length of hospital stay at end of follow-up (Continuous) IMPORTANT - Avoidable adverse events at end of follow-up (Dichotomous) CRITICAL - Number of GP presentations at end of follow-up (Dichotomous) IMPORTANT - Length of stay in programme at end of follow-up (Continuous) IMPORTANT
Study design	Systematic Review RCT Quasi-RCT Non-randomised comparative study Prospective cohort study Retrospective cohort study

	Case control study Historical controlled study Before and after study Controlled before and after study Interrupted Time series
Unit of randomisation	Patient
Crossover study	Permitted
Minimum duration of study	Not defined
Other exclusions	Major trauma
Subgroup analyses if there is heterogeneity	- Frail elderly (Frail elderly; Not frail elderly); Different from younger population
Search criteria	Databases: Medline, Embase, the Cochrane Library Date limits for search: none Language: English only

1
2

Appendix B: Clinical article selection

Figure 1: Flow chart of clinical article selection for the review of advance care planning



Appendix C: Forest plots

C.1 Advance care planning versus standard care

Figure 2: Patient and/or carer satisfaction with hospital stay

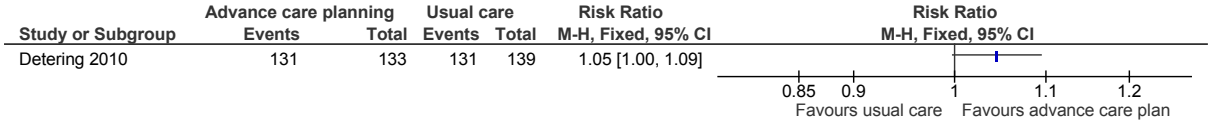


Figure 3: Family satisfaction with quality of death

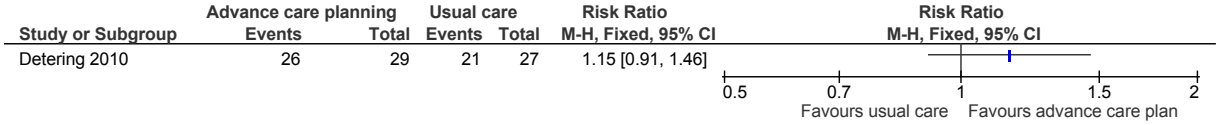


Figure 4: Patient and/or carer satisfaction

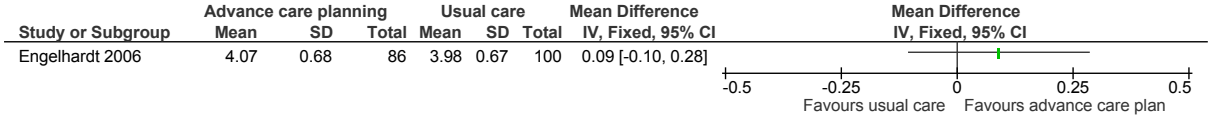


Figure 5: Family satisfaction (number of problems reported)

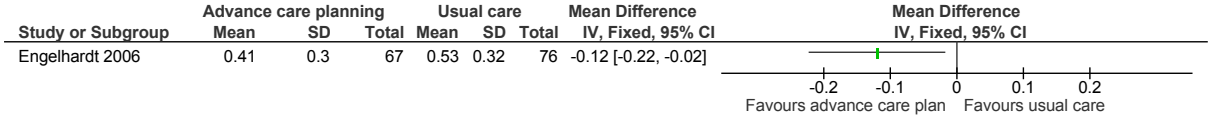


Figure 6: Quality of life: SF-12 Physical standardised score

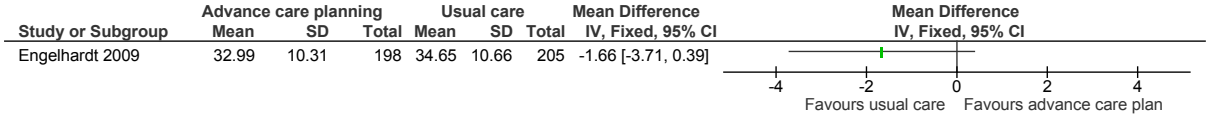


Figure 7: Quality of life: SF-12 Mental standardised score

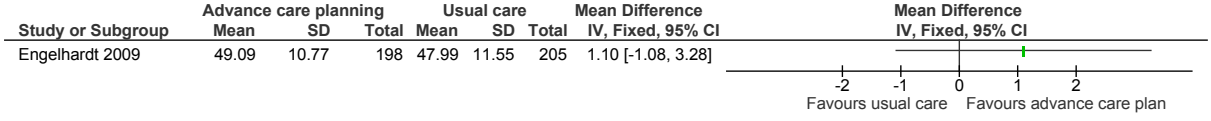


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Figure 8: Quality of life: McGill questionnaire

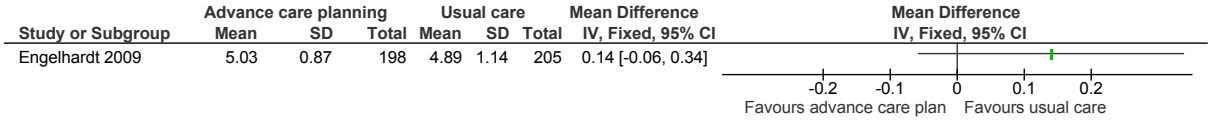

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Figure 9: Number of ED visits

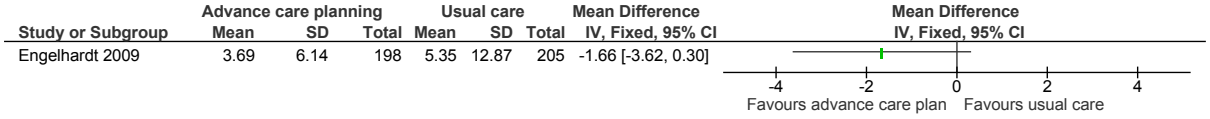

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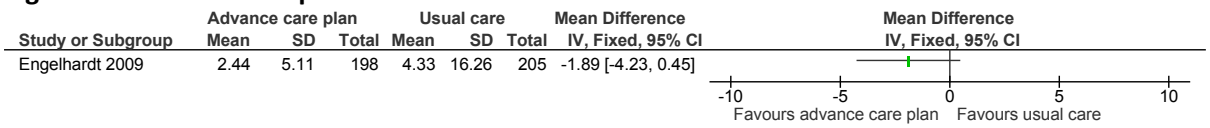
Figure 10: Number of inpatient admissions



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Appendix D: Clinical evidence tables

Study	Detering 2010 {Detering 2010}
Study type	RCT (Patient randomised; Parallel)
Number of studies (number of participants)	1 (n=309)
Countries and setting	Conducted in Australia; Setting: Internal medicine, cardiology or respiratory medicine at a large university hospital in Melbourne, Australia
Line of therapy	Not applicable
Duration of study	Intervention + follow up: 6 months
Method of assessment of guideline condition	Adequate method of assessment/diagnosis
Stratum	Overall
Subgroup analysis within study	Not applicable
Inclusion criteria	Elderly patients aged over 80 admitted under internal medicine, cardiology or respiratory medicine in a large university hospital in Melbourne, Australia. Able to complete advance care planning during current hospital admission.
Exclusion criteria	Incompetent, cannot speak English, expected to die or be discharged within 24 hours, had previous formal advance care planning, and had no family.
Age, gender and ethnicity	Age - Median (IQR): Intervention group: 85 (82-88), control group: 84 (81-87). Gender (M:F): Intervention group: 54% men, Control group: 41% men. Ethnicity: nr
Further population details	1. Frail elderly
Extra comments	86% of the intervention group expressed wishes on end of life care by completing an advance care plan or verbally.
Indirectness of population	No indirectness
Interventions	(n=154) Intervention 1: Advance care directives. Formal advance care planning from a trained facilitator (nurse or allied health worker) using the Respecting Patient Choices model. The programme involved a co-ordinated approach to advance care planning whereby trained non-medical facilitators, in collaboration with treating doctors, assist patients and their families to reflect on the patient's goals, values and beliefs and to discuss and document their future choices about healthcare. Patients are encouraged to appoint a surrogate and to document their wishes about end of life care, including the wish for life prolonging treatments and cardiopulmonary resuscitation recorded on an advance care plan. As needed, treating doctors participated in this discussion to ensure that the patients understood their illness, treatment options and likely prognosis. This

Study	Detering 2010 {Detering 2010}
	programme utilises relevant legislation by enabling appointment of legal surrogates and ensures a systematic approach to filing of completed documents in hospital medical records so that they are readily available. Patients were encouraged to include their families, particularly their nominated surrogates, in discussions. The aim was to complete advance care planning before hospital discharge. 81% of the intervention group received advance care planning and of these 84% completed an advance care directive. A 5 question survey was used to assess patient and/or carer satisfaction on their hospital stay. Additionally the quality of end of life care questionnaire, an 8 item locally developed tool to assess a family member's satisfaction with the quality of the patient's death, was used. Duration Median discussion length 60 minutes (range 10-200 minutes) over 1-3 meetings. Concurrent medication/care: None. (n=155) Intervention 2: Usual Care. Consistent with usual practice, control patients received usual medical care but no advance care planning unless it was specifically requested. Duration nr. Concurrent medication/care: N/A
Funding	Academic or government funding
RESULTS (NUMBERS ANALYSED) AND RISK OF BIAS FOR COMPARISON: ADVANCE CARE DIRECTIVES versus USUAL CARE Of the 108 patients who expressed wishes on end of life care, 82% expressed wishes about cardiopulmonary resuscitation and 75% about life prolonging treatment. Protocol outcome 1: Mortality at during study period - Actual outcome: Mortality at Six months; Group 1: 29/154, Group 2: 27/155 Risk of bias: All domain - Low, Selection - Low, Blinding - Low, Incomplete outcome data - Low, Outcome reporting - Low, Measurement - Low, Crossover - Low; Indirectness of outcome: No indirectness Protocol outcome 2: Patient and/ or carer satisfaction at during study period - Actual outcome: Patient (or family if patient died before discharge) satisfied with hospital stay at Before discharge; Group 1: 131/133, Group 2: 131/139; Risk of bias: All domain - High, Selection - Low, Blinding - Low, Incomplete outcome data - Low, Outcome reporting - Low, Measurement - High, Crossover - Low, Comments - Unvalidated questionnaire; Indirectness of outcome: No indirectness, Comments: No indirectness- Actual outcome: Family satisfied with quality of death at Before discharge; Group 1: 26/29, Group 2: 21/27; Risk of bias: All domain - High, Selection - Low, Blinding - Low, Incomplete outcome data - Low, Outcome reporting - Low, Measurement - High, Crossover - Low, Comments - Unvalidated questionnaire; Indirectness of outcome: No indirectness, Comments: No indirectnessindirectness	
Protocol outcomes not reported by the study	Quality of life at during study period; Avoidable adverse events at during study period; Number of presentations to Emergency Department at during study period; Number of admissions to hospital at After 28 days of first admission; Number of GP presentations at during study period; Readmission; Length of stay in programme at during study period; Length of hospital stay at during study period

Study	Engelhardt 2006 {Engelhardt 2006}
Study type	RCT (Patient randomised; Parallel)
Number of studies (number of participants)	1 (n=Intervention group: 133, usual care group: 142)
Countries and setting	Conducted in USA; Setting: Three Department of Veterans Affairs Medical centres, a home care organisation and 2 managed care organisations.
Line of therapy	Not applicable
Duration of study	Intervention + follow up: 3 months
Method of assessment of guideline condition	Adequate method of assessment/diagnosis: Advanced illness defined as: COPD, chronic heart failure or cancer.
Stratum	Overall
Subgroup analysis within study	Not applicable
Inclusion criteria	Patients with chronic obstructive pulmonary disease, chronic heart failure or cancer diagnoses including those of the oesophagus, trachea, colon, liver, pancreas, lung or uterus, cancers of the prostate or breast with metastasis, melanoma, leukaemia, lymphosarcoma, Hodgkin's disease or multiple myeloma. Patients with COPD or CHF were eligible if they had experienced 1 or more admissions to an intensive care unit or 2 or more acute-care admissions in the last 6 months.
Exclusion criteria	Nr
Recruitment/selection of patients	Nr
Age, gender and ethnicity	Age - Mean (SD): Intervention group: 70.72, usual care group: 70.8. Gender (M:F): Intervention group: 18.8% female, 81.2% male; usual care group: 23.9% female, 76.1% male. Ethnicity: Intervention group: 88% white, 11.3% black, 0.8% other; usual care group: 85.7% white, 11.4% black, 2.9% other
Further population details	1. Frail elderly
Indirectness of population	No indirectness
Interventions	(n=133) Intervention 1: Advance care directives. The AICCP delivers care coordination and support through 6 functions. The first is physician support, which consists of helping patients develop well-organised questions to make economical use of provider time and ensuring that physicians have complete information about patients. The second is health literacy, which is the capacity to understand basic health information. The AICCP addresses literacy concerns in each session (for example, by helping patients comprehend specialised medical terminology, which both increases their understanding and reduces their embarrassment). The third function is care coordination, which is locating and arranging linkages to medical services. The fourth is prevention, which refers to a focus on those aspects of EOL planning that often are avoided and emotionally charged. In this study, prevention referred to efforts to reduce or eliminate common psychosocial

Study	Engelhardt 2006 {Engelhardt 2006}
	concerns related to advanced illness such as (1) coping with the loss of ability to perform valued activities; (2) identifying and addressing family conflict around difficult advanced illness and EOL decisions (for example, patient relocation, financial burdens of illness); (3) avoiding caregiver burnout (for example, by dividing care among family members);(4) anticipating emotional reactions (for example, anticipatory grief, fear of death); (5) enhancing self-management skills by preparing patients and families to cope with health system delivery shortfalls (for example, fragmentation of care delivery, gaps in care); and (6) promoting advance planning, because timely planning may avert decision making in crisis situations. Care coordinators help clarify patient preferences for care under different health scenarios, using worksheets designed for this purpose. If patients engage in advance planning, care coordinators assist them in formulating and documenting ADs and discussing them with providers. Family misunderstandings about care issues frequently can be resolved during meetings with care coordinators, reducing physician time spent mediating between family members. Care coordinators also provide emotional and social support. Emotional support consists of attending to affective components of illness, identifying specific motions, helping patients cope with suffering, and providing referrals for on-going counselling. Social support includes guidance and information, as well as tangible support. In the AICCP, structured guidance support helps patients and caregivers complete tasks needed to maintain health and function. The AICCP provides information support in the form of guiding patients through the immense amount of medical information available to sources that are (1)adjusted for health literacy,(2) endorsed by their physicians, and (3) relevant to their situations. It provides tangible support by locating and arranging social support services. These functions are performed by nurses, nurse practitioners or social workers. The AICCP was implemented in a 6-session format and delivered by existing personnel who were familiar with institutional policies and who had on-going relationships with providers. These personnel were chosen because a reported barrier to effective implementation of an EOL program was using staff without an institutional identity and credibility. Care coordinators' salaries were contributed by study sites. Sites replaced care coordinators if their resources allowed; if not, care coordinators' duties were reconfigured to focus on patients with advanced illness. Each care coordinator attended training and reviewed assigned readings, including the AICCP training manual 15, 17. Program delivery was standardised across sites through conference calls and followed a structured-visit format. Care coordinators were taught to individualise the program to meet specific needs; for example, patients could schedule extra meetings. The mean number of visits was 4.92(SD = 2.94). Treatment implementation checklists, covering AICCP-recommended interventions, were examined for a randomly selected subset of patients. Intervention elements were completed in a mean of 83% of patients. The most common reason for not completing an element was that it did not apply to the patient's circumstances. Duration 6 sessions. Concurrent medication/care: 2 AICCP participants crossed over to usual care. (n=142) Intervention 2: Usual Care nr. Duration 3 months including follow up. Concurrent medication/care: 18 usual care participants crossed over to AICCP.

Study	Engelhardt 2006 {Engelhardt 2006}
Funding	Academic or government funding (Robert Wood Johnson Foundation, Fan Fox/Leslie R Samuels Foundation and the Nathan Cummings Foundation)
RESULTS (NUMBERS ANALYSED) AND RISK OF BIAS FOR COMPARISON: ADVANCE CARE PLANNING versus USUAL CARE Protocol outcome 1: Patient and/ or carer satisfaction at during study period - Actual outcome: Patient and/or carer satisfaction with healthcare measured on a five-point Likert-type scale at Enrolment, 3 and 6 months post enrolment; Group 1: mean 4.07 (SD 0.68); n=86, Group 2: mean 3.98 (SD 0.67); n=100; Risk of bias: All domain - Very high, Selection - Low, Blinding - Low, Incomplete outcome data - High, Outcome reporting - Low, Measurement - High, Crossover - Low, Subgroups - Low, Other 1 - High, Other 2 - Low, Other 3 - Low, Comments - 18 usual care participants crossed over to AICCP and 2 AICCP participants crossed over onto usual care however ITT analysis was performed.; Indirectness of outcome: No indirectness ; Group 1 Number missing: 47, Reason: nr; Group 2 Number missing: 42, Reason: nr - Actual outcome: Surrogate (family) satisfaction with healthcare using a modified EOL Family Interview. Number of problems in 7 domains (shared decision making, physical comfort and emotional support, advance care planning, co-ordination of care, personal care and respect, family self-efficacy, family emotional and spiritual support. at Three months post-enrolment; Group 1: mean 0.41 (SD 0.3); n=67, Group 2: mean 0.53 (SD 0.32); n=76; Risk of bias: All domain - Very high, Selection - Low, Blinding - Low, Incomplete outcome data - High, Outcome reporting - Low, Measurement - High, Crossover - Low, Subgroups - Low, Other 1 - High, Other 2 - Low, Other 3 - Low, Comments - 18 usual care participants crossed over to AICCP and 2 AICCP participants crossed over onto usual care however ITT analysis was performed.; Indirectness of outcome: No indirectness ; Group 1 Number missing: 47, Reason: nr; Group 2 Number missing: 42, Reason: nr	
Protocol outcomes not reported by the study	Quality of life at during study period; Avoidable adverse events at during study period; Number of presentations to Emergency Department at during study period; Number of admissions to hospital at After 28 days of first admission; Number of GP presentations at during study period; Readmission; Length of stay in programme at during study period; Number of radiology tests at during study period; Number of outpatient visits at during study period; Number of laboratory tests ordered at during study period; Number of home health visits at during study period; Number of pharmacy prescriptions at during study period; Length of hospital stay at during study period

Study	Engelhardt 2009 {Engelhardt 2009}
Study type	RCT (Patient randomised; Parallel)
Number of studies (number of participants)	1 (n=532)
Countries and setting	Conducted in USA
Line of therapy	Not applicable
Duration of study	Intervention + follow up: 6 session intervention plus a 4 month follow up

Study	Engelhardt 2009 {Engelhardt 2009}
Method of assessment of guideline condition	Adequate method of assessment/diagnosis: Advanced illness defined as: COPD, chronic heart failure or cancer.
Stratum	Overall
Subgroup analysis within study	Not applicable
Inclusion criteria	Patients with chronic obstructive pulmonary disease, chronic heart failure or cancer diagnoses including those of the oesophagus, trachea, colon, liver, pancreas, lung or uterus, cancers of the prostate or breast with metastasis, melanoma, leukaemia, lymphosarcoma, Hodgkin's disease or multiple myeloma. Patients with COPD or CHF were eligible if they had experienced 1 or more admissions to an intensive care unit or 2 or more acute-care admissions in the last 6 months.
Exclusion criteria	NR
Age, gender and ethnicity	Age - --: Gender (M:F): Define. Ethnicity: Intervention: 84.8% white, 15.2% non-white; usual care: 91% white, 9% non-white
Further population details	1. Frail elderly:
Indirectness of population	--
Interventions	(n=267) Intervention 1: Advance care directives. The 6-session model has the following 3 components: (1) nondirective health counselling, (2) education and (3) care coordination. AICCP was delivered by social workers and a health educator with 16 hours of initial training and with 20 hours of follow-up. AICCP meetings were face to face, lasting a mean of 59.0 (SD = 22.1) minutes, including brief follow-up telephone contacts. The mean number of sessions was 4.9 (SD = 2.1) (range 0-10 [mode, 6]), with 81.9% of patients completing 3 to 7 sessions. On average, caregivers attended 50% of sessions based on patient preference, caregiver availability, and need. The topics covered across sessions were structured in a biopsychosocial 3-domain format, including the following: (1)health-related topics included but were not limited to understanding illness, treatment expectations, emerging symptoms, adherence to treatment recommendations, communication with health professionals, and advance planning; (2) coping with loss of role, functional capacity or health status; evaluating whether situations are amenable to change or, if not, whether reactions to unchangeable situations are modifiable; and monitoring for anxiety or depression, interpersonal conflict and existential concerns; and (3) caregiving concerns, maximising health system benefits, home environmental modifications, home care, and long-term care planning. This structure was delivered using a nondirective health counselling format, patient education and care coordination. It facilitated recognition and normalisation of the consequences of living with on-going health problems in domains of function beyond physical health per se. It promoted identification of psychosocial needs and supports and facilitated initiation of discussions about ways to adapt to and compensate for losses induced by reduced health status. An electronic web tool operationalised each session of AICCP by providing a checklist of health education topics and tasks to be completed in interviews. For example, at these meetings, coordinators introduced advance planning. If an

Study	Engelhardt 2009 {Engelhardt 2009}
	expected task was not addressed at a specified meeting, coordinators were given pop-up reminders to complete them at subsequent meetings. Health education also included, as needed, information about health-related benefits within their health system and their community. Duration 6 sessions. Concurrent medication/care: n/a. (n=265) Intervention 2: Usual Care. Usual care. Duration n/a. Concurrent medication/care: n/a
Funding	Academic or government funding (The Garfield Foundation)
RESULTS (NUMBERS ANALYSED) AND RISK OF BIAS FOR COMPARISON: ADVANCE CARE PLANNING versus USUAL CARE Protocol outcome 1: Quality of life at during study period - Actual outcome: SF-12 physical standardised score at Post -test; Group 1: mean 32.99 (SD 10.31); n=198, Group 2: mean 34.65 (SD 10.66); n=205; Risk of bias: All domain - High, Selection - Low, Blinding - Low, Incomplete outcome data - High, Outcome reporting - Low, Measurement - Low, Crossover - Low, Subgroups - Low, Other 1 - Low, Other 2 - Low, Other 3 - Low; Indirectness of outcome: No indirectness ; Baseline details: Age differed between the two groups but statistically controlled for; Group 1 Number missing: 69, Reason: nr; Group 2 Number missing: 60, Reason: nr Protocol outcome 2: Number of presentations to Emergency Department at during study period - Actual outcome: ED visits at Post- test; Group 1: mean 3.69 (SD 6.14); n=198, Group 2: mean 5.35 (SD 12.87); n=205; Risk of bias: All domain - High, Selection - Low, Blinding - Low, Incomplete outcome data - High, Outcome reporting - Low, Measurement - Low, Crossover - Low, Subgroups - Low, Other 1 - Low, Other 2 - Low, Other 3 - Low; Indirectness of outcome: No indirectness ; Baseline details: Age differed between the two groups but statistically controlled for; Group 1 Number missing: 69, Reason: nr; Group 2 Number missing: 60, Reason: nr - Actual outcome: SF-12 mental standardised score at Post-test; Group 1: mean 49.09 (SD 10.77); n=198, Group 2: mean 47.99 (SD 11.55); n=205; Risk of bias: All domain - High, Selection - Low, Blinding - Low, Incomplete outcome data - High, Outcome reporting - Low, Measurement - Low, Crossover - Low, Subgroups - Low, Other 1 - Low, Other 2 - Low, Other 3 - Low; Indirectness of outcome: No indirectness ; Baseline details: Age differed between the two groups but statistically controlled for; Group 1 Number missing: 69, Reason: nr; Group 2 Number missing: 60, Reason: nr - Actual outcome: McGill Quality of Life Questionnaire at Post- test; Group 1: mean 5.03 (SD 0.87); n=198, Group 2: mean 4.89 (SD 1.14); n=205; Risk of bias: All domain - Very high, Selection - Low, Blinding - Low, Incomplete outcome data - High, Outcome reporting - Low, Measurement - High, Crossover - Low, Subgroups - Low, Other 1 - Low, Other 2 - Low, Other 3 - Low; Indirectness of outcome: No indirectness ; Baseline details: Age differed between the two groups but statistically controlled for; Group 1 Number missing: 69, Reason: nr; Group 2 Number missing: 60, Reason: nr Protocol outcome 3: Number of admissions to hospital at After 28 days of first admission - Actual outcome: Inpatient admissions at Post- test; Group 1: mean 2.44 (SD 5.11); n=198, Group 2: mean 4.33 (SD 16.26); n=205; Risk of bias: All domain - High, Selection - Low, Blinding - Low, Incomplete outcome data - High, Outcome reporting - Low, Measurement - Low, Crossover - Low, Subgroups - Low, Other 1 - Low, Other 2 - Low, Other 3 - Low; Indirectness of outcome: No indirectness ; Baseline details: Age differed between the two groups but statistically controlled for; Group 1 Number missing: 69, Reason: nr; Group 2 Number missing: 60, Reason: nr	
Protocol outcomes not reported by the study	Avoidable adverse events at during study period; Patient and/ or carer satisfaction at during study period; Number of

Study	Engelhardt 2009 {Engelhardt 2009}
	GP presentations at during study period; Readmission; Length of stay in programme at during study period; Number of radiology tests at during study period; Number of outpatient visits at during study period; Number of laboratory tests ordered at during study period; Number of home health visits at during study period; Number of pharmacy prescriptions at during study period; Length of hospital stay at during study period

Appendix E: Economic evidence tables

No studies were included.

Appendix F: GRADE tables

Table 6: Clinical evidence profile: Advance care planning versus usual care, RCT evidence

Quality assessment							No of patients		Effect		Quality	Importance
No of studies	Design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations	Advance care planning	Control	Relative (95% CI)	Absolute		
Patient satisfaction												
1	randomised trials	serious[1]	no serious inconsistency	no serious indirectness	no serious imprecision	none	131/133 (98.5%)	94.2%	RR 1.05 (1 to 1.09)	47 more per 1000 (from 0 more to 85 more)	⊕⊕⊕O MODERATE	CRITICAL
Family satisfaction												
1	randomised trials	serious[1]	no serious inconsistency	no serious indirectness	Serious[2]	none	26/29 (89.7%)	77.8%	RR 1.15 (0.91 to 1.46)	117 more per 1000 (from 70 fewer to 358 more)	⊕⊕OO LOW	CRITICAL
Patient satisfaction (Better indicated by higher values)												
1	randomised trials	very serious[1]	no serious inconsistency	no serious indirectness	no serious imprecision	none	86	100	-	MD 0.09 higher (0.1 lower to 0.28 higher)	⊕⊕OO LOW	CRITICAL
Family satisfaction (problems reported) (Better indicated by lower values)												
1	randomised trials	very serious[1]	no serious inconsistency	no serious indirectness	no serious imprecision	none	67	76	-	MD 0.12 lower (0.22 to 0.02 lower)	⊕⊕OO LOW	CRITICAL
QOL: SF-12 Physical standardised score (Better indicated by higher values)												
1	randomised trials	serious[1]	no serious inconsistency	no serious indirectness	Serious[2]	none	198	205	-	MD 1.66 lower (3.71 lower to 0.39 higher)	⊕⊕OO LOW	CRITICAL
QOL: SF-12 Mental standardised score (Better indicated by higher values)												

1	randomised trials	serious[1]	no serious inconsistency	no serious indirectness	very serious[2]	none	198	205	-	MD 1.1 higher (1.08 lower to 3.28 higher)	⊕OOO VERY LOW	CRITICAL
McGill QOL questionnaire (Better indicated by lower values)												
1	randomised trials	very serious[1]	no serious inconsistency	no serious indirectness	no serious imprecision	none	198	205	-	MD 0.14 higher (0.06 lower to 0.34 higher)	⊕⊕OO LOW	CRITICAL
Number of ED visits (Better indicated by lower values)												
1	randomised trials	serious[1]	no serious inconsistency	no serious indirectness	Serious[2]	none	198	205	-	MD 1.66 lower (3.62 lower to 0.3 higher)	⊕⊕OO LOW	CRITICAL
Number of inpatient admissions (Better indicated by lower values)												
1	randomised trials	serious[1]	no serious inconsistency	no serious indirectness	Serious[2]	None	198	205	-	MD 1.89 lower (4.23 lower to 0.45 higher)	⊕⊕OO LOW	CRITICAL

[1] Downgraded by 1 increment if the majority of the evidence was at high risk of bias, and downgraded by 2 increments if the majority of the evidence was at very high risk of bias
[2] Downgraded by 1 increment if the confidence interval crossed 1 MID or by 2 increments if the confidence interval crossed both MIDs.

Appendix G: Excluded clinical studies

Table 7: Studies excluded from the clinical review

Study	Exclusion reason
ALBERTA 2005[2]	Review paper checked for references.
ALIFRANGIS 2011[3]	Qualitative study. No outcomes of interest
ALLEN 2005[4]	Observational study (RCT evidence available).
AMERING 2005[5]	Incorrect population. Qualitative study.
AMJAD 2014[6]	No outcomes of interest
ANDERSON 1994[7]	No outcomes of interest
ARENSON 1996[8]	Narrative paper checked for references
ATKINSON 2003[9]	Qualitative study
ATTWOOD 2001[10]	Review does not match protocol
AU 2012[11]	No outcomes of interest
BRAUN 2006[12]	No outcomes of interest
BRAVO 2008[14]	Systematic review does not match protocol.
BRAVO 2012[13]	Methodological paper (no results reported)
BRIGGS 2004[15]	No outcomes of interest
BRINK 2008[16]	No outcomes of interest.
BROADWELL 1993[17]	Qualitative study
BRODY 2006[18]	Incorrect topic
CAMPBELL 2009[19]	Incorrect population
CAPEL 2012[20]	No outcomes of interest.
CAPLAN 2006[21]	Observational study (RCT evidence available).
CATIC 2013[22]	Incorrect intervention
CHEN 2014[24]	Observational study (RCT evidence available).
CLAYTON 2007[25]	Incorrect intervention
CONNORS 1995[26]	Multiple interventions without a clear focus on advance care planning, therefore ACP not tested in trial.
DEKORTE-VERHOEF 2014[27]	No outcomes of interest
DENING 2011A[29]	Systematic review checked for references
DEV 2013[31]	No outcomes of interest
DEVLEMINCK2016 [28]	Incorrect intervention. The objective of the study was to develop an intervention to support the initiation of advance care planning in general practice.
DONZE 2014[32]	Incorrect study design (case-control)
EFFIONG 2013[33]	Cochrane protocol does not sufficiently match protocol
EVANS 2012A[36]	Review checked for references
GADE 2008[37]	RCT of palliative care team provision; not advanced care planning.
GLAUDEMANS 2015 [39]	Structured review. Checked references

HAJIZADEH 2013[40]	Theoretical modeling
HENDERSON 1997[42]	Narrative paper
HESSE 1995[43]	Observational study (RCT evidence available).
HIRSCHMAN 2012[44]	No outcomes of interest
HO 2000[45]	Observational study (RCT evidence available).
HOFMANN 1992[46]	Narrative paper
HOUBEN 2014[48]	Methodological paper (no results reported)
HOUBEN 2014A[47]	Systematic review checked for references
HOUTTEKIER 2012[49]	Cochrane protocol (review not completed)
INDERSCHMITTEN 2011[50]	Methodological paper (no results reported)
ISHIHARA 1996[51]	No outcomes of interest
JAIN 2015 [52]	Systematic review. Checked references
JETHWA 2015[53]	Literature review. Checked references
JOHNSON 1995[54]	Observational study (RCT evidence available).
JONES 2011[55]	Not an RCT of advance care planning; a trial of whether patients wish to discuss ACP
KASSBARTELMES 2004[56]	Review paper checked for references
KHANDELWAL2015 [57]	Systematic review. Checked references
KHAZAAL 2009[58]	Incorrect population
LA PUMA 1991[59]	Narrative checked for references
LEVY 2008[60]	Observational study (RCT evidence available).
LUKAS 2013[61]	Observational study (RCT evidence available).
MEI 2014[62]	Systematic review does not match protocol.
MENTZ 2014[63]	Methodological paper (no results reported)
MEZEY 1996A[64]	No outcomes of interest
MITCHELL 2004[65]	Incorrect comparison (terminal care in nursing homes versus community)
MOLLOY 1991A[66]	Observational study (RCT evidence available).
MOLLOY 2000A[67]	Care planning not tested; education about the existence of directives
MORRISON 2005[68]	Social workers were randomized to ACP education, not patients randomized to receive or not receive ACP
MOTLEY 2013[69]	Review checked for references
MULARSKI 2007[70]	Systematic review does not match protocol
NICHOLAS 2011[75]	Observational study (RCT evidence available).
NICHOLAS 2014[74]	Observational study (RCT evidence available).
NORRIS 2007[76]	Qualitative study
OULTON 2015 [77]	Systematic review. Checked references. Studies included in the review were of methodology not considered in our protocol (surveys, interviews)
PAPAGEORGIOU 2002[79]	Incorrect population
PAPAGEORGIOU 2004[78]	Incorrect population
PIAMJARIYAKUL 2014[80]	Qualitative study
RABOW 2004[81]	Intervention group also received psychosocial support and family caregiver training.

RAYMOND 2014[82]	Review paper, incorrect population.
SAMPSON 2011 [29]	Incorrect intervention. The study aimed to assess the feasibility of implementing a 2 component intervention (palliative assessment and advance care planning) to improve end of life care for people with advance dementia.
SCHELLINGER 2011[83]	Observational study (RCT evidence available).
SCHMIDT 2014[84]	No outcomes of interest
SCHNEIDERMAN 1992[85]	No outcomes of interest
SHERWEN 2010[86]	Narrative
SOLLOWAY 2005[87]	Observational study (RCT evidence available).
SONG 2004[89]	Systematic review checked for references
SONG 2015 [90]	No protocol outcomes reported
Song2016A[88]	Systematic review- not AME patients. Advance care planning in patients with primary malignant brain tumours
SUDORE 2015[91]	Study protocol for a RCT
TENO 1994[94]	Observational study (RCT evidence available).
TENO 1997[92]	Incorrect comparison (advance directives that were documented on medical charts versus those that were not).
TENO 2007[93]	Observational study (RCT evidence available).
THOMAS 2006B[95]	Review paper checked for references
WENGERS 1996[96]	Incorrect comparison
WU 2008[98]	Observational study (RCT evidence available).
YOO 2013[99]	Observational study (RCT evidence available).

Appendix H: Excluded economic studies

No studies were excluded.