National Institute for Health and Care Excellence

Final

End of life care for adults: service delivery

[F] Evidence review: Advance care planning

NICE guideline NG142

Evidence review

October 2019

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ISBN 978-1-4731-3560-4

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1.1 Review question: What are the best service models to support advance care planning in people who may be entering the last year of life (including when it should be facilitated and by whom)?

1.2 Introduction

The General Medical Council's Guidance on Advance Care Planning at End of life Care (May 2010)[86] states 'As treatment and care towards the end of life are delivered by multiprofessional teams often working across local health, social care and voluntary sector services, you must plan ahead as much as possible to ensure timely access to safe, effective care and continuity in its delivery to meet the patient's needs'. Despite such clear guidance many patients in their last year of life continue to experience unscheduled admissions to hospital and multiple visits to specialist clinics. They are not dying in their place of choice, and are sometimes receiving treatments they may have preferred not to have. The burden of some treatments often outweighs the benefit of prolonging life or improving a patient's condition.

Although advance care planning with people who may be entering the last year of life would help to involve them and their carers, as well as helping to ensure that services are flexible and appropriate, this review set out to evaluate the effectiveness of service models to support advance care planning in palliative care.

Advance care planning toolkits are being used to collect information from patients, for example patients' preferred place of care, preferred place of death, cardiopulmonary resuscitation, artificial and nutrition. However, this may be poorly translated into practice as the number of hospital deaths continue to rise. Health professionals still find discussion on withdrawal of treatment and end of life care difficult, especially when it is not initiated by the patient, and the implementation of advance care planning is inconsistent and patchy across the UK with very little consensus as to what constitutes a good advance care plan.

It seems that, in order to ensure advance care planning is effective, systems need to be put in place that not only prompt its creation, but also facilitates health and care professionals access to the most recent advance care plan and allows them to respond rapidly to any changes made in the plan. Furthermore, as advance care plans are especially important when supporting people who may have lost their capacity to make their own decisions, the earlier they are created the better so that the person entering their last year of life, and those people important to them, are as involved as possible and their wishes known. The involvement of carers, and other people important to the person entering the last year of life, in the creation, reviewing and updating of any plans is valuable here.

An advance care plan may be just one document the person has under their Advance Planning umbrella. Others may include: Goals and Wishes, Advance decision to refuse treatment (ADRT) DNACPR, Lasting Powers of Attorney, Funeral Wishes and Wills. These may have been in place for some time and will need considering when discussing and creating advance care plans for people entering their last year of life.

1.3 PICO table

For full details see the review protocol in Appendix A.

Table 1: PICO characteristics of review question

Population	Adults (aged over 18) with progressive life-limiting conditions thought to be entering the last year of life.
Interventions/ Comparisons	• Service models to facilitate or support ACP *versus* no identified service model • Service models to facilitate or support ACP *versus* other service model to facilitate or support ACP • Early service model to facilitate or support ACP *versus* late service model to facilitate or support ACP
Outcomes	CRITICAL - Quality of life (Continuous) - Preferred and actual place of death (Dichotomous) - Preferred and actual place of care (Dichotomous) IMPORTANT - Length of survival (Dichotomous) - Length of stay (Continuous) - Hospitalisation (Dichotomous) - Number of hospital visits (Dichotomous) - Number of visits to accident and emergency (Dichotomous) - Number of unscheduled admissions (Dichotomous) - Use of community services (Dichotomous) - Avoidable/inappropriate admissions to ICU (Dichotomous) - Inappropriate attempt at cardiopulmonary resuscitation (Dichotomous) - Staff satisfaction (Continuous) - Patient/carer reported outcomes (satisfaction) (Continuous)
Study design	• Systematic reviews • RCTs • Non-randomised comparative studies, including before and after studies

1.4 Clinical evidence

Four studies were included in the review;[45, 137, 165, 185] these are summarised in Table 2 below. Evidence from these studies is summarised in the clinical evidence summary below (Table 3 and Table 4). See also the study selection flow chart in Appendix C, forest plots in Appendix E, study evidence tables in Appendix D, GRADE tables in Appendix F and excluded studies list in Appendix H.

Table 2: **Summary of studies included in the review**

Study	Intervention and comparison	Population	Outcomes	Comments
Bristowe 2015[45]	Service models to facilitate or support ACP: AMBER care bundle; developed to improve care for patients who are deteriorating, clinically unstable, with limited reversibility and at risk of dying in the next 1-2 months. Bundle has an algorithmic approach intended to encourage the clinical team to develop and document a clear medical plan and consider anticipated outcomes and resuscitation and escalation status; this is revisited daily. The bundle also aims to increase frequency of communication with patients and family regarding treatment plans, preferred place of care and other concerns. No identified service model: usual care	Patients under the care of a palliative care team; supported by the AMBER care bundle (or would be appropriate for AMBER care bundle if on the AMBER care ward (comparison group)). N=95 UK	Length of hospital stay Preferred and actual place of death (preferred place of death – as far as next of kin was aware) Preferred and actual place of death (actual place of death)	Non-randomised comparative study
Livingston 2013[137]	Service models to facilitate or support ACP: A ten-session manualised interactive training program devised by a consultant physician and care home senior managers. The head of home had already been trained in Gold Standard Framework (a program for care homes in the UK to enable generalist to deliver high quality end-of-life care. It is not designed for those with dementia), the other managers undertook Gold Standard Framework training alongside this intervention. The training program topics were: the challenges of dementia end-of-life care; emotional and psychological needs at end-of-life; planning for end-of-life care; (advance) care planning and communication with residents and relatives; religion and spirituality at end-of-life; holistic care for people with dementia at end-of-life; summarizing and reflective sessions. The program emphasises preferred place of care, how to have difficult conversations, structured listening, communication, observation, kindness, empathy, and compassion. It included discussions with senior unit mangers and role	Residents of the nursing home with dementia who had died in the 12 months pre or post intervention. N=98 UK	Length of hospital stay Preferred and actual place of death (deaths at nursing home) Preferred and actual place of death (deaths at hospital)	Non-randomised comparative study (before and after)

Study	Intervention and comparison	Population	Outcomes	Comments
	playing around advance wishes and care plans. The training was given to residential and senior care workers and general nurses. No identified service model: usual care			
Overbeek 2018	Service models to facilitate or support ACP: Intervention based on Respecting Choices ACP facilitator training, education materials and tools. The program involves trained facilitators who assist individuals in exploring the understanding of their illness reflecting on goals, values and beliefs; discussing healthcare preferences and appointing a surrogate decision-maker (modified for Dutch context).Nurses trained to deliver the intervention. Three day training. The intervention had 3 core elements; information provision through leaflets; facilitated ACP conversations based on scripted interview cards; and completion of an AD, including appointment of a surrogate decision- maker. No identified service model: usual care	Residents in residential care homes (including adults receiving home care) aged 75 years and older , frail (Tilburg Frailty Index $\geq$ 5, range 0-15). N=201	QoL(SF 12) Satisfaction (PSQ-18)	Cluster RCT of 16 residential care homes. Care homes randomised according to socio economic status
Sampson 2011[185]	Service models to facilitate or support ACP: A palliative care assessment which informed ACP discussion with the carer, who was offered the opportunity to write an ACP for the person with dementia. Palliative care needs assessment; 30 minute structured clinical approach that built on usual care, covering domains including dementia severity, presence of delirium, communication, pressure sore risk and severity, food and fluid intake, swallowing and feeding. The assessment generated a list of problems. A management plan was formulated and used to inform subsequent discussions with the carer. Assessment informed ACP discussion with the carer, who was offered up to four consultations (at least 5 days apart). The first consultation involved discussions with the carer to assess (i) level of knowledge about patient dementia, (ii) severity of dementia and prognosis	Patients who had undergone emergency hospital admission and had severe dementia. (~50% had died during the 6-month follow up period). N=33 UK	Carer QoL (EQ5D) Carer satisfaction (LSQ; DSI; SWC-EOLCD)*	RCT Of the 33 carers (and patients), only 7 made ACPs – all from the intervention group.

Study	Intervention and comparison	Population	Outcomes	Comments
	for the patient, (iii) the patients physical needs, (iv) the social situation and current levels of social support, and (v) any records of records of previous preference for care. Subsequent consultations involved basic education on dementia as a neuro-degenerative disease. Carers then given the opportunity to write an ACP for the person with dementia. No identified service model: usual care		*see comments in clinical evidence table (Appendix E) for details	

Table 3: **Service models to facilitate or support ACP versus usual care: data unsuitable for GRADE due to inadequate reporting of outcome measure**

Study	Outcome	Intervention results	Intervention group (n)	Comparison results	Comparison group (n)	Risk of bias[a]
Bristowe (2015)	Length of hospital stay (days)	Median: 14 (range 1-87)	41	Median: 31 (range 6-70)	19	Very high
Livingston (2013)	Days spent in hospital in three months prior to death (median; range; IQR)	4 (0-34; 15.75)	42	1.25 (0-68; 9.5)	56	Very high

[a] Risk of bias is from checklist for individual studies, see evidence tables for more details.

Table 4: Clinical evidence summary: AMBER care bundle versus usual care

Outcomes	No of Participants (studies) Follow up	Quality of the evidence (GRADE)	Relative effect (95% CI)	Anticipated absolute effects	
				Risk with Usual care	Risk difference with AMBER care bundle (95% CI)
Length of hospital stay (days)	60 (1 study1) 4-10 months	⊕⊝⊝⊝ VERY LOW[a,b,c] due to imprecision		The mean length of hospital stay (days) in the control groups was 29.3 days	The mean length of hospital stay (days) in the intervention groups was 9 lower (19.89 lower to 1.89 higher)

Outcomes	No of Participants (studies) Follow up	Quality of the evidence (GRADE)	Relative effect (95% CI)	Anticipated absolute effects	
				Risk with Usual care	Risk difference with AMBER care bundle (95% CI)
Number of residents wishing to die at home (next of kin opinion)	79 (1 study1) 4-10 months	⊕⊖⊖⊖ VERY LOW[a,b,c] due to indirectness, imprecision	RR 1.15 (0.66 to 1.99)	393 per 1000	59 more per 1000 (from 134 fewer to 389 more)
Number of residents wishing to die at hospice (next of kin opinion)	79 (1 study1) 4-10 months	⊕⊖⊖⊖ VERY LOW[a,b,c] due to indirectness, imprecision	RR 1.65 (0.59 to 4.63)	143 per 1000	93 more per 1000 (from 59 fewer to 519 more)
Number of residents wishing to die at hospital (next of kin opinion)	79 (1 study1) 4-10 months	⊕⊖⊖⊖ VERY LOW[a,b,c] due to indirectness, imprecision	RR 0.6 (0.29 to 1.24)	357 per 1000	143 fewer per 1000 (from 254 fewer to 86 more)
Number of residents wishing to die at care home (next of kin opinion)	79 (1 study1) 4-10 months	⊕⊖⊖⊖ VERY LOW[a,b,c] due to indirectness, imprecision	RR 0.55 (0.12 to 2.54)	107 per 1000	48 fewer per 1000 (from 94 fewer to 165 more)
Number of residents wishing to die elsewhere (next of kin opinion)	79 (1 study1) 4-10 months	⊕⊖⊖⊖ VERY LOW[a,b,c] due to indirectness, imprecision	RR 2.79 (0.14 to 56.13)	0 per 1000	-
Number of residents dying in home	94 (1 study1) 4-10 months	⊕⊖⊖⊖ VERY LOW[a,b,c] due to indirectness, imprecision	RR 2.37 (0.72 to 7.83)	86 per 1000	117 more per 1000 (from 24 fewer to 585 more)

Outcomes	No of Participants (studies) Follow up	Quality of the evidence (GRADE)	Relative effect (95% CI)	Anticipated absolute effects	
				Risk with Usual care	Risk difference with AMBER care bundle (95% CI)
Number of residents dying in hospice	94 (1 study1) 4-10 months	⊕⊖⊖⊖ VERY LOW[a,b,c] due to indirectness, imprecision	RR 2.37 (0.72 to 7.83)	86 per 1000	117 more per 1000 (from 24 fewer to 585 more)
Number of residents dying in hospital	94 (1 study1) 4-10 months	⊕⊖⊖⊖ VERY LOW[a,b,c] due to indirectness, imprecision	RR 0.74 (0.53 to 1.04)	686 per 1000	178 fewer per 1000 (from 322 fewer to 27 more)
Number of residents dying in care home	94 (1 study1) 4-10 months	⊕⊖⊖⊖ VERY LOW[a,b,c] due to indirectness, imprecision	RR 0.59 (0.18 to 1.91)	143 per 1000	59 fewer per 1000 (from 117 fewer to 130 more)

[a] Downgraded by 2 increments if the majority of the evidence was from studies with observational/non-randomised study design. 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 or 2 increments because the majority of the evidence had indirect outcomes
[c] Downgraded by 1 increment if the confidence interval crossed 1 MID or by 2 increments if the confidence interval crossed both MIDs

Table 5: Clinical evidence summary: Training program vs usual care

Outcomes	No of Participants (studies) Follow up	Quality of the evidence (GRADE)	Relative effect (95% CI)	Anticipated absolute effects	
				Risk with Usual care	Risk difference with Training program (95% CI)
Number of residents dying in care home	59 (1 study1) 2 years	⊕⊖⊖⊖ VERY LOW[a,b,c] due to indirectness, imprecision	RR 1.63 (1.05 to 2.51)	467 per 1000	294 more per 1000 (from 23 more to 705 more)

Outcomes	No of Participants (studies) Follow up	Quality of the evidence (GRADE)	Relative effect (95% CI)	Anticipated absolute effects	
				Risk with Usual care	Risk difference with Training program (95% CI)
Number of residents dying in hospital	59 (1 study1) 2 years	⊕⊖⊖⊖ VERY LOW[a,b,c] due to indirectness, imprecision	RR 0.45 (0.22 to 0.94)	533 per 1000	293 fewer per 1000 (from 32 fewer to 416 fewer)

[a] Downgraded by 2 increments if the majority of the evidence was from studies with observational/non-randomised study design. 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 or 2 increments because the majority of the evidence had indirect outcomes
[c] Downgraded by 1 increment if the confidence interval crossed 1 MID or by 2 increments if the confidence interval crossed both MIDs

Table 6: Clinical evidence summary: Adjusted choices vs usual care

Outcomes	No of Participants (studies) Follow up	Quality of the evidence (GRADE)	Relative effect (95% CI)	Anticipated absolute effects	
				Risk with Usual care	Risk difference with Adjusted Choices (95% CI)
SF_12 Physical component Scale from: 0 to 100.	160 (1 study) 12 months	⊕⊕⊖⊖ **LOW**[a,b] due to risk of bias, imprecision		The mean SF_12 physical component in the control groups was 34	The mean sf_12 physical component in the intervention groups was **2 lower** (4.95 lower to 0.95 higher)
SF_12 Mental component Scale from: 0 to 100.	160 (1 study) 12 months	⊕⊕⊖⊖ **LOW**[a,b] due to risk of bias, imprecision		The mean SF_12 mental component in the control groups was 46	The mean sf_12 mental component in the intervention groups was **2 higher** (1.55 lower to 5.55 higher)
Patient Satisfaction (PSQ-18 _1subscale) Scale from: 1 to 5.	160 (1 study) 12 months	⊕⊕⊕⊖ **MODERATE**[a] due to risk of bias		The mean patient satisfaction (psq-18 _1subscale) in the control	The mean patient satisfaction (psq-18 _1subscale) in the intervention groups was **0 higher** (0.23 lower to 0.23 higher)

| | | | groups was 4 | |

a Downgraded by 1 increment for risk of bias
b Downgraded by 1 increment if the confidence interval crossed by 1 MID

Table 7: Clinical evidence summary: Palliative assessment, carer consultation, ACP vs usual care

Outcomes	No of Participants (studies) Follow up	Quality of the evidence (GRADE)	Anticipated absolute effects	
			Risk with Usual care	Risk difference with Palliative assessment, carer consultation, ACP (95% CI)
Carers quality of life at baseline (EQ5D; scale 0-1, low score indicates poor health)	31 (1 study) 6 months	⊕⊖⊖⊖ VERY LOW[a,b] due to risk of bias, imprecision	The mean carers quality of life at baseline (EQ5D; scale 0-1, low score indicates poor health) in the control groups was 0.6	The mean carers quality of life at baseline (EQ5D; scale 0-1, low score indicates poor health) in the intervention groups was 0.1 higher (0.16 lower to 0.36 higher)
Carers quality of life at 6 weeks (EQ5D; scale 0-1, low score indicates poor health)	15 (1 study) 6 months	⊕⊖⊖⊖ VERY LOW[a,b] due to risk of bias, imprecision	The mean carers quality of life at 6 weeks (EQ5D; scale 0-1, low score indicates poor health) in the control groups was 0.8	The mean carers quality of life at 6 weeks (EQ5D; scale 0-1, low score indicates poor health) in the intervention groups was 0 higher (0.1 lower to 0.1 higher)
Carers quality of life at 6 months (EQ5D; scale 0-1, low score indicates poor health)	11 (1 study) 6 months	⊕⊖⊖⊖ VERY LOW[a,b] due to risk of bias, imprecision	The mean carers quality of life at 6 months (EQ5D; scale 0-1, low score indicates poor health) in the control groups was 0.8	The mean carers quality of life at 6 months (EQ5D; scale 0-1, low score indicates poor health) in the intervention groups was 0 higher (0.12 lower to 0.12 higher)
Carers quality of life at post-bereavement (EQ5D; scale 0-1, low score indicates poor health)	5 (1 study) 6 months	⊕⊕⊖⊖ LOW[a] due to risk of bias	The mean carers quality of life at post-bereavement (EQ5D; scale 0-1, low score indicates poor health) in the control groups was 0.9	The mean carers quality of life at post-bereavement (EQ5D; scale 0-1, low score indicates poor health) in the intervention groups was 0.3 lower (see comments)[c]

Outcomes	No of Participants (studies) Follow up	Quality of the evidence (GRADE)	Anticipated absolute effects	
			Risk with Usual care	Risk difference with Palliative assessment, carer consultation, ACP (95% CI)
Carers life satisfaction at baseline (LSQ; scale 0-7, high score indicates best possible outcome)	31 (1 study) 6 months	⊕⊖⊖⊖ VERY LOW[a,b] due to risk of bias, imprecision	The mean carers life satisfaction at baseline (LSQ; scale 0-7, high score indicates best possible outcome) in the control groups was 4.6	The mean carers life satisfaction at baseline (LSQ; scale 0-7, high score indicates best possible outcome) in the intervention groups was 0.1 lower (0.98 lower to 0.78 higher)
Carers life satisfaction at 6 weeks (LSQ; scale 0-7, high score indicates best possible outcome)	15 (1 study) 6 months	⊕⊖⊖⊖ VERY LOW[a,b] due to risk of bias, imprecision	The mean carers life satisfaction at 6 weeks (LSQ; scale 0-7, high score indicates best possible outcome) in the control groups was 5.5	The mean carers life satisfaction at 6 weeks LSQ; scale 0-7, high score indicates best possible outcome) in the intervention groups was 0.6 lower (1.58 lower to 0.38 higher)
Carers life satisfaction at 6 months (LSQ; scale 0-7, high score indicates best possible outcome)	11 (1 study) 6 months	⊕⊖⊖⊖ VERY LOW[a,b] due to risk of bias, imprecision	The mean carers life satisfaction at 6 months (LSQ; scale 0-7, high score indicates best possible outcome) in the control groups was 5.5	The mean carers life satisfaction at 6 months (LSQ; scale 0-7, high score indicates best possible outcome) in the intervention groups was 0.1 lower (0.99 lower to 0.79 higher)
Carers life satisfaction at post-bereavement (LSQ; scale 0-7, high score indicates best possible outcome)	5 (1 study) 6 months	⊕⊖⊖⊖ VERY LOW[a,b] due to risk of bias, imprecision	The mean carers life satisfaction at post-bereavement (LSQ; scale 0-7, high score indicates best possible outcome) in the control groups was 6	The mean carers life satisfaction at post-bereavement (LSQ; scale 0-7, high score indicates best possible outcome) in the intervention groups was 3 lower (see comments)[c]
Carers decision satisfaction at baseline (DSI; range 10-50; high score indicates less satisfaction)	31 (1 study) 6 months	⊕⊖⊖⊖ VERY LOW[a,b] due to risk of bias, imprecision	The mean carers decision satisfaction at baseline (DSI; range 10-50; high score indicates less satisfaction) in the control groups was 26.5	The mean carers decision satisfaction at baseline (DSI; range 10-50; high score indicates less satisfaction) in the intervention groups was 0.5 lower (4.86 lower to 3.86 higher)
Carers decision satisfaction at 6 weeks (DSI; range 10-50; high score indicates less satisfaction)	15 (1 study) 22 months	⊕⊖⊖⊖ VERY LOW[a,b] due to risk of bias, imprecision	The mean carers decision satisfaction at 6 weeks (DSI; range 10-50; high score indicates less	The mean carers decision satisfaction at 6 weeks (DSI; range 10-50; high score indicates less satisfaction) in the intervention

Outcomes	No of Participants (studies) Follow up	Quality of the evidence (GRADE)	Anticipated absolute effects	
			Risk with Usual care	Risk difference with Palliative assessment, carer consultation, ACP (95% CI)
			satisfaction) in the control groups was 22	groups was 0.2 lower (7.98 lower to 7.58 higher)
Carers decision satisfaction at 6 months (DSI; range 10-50; high score indicates less satisfaction)	11 (1 study) 6 months	⊕⊖⊖⊖ VERY LOW[a,b] due to risk of bias, imprecision	The mean carers decision satisfaction at 6 months (DSI; range 10-50; high score indicates less satisfaction) in the control groups was 16.3	The mean carers decision satisfaction at 6 months (DSI; range 10-50; high score indicates less satisfaction) in the intervention groups was 5.9 higher (1.61 lower to 13.41 higher)
Carers decision satisfaction at post-bereavement (DSI; range 10-50; high score indicates less satisfaction)	5 (1 study) 6 months	⊕⊕⊖⊖ LOW[a] due to risk of bias	The mean carers decision satisfaction at post-bereavement (DSI; range 10-50; high score indicates less satisfaction) in the control groups was 32	The mean carers decision satisfaction at post-bereavement (DSI; range 10-50; high score indicates less satisfaction) in the intervention groups was 4 lower (see comments)[c]
Carers satisfaction with end of life care at post-bereavement (SWC-EOLCD; range 10-40; high score indicates greater satisfaction)	5 (1 study) 6 months	⊕⊕⊖⊖ LOW[a] due to risk of bias	The mean carers satisfaction with end of life care at post-bereavement (SWC-EOLCD; range 10-40; high score indicates greater satisfaction) in the control groups was 23	The mean carers satisfaction with end of life care at post-bereavement (SWC-EOLCD; range 10-40; high score indicates greater satisfaction) in the intervention groups was 4.6 higher (see comments)[c]

[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
[c] Confidence interval not estimable

See Appendix F for full GRADE tables.

1.5 Economic evidence

1.5.1 Included studies

Two health economic studies were identified with the relevant comparison and have been included in this review. {3558}[174] This is summarised in the health economic evidence profile below (Table 8) and the health economic evidence tables in Appendix H.

See also the health economic study selection flow chart in Appendix G.

1.5.2 Excluded studies

No health economic studies that were relevant to this question were excluded due to assessment of limited applicability or methodological limitations.

See also the health economic study selection flow chart in Appendix G.

1.5.3 Summary of studies included in the economic evidence review

Table 8: Health economic evidence profile: Advanced care planning (ACP) versus no ACP

Study	Applicability	Limitations	Other comments	Incremental cost	Incremental effects	Cost-effectiveness	Uncertainty
Overbeek 2019{3558} Netherlands	Partially applicable[(a)]	Potentially serious limitations[(b)]	Study design: Cluster randomised trial	ACP Saves £7,937	None	ACP dominates usual care	No sensitivity analysis conducted
Pham 2014 [174] Canada	Partially applicable[(c)]	Very Serious Limitations[(d)]	Study design: Probabilistic decision analytic Markov model (microsimulation)	ACP Saves £15	0.01 more quality-adjusted life days	ACP dominates usual care	A number of one-way sensitivity analyses and probabilistic analysis were conducted to explore key sources of variability and uncertainty in the simulated model. The sensitivity analysis found that the results were uncertain and might change with additional data.

Abbreviations: PCPDs: patient care planning decision; LTC: long term care; EPC: early palliative care
(a) Not UK NHS perspective; not clear if all costs would fall within an NHS and personal social services perspective (e.g. residential home costs); no QALYs.
(b) Charges used as a proxy for costs. No sensitivity analysis
(c) Not a UK study therefore study population and costs not directly applicable.
(d) Model assumes that last year of life is known which does not reflect reality. Model assumes that interventions do not affect survival time which does not reflect reality. Model assumes that a palliative prognosis can be determined by resource use of patients therefore doesn't account for patients with a terminal illness who do not receive EOL care services in the last year of life, it is not clear how this effects the cost effectiveness results. Cost effectiveness results for in-home palliative care are subject to EOL care in the control group of the RCT study being the same as the usual care strategy; this is unlikely to be true. The model does not explicitly take into account that some of the interventions are currently provided as part of usual care therefore it is likely that the treatment effects are overestimated. Estimating the intervention effect on HRQOL as well as decrements in QALY weights through downstream resource use risks the possibility of double counting.
(e) Intervention: ACP: based on Respecting Choices ACP facilitator training, education materials, and tools
(f) Intervention: Patient Care Planning Decisions (PCPDs): Identifying LTC residents with EoL goals and preferences for EPC

1.5.4 Unit costs

Table 9 reports the unit costs of staff time for some health care professionals who may be involved in advance care planning with individuals identified as thought to be in the last year of life. The cost of patient contact as opposed to per working hour has been reported where available.

Table 9: UK costs of staff time for health care professionals who might undertake advance care planning with someone thought to be in the last year of life

Staff Member	Unit Cost of Staff Time[a]
Hospital-based staff	
Hospital-based scientific and professional staff[b]	£24-£77 per working hour (Band 2 – Band 8b)
Hospital-based nurses	£86-£130 per hour of patient contact (Band 5 – 7)
Hospital-based doctors	£29-£106 (FY1 – Consultant)
Community-based staff	
General practitioner	£199 per hour of patient contact
Community-based scientific and professional Staff[b]	£23-£74 per working hour (Band 2 – Band 8b)
Community nurse	£22-£73 per working hour (Band 2 – Band 8b)
Nurse (GP practice)	£36 per working hour
Social Worker (adult services)	£55 per hour of client-related work

Source/Note: Curtis (2016)[66]

Source/Note: Please see Curtis (2016)[66] for details of the health care professionals included in this category by band. Examples include: Physiotherapists, Occupational therapists, Counsellors, Pharmacists

1.6   Resource costs

The recommendations made based on this review (see section **Error! Reference source n ot found.** may have a substantial impact on resources.

Additional costs could be incurred for the following reasons: cost of the implementation of processes to undertake advanced care planning with people thought to be in the last year of life and their carers or those important to them if appropriate. The magnitude of the resource impact depends on the scale to which the above is already part of current practice of end of life care. This will depend on local circumstances. Savings could be made through: hospital admissions and hospital deaths avoided; reduced length of stay in hospital spells for people in the last year of life and earlier withdrawals of active treatment for people in the last year of life. Further detail can be found in the resource impact tools that support the guideline which will be available after final publication.

1.7 Evidence statements

1.7.1   Clinical evidence statements

AMBER care bundle versus usual care

There was evidence of clinically important benefit in the number of people dying at home, at hospice, at hospital, and in care home in favour of the intervention group. No clinically importance difference was observed between groups in the length of hospital stay (1 study; n=79; very low quality).

Training program versus usual care

There was a clinically important difference in favour of the intervention group for the number of residents dying in care home, and in hospital. There was also evidence of reduced length of hospital stay in the intervention group (1 study; n=59; very low quality).

Palliative assessment, carer consultation, ACP versus usual care

No clinically importance difference was observed between groups in the quality of life of carers, carer life satisfaction, decision satisfaction, or satisfaction with end of life care (1 study; n=33; low to very low quality).

1.7.2 Health economic evidence statements

- One cost-utility analysis found that having patient care planning decisions (identifying long term care residents with end of life goals and preferences for early palliative care) dominated usual care (same effects and slightly less costly). This study was assessed as partially applicable with very serious limitations.
- One cost-consequences analysis found that having advanced care planning dominated usual care (same effects and was less costly). This study was assessed as partially applicable with potentially serious limitations.

1.8 The committee's discussion of the evidence

1.8.1 Interpreting the evidence

1.8.1.1 The outcomes that matter most

The Committee identified quality of life, and preferred place of care and death as the critical outcomes for identifying people in their last year of life. The following outcomes were identified as important: length of survival, length of stay, length of survival hospitalisation, number of hospital visits, number of visits to accident and emergency, number of unscheduled admissions, use of community services, avoidable or inappropriate admissions to ICU, inappropriate attempts at cardiopulmonary resuscitation, staff satisfaction, patient or carer reported outcomes and carer health.

See tables 7 and 8 in the Methods chapter for a detailed explanation of why the committee selected these outcomes.

For the critically important outcomes, two studies reported actual place of death, which was an indirect outcome for actual place of death compared to preferred place of death. One study reported actual and preferred pace of death, but these were reported as two separate results so could not directly demonstrate the number of people achieving their preferred place of death. None of the studies reported actual and preferred place of care. Carer quality of life was also reported by one study.

For the important outcomes, two studies reported the length of hospital stay. One study reported carer satisfaction.

1.8.1.2 The quality of the evidence

The quality of the evidence ranged from very low to low.. This was due to study design, selection and performance bias, resulting in a high risk of bias rating, and imprecision.. Indirectness in some outcomes (for example: actual and final place of death; hospitalisation) further contributed to the final GRADE rating.

The length of hospital stay was reported as a median and conclusions on the efficacy based on these outcomes could not be made with confidence,

1.8.1.3 Benefits and harms

The Committee acknowledged the potential for tools such as the AMBER care bundle to both identify people entering the last year of life, and to trigger the process of advance care planning although there was not enough evidence to recommend a specific service model. The Committee agreed that training programmes for HCPs could facilitate the process of HCPs engaging with people in the last year of life to offer support for the completion of ACP.

Although the evidence showed a mixed benefit of advance care planning the Committee agreed that in their experience where ACP was actively supported people were enabled to access the right care to allow them to be looked after in their preferred place of care.

Overall, the Committee agreed that after people had been identified as likely to be in the last year of life service models should be in place to provide the opportunity for advance care, respecting the wishes of patients and carers to engage in ACP.

The Committee noted the role of carers in supporting advance care planning. Where the person in the last year of life agrees, carers of all ages should be supported to be involved in advance care planning. Where the consent of the person in the last year of life is not possible carers views should be taken into account.

To ensure that an ACP is implemented it should be available and accessible to all the professionals providing care. The Committee were keen to note that in the case of ACPs a paper copy should be held at the person's residence. This would help to avoid difficult situations and unnecessary hospital admission when professionals unaware of the persons wishes have contact with them (for example, an ambulance crew). (see information sharing recs). Some people entering the last year of life will already have advancedcare plans (MND section 1.7 Planning for the end of life; Dementia: supporting people with dementia and their carer's in health and social care NG42). Services should have systems in place for earlier engagement for people who will lose the mental capacity to engage in advance care planning, this will ensure their wishes are met.

The Committee noted that advance care plans need to be reviewed and the service needs adapted to the changing needs of patient and carer. This will occur at transition points (for example, when a person's condition changes).

1.8.2 Cost effectiveness and resource use

Two economic evaluations were found.

One study was a cost-consequences analysis from the Netherlands. It found no difference in patients' quality of life. There was a slight increase in hospital costs and care in the home but a substantial reduction in residential care costs meant that overall costs were reduced by almost £8,000.

A cost utility analysis conducted in Canada, using Canadian administrative data, was identified that compared identifying long term care residents with end of life goals and preferences for early palliative care versus usual care. The study found a neglible difference in both costs and quality of life.

The committee felt that as these studies were not based on UK data, the results could not be transferred to a UK setting.

The costs of established service model tools such as the Amber Care Bundle or Gold Standards Framework which can help facilitate advance care planning discussions are highly dependent on a number of factors including the level of support/training/tool packages

considered appropriate for the particular institutions (for example: hospitals/GP practices/care homes) and the size and baseline starting point of the institutions.

The cost of routine advance care planning depends on the level of healthcare professional considered responsible for establishing advance care plans with the people identified as thought to be in the last year of life. How often plans are reviewed, what conditions people are dying from and the level of detail considered appropriate in the plans, will be somewhat determined by many variables, for example: conditions, comorbidities, family/carer situation and cultural/social/religious considerations.

The committee highlighted that although advance care planning is widely considered to be good practice, it is currently not widely being carried out; especially for people with non-cancer diagnoses. Recommending routine advance care planning to all people identified as thought to be in the last year of life will have a significant resource impact for places that do not currently have service models established that support advance care planning, such as necessary staff training available and clear guidance on which healthcare professionals are responsible for establishing the plans.

1.8.3 Other factors the committee took into account

Offer advance care planning to people who are approaching the end of life and are at risk of a medical emergency. [AME - See chapter 15 on advance care planning.’]

The Committee highlighted a number of tools that should be available with regards to ACP for those entering the last year of life, for example:

- ADRT – Advance decision to refuse treatment
- ACP – Advance care planning
- Adjusted Choices
- Ceiling of care/TEP – Treatment escalation plan
- DNACPR – Do not attempt cardiopulmonary resuscitation
- ReSPECT – Recommended Summary Plan for Emergency Care and Treatment
- Lasting power of attorney

Patients and carers may have conflicting views and wishes, which may change. This needs to be considered when engaging in ACP and throughout the course of support.

References

Appendices

Appendix A: Review protocols

Table 10: Review protocol for what are the best service models to support advance care planning in people who may be entering the last year of life (including when it should be facilitated and by whom)?

Question number: 14

Relevant section of Scope:

Planning, coordinating and integrating the delivery of services, including sharing information between multidisciplinary teams.

Service delivery models for end of life care, including both acute, community and third sector settings covering:

- types of services (supportive and palliative care) provided by generalists and specialists during the course of the last year of life,
- who delivers the services and how, multidisciplinary team composition,
- timing and review of service provision,
- location of services, for example, place of care,
- out of hours, weekend and 24/7 availability of services.

Field names are based on PRISMA-P.]

ID	Field	Content
I	Review question	What are the best service models to support advance care planning in people who may be entering the last year of life (including when it should be facilitated and by whom)?
II	Type of review question	Intervention A review of health economic evidence related to the same review question was conducted in parallel with this review. For details see the health economic review protocol for this NICE guideline.
III	Objective of the review	To identify the best service models to support advance care planning in people who might be entering the last year of life, including when ACP should be facilitated and by whom
IV	Eligibility criteria – population / disease / condition / issue / domain	Adults (aged over 18) with progressive life-limiting conditions thought to be entering the last year of life.
V	Eligibility criteria – intervention(s) / exposure(s) / prognostic factor(s)	• Service models to facilitate or support ACP
VI	Eligibility criteria – comparator(s) / control	• No identified service model • Other service model to facilitate or support ACP

	or reference (gold) standard	• Early service model to facilitate or support ACP versus late service model to facilitate or support ACP
VII	Outcomes and prioritisation	CRITICAL • Quality of life (Continuous) • Preferred and actual place of death (Dichotomous) • Preferred and actual place of care (Dichotomous) IMPORTANT • Length of survival (Dichotomous) • Length of stay (Continuous) • Hospitalisation (Dichotomous) • Number of hospital visits (Dichotomous) • Number of visits to accident and emergency (Dichotomous) • Number of unscheduled admissions (Dichotomous) • Use of community services (Dichotomous) • Avoidable/inappropriate admissions to ICU (Dichotomous) • Inappropriate attempt at cardiopulmonary resuscitation (Dichotomous) Staff satisfaction (Continuous) • Patient/carer reported outcomes (satisfaction) (Continuous)
VIII	Eligibility criteria – study design	• Systematic reviews • RCTs • Non-randomised comparative studies, including before and after studies.
IX	Other inclusion exclusion criteria	Exclusions: • Children (17 years or younger) • Studies will only be included if they reported one or more of the outcomes listed above • Descriptive (non-comparative) studies will be excluded
X	Proposed sensitivity / subgroup analysis, or meta-regression	Subgroups to be analysed if heterogeneity found: • Younger adults (aged 18-25) • Frail elderly • People with dementia • People with hearing loss • People with advanced heart and lung disease • People in prisons • Socioeconomic inequalities (people from lower income brackets) • Homeless people/vulnerably housed • Travellers • People with learning difficulties • People with disabilities • People with mental health problems • Migrant workers • LGBT

		• People in whom life-prolonging therapies are still an active option
XI	Selection process – duplicate screening / selection / analysis	Quality assurance will be undertaken by a senior research fellow prior to completion. Review strategy/other analysis: • Information on identification tools used as part of a service will be extracted. • Due to the expected complexity of the service models implemented in the studies, studies will be reported separately if necessary. In such case, studies on the populations included in the subgroup list will be highlighted to the Committee and will be considered when making the recommendations
XII	Data management (software)	• Pairwise meta-analyses were performed using Cochrane Review Manager (RevMan5). • GRADEpro was used to assess the quality of evidence for each outcome. • Endnote was used for: ○ Bibliography, citations, sifting and reference management • Evibase was used for • Data extraction and quality assessment / critical appraisal
XIII	Information sources – databases and dates	Clinical search databases to be used: Medline, Embase, Cochrane Library, Current Nursing and Allied Health Literature (CINAHL), PsycINFO, Healthcare Management Information Consortium (HMIC), Social Policy and Practice (SSP), Applied Social Sciences Index and Abstracts (ASSIA) Date: All years Health economics search databases to be used: Medline, Embase, NHSEED, HTA Date: Medline, Embase from 2014 NHSEED, HTA – All years Language: Restrict to English only A call for evidence was also conducted.
XIV	Identify if an update	Not applicable
XV	Author contacts	https://www.nice.org.uk/guidance/indevelopment/gid-cgwave0799
XVI	Highlight if amendment to previous protocol	For details please see section 4.5 of Developing NICE guidelines: the manual.
XVII	Search strategy – for one database	For details please see Appendix B
XVIII	Data collection process – forms / duplicate	A standardised evidence table format will be used, and published as appendix D of the evidence report.
XIX	Data items – define all variables to be collected	For details please see evidence tables in Appendix D (clinical evidence tables) or G (health economic evidence tables).

XX	Methods for assessing bias at outcome / study level	Standard study checklists were used to critically appraise individual studies. For details please see section 6.2 of Developing NICE guidelines: the manual The risk of bias across all available evidence was evaluated for each outcome using an adaptation of the 'Grading of Recommendations Assessment, Development and Evaluation (GRADE) toolbox' developed by the international GRADE working group http://www.gradeworkinggroup.org/ [Please document any deviations/alternative approach when GRADE isn't used or if a modified GRADE approach has been used for non-intervention or non-comparative studies.]
XXI	Criteria for quantitative synthesis	For details please see section 6.4 of Developing NICE guidelines: the manual.
XXII	Methods for quantitative analysis – combining studies and exploring (in)consistency	For details please see the separate Methods report for this guideline.
XXIII	Meta-bias assessment – publication bias, selective reporting bias	For details please see section 6.2 of Developing NICE guidelines: the manual.
XXIV	Confidence in cumulative evidence	For details please see sections 6.4 and 9.1 of Developing NICE guidelines: the manual.
XXV	Rationale / context – what is known	For details please see the introduction to the evidence review.
XXVI	Describe contributions of authors and guarantor	A multidisciplinary committee [https://www.nice.org.uk/guidance/indevelopment/gid-cgwave0799] developed the evidence review. The committee was convened by the National Guideline Centre (NGC) and chaired by Mark Thomas in line with section 3 of Developing NICE guidelines: the manual. Staff from NGC undertook systematic literature searches, appraised the evidence, conducted meta-analysis and cost-effectiveness analysis where appropriate, and drafted the evidence review in collaboration with the committee. For details please see Developing NICE guidelines: the manual.
XXVII	Sources of funding / support	NGC is funded by NICE and hosted by the Royal College of Physicians.
XXVIII	Name of sponsor	NGC is funded by NICE and hosted by the Royal College of Physicians.
XXIX	Roles of sponsor	NICE funds NGC to develop guidelines for those working in the NHS, public health and social care in England.
XXX	PROSPERO registration number	Not registered

Table 11: Health economic review protocol

Review question	All questions – health economic evidence
Objectives	To identify health economic studies relevant to any of the review questions.
Search criteria	• Populations, interventions and comparators must be as specified in the clinical review protocol above.

	• Studies must be of a relevant health economic study design (cost–utility analysis, cost-effectiveness analysis, cost–benefit analysis, cost–consequences analysis, comparative cost analysis). • Studies must not be a letter, editorial or commentary, or a review of health economic evaluations. (Recent reviews will be ordered although not reviewed. The bibliographies will be checked for relevant studies, which will then be ordered.) • Unpublished reports will not be considered unless submitted as part of a call for evidence. • Studies must be in English.
Search strategy	A health economic study search will be undertaken using population-specific terms and a health economic study filter – see Appendix G *[in the Full guideline]*
Review strategy	Studies not meeting any of the search criteria above will be excluded. Studies published before 2007, abstract-only studies and studies from non-OECD countries or the USA will also be excluded. Each remaining study will be assessed for applicability and methodological limitations using the NICE economic evaluation checklist which can be found in Appendix H of Developing NICE guidelines: the manual (2014).[157] **Inclusion and exclusion criteria** • If a study is rated as both 'Directly applicable' and with 'Minor limitations' then it will be included in the guideline. A health economic evidence table will be completed and it will be included in the health economic evidence profile. • If a study is rated as either 'Not applicable' or with 'Very serious limitations' then it will usually be excluded from the guideline. If it is excluded then a health economic evidence table will not be completed and it will not be included in the health economic evidence profile. • If a study is rated as 'Partially applicable', with 'Potentially serious limitations' or both then there is discretion over whether it should be included. **Where there is discretion** The health economist will make a decision based on the relative applicability and quality of the available evidence for that question, in discussion with the guideline committee if required. The ultimate aim is to include health economic studies that are helpful for decision-making in the context of the guideline and the current NHS setting. If several studies are considered of sufficiently high applicability and methodological quality that they could all be included, then the health economist, in discussion with the committee if required, may decide to include only the most applicable studies and to selectively exclude the remaining studies. All studies excluded on the basis of applicability or methodological limitations will be listed with explanation as excluded health economic studies in Appendix M. The health economist will be guided by the following hierarchies. *Setting:* • UK NHS (most applicable). • OECD countries with predominantly public health insurance systems (for example, France, Germany, Sweden). • OECD countries with predominantly private health insurance systems (for example, Switzerland). • Studies set in non-OECD countries or in the USA will be excluded before being assessed for applicability and methodological limitations. *Health economic study type:* • Cost–utility analysis (most applicable). • Other type of full economic evaluation (cost–benefit analysis, cost-effectiveness analysis, cost–consequences analysis). • Comparative cost analysis.

- Non-comparative cost analyses including cost-of-illness studies will be excluded before being assessed for applicability and methodological limitations.

Year of analysis:

- The more recent the study, the more applicable it will be.
- Studies published in 2007 or later but that depend on unit costs and resource data entirely or predominantly from before 2007 will be rated as 'Not applicable'.
- Studies published before 2007 will be excluded before being assessed for applicability and methodological limitations.

Quality and relevance of effectiveness data used in the health economic analysis:

- The more closely the clinical effectiveness data used in the health economic analysis match with the outcomes of the studies included in the clinical review the more useful the analysis will be for decision-making in the guideline.

Appendix B: Literature search strategies

The literature searches for this review are detailed below and complied with the methodology outlined in Developing NICE guidelines: the manual 2014, updated 2017 https://www.nice.org.uk/guidance/pmg20/resources/developing-nice-guidelines-the-manual-pdf-72286708700869

For more detailed information, please see the Methodology Review.

B.1   Clinical search literature search strategy

Searches for were constructed using a PICO framework where population (P) terms were combined with Intervention (I) and in some cases Comparison (C) terms. Outcomes (O) are rarely used in search strategies for interventions as these concepts may not be well described in title, abstract or indexes and therefore difficult to retrieve. Search filters were applied to the search where appropriate.

Table 12: Database date parameters and filters used

Database	Dates searched	Search filter used
Medline (Ovid)	1946 – 04 January 2019	Exclusions
Embase (Ovid)	1974 – 04 January 2019	Exclusions
The Cochrane Library (Wiley)	Cochrane Reviews to Issue 1 of 12, January 2019 CENTRAL to Issue 1 of 12, January 2019 DARE, and NHSEED to Issue 2 of 4 2015 HTA to Issue 4 of 4 2016	None
CINAHL, Current Nursing and Allied Health Literature (EBSCO)	Inception – 04 January 2019	Limiters - English Language; Exclude MEDLINE records; Publication Type: Clinical Trial, Journal Article, Meta Analysis, Randomized Controlled Trial, Systematic Review: Age Groups: All Adult; Language: English
PsycINFO (ProQuest)	Inception – 04 January 2019	Study type

Database	Dates searched	Search filter used
HMIC. Healthcare Management Information Consortium (Ovid)	1979 – 04 January 2019	Exclusions
SPP, Social Policy and Practice	1981 – 04 January 2019	Study types
ASSIA, Applied Social Sciences Index and Abstracts (ProQuest)	1987 – 04 January 2019	None

Medline (Ovid) search terms

1.	Palliative care/
2.	Terminal care/
3.	Hospice care/
4.	palliat*.ti,ab.
5.	Terminally Ill/
6.	((terminal* or long term or longterm) adj2 (care* or caring or ill*)).ti,ab.
7.	((dying or terminal) adj (phase* or stage*)).ti,ab.
8.	life limit*.ti,ab.
9.	Nursing Homes/
10.	((care or nursing) adj2 (home or homes)).ti,ab.
11.	Respite Care/
12.	((respite or day) adj2 (care or caring)).ti,ab.
13.	Hospices/
14.	hospice*.ti,ab.
15.	*Patient care planning/
16.	*"Continuity of Patient Care"/
17.	((advance* or patient*) adj3 (care or caring) adj3 (continu* or plan*)).ti,ab.
18.	*Attitude to Death/
19.	(attitude* adj3 (death* or dying*)).ti,ab.
20.	*Physician-Patient Relations/
21.	*Long-Term Care/
22.	*"Delivery of Health Care"/
23.	(end adj2 life).ti,ab.

24.	EOLC.ti,ab.
25.	((last or final) adj2 (year or month*) adj2 life).ti,ab.
26.	((dying or death) adj2 (patient* or person* or people or care or caring)).ti,ab.
27.	or/1-26
28.	letter/
29.	editorial/
30.	news/
31.	exp historical article/
32.	Anecdotes as Topic/
33.	comment/
34.	case report/
35.	(letter or comment*).ti.
36.	or/28-35
37.	randomized controlled trial/ or random*.ti,ab.
38.	36 not 37
39.	animals/ not humans/
40.	exp Animals, Laboratory/
41.	exp Animal Experimentation/
42.	exp Models, Animal/
43.	exp Rodentia/
44.	(rat or rats or mouse or mice).ti.
45.	or/38-44
46.	27 not 45
47.	limit 46 to English language
48.	(exp child/ or exp pediatrics/ or exp infant/) not (exp adolescent/ or exp adult/ or exp middle age/ or exp aged/)
49.	47 not 48
50.	exp Advance Care Planning/
51.	(advance* adj2 (plan* or decision* or directive*)).ti,ab.
52.	living will*.ti,ab.
53.	or/50-52
54.	49 and 53
55.	(service* adj3 (provision* or deliver* or addition* or method* or time* or timing or frequent* or frequenc* or review* or ident* or assess*)).ti,ab.
56.	49 and 55
57.	54 not 56
58.	patient care team/
59.	interdisciplinary communication/
60.	(((interdisciplin* or inter-disciplin* or interprofession* or inter-profession* or multidisciplin* or multi-disciplin* or multi-profession* or multiprofession* or transprofession* or trans-profession*) adj2 (team* or staff* or meeting* or manag* or appointment* or system* or program* or practic* or advic* or advis* or caring or intervention* or ward* or round* or panel* or forum* or fora or communicat* or collaborat* or relat*)) or MDT or IDT).ti,ab.
61.	(((integrat* or network*) adj2 (team* or staff* or meeting* or manag* or appointment* or system* or program* or practic* or advic* or advis* or caring or intervention* or ward* or round* or panel* or forum* or fora or communicat* or collaborat* or relat*)) or MDT or IDT).ti,ab.

62.	(key adj2 work*).ti,ab.
63.	((healthcare or care) adj2 (lead or leader or leads or facilitat*)).ti,ab.
64.	((healthcare or care) adj1 profession*).ti,ab.
65.	*Case Management/
66.	(case adj2 manage*).ti,ab.
67.	(co-ordinator* or coordinator* or coordinate* or co-ordinate*).ti,ab.
68.	Or/58-67
69.	interdisciplinary communication/
70.	exp Communication Barriers/
71.	(communicat* or discuss* or speak* or talk* or convers* or contact).ti,ab.
72.	((handover or hand over or share or shared or sharing or transfer*) adj3 information*).ti,ab.
73.	(followup or follow up).ti,ab.
74.	(palliativ* adj2 (care or caring)).ti,ab.
75.	Or/69-74
76.	49 and 68 and 75
77.	Social Welfare/ec, ed, es, eh, ma, st, sn, td [Economics, Education, Ethics, Ethnology, Manpower, Standards, Statistics & Numerical Data, Trends]
78.	Charities/ec, ed, es, ma, mt, og, st, sn, sd, td, ut [Economics, Education, Ethics, Manpower, Methods, Organization & Administration, Standards, Statistics & Numerical Data, Supply & Distribution, Trends, Utilization]
79.	Home Care Services/ec, ed, es, ma, mt, og, st, sn, sd, td, ut [Economics, Education, Ethics, Manpower, Methods, Organization & Administration, Standards, Statistics & Numerical Data, Supply & Distribution, Trends, Utilization]
80.	Community Health Nursing/ec, ed, es, ma, mt, og, st, sn, sd, td, ut [Economics, Education, Ethics, Manpower, Methods, Organization & Administration, Standards, Statistics & Numerical Data, Supply & Distribution, Trends, Utilization]
81.	Telemedicine/ec, es, ma, mt, og, st, sn, td, ut [Economics, Ethics, Manpower, Methods, Organization & Administration, Standards, Statistics & Numerical Data, Trends, Utilization]
82.	exp remote consultation/
83.	*telemedicine/ or *telepathology/ or *teleradiology/ or *telerehabilitation/
84.	(telemedicine or tele medicine or telehealth or tele health or virtual hospital* or helpline* or help line* or rapid response team* or telepathology or teleradiology or telerehabilitatio).ti,ab.
85.	((tele* or remote) adj2 consult*).ti,ab.
86.	Mobile Health Units/ec, es, ma, og, st, sn, sd, td, ut [Economics, Ethics, Manpower, Organization & Administration, Standards, Statistics & Numerical Data, Supply & Distribution, Trends, Utilization]
87.	(mobile adj2 (health or care) adj2 unit*).ti,ab.
88.	(hospital-based home care or HBHC or hospital-based hospice care or acute hospital care).ti,ab.
89.	(hospital adj3 (domicil* or home)).ti,ab.
90.	home hospitali*ation.ti,ab.
91.	exp Home Care Agencies/
92.	(social adj (welfare or care)).ti,ab.
93.	(nurs* adj4 (home-visit* or home visit* or home-based or home based)).ti,ab.
94.	((district* or communit* or home or visit*) adj nurs*).ti,ab.
95.	(community adj2 (health care or healthcare or nursing or nurse*)).ti,ab.

96.	((hospitali*ation* or admission* or readmission* or admit*) adj3 (reduc* or avoid* or prevent* or inappropiate or increase* or risk*)).ti,ab.
97.	Or/77-96
98.	After-Hours Care/
99.	((morning* or evening* or weekday or weekend* or 7 day or seven day or seven-day or after-hour* or 24 hour* or 24hour* or twenty-four-hour* or out-of-hour* or 9-5 or Monday-Friday or Saturday or Sunday) adj3 (service* or access* or availab* or hour* or appointment* or care or caring or palliativ* or pharmacy* or telephone* or advic* or advis* or consult* or support* or nurs* or speciali* or physician* or doctor* or expert* or professional* or paramedic* or general practioner* or GP* or social worker* or case worker* or ambulance* or health worker* or physiotherapist* or therapist*)).ti,ab.
100.	rapid response.ti,ab.
101.	Hospital Rapid Response Team/
102.	(critical care adj2 outreach).ti,ab.
103.	medical emergency team*.ti,ab.
104.	(hospital* adj2 home*).ti,ab.
105.	hospital at night.ti,ab.
106.	("NHS 111" or "NHS 24" or "NHS Direct").ti,ab.
107.	exp telemedicine/
108.	(telehealth* or tele-health* or telemedicine* or tele-medicine* or teleconsult* or tele-consult* or tele-monitor* or telemonitor* or telemanag* or tele-manag* or telepharm* or tele-pharm* or telenurs* or tele-nurs* or tele-homecare or telehomecare or tele-support or telesupport or mobile health or ehealth or e-health or mhealth or m-health).ti,ab.
109.	hotlines/
110.	(hotline* or helpline* or help-line* or call cent* or call service*).ti,ab.
111.	((email* or e-mail* or telephone* or phone* or video*) adj3 (servic* or advic* or advis* or consult* or support* or care* or caring* or appoint*)).ti,ab.
112.	Or/98-111
113.	(commission* adj2 (support* or service* or model*)).ti,ab.
114.	((service* or program* or co-ordinat* or co ordinat* or coordinat*) adj2 (model* or deliver* or strateg* or support* or access* or method* or system* or policies or policy or availab*)).ti,ab.
115.	Critical Pathways/
116.	((critical or clinic* or service* or care) adj2 path*).ti,ab.
117.	Or/113-116
118.	49 and 117
119.	Patient Care Bundles/
120.	(care adj2 (bundle* or service* or package* or standard*)).ti,ab.
121.	or/117-118
122.	(assess* or criteria* or predict* or recogni* or identif* or refer*).ti,ab.
123.	49 and 121 and 122
124.	gold standard*.ti,ab.
125.	49 and 124
126.	(amber adj2 bundle).ti,ab.
127.	123 or 125 or 126
128.	118 not 127
129.	49 and (68 or 97 or 112)
130.	57 or 76 or 128 or 129

Embase (Ovid) search terms

1.	*Palliative therapy/
2.	*Terminal care/
3.	*Hospice care/
4.	palliat*.ti,ab.
5.	*Terminally ill patient/
6.	((terminal* or long term or longterm) adj2 (care* or caring or ill*)).ti,ab.
7.	((dying or terminal) adj (phase* or stage*)).ti,ab.
8.	life limit*.ti,ab.
9.	*Nursing home/
10.	((care or nursing) adj2 (home or homes)).ti,ab.
11.	*Respite Care/
12.	((respite or day) adj2 (care or caring)).ti,ab.
13.	*Hospice/
14.	hospice*.ti,ab.
15.	*Patient care planning/
16.	((advance* or patient*) adj3 (care or caring) adj3 (continu* or plan*)).ti,ab.
17.	*Patient care/
18.	*Attitude to Death/
19.	(attitude* adj3 (death* or dying*)).ti,ab.
20.	*Doctor patient relation/
21.	*Long term care/
22.	*Health care delivery/
23.	(end adj2 life).ti,ab.
24.	EOLC.ti,ab.
25.	((last or final) adj2 (year or month*) adj2 life).ti,ab.
26.	((dying or death) adj2 (patient* or person* or people or care or caring)).ti,ab.
27.	or/1-26
28.	letter.pt. or letter/
29.	note.pt.
30.	editorial.pt.
31.	case report/ or case study/
32.	(letter or comment*).ti.
33.	or/28-32
34.	randomized controlled trial/ or random*.ti,ab.
35.	33 not 34
36.	animal/ not human/
37.	nonhuman/
38.	exp Animal Experiment/
39.	exp Experimental Animal/
40.	animal model/
41.	exp Rodent/
42.	(rat or rats or mouse or mice).ti.
43.	or/35-42
44.	27 not 43

45.	(exp child/ or exp pediatrics/ or exp infant/) not (exp adolescent/ or exp adult/ or exp middle age/ or exp aged/)
46.	44 not 45
47.	limit 46 to English language
48.	(advance* adj2 (plan* or decision* or directive*)).ti,ab.
49.	living will*.ti,ab.
50.	48 or 49
51.	47 and 50
52.	(service* adj3 (provision* or deliver* or addition* or method* or time* or timing or frequent* or frequenc* or review* or ident* or assess*)).ti,ab.
53.	47 and 52
54.	51 not 53
55.	interdisciplinary communication/
56.	patient care team*.ti,ab.
57.	(((interdisciplin* or inter-disciplin* or interprofession* or inter-profession* or multidisciplin* or multi-disciplin* or multi-profession* or multiprofession* or transprofession* or trans-profession*) adj2 (team* or staff* or meeting* or manag* or appointment* or system* or program* or practic* or advic* or advis* or caring or intervention* or ward* or round* or panel* or forum* or fora or communicat* or collaborat* or relat*)) or MDT or IDT).ti,ab.
58.	(((integrat* or network*) adj2 (team* or staff* or meeting* or manag* or appointment* or system* or program* or practic* or advic* or advis* or caring or intervention* or ward* or round* or panel* or forum* or fora or communicat* or collaborat* or relat*)) or MDT or IDT).ti,ab.
59.	(key adj2 work*).ti,ab.
60.	((healthcare or care) adj2 (lead or leader or leads or facilitat*)).ti,ab.
61.	((healthcare or care) adj1 profession*).ti,ab.
62.	*Case Management/
63.	(case adj2 manage*).ti,ab.
64.	(co-ordinator* or coordinator* or coordinate* or co-ordinate*).ti,ab.
65.	Or/55-64
66.	interdisciplinary communication/
67.	(communicat* or discuss* or speak* or talk* or convers* or contact).ti,ab.
68.	((handover or hand over or share or shared or sharing or transfer*) adj3 information*).ti,ab.
69.	(followup or follow up).ti,ab.
70.	(palliativ* adj2 (care or caring)).ti,ab.
71.	Or/66-70
72.	47 and 65 and 71
73.	*social welfare/
74.	*community health nursing/ or *community care/
75.	*senior center/
76.	*telemedicine/ or *telehealth/
77.	*teleconsultation/
78.	(telehealth or tele health or virtual hospital* or helpline* or help line* or rapid response team* or mobile health unit*).ti,ab.
79.	*home care/ or *home health agency/ or *home monitoring/ or *home oxygen therapy/ or *home physiotherapy/ or *home rehabilitation/ or *home respiratory care/ or *respite care/ or *visiting nursing service/

80.	*health care personnel/ or *health auxiliary/ or *nursing home personnel/
81.	(telemedicine or tele medicine or telehealth or tele health or virtual hospital* or helpline* or help line* or rapid response team* or telepathology or teleradiology or telerehabilitatio).ti,ab.
82.	((tele* or remote) adj2 consult*).ti,ab.
83.	(mobile adj2 (health or care) adj2 unit*).ti,ab.
84.	(hospital-based home care or HBHC or hospital-based hospice care or acute hospital care).ti,ab.
85.	(hospital adj3 (domicil* or home)).ti,ab.
86.	home hospitali*ation.ti,ab.
87.	(social adj (welfare or care)).ti,ab.
88.	(nurs* adj4 (home-visit* or home visit* or home-based or home based)).ti,ab.
89.	((district* or communit* or home or visit*) adj nurs*).ti,ab.
90.	(community adj2 (health care or healthcare or nursing or nurse*)).ti,ab.
91.	((hospitali*ation* or admission* or readmission* or admit*) adj3 (reduc* or avoid* or prevent* or inappropiate or increase* or risk*)).ti,ab.
92.	Or/73-91
93.	(after hours care or after-hours care).ti,ab.
94.	((morning* or evening* or weekday or weekend* or 7 day or seven day or seven-day or after-hour* or 24 hour* or 24hour* or twenty-four-hour* or out-of-hour* or 9-5 or Monday-Friday or Saturday or Sunday) adj3 (service* or access* or availab* or hour* or appointment* or care or caring or palliativ* or pharmacy* or telephone* or advic* or advis* or consult* or support* or nurs* or speciali* or physician* or doctor* or expert* or professional* or paramedic* or general practioner* or GP* or social worker* or case worker* or ambulance* or health worker* or physiotherapist* or therapist*)).ti,ab.
95.	rapid response.ti,ab.
96.	rapid response team/
97.	(critical care adj2 outreach).ti,ab.
98.	medical emergency team*.ti,ab.
99.	(hospital* adj2 home*).ti,ab.
100.	hospital at night.ti,ab.
101.	("NHS 111" or "NHS 24" or "NHS Direct").ti,ab.
102.	exp telehealth/
103.	(telehealth* or tele-health* or telemedicine* or tele-medicine* or teleconsult* or tele-consult* or tele-monitor* or telemonitor* or telemanag* or tele-manag* or telepharm* or tele-pharm* or telenurs* or tele-nurs* or tele-homecare or telehomecare or tele-support or telesupport or mobile health or ehealth or e-health or mhealth or m-health).ti,ab.
104.	telephone/
105.	(hotline* or helpline* or help-line* or call cent* or call service*).ti,ab.
106.	((email* or e-mail* or telephone* or phone* or video*) adj3 (servic* or advic* or advis* or consult* or support* or care* or caring* or appoint*)).ti,ab.
107.	or/93-106
108.	(commission* adj2 (support* or service* or model*)).ti,ab.
109.	((service* or program* or co-ordinat* or co ordinat* or coordinat*) adj2 (model* or deliver* or strateg* or support* or access* or method* or system* or policies or policy or availab*)).ti,ab.
110.	*Clinical Pathway/
111.	((critical or clinic* or service* or care) adj2 path*).ti,ab.
112.	Or/108-111
113.	*Care Bundle/

114.	(care adj2 (bundle* or service* or package* or standard*)).ti,ab.
115.	or/113-114
116.	(assess* or criteria* or predict* or recogni* or identif* or refer*).ti,ab.
117.	47 and 115 and 116
118.	gold standard*.ti,ab.
119.	47 and 118
120.	(amber adj2 bundle).ti,ab.
121.	117 or 119 or 120
122.	47 and 112
123.	122 not 121
124.	47 and (65 or 92 or 107)
125.	54 or 74 or 123 or 124

Cochrane Library (Wiley) search terms

#1.	MeSH descriptor: [Palliative Care] this term only
#2.	MeSH descriptor: [Terminal Care] this term only
#3.	MeSH descriptor: [Hospice Care] this term only
#4.	palliat*:ti,ab
#5.	MeSH descriptor: [Terminally Ill] this term only
#6.	((terminal* or long term or longterm) near/2 (care* or caring or ill*)):ti,ab
#7.	((dying or terminal) near (phase* or stage*)):ti,ab
#8.	life limit*:ti,ab
#9.	MeSH descriptor: [Nursing Homes] explode all trees
#10.	((care or nursing) near/2 (home or homes)):ti,ab
#11.	MeSH descriptor: [Respite Care] this term only
#12.	((respite or day) near/2 (care or caring)):ti,ab
#13.	MeSH descriptor: [Hospices] this term only
#14.	hospice*:ti,ab
#15.	MeSH descriptor: [Patient Care Planning] this term only
#16.	MeSH descriptor: [Continuity of Patient Care] this term only
#17.	((advance* or patient*) near/3 (care or caring) near/3 (continu* or plan*)):ti,ab
#18.	MeSH descriptor: [Attitude to Death] explode all trees
#19.	(attitude* near/3 (death* or dying*)):ti,ab
#20.	MeSH descriptor: [Physician-Patient Relations] this term only
#21.	MeSH descriptor: [Long-Term Care] this term only
#22.	MeSH descriptor: [Delivery of Health Care] this term only
#23.	(end near/2 life):ti,ab
#24.	EOLC:ti,ab
#25.	((last or final) near/2 (year or month*) near/2 life):ti,ab
#26.	((dying or death) near/2 (patient* or person* or people or care or caring)):ti,ab
#27.	(or #1-#26)
#28.	MeSH descriptor: [Advance Care Planning] explode all trees
#29.	(advance* near/2 (plan* or decision* or directive*)):ti,ab
#30.	living will*:ti,ab
#31.	(or #28-#30)

#32.	service* near/3 (provision* or deliver* or addition* or method* or time* or timing or frequent* or frequenc* or review* or ident* or assess*):ti,ab
#33.	#27 and #32
#34.	#31 not #32
#35.	MeSH descriptor: [Patient Care Team] explode all trees
#36.	MeSH descriptor: [Interdisciplinary Communication] explode all trees
#37.	(((interdisciplin* or inter-disciplin* or interprofession* or inter-profession* or multidisciplin* or multi-disciplin* or multi-profession* or multiprofession* or transprofession* or trans-profession*) near/2 (team* or staff* or meeting* or manag* or appointment* or system* or program* or practic* or advic* or advis* or caring or intervention* or ward* or round* or panel* or forum* or fora or communicat* or collaborat* or relat*)) or MDT or IDT):ti,ab
#38.	((integrat* or network*) near/2 (team* or staff* or meeting* or manag* or appointment* or system* or program* or practic* or advic* or advis* or caring or intervention* or ward* or round* or panel* or forum* or fora or communicat* or collaborat* or relat*)):ti,ab
#39.	(key near/2 work*):ti,ab
#40.	((healthcare or care) near/2 (lead or leader or leads or facilitat*)):ti,ab
#41.	((healthcare or care) near/1 profession*):ti,ab
#42.	MeSH descriptor: [Case Management] this term only
#43.	(case near/2 manage*):ti,ab
#44.	(co-ordinator* or coordinator* or coordinate* or co-ordinate*):ti,ab
#45.	(or #35-#44)
#46.	MeSH descriptor: [Interdisciplinary Communication] explode all trees
#47.	MeSH descriptor: [Communication Barriers] explode all trees
#48.	(communicat* or discuss* or speak* or talk* or convers* or contact):ti,ab
#49.	((handover or hand over or share or shared or sharing or transfer*) near/3 information*):ti,ab
#50.	(followup or follow up):ti,ab
#51.	(palliativ* near/2 (care or caring)):ti,ab
#52.	(or #46-#51)
#53.	#27 and #45 and #52
#54.	MeSH descriptor: [Social Welfare] explode all trees
#55.	MeSH descriptor: [Charities] explode all trees
#56.	MeSH descriptor: [Adult Day Care Centers] explode all trees
#57.	MeSH descriptor: [Community Health Nursing] explode all trees
#58.	MeSH descriptor: [Home Care Services] explode all trees
#59.	MeSH descriptor: [Senior Centers] explode all trees
#60.	MeSH descriptor: [Telemedicine] this term only
#61.	MeSH descriptor: [Remote Consultation] explode all trees
#62.	(telehealth or tele health or virtual hospital* or helpline* or help line* or rapid response team*):ti,ab
#63.	MeSH descriptor: [Mobile Health Units] explode all trees
#64.	((community based or community dwelling home or rural) near/3 (care or health care or healthcare)):ti,ab
#65.	(hospital-based home care or HBHC or hospital-based hospice care or acute hospital care):ti,ab
#66.	((hospitali*ation* or admission* or readmission* or admit*) near/3 (reduc* or avoid* or prevent* or inappropiate or increase* or risk*)):ti,ab
#67.	(home based versus hospital based):ti,ab

#68.	(hospital near/3 (domicil* or home)):ti,ab
#69.	(home hospitali*ation):ti,ab
#70.	MeSH descriptor: [Home Care Services, Hospital-Based] explode all trees
#71.	MeSH descriptor: [Home Health Nursing] explode all trees
#72.	MeSH descriptor: [Homemaker Services] explode all trees
#73.	MeSH descriptor: [Home Care Agencies] explode all trees
#74.	MeSH descriptor: [Home Health Aides] explode all trees
#75.	(social care):ti,ab
#76.	MeSH descriptor: [Nurses, Community Health] explode all trees
#77.	(nurs* near/4 (home-visit* or home visit* or home-based or home based)):ti,ab
#78.	((district* or communit* or home or visit*) near nurs*):ti,ab
#79.	(Or #54-#78)
#80.	MeSH descriptor: [After-Hours Care] explode all trees
#81.	((morning* or evening* or weekday or weekend* or 7 day or seven day or seven-day or after-hour* or 24 hour* or 24hour* or twenty-four-hour* or out-of-hour* or 9-5 or Monday-Friday or Saturday or Sunday) near/3 (service* or access* or availab* or hour* or appointment* or care or caring or palliativ* or pharmacy* or telephone* or advic* or advis* or consult* or support* or nurs* or speciali* or physician* or doctor* or expert* or professional* or paramedic* or general practioner* or GP* or social worker* or case worker* or ambulance* or health worker* or physiotherapist* or therapist*)):ti,ab
#82.	rapid next response:ti,ab
#83.	MeSH descriptor: [Hospital Rapid Response Team] explode all trees
#84.	medical next emergency next team*:ti,ab
#85.	(hospital* near/2 home*):ti,ab
#86.	hospital next at next night:ti,ab
#87.	(NHS next (111 or 24 or direct)):ti,ab
#88.	MeSH descriptor: [Telemedicine] this term only
#89.	(telehealth* or tele-health* or telemedicine* or tele-medicine* or teleconsult* or tele-consult* or tele-monitor* or telemonitor* or telemanag* or tele-manag* or telepharm* or tele-pharm* or telenurs* or tele-nurs* or tele-homecare or telehomecare or tele-support or telesupport or mobile health or ehealth or e-health or mhealth or m-health):ti,ab
#90.	MeSH descriptor: [Hotlines] explode all trees
#91.	(hotline* or helpline* or help-line* or call cent* or call service*):ti,ab
#92.	((email* or e-mail* or telephone* or phone* or video*) near/3 (servic* or advic* or advis* or consult* or support* or care* or caring* or appoint*)):ti,ab
#93.	(or #80-#92)
#94.	(commission* near/2 (support* or service* or model*)):ti,ab
#95.	((service* or program* or co-ordinat* or co ordinat* or coordinat*) near/2 (model* or deliver* or strateg* or support* or access* or method* or system* or policies or policy or availab*)):ti,ab
#96.	MeSH descriptor: [Critical Pathways] explode all trees
#97.	((critical or clinic* or service* or care) near/2 path*):ti,ab
#98.	(or #94-97)
#99.	#27 and #98
#100.	MeSH descriptor: [Patient Care Bundles] explode all trees
#101.	(care near/2 (bundle* or service* or package* or standard*)):ti,ab
#102.	(or #100-#101)
#103.	(assess* or criteria* or predict* or recogni* or identif* or refer*):ti,ab

#104.	#27 and #102 and #103
#105.	gold standard*:ti,ab
#106.	#27 and #105
#107.	(amber near/2 bundle):ti,ab
#108.	#104 or #106 or #107
#109.	#99 not #108
#110.	#27 and (#45 or #79 or #93)
#111.	#34 or #53 or #109 or #110

CINAHL (EBSCO) search terms

S1.	MH Palliative care
S2.	MH Terminal care
S3.	MH Hospice care
S4.	TI palliat* OR AB palliat*
S5.	MW Terminally ill
S6.	TI (terminal* or long term or longterm) AND TI (care* or caring or ill*)
S7.	AB (terminal* or long term or longterm) AND AB (care* or caring or ill*)
S8.	TI (dying or terminal) AND TI (phase* or stage*)
S9.	AB (dying or terminal) AND AB (phase* or stage*)
S10.	TI life limit* OR AB life limit*
S11.	MH Nursing homes
S12.	TI (care or nursing) AND TI (home or homes)
S13.	AB (care or nursing) AND AB (home or homes)
S14.	MH Respite care
S15.	TI (respite or day) AND TI (care or caring)
S16.	AB (respite or day) AND AB (care or caring)
S17.	MH Hospices
S18.	TI Hospice* OR AB Hospice*
S19.	(MH "Patient Care Plans")
S20.	MH Attitude to Death
S21.	TI attitude* AND TI (death* or dying)
S22.	AB attitude* AND AB (death* or dying)
S23.	MH Physician-Patient Relations
S24.	(MH "Long Term Care")
S25.	(MH "Health Care Delivery")
S26.	TI end AND TI life OR AB end AND AB life
S27.	TI EOLC OR AB EOLC
S28.	TI (last or final) AND TI (year or month) AND TI life
S29.	AB (last or final) AND AB (year or month) AND AB life
S30.	TI (dying or death) AND TI (patient* or person* or people or care or caring)
S31.	AB (dying or death) AND AB (patient* or person* or people or care or caring)
S32.	S1 OR S2 OR S3 OR S4 OR S5 OR S6 OR S7 OR S8 OR S9 OR S10 OR S11 OR S12 OR S13 OR S14 OR S15 OR S16 OR S17 OR S18 OR S19 OR S20 OR S21 OR S22 OR S23 OR S24 OR S25 OR S26 OR S27 OR S28 OR S29 OR S30 OR S31
S33.	TI advance* AND TI (plan* or decision* or directive*)
S34.	AB advance* AND AB (plan* or decision* or directive*)

S35.	S33 OR S34
S36.	S32 and S35
S37.	(MH "Multidisciplinary Care Team+")
S38.	MDT OR IDT
S39.	((interdisciplin* or inter-disciplin* or interprofession* or inter-profession* or multidisciplin* or multi-disciplin* or multi-profession* or multiprofession* or transprofession* or trans-profession*) n2 (team* or staff* or meeting* or manag* or appointment* or system* or program* or practic* or advic* or advis* or caring or intervention* or ward* or round* or panel* or forum* or fora or communicat* or collaborat* or relat*))
S40.	((integrat* or network*) n2 (team* or staff* or meeting* or manag* or appointment* or system* or program* or practic* or advic* or advis* or caring or intervention* or ward* or round* or panel* or forum* or fora or communicat* or collaborat* or relat*))
S41.	TI (key n2 work*) OR AB (key n2 work*)
S42.	TI (((healthcare or care) n2 (lead or leader or leads or facilitat*))) OR AB (((healthcare or care) n2 (lead or leader or leads or facilitat*)))
S43.	TI (((healthcare or care) n1 profession*)) OR AB (((healthcare or care) n1 profession*))
S44.	MH Case Management
S45.	TI (case n2 manage*) OR AB (case n2 manage*)
S46.	TI ((co-ordinator* or coordinator* or coordinate* or co-ordinate*)*)) OR AB ((co-ordinator* or coordinator* or coordinate* or co-ordinate*))
S47.	S37 OR S38 OR S39 OR S40 OR S41 OR S42 OR S43 OR S44 OR S45 OR S46
S48.	MeSH descriptor: [Interdisciplinary Communication] explode all trees
S49.	MeSH descriptor: [Communication Barriers] explode all trees
S50.	(communicat* or discuss* or speak* or talk* or convers* or contact):ti,ab
S51.	((handover or hand over or share or shared or sharing or transfer*) near/3 information*):ti,ab
S52.	(followup or follow up):ti,ab
S53.	(palliativ* near/2 (care or caring)):ti,ab
S54.	S48 OR S49 OR S50 OR S51 OR S52 OR S53
S55.	S32 AND S47 AND S54
S56.	(MM "Social Welfare")
S57.	(MH "Charities")
S58.	(MM "Adult Day Center (Saba CCC)") OR (MM "Housing for the Elderly") OR (MM "Older Adult Care (Saba CCC)")
S59.	(MH "Community Health Nursing+") OR (MM "Community Health Centers")
S60.	(MH "Home Health Care+") OR (MM "Home Health Aides") OR (MM "Home Health Care Information Systems") OR (MM "Home Health Aide Service (Saba CCC)")
S61.	(MM "Housing for the Elderly") OR (MM "Rural Health Centers") OR (MM "Community Health Centers")
S62.	(MH "Telemedicine+") OR (MH "Telehealth+")
S63.	(MM "Remote Consultation") OR (MM "Telephone Consultation (Iowa NIC)") OR (MM "Services for Australian Rural and Remote Allied Health")
S64.	telehealth or tele health or virtual hospital* or helpline* or help line* or rapid response team* or senior center*
S65.	(MM "Rural Health Personnel") OR (MM "Mobile Health Units")
S66.	remote consultation
S67.	((community based or community dwelling home or rural) n3 (care or health care or healthcare))

S68.	hospital-based home care or HBHC or hospital-based hospice care or acute hospital care
S69.	((hospitali?ation* or admission* or readmission* or admit*) n3 (reduc* or avoid* or prevent* or inappropiate or increase* or risk*))
S70.	home based versus hospital based
S71.	(hospital n3 (domicil* or home))
S72.	home hospitali?ation
S73.	home care service*
S74.	(MM "Home Health Agencies") OR (MM "Nursing Home Personnel")
S75.	(MM "Homemaker Services") OR (MM "Health Services for the Aged")
S76.	(MH "Home Health Care+") OR (MM "Home Care Equipment and Supplies") OR (MH "Nursing Homes") OR (MM "National Association for Home Care & Hospice") OR (MM "Nursing Home Patients")
S77.	social care
S78.	(MM "Hospitals, Community")
S79.	(MM "Home Nursing") OR (MM "Home Nursing, Professional")
S80.	(nurs* n4 (home-visit* or home visit* or home-based or home based))
S81.	((district* or communit* or home or visit*) n nurs*))
S82.	S56 OR S57 OR S58 OR S59 OR S60 OR S61 OR S62 OR S63 OR S64 OR S65 OR S66 OR S67 OR S68 OR S69 OR S70 OR S71 OR S72 OR S73 OR S74 OR S75 OR S76 OR S77 OR S78 OR S79 OR S80 OR S81
S83.	out of hours care
S84.	((morning* or evening* or weekday or weekend* or 7 day or seven day or seven-day or after-hour* or 24 hour* or 24hour* or twenty-four-hour* or out-of-hour* or 9-5 or Monday-Friday or Saturday or Sunday) n3 (service* or access* or availab* or hour* or appointment* or care or caring or palliativ* or pharmacy* or telephone* or advic* or advis* or consult* or support* or nurs* or speciali* or physician* or doctor* or expert* or professional* or paramedic* or general practioner* or GP* or social worker* or case worker* or ambulance* or health worker* or physiotherapist* or therapist*))
S85.	rapid response
S86.	(critical care n2 outreach) OR medical emergency team* OR (hospital* n2 home*) OR hospital at night
S87.	NHS 111 OR NHS 24 OR NHS Direct
S88.	(MH "Telemedicine") OR (MH "Telehealth")
S89.	(telehealth* or tele-health* or telemedicine* or tele-medicine* or teleconsult* or tele-consult* or tele-monitor* or telemonitor* or telemanag* or tele-manag* or telepharm* or tele-pharm* or telenurs* or tele-nurs* or tele-homecare or telehomecare or tele-support or telesupport or mobile health or ehealth or e-health or mhealth or m-health)
S90.	(MH "Telephone Information Services")
S91.	(hotline* or helpline* or help-line* or call cent* or call service*)
S92.	((email* or e-mail* or telephone* or phone* or video*) n3 (servic* or advic* or advis* or consult* or support* or care* or caring* or appoint*))
S93.	S83 OR S84 OR S85 OR S86 OR S87 OR S88 OR S89 OR S90 OR S91 OR S92
S94.	TI commission* AND TI ((support* or service* or model*))
S95.	AB commission* AND AB ((support* or service* or model*))
S96.	TI (service* or program* or co-ordinat* or co ordinat* or coordinat*) AND TI (model* or deliver* or strateg* or support* or access* or method* or system* or policies or policy or availab*)
S97.	AB (service* or program* or co-ordinat* or co ordinat* or coordinat*) AND AB (model* or deliver* or strateg* or support* or access* or method* or system* or policies or policy or availab*)

S98.	TI (critical or clinic* or service* or care) AND TI path*
S99.	AB (critical or clinic* or service* or care) AND AB path*
S100.	S94 OR S95 OR S96 OR S97 OR S98 OR S99
S101.	S32 AND S100
S102.	TI care AND TI (bundle* or service* or package* or standard*)
S103.	AB care AND AB (bundle* or service* or package* or standard*)
S104.	S102 OR S103
S105.	TI (assess* or criteria* or predict* or recogni* or identif* or refer*) OR AB (assess* or criteria* or predict* or recogni* or identif* or refer*)
S106.	S32 AND S104 AND S105
S107.	TI gold standard* OR AB gold standard*
S108.	S32 AND S107
S109.	TI amber AND TI bundle
S110.	AB amber AND AB bundle
S111.	S109 OR S110
S112.	S106 OR S108 OR S111
S113.	S101 NOT S112
S114.	S31 AND (S47 OR S82 OR S93)
S115.	S36 OR S55 OR S113 OR S114

PsycINFO (ProQuest) search terms

1.	(ti,ab(commission* NEAR/2 (support* OR service* OR model*)) OR ((service* OR program* OR co-ordinat* OR coordinat*) NEAR/2 (model* OR deliver* OR strateg* OR support* OR access* OR method* OR system* OR policies OR policy OR availab*))) AND (SU.EXACT("Palliative Care") OR SU.EXACT("Terminally Ill Patients") OR SU.EXACT("Hospice") OR ti,ab(palliat*) OR ti,ab((terminal* OR long-term OR longterm) NEAR/2 (care* OR caring OR ill*)) OR ti,ab((dying OR terminal) NEAR/1 (phase* OR stage*)) OR ti,ab(life-limit*) OR SU.EXACT("Nursing Homes") OR ti,ab((care OR nursing) NEAR/2 (home OR homes)) OR SU.EXACT("Respite Care") OR ti,ab((respite OR day) NEAR/2 (care OR caring)) OR ti,ab(hospice*) OR MJSUB.EXACT("Treatment Planning") OR MJSUB.EXACT("Continuum of Care") OR ti,ab((advance* OR patient*) NEAR/3 (care OR caring) NEAR/3 (continu* OR plan*)) OR MJSUB.EXACT("Long Term Care") OR ti,ab(attitude* NEAR/3 (death* OR dying*)) OR ti,ab(end NEAR/2 life) OR ti,ab(EOLC) OR ti,ab((last OR final) NEAR/2 (year OR month*) NEAR/2 life) OR ti,ab((dying OR death) NEAR/2 (patient* OR person* OR people OR care OR caring)))
2.	Adolescence (13-17 Yrs), Adulthood (18 Yrs & Older), Aged (65 Yrs & Older), Middle Age (40-64 Yrs), Thirties (30-39 Yrs), Very Old (85 Yrs & Older), Young Adulthood (18-29 Yrs)
3.	1 and 2
4.	Conference Proceedings, Journal Article, Peer Reviewed Journal
5.	3 and 4

HMIC (Ovid) search terms

1.	exp End of life care/
2.	(terminal* adj ill*).ti,ab.
3.	((dying or terminal) adj (phase* or stage*)).ti,ab.
4.	life limit*.ti,ab.
5.	(end adj2 life).ti,ab.
6.	EOLC.ti,ab.
7.	((last or final) adj2 (year or month*) adj2 life).ti,ab.

8.	((dying or death) adj2 (patient* or person* or people or care or caring)).ti,ab.
9.	or/2-8
10.	(exp child/ or exp Paediatrics/ or exp infant/) not (exp adolescent/ or exp adult/ or exp middle age/ or exp older people/)
11.	9 not 10
12.	limit 11 to English
13.	limit 12 to (audiovis or book or chapter dh helmis or circular or microfiche dh helmis or multimedias or website)
14.	limit 12 to (audiocass or books or cdrom or chapter or dept pubs or diskettes or folio pamp or "map" or marc or microfiche or multimedia or pamphlet or parly or press or press rel or thesis or trustdoc or video or videos or website)
15.	13 or 14
16.	12 not 15
17.	euthanasia/
18.	euthanasia.ti,ab.
19.	17 or 18
20.	16 not 19

SPP (Ovid) search terms

1.	palliat*.ti,ab.
2.	((dying or terminal) adj (phase* or stage*)).ti,ab.
3.	life limit*.ti,ab.
4.	hospice*.ti,ab.
5.	(advance* adj2 (plan* or decision* or directive*)).ti,ab.
6.	living will*.ti,ab.
7.	((advance* or patient*) adj3 (care or caring) adj3 (continu* or plan*)).ti,ab.
8.	(attitude* adj3 (death* or dying*)).ti,ab.
9.	(end adj2 life).ti,ab.
10.	EOLC.ti,ab.
11.	((last or final) adj2 (year or month*) adj2 life).ti,ab.
12.	((dying or death) adj2 (patient* or person* or people or care or caring)).ti,ab.
13.	(nursing adj2 (home or homes)).ti,ab.
14.	(terminal* adj2 ill*).ti,ab.
15.	(respite adj2 (care or caring)).ti,ab.
16.	or/1-15
17.	(child* or infant*).ti,ab.
18.	(adult* or adolescent*).ti,ab.
19.	17 not 18
20.	16 not 19
21.	limit 20 to (journal or journal article or online resource or online report or report)

ASSIA (ProQuest) search terms

| 1. | palliat*.ti,ab. ((ti,ab(commission* N/2 (support* or service* or model*)) OR ti,ab((service* or program* or co-ordinat* or coordinat*) N/2 (model* or deliver* or strateg* or support* or access* or method* or system* or policies or policy or availab*))) AND ((SU.EXACT("Care" OR "Clinical nursing" OR "Community homes" OR "Community nursery nursing" OR "Community nursing" OR "Compassionate care" OR "Continuing care" OR "District nursing" OR "Family centred care" OR "Geriatric wards" OR "Group care" OR "Health visiting" OR "Home care" OR "Home from home care" |

| | OR "Home health aides" OR "Home helps" OR "Hospices" OR "Hostel wards" OR "Informal care" OR "Integrated care pathways" OR "Intentional care" OR "Intermediate care" OR "Intermediate care centres" OR "Lack of care" OR "Learning disability nursing" OR "Length of stay" OR "Liaison nursing" OR "Long stay wards" OR "Long term care" OR "Long term home care" OR "Long term residential care" OR "Nurse led care" OR "Nursing" OR "Occupational health nursing" OR "Ontological care" OR "Out of home care" OR "Outreach nursing" OR "Palliative care" OR "Paranursing" OR "Pastoral care" OR "Patient care" OR "Primary nursing" OR "Private residential care" OR "Process centred care" OR "Quality of care" OR "Radical health visiting" OR "Residential care" OR "Residential group care" OR "Respite care" OR "Shared care" OR "Social care" "Temporary care" OR "Terminal care" OR "Wards") OR (SU.EXACT("Terminally ill elderly people") OR SU.EXACT("Terminally ill fathers") OR SU.EXACT("Terminally ill elderly men") OR SU.EXACT("Terminally ill elderly women") OR SU.EXACT("Terminally ill young adults") OR SU.EXACT("Terminally ill parents") OR SU.EXACT("Terminally ill women") OR SU.EXACT("Terminally ill widowed sisters") OR SU.EXACT("Terminally ill colleagues") OR SU.EXACT("Terminally ill young girls") OR SU.EXACT("Terminally ill people") OR SU.EXACT("Terminally ill men")) OR SU.EXACT("Advance directives" OR "Do not resuscitate orders" OR "Durable power of attorney for health care" OR "Living wills" OR "Treatment preferences" OR "Treatment needs")) OR (ti,ab((advance* or patient*) N/3 (care or caring) N/3 (continu* or plan*)) or ti,ab(attitude* N/3 (death* or dying*)) or ti,ab(end N/2 life) or ti,ab(EOLC) or ti,ab((last or final) N/2 (year or month*) N/2 life) or ti,ab((dying or death) N/2 (patient* or person* or people or care or caring))))) OR SU.EXACT("End of life decisions") |

B.2 Health Economics literature search strategy

Health economic evidence was identified by conducting a broad search relating to end of life care in NHS Economic Evaluation Database (NHS EED – this ceased to be updated after March 2015) and the Health Technology Assessment database (HTA) with no date restrictions. NHS EED and HTA databases are hosted by the Centre for Research and Dissemination (CRD). Additional searches were run on Medline and Embase for health economics, economic modelling and quality of life studies.

Table 13: Database date parameters and filters used

Database	Dates searched	Search filter used
Medline	2014 – 04 January 2019	Exclusions Health economics studies Health economics modelling studies Quality of life studies
Embase	2014 – 04 January 2019	Exclusions Health economics studies Health economics modelling studies Quality of life studies
Centre for Research and Dissemination (CRD)	HTA - Inception – 04 January 2019 NHSEED - Inception to March 2015	None

Medline (Ovid) search terms

1.	Palliative care/
2.	Terminal care/

3.	Hospice care/
4.	palliat*.ti,ab.
5.	Terminally Ill/
6.	((terminal* or long term or longterm) adj2 (care* or caring or ill*)).ti,ab.
7.	((dying or terminal) adj (phase* or stage*)).ti,ab.
8.	life limit*.ti,ab.
9.	Nursing Homes/
10.	((care or nursing) adj2 (home or homes)).ti,ab.
11.	Respite Care/
12.	((respite or day) adj2 (care or caring)).ti,ab.
13.	Hospices/
14.	hospice*.ti,ab.
15.	exp Advance Care Planning/
16.	(advance* adj2 (plan* or decision* or directive*)).ti,ab.
17.	living will*.ti,ab.
18.	*Patient care planning/
19.	*"Continuity of Patient Care"/
20.	((advance* or patient*) adj3 (care or caring) adj3 (continu* or plan*)).ti,ab.
21.	*Attitude to Death/
22.	(attitude* adj3 (death* or dying*)).ti,ab.
23.	*Physician-Patient Relations/
24.	*Long-Term Care/
25.	*"Delivery of Health Care"/
26.	(end adj2 life).ti,ab.
27.	EOLC.ti,ab.
28.	((last or final) adj2 (year or month*) adj2 life).ti,ab.
29.	((dying or death) adj2 (patient* or person* or people or care or caring)).ti,ab.
30.	or/1-29
31.	letter/
32.	editorial/
33.	news/
34.	exp historical article/
35.	Anecdotes as Topic/
36.	comment/
37.	case report/
38.	(letter or comment*).ti.
39.	or/31-38
40.	randomized controlled trial/ or random*.ti,ab.
41.	39 not 40
42.	animals/ not humans/
43.	exp Animals, Laboratory/
44.	exp Animal Experimentation/
45.	exp Models, Animal/
46.	exp Rodentia/

47.	(rat or rats or mouse or mice).ti.
48.	or/41-47
49.	30 not 48
50.	limit 49 to English language
51.	(exp child/ or exp pediatrics/ or exp infant/) not (exp adolescent/ or exp adult/ or exp middle age/ or exp aged/)
52.	50 not 51
53.	economics/
54.	value of life/
55.	exp "costs and cost analysis"/
56.	exp Economics, Hospital/
57.	exp Economics, medical/
58.	Economics, nursing/
59.	economics, pharmaceutical/
60.	exp "Fees and Charges"/
61.	exp budgets/
62.	budget*.ti,ab.
63.	cost*.ti.
64.	(economic* or pharmaco?economic*).ti.
65.	(price* or pricing*).ti,ab.
66.	(cost* adj2 (effectiv* or utilit* or benefit* or minimi* or unit* or estimat* or variable*)).ab.
67.	(financ* or fee or fees).ti,ab.
68.	(value adj2 (money or monetary)).ti,ab.
69.	or/53-68
70.	exp models, economic/
71.	*Models, Theoretical/
72.	*Models, Organizational/
73.	markov chains/
74.	monte carlo method/
75.	exp Decision Theory/
76.	(markov* or monte carlo).ti,ab.
77.	econom* model*.ti,ab.
78.	(decision* adj2 (tree* or analy* or model*)).ti,ab.
79.	or/70-78
80.	quality-adjusted life years/
81.	sickness impact profile/
82.	(quality adj2 (wellbeing or well being)).ti,ab.
83.	sickness impact profile.ti,ab.
84.	disability adjusted life.ti,ab.
85.	(qal* or qtime* or qwb* or daly*).ti,ab.
86.	(euroqol* or eq5d* or eq 5*).ti,ab.
87.	(qol* or hql* or hqol* or h qol* or hrqol* or hr qol*).ti,ab.
88.	(health utility* or utility score* or disutilit* or utility value*).ti,ab.
89.	(hui or hui1 or hui2 or hui3).ti,ab.
90.	(health* year* equivalent* or hye or hyes).ti,ab.

91.	discrete choice*.ti,ab.
92.	rosser.ti,ab.
93.	(willingness to pay or time tradeoff or time trade off or tto or standard gamble*).ti,ab.
94.	(sf36* or sf 36* or short form 36* or shortform 36* or shortform36*).ti,ab.
95.	(sf20 or sf 20 or short form 20 or shortform 20 or shortform20).ti,ab.
96.	(sf12* or sf 12* or short form 12* or shortform 12* or shortform12*).ti,ab.
97.	(sf8* or sf 8* or short form 8* or shortform 8* or shortform8*).ti,ab.
98.	(sf6* or sf 6* or short form 6* or shortform 6* or shortform6*).ti,ab.
99.	or/80-98
100.	52 and (69 or 79 or 99)

Embase (Ovid) search terms

1.	*Palliative therapy/
2.	*Terminal care/
3.	*Hospice care/
4.	palliat*.ti,ab.
5.	*Terminally ill patient/
6.	((terminal* or long term or longterm) adj2 (care* or caring or ill*)).ti,ab.
7.	((dying or terminal) adj (phase* or stage*)).ti,ab.
8.	life limit*.ti,ab.
9.	*Nursing home/
10.	((care or nursing) adj2 (home or homes)).ti,ab.
11.	*Respite Care/
12.	((respite or day) adj2 (care or caring)).ti,ab.
13.	*Hospice/
14.	hospice*.ti,ab.
15.	*Patient care planning/
16.	(advance* adj2 (plan* or decision* or directive*)).ti,ab.
17.	living will*.ti,ab.
18.	*Patient care/
19.	((advance* or patient*) adj3 (care or caring) adj3 (continu* or plan*)).ti,ab.
20.	*Attitude to Death/
21.	(attitude* adj3 (death* or dying*)).ti,ab.
22.	*Doctor patient relation/
23.	*Long term care/
24.	*Health care delivery/
25.	(end adj2 life).ti,ab.
26.	EOLC.ti,ab.
27.	((last or final) adj2 (year or month*) adj2 life).ti,ab.
28.	((dying or death) adj2 (patient* or person* or people or care or caring)).ti,ab.
29.	or/1-28
30.	letter.pt. or letter/

31.	note.pt.
32.	editorial.pt.
33.	case report/ or case study/
34.	(letter or comment*).ti.
35.	or/30-34
36.	randomized controlled trial/ or random*.ti,ab.
37.	35 not 36
38.	animal/ not human/
39.	nonhuman/
40.	exp Animal Experiment/
41.	exp Experimental Animal/
42.	animal model/
43.	exp Rodent/
44.	(rat or rats or mouse or mice).ti.
45.	or/37-44
46.	29 not 45
47.	limit 46 to English language
48.	(exp child/ or exp pediatrics/ or exp infant/) not (exp adolescent/ or exp adult/ or exp middle age/ or exp aged/)
49.	47 not 48
50.	health economics/
51.	exp economic evaluation/
52.	exp health care cost/
53.	exp fee/
54.	budget/
55.	funding/
56.	budget*.ti,ab.
57.	cost*.ti.
58.	(economic* or pharmaco?economic*).ti.
59.	(price* or pricing*).ti,ab.
60.	(cost* adj2 (effectiv* or utilit* or benefit* or minimi* or unit* or estimat* or variable*)).ab.
61.	(financ* or fee or fees).ti,ab.
62.	(value adj2 (money or monetary)).ti,ab.
63.	or/50-62
64.	statistical model/
65.	exp economic aspect/
66.	64 and 65
67.	*theoretical model/
68.	*nonbiological model/
69.	stochastic model/
70.	decision theory/

71.	decision tree/
72.	monte carlo method/
73.	(markov* or monte carlo).ti,ab.
74.	econom* model*.ti,ab.
75.	(decision* adj2 (tree* or analy* or model*)).ti,ab.
76.	or/66-75
77.	quality-adjusted life years/
78.	"quality of life index"/
79.	short form 12/ or short form 20/ or short form 36/ or short form 8/
80.	sickness impact profile/
81.	(quality adj2 (wellbeing or well being)).ti,ab.
82.	sickness impact profile.ti,ab.
83.	disability adjusted life.ti,ab.
84.	(qal* or qtime* or qwb* or daly*).ti,ab.
85.	(euroqol* or eq5d* or eq 5*).ti,ab.
86.	(qol* or hql* or hqol* or h qol* or hrqol* or hr qol*).ti,ab.
87.	(health utility* or utility score* or disutilit* or utility value*).ti,ab.
88.	(hui or hui1 or hui2 or hui3).ti,ab.
89.	(health* year* equivalent* or hye or hyes).ti,ab.
90.	discrete choice*.ti,ab.
91.	rosser.ti,ab.
92.	(willingness to pay or time tradeoff or time trade off or tto or standard gamble*).ti,ab.
93.	(sf36* or sf 36* or short form 36* or shortform 36* or shortform36*).ti,ab.
94.	(sf20 or sf 20 or short form 20 or shortform 20 or shortform20).ti,ab.
95.	(sf12* or sf 12* or short form 12* or shortform 12* or shortform12*).ti,ab.
96.	(sf8* or sf 8* or short form 8* or shortform 8* or shortform8*).ti,ab.
97.	(sf6* or sf 6* or short form 6* or shortform 6* or shortform6*).ti,ab.
98.	or/77-97
99.	49 and (63 or 76 or 98)

NHS EED and HTA (CRD) search terms

#1.	MeSH DESCRIPTOR Palliative Care IN NHSEED,HTA
#2.	MeSH DESCRIPTOR Terminal Care IN NHSEED,HTA
#3.	MeSH DESCRIPTOR Hospice Care IN NHSEED,HTA
#4.	(palliat*) IN NHSEED, HTA
#5.	MeSH DESCRIPTOR Terminally Ill IN NHSEED,HTA
#6.	(((terminal* or long term or longterm) adj2 (care* or caring or ill*))) IN NHSEED, HTA
#7.	(((dying or terminal) adj (phase* or stage*))) IN NHSEED, HTA
#8.	(life limit*) IN NHSEED, HTA
#9.	MeSH DESCRIPTOR Nursing Homes IN NHSEED,HTA
#10.	(((care or nursing) adj2 (home or homes))) IN NHSEED, HTA
#11.	MeSH DESCRIPTOR Respite Care IN NHSEED,HTA

#12.	(((respite or day) adj2 (care or caring))) IN NHSEED, HTA
#13.	MeSH DESCRIPTOR Hospices IN NHSEED,HTA
#14.	(hospice*) IN NHSEED, HTA
#15.	MeSH DESCRIPTOR Advance Care Planning EXPLODE ALL TREES IN NHSEED,HTA
#16.	((advance* adj2 (plan* or decision* or directive*))) IN NHSEED, HTA
#17.	(living will*) IN NHSEED, HTA
#18.	MeSH DESCRIPTOR Patient Care Planning IN NHSEED,HTA
#19.	MeSH DESCRIPTOR Continuity of Patient Care IN NHSEED,HTA
#20.	(((advance* or patient*) adj3 (care or caring) adj3 (continu* or plan*))) IN NHSEED, HTA
#21.	MeSH DESCRIPTOR Attitude to Death IN NHSEED,HTA
#22.	((attitude* adj3 (death* or dying*))) IN NHSEED, HTA
#23.	MeSH DESCRIPTOR Physician-Patient Relations IN NHSEED,HTA
#24.	MeSH DESCRIPTOR Long-Term Care IN NHSEED,HTA
#25.	MeSH DESCRIPTOR Delivery of Health Care IN NHSEED,HTA
#26.	((end adj2 life)) IN NHSEED, HTA
#27.	(EOLC) IN NHSEED, HTA
#28.	(((last or final) adj2 (year or month*) adj2 life)) IN NHSEED, HTA
#29.	(((dying or death) adj2 (patient* or person* or people or care or caring))) IN NHSEED, HTA
#30.	#1 OR #2 OR #3 OR #4 OR #5 OR #6 OR #7 OR #8 OR #9 OR #10 OR #11 OR #12 OR #13 OR #14 OR #15 OR #16 OR #17 OR #18 OR #19 OR #20 OR #21 OR #22 OR #23 OR #24 OR #25 OR #26 OR #27 OR #28 OR #29
#31.	(#30) IN NHSEED
#32.	(#30) IN HTA

Appendix C: Clinical evidence selection

Figure 1: Flow chart of clinical study selection for the review of service models to facilitate/support ACP.

```
┌─────────────────────────────┐        ┌─────────────────────────────┐
│ Records identified through  │        │ Additional records          │
│ database searching, n=8492  │        │ identified through          │
│                             │        │ other sources, n=0          │
└─────────────┬───────────────┘        └──────────────┬──────────────┘
              │                                        │
              └────────────────┬───────────────────────┘
                               ▼
              ┌─────────────────────────────┐
              │ Records screened, n=8492    │
              └─────────────┬───────────────┘
                            │                  ┌─────────────────────────────┐
                            ├─────────────────▶│ Records excluded, n=8268    │
                            ▼                  └─────────────────────────────┘
              ┌─────────────────────────────┐
              │ Full-text papers assessed   │
              │ for eligibility, n=224      │
              └─────────────┬───────────────┘
                            │
              ┌─────────────┴───────────────┐
              ▼                             ▼
┌─────────────────────────┐   ┌─────────────────────────────┐
│ Papers included in      │   │ Papers excluded from        │
│ review, n=4             │   │ review, n=220               │
│                         │   │                             │
│                         │   │ Reasons for exclusion: see  │
│                         │   │ Appendix H                  │
└─────────────────────────┘   └─────────────────────────────┘
```
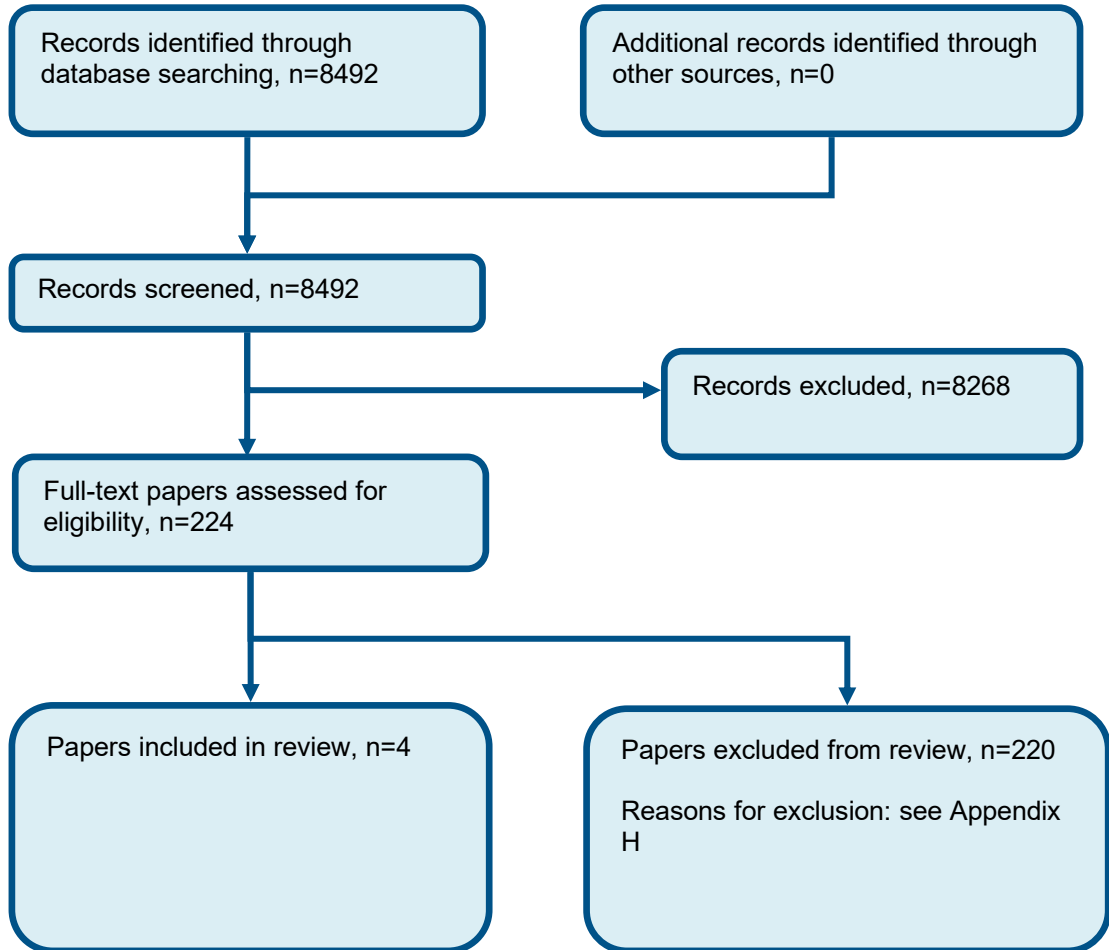
Figure 2: Flow chart of health economic study selection for the guideline

Records identified through database searching, n=13,975

Additional records identified through other sources: reference searching, n=11; provided by committee members; n=0

Records screened in 1st sift, n=13,975

Records excluded* in 1st sift, n=13,846

Full-text papers assessed for eligibility in 2nd sift, n=129

Papers excluded* in 2nd sift, n=117

Full-text papers assessed for applicability and quality of methodology, n=12

Papers included, n=12 (10 studies)

Studies included by review:

- Review A: n=0
- Review B: n=0
- Review C: n=0
- Review D: n=0
- Review E: n=2
- Review F: n=1
- Review G: n=0
- Review H: n=1
- Review I: n=0
- Review J: n=0
- Review K: n=0
- Review L: n=8
- Review M: n=0

Papers selectively excluded, n=0

Papers excluded, n=2 (2 studies)

Studies excluded by review:

- Review A: n=0
- Review B: n=0
- Review C: n=0
- Review D: n=0
- Review E: n=1
- Review F: n=0
- Review G: n=0
- Review H: n=0
- Review I: n=0
- Review J: n=0
- Review K: n=1
- Review L: n=0
- Review M: n=0

Reasons for exclusion: see appendix H.2

* Non-relevant population, intervention, comparison, design or setting; non-English language

Appendix D: Clinical evidence tables

Study	Bristowe 2015[45]
Study type	Non-randomised comparative study
Number of studies (number of participants)	1 (n=95)
Countries and setting	Conducted in United Kingdom, Zimbabwe; Setting: Acute tertiary NHS hospitals in London
Line of therapy	Unclear
Duration of study	Follow up (post intervention): 4-10 months
Method of assessment of guideline condition	Adequate method of assessment/diagnosis
Stratum	Adults (aged 18 years or over)
Subgroup analysis within study	Not applicable
Inclusion criteria	Patients under the care of a palliative care team; supported by the AMBER care bundle (or would be appropriate for AMBER care bundle if on the AMBER care ward (comparison group)).
Exclusion criteria	Not reported
Recruitment/selection of patients	Survey sent to next of kin
Age, gender and ethnicity	Age - Mean (range): 77 (28-102). Gender (M:F): 46/49. Ethnicity: White 80%
Further population details	1. Any specific population: Not applicable
Indirectness of population	No indirectness
Interventions	(n=59) Intervention 1: Service models to facilitate or support ACP. AMBER care bundle; developed to improve care for patients who are deteriorating, clinically unstable, with limited reversibility and at risk of dying in the next 1-2 months. Bundle has an algorithmic approach intended to encourage the clinical team to develop and document a clear medical plan and consider anticipated outcomes and resuscitation and escalation status; this is revisited daily. The bundle also aims to increase frequency of communication with patients and family regarding treatment plans, preferred place of care and other concerns. Duration NA. Concurrent medication/care: Usual care

	(n=36) Intervention 2: No identified service model to facilitate or support ACP . Duration NA. Concurrent medication/care: Usual care
Funding	Academic or government funding (Funded by the Guy's and St Thomas's Charity.)

RESULTS (NUMBERS ANALYSED) AND RISK OF BIAS FOR COMPARISON: SERVICE MODELS TO FACILITATE OR SUPPORT ACP versus NO IDENTIFIED SERVICE MODEL TO FACILITATE OR SUPPORT ACP

Protocol outcome 1: Length of stay
- Actual outcome for Adults (aged 18 years or over): Length of hospital stay (days)Group 1: mean 30.3 days (SD 19.2); n=41, Group 2: mean 29.3 days (SD 20.4); n=19
Risk of bias: All domain - Very high, Selection - Very high, Blinding - Low, Incomplete outcome data - Low, Outcome reporting - Low, Measurement - Low, Crossover - Low; Indirectness of outcome: No indirectness; Group 1 number missing: 18, Group 2 number missing: 17

Protocol outcome 2: Preferred and actual place of death
- Actual outcome for Adults (aged 18 years or over): Preferred place of death (as far as next of kin was aware) - homeGroup 1: 23/51, Group 2: 11/28
Risk of bias: All domain - Very high, Selection - Very high, Blinding - Low, Incomplete outcome data - Low, Outcome reporting - Low, Measurement - Low, Crossover - Low; Indirectness of outcome: No indirectness, Comments: Not reported if this was achieved; Group 1 number missing: 8, Group 2 number missing: 8
- Actual outcome for Adults (aged 18 years or over): Preferred place of death (as far as next of kin was aware) - hospice
Group 1: 12/51, Group 2: 4/28
Risk of bias: All domain - Very high, Selection - Very high, Blinding - Low, Incomplete outcome data - Low, Outcome reporting - Low, Measurement - Low, Crossover - Low; Indirectness of outcome: No indirectness, Comments: Not reported if this was achieved; Group 1 number missing: 8, Group 2 number missing: 8
- Actual outcome for Adults (aged 18 years or over): Preferred place of death (as far as next of kin was aware) - hospital
Group 1: 11/51, Group 2: 10/28
Risk of bias: All domain - Very high, Selection - Very high, Blinding - Low, Incomplete outcome data - Low, Outcome reporting - Low, Measurement - Low, Crossover - Low; Indirectness of outcome: No indirectness, Comments: Not reported if this was achieved; Group 1 number missing: 8, Group 2 number missing: 8
- Actual outcome for Adults (aged 18 years or over): Preferred place of death (as far as next of kin was aware) - nursing home
Group 1: 3/51, Group 2: 3/28
Risk of bias: All domain - Very high, Selection - Very high, Blinding - Low, Incomplete outcome data - Low, Outcome reporting - Low, Measurement - Low, Crossover - Low; Indirectness of outcome: No indirectness, Comments: Not reported if this was achieved; Group 1 Number missing: ; Group 2 Number missing:
- Actual outcome for Adults (aged 18 years or over): Preferred place of death (as far as next of kin was aware) - elsewhere; Group 1 number missing: 8, Group 2 number missing: 8
Group 1: 2/51, Group 2: 0/28
Risk of bias: All domain - Very high, Selection - Very high, Blinding - Low, Incomplete outcome data - Low, Outcome reporting - Low, Measurement - Low, Crossover - Low; Indirectness of outcome: No indirectness, Comments: Not reported if this was achieved; Group 1 number missing: 0, Group 2 number missing: 1
- Actual outcome for Adults (aged 18 years or over): Actual place of death - home
Group 1: 12/59, Group 2: 3/35

Risk of bias: All domain - Very high, Selection - Very high, Blinding - Low, Incomplete outcome data - Low, Outcome reporting - Low, Measurement - Low, Crossover - Low; Indirectness of outcome: No indirectness, Comments: Not reported if this was preferred place of death; Group 1 number missing: 0, Group 2 number missing: 1 - Actual outcome for Adults (aged 18 years or over): Actual place of death - hospice

Group 1: 12/59, Group 2: 3/35

Risk of bias: All domain - Very high, Selection - Very high, Blinding - Low, Incomplete outcome data - Low, Outcome reporting - Low, Measurement - Low, Crossover - Low; Indirectness of outcome: No indirectness, Comments: Not reported if this was preferred place of death; Group 1 number missing: 0, Group 2 number missing: 1 - Actual outcome for Adults (aged 18 years or over): Actual place of death - hospital

Group 1: 30/59, Group 2: 24/35

Risk of bias: All domain - Very high, Selection - Very high, Blinding - Low, Incomplete outcome data - Low, Outcome reporting - Low, Measurement - Low, Crossover - Low; Indirectness of outcome: No indirectness, Comments: Not reported if this was preferred place of death; Group 1 number missing: 0, Group 2 number missing: 1 - Actual outcome for Adults (aged 18 years or over): Actual place of death - nursing home

Group 1: 5/59, Group 2: 5/35

Risk of bias: All domain - Very high, Selection - Very high, Blinding - Low, Incomplete outcome data - Low, Outcome reporting - Low, Measurement - Low, Crossover - Low; Indirectness of outcome: No indirectness, Comments: Not reported if this was preferred place of death; Group 1 number missing: 0, Group 2 number missing: 1

Protocol outcomes not reported by the study	Quality of life ; Number of hospital visits ; Number of visits to accident and emergency ; Number of unscheduled admissions ; Use of community services ; Length of survival ; Staff satisfaction ; Avoidable/inappropriate admissions to ICU ; Inappropriate attempts at cardiopulmonary resuscitation ; Patient/Carer reported outcomes (satisfaction) ; Preferred and actual place of care ; Hospitalisation

Study	Livingston 2013[137]
Study type	Non-randomised comparative study
Number of studies (number of participants)	1 (n=98)
Countries and setting	Conducted in United Kingdom; Setting: Nursing home providing care recognising Jewish traditions, beliefs and cultures, for people throughout the religion spectrum.
Line of therapy	Unclear
Duration of study	Intervention + follow up: 2 years
Method of assessment of guideline condition	Adequate method of assessment/diagnosis
Stratum	Adults (aged 18 yrs or over)
Subgroup analysis within study	Not applicable
Inclusion criteria	Residents of the nursing home with dementia who had died in the 12 months pre or post intervention.
Exclusion criteria	Not reported
Recruitment/selection of patients	Recruited from nursing home
Age, gender and ethnicity	Age - Mean (SD): Usual care: 85.5 (7.9), Training program: 88.1 (7.1). Gender (M:F): 39/59. Ethnicity: Not reported
Further population details	1. Any specific population: Not applicable
Indirectness of population	No indirectness
Interventions	(n=42) Intervention 1: Service models to facilitate or support ACP. A ten-session manualised interactive training program devised by a consultant physician and care home senior managers. The head of home had already been trained in Gold standard Framework (a program for care homes in the UK to enable generalist to deliver high quality end-of-life care. It is not designed for those with dementia), the other managers undertook Gold Standard Framework training alongside this intervention. The training program topics were: the challenges of dementia end-of-life care; emotional and psychological needs at end-of-life; planning for end-of-life care; (advance) care planning and communication with residents and relatives; religion and spirituality at end-of-life; holistic care for people with dementia at end-of-life; summarizing and reflective sessions. The program emphasises preferred place of care, how to have difficult conversations, structured listening, communication, observation, kindness, empathy, and compassion. It included discussions with senior unit mangers and role playing around advance wishes and care plans. The training was given to residential and senior care workers and general nurses.

	Duration 12 months. Concurrent medication/care: Usual care (n=56) Intervention 2: No identified service model to facilitate or support ACP . NA. Duration 12 months. Concurrent medication/care: Usual care
Funding	Academic or government funding (The Kings Fund)

RESULTS (NUMBERS ANALYSED) AND RISK OF BIAS FOR COMPARISON: SERVICE MODELS TO FACILITATE OR SUPPORT ACP versus NO IDENTIFIED SERV
ICE MODEL TO FACILITATE OR SUPPORT ACP

Protocol outcome 1: Length of stay
- Actual outcome for Adults (aged 18 years or over): Days spent in hospital in three months prior to death (median; range; IQR) at 3 months; median (range; IQR): Pre: 4
(0-34; 15.75), Post: 1.25 (0-68; 9.5));
Risk of bias: All domain - Very high, Selection - Very high, Blinding - Low, Incomplete outcome data - Low, Outcome reporting - Low, Measurement - Low, Crossover -
Low; Indirectness of outcome: No indirectness

Protocol outcome 2: Preferred and actual place of death
- Actual outcome for Adults (aged 18 years or over): Deaths in care home at 12 months; Group 1: 22/29, Group 2: 14/30
Risk of bias: All domain - Very high, Selection - Very high, Blinding - Low, Incomplete outcome data - Low, Outcome reporting - Low, Measurement - Low, Crossover -
Low; Indirectness of outcome: No indirectness, Comments: No reference to preference of place of death. ; Group 1 Number missing: 13; Group 2 Number missing: 26
- Actual outcome for Adults (aged 18 years or over): Deaths in hospital at 12 months; Group 1: 7/29, Group 2: 16/30
Risk of bias: All domain - Very high, Selection - Very high, Blinding - Low, Incomplete outcome data - Low, Outcome reporting - Low, Measurement - Low, Crossover -
Low; Indirectness of outcome: No indirectness, Comments: No reference to preference of place of death. ; Group 1 Number missing: 13; Group 2 Number missing: 26

Protocol outcomes not reported by the study	Quality of life; Number of hospital visits; Number of visits to accident and emergency; Number of unscheduled admissions; Use of community services; Length of survival; Staff satisfaction; Avoidable/inappropriate admissions to ICU; Inappropriate attempts at cardiopulmonary resuscitation; Patient/Carer reported outcomes (satisfaction); Preferred and actual place of care; Hospitalisation

Study	Overbeek 2018 [165]

Study type	RCT (Cluster randomized nursing homes; Parallel)
Number of studies (number of participants)	1 (n=201), 16 residential care homes
Countries and setting	Conducted in The Netherlands ; Setting: Patients at care home
Line of therapy	Unclear
Duration of study	Intervention + follow up: 12 months
Method of assessment of guideline condition	Adequate method of assessment/diagnosis
Stratum	Adults (aged 75 years or over)
Subgroup analysis within study	Not applicable
Inclusion criteria	People aged 75 years and over with a Tilburg Fraility Index Score 5 and over and capable to consent to participation (Mini-Mental State Examination score 17 and over, living in a residential care home or in the immediate surroundings while receiving home care.
Exclusion criteria	Not reported
Recruitment/selection of patients	Patients at care homes by general letter and then in person or by telephone
Age, gender and ethnicity	Age – intervention Mean (SD): 86 (6.0). Usual care Mean (SD) :87 (5.2) Gender intervention (M 32:F69) Usual care : (M 28:F72) Residence care home intervention 39, community 62 Usual care home 51 community 49
Indirectness of population	No indirectness
Interventions	Intervention N=101: Intervention based on Respecting Choices ACP facilitator training, education materials and tools. The program involves trained facilitators who assist individuals in exploring the understanding of their illness reflecting on goals, values and beliefs; discussing healthcare preferences and appointing a surrogate decision-maker (modified for Dutch context).Nurses trained to deliver the intervention. Three day training. The intervention had 3 core elements; information provision through leaflets; facilitated ACP conversations based on scripted interview cards; and completion of an AD, including appointment of a surrogate decision- maker. Usual care (n=100): No identified service model to facilitate or support ACP .
Funding	Netherlands Organisation for Health Research and Development project 837001009

RESULTS (NUMBERS ANALYSED) AND RISK OF BIAS FOR COMPARISON: Adjusted Choices versus usual care

Protocol outcome 1: Quality of life
SF_12 Physical component score scale 0-100, high score indicates better score
Baseline; Group 1: mean 31 (SD 10.00); n=77, Group 2: mean 33 (SD 9.0); n=83; Risk of bias: All domain - high, Selection - low, Blinding - high, Incomplete outcome data - Low, Outcome reporting - Low, Measurement - Low, Crossover - Low; Indirectness of outcome: No indirectness

 at 12 months Group 1: mean 32 (SD 10.01); n=77, Group 2: mean 34 (SD 8.8); n=83; Risk of bias: All domain - high, Selection - low, Blinding - high, Incomplete outcome data - Low, Outcome reporting - Low, Measurement - Low, Crossover - Low; Indirectness of outcome: No indirectness

Protocol outcome 1: Quality of life
SF_12 Mental component score scale 0-100, high score indicates better score
Baseline; Group 1: mean 52 (SD 9.9); n=77, Group 2: mean 50 (SD 10.3); n=83; Risk of bias: All domain - high, Selection - low, Blinding - high, Incomplete outcome data - Low, Outcome reporting - Low, Measurement - Low, Crossover - Low; Indirectness of outcome: No indirectness

 at 12 months Group 1: mean 48 (SD 10.08); n=77, Group 2: mean 46 (SD 12.1); n=83; Risk of bias: All domain - high, Selection - low, Blinding - high, Incomplete outcome data - Low, Outcome reporting - Low, Measurement - Low, Crossover - Low; Indirectness of outcome: No indirectness

 Protocol outcome 3: Patient Satisfaction
PSQ-18 1-5, high score indicates better score
Baseline; Group 1: mean 4 (SD 0.8); n=77, Group 2: mean 4 (SD 0.8); n=83; Risk of bias: All domain - high, Selection - low, Blinding - high, Incomplete outcome data - Low, Outcome reporting - Low, Measurement - Low, Crossover - Low; Indirectness of outcome: No indirectness

 at 12 months Group 1: mean 4 (SD 0.8); n=77, Group 2: mean 4 (SD0.7); n=83; Risk of bias: All domain - high, Selection - low, Blinding - high, Incomplete outcome data - Low, Outcome reporting - Low, Measurement - Low, Crossover - Low; Indirectness of outcome: No indirectness

| Protocol outcomes not reported by the study | Hospitalisation ; Number of hospital visits ; Number of visits to accident and emergency ; Number of unscheduled admissions ; Use of community services ; Preferred and actual place of death ; Length of survival ; |

End of life care for adults: service delivery: Final

	Avoidable/inappropriate admissions to ICU ; Inappropriate attempts at cardiopulmonary resuscitation ; Carer reported outcomes (satisfaction) ; Preferred and actual place of care ; Length of stay

Study	Sampson 2011[185]
Study type	RCT (Patient randomised; Parallel)
Number of studies (number of participants)	1 (n=32)
Countries and setting	Conducted in United Kingdom; Setting: Patients at care home. Follow up questionnaires sent to next of kin in the community.
Line of therapy	Unclear
Duration of study	Intervention + follow up: 6 months
Method of assessment of guideline condition	Adequate method of assessment/diagnosis
Stratum	Adults (aged 18 years or over)
Subgroup analysis within study	Not applicable
Inclusion criteria	Patients who had undergone emergency hospital admission and had severe dementia. (~50% had died during the 6-month follow up period).
Exclusion criteria	Not reported
Recruitment/selection of patients	Patients at care home and next of kin approached
Age, gender and ethnicity	Age - Mean (SD): 87 (6.2). Gender (M:F): Define. Ethnicity: 87% white
Further population details	1. Any specific population:
Indirectness of population	No indirectness
Interventions	(n=22) Intervention 1: Service models to facilitate or support ACP. A palliative care assessment which informed ACP discussion with the carer, who was offered the opportunity to write an ACP for the person with dementia. Palliative care needs assessment; 30 minute structured clinical approach that built on usual care, covering domains including dementia severity, presence of delirium, communication, pressure sore risk and severity, food and fluid intake, swallowing and feeding. The assessment generated a list of problems. A management plan was formulated and used to inform subsequent discussions with the carer. Assessment informed ACP discussion with the carer, who was offered up to four consultations (at least 5 days apart). The first consultation involved discussions with the carer to assess (i) level of knowledge about patient dementia, (ii) severity of dementia and prognosis for the patient, (iii) the patients physical needs, (iv) the social situation and current levels of social support, and (v) any records of records of previous preference for care. Subsequent consultations involved basic education on dementia as a neuro-degenerative disease. Carers were then given the opportunity to write an ACP for the person with dementia.

	Duration up to 20 days. Concurrent medication/care: Usual care
	(n=11) Intervention 2: No identified service model to facilitate or support ACP . NA. Duration NA. Concurrent medication/care: Usual care
Funding	Study funded by industry (Supported by a grant from the BUPA foundation)

RESULTS (NUMBERS ANALYSED) AND RISK OF BIAS FOR COMPARISON: SERVICE MODELS TO FACILITATE OR SUPPORT ACP versus NO IDENTIFIED SERVICE MODEL TO FACILITATE OR SUPPORT ACP

Protocol outcome 1: Quality of life
- Actual outcome for Adults (aged 18 years or over): Carer QoL (EQ5D) – scale 0-1; low score indicates poor health. Comments: **A measure of health status and quality of life, comprises a 5-item scale indicating overall health state.** at Baseline; Group 1: mean 0.7 (SD 0.2); n=21, Group 2: mean 0.6 (SD 0.4); n=10; EQ5D 0-1 Top=High is good outcome; Risk of bias: All domain - Very high, Selection - High, Blinding - High, Incomplete outcome data - Low, Outcome reporting - Low, Measurement - Low, Crossover - Low; Indirectness of outcome: No indirectness
- Actual outcome for Adults (aged 18 years or over): Carer QoL (EQ5D) – scale 0-1; low score indicates poor health.

 at 6 weeks; Group 1: mean 0.8 (SD 0.1); n=9, Group 2: mean 0.8 (SD 0.1); n=6; EQ5D 0-1 Top=High is good outcome
Risk of bias: All domain - Very high, Selection - High, Blinding - High, Incomplete outcome data - Low, Outcome reporting - Low, Measurement - Low, Crossover - Low; Indirectness of outcome: No indirectness
- Actual outcome for Adults (aged 18 years or over): Carer QoL (EQ5D) – scale 0-1; low score indicates poor health.

 at 6 months; Group 1: mean 0.8 (SD 0.1); n=7, Group 2: mean 0.8 (SD 0.1); n=4; EQ5D 0-1 Top=High is good outcome
Risk of bias: All domain - Very high, Selection - High, Blinding - High, Incomplete outcome data - Low, Outcome reporting - Low, Measurement - Low, Crossover - Low; Indirectness of outcome: No indirectness
- Actual outcome for Adults (aged 18 years or over): Carer QoL (EQ5D) – scale 0-1; low score indicates poor health.

 at Post-bereavement; Group 1: mean 0.6 (SD 0.3); n=4,
Risk of bias: All domain - Very high, Selection - High, Blinding - High, Incomplete outcome data - Low, Outcome reporting - Low, Measurement - Low, Crossover - Low; Indirectness of outcome: No indirectness

Protocol outcome 2: Staff satisfaction
- Actual outcome for Adults (aged 18 years or over): Life satisfaction (LSQ) – scale 0-7; high score indicates best possible outcome. Comments: **Obtained from the Lancashire Quality of Life Profile, this is a seven point 'ladder scale' anchored at 0, representing 'the very worst outcome that you could expect to have in life', rising to 7 with the top representing 'the very best outcome that you could expect to have in life'.**

at Baseline; Group 1: mean 4.5 (SD 1.1); n=21, Group 2: mean 4.6 (SD 1.2); n=10; Risk of bias: All domain - Very high, Selection - High, Blinding - High, Incomplete outcome data - Low, Outcome reporting - Low, Measurement - Low, Crossover - Low; Indirectness of outcome: No indirectness ; Group 1 Number missing: ; Group 2 Number missing:
- Actual outcome for Adults (aged 18 years or over): Life satisfaction (LSQ) – scale 0-7; high score indicates best possible outcome.

at 6 weeks; Group 1: mean 4.9 (SD 1.3); n=9, Group 2: mean 5.5 (SD 0.6); n=6; LSQ 0-7 Top=High is good outcome
Risk of bias: All domain - Very high, Selection - High, Blinding - High, Incomplete outcome data - Low, Outcome reporting - Low, Measurement - Low, Crossover - Low; Indirectness of outcome: No indirectness
- Actual outcome for Adults (aged 18 years or over): Life satisfaction (LSQ) – scale 0-7; high score indicates best possible outcome.

at 6 months; Group 1: mean 5.4 (SD 0.9); n=7, Group 2: mean 5.5 (SD 0.6); n=4; LSQ 0-7 Top=High is good outcome
Risk of bias: All domain - Very high, Selection - High, Blinding - High, Incomplete outcome data - Low, Outcome reporting - Low, Measurement - Low, Crossover - Low; Indirectness of outcome: No indirectness
- Actual outcome for Adults (aged 18 years or over): Life satisfaction (LSQ) – scale 0-7; high score indicates best possible outcome.

at Post-bereavement; Group 1: mean 3 (SD 2); n=4,
Risk of bias: All domain - Very high, Selection - High, Blinding - High, Incomplete outcome data - Low, Outcome reporting - Low, Measurement - Low, Crossover - Low; Indirectness of outcome: No indirectness
- Actual outcome for Adults (aged 18 years or over): Decision satisfaction inventory (DSI) – range 10-50; high score indicates less satisfaction.

Protocol outcome 3: Staff satisfaction
- Actual outcome for Adults (aged 18 years or over): Decision satisfaction inventory (DSI) – range 10-50; high score indicates less satisfaction. Comments: **DSI applies to Healthcare proxies (those with power of attorney i.e. next of kin). Gives an overall satisfaction score of the decision making process and decisions made.**

at Baseline; Group 1: mean 26 (SD 3.2); n=21, Group 2: mean 26.5 (SD 6.7); n=10; DSI 10-50 Top=High is poor outcome;
Risk of bias: All domain - Very high, Selection - High, Blinding - High, Incomplete outcome data - Low, Outcome reporting - Low, Measurement - Low, Crossover - Low; Indirectness of outcome: No indirectness
- Actual outcome for Adults (aged 18 years or over): Decision satisfaction inventory (DSI) – range 10-50; high score indicates less satisfaction.

at 6 weeks; Group 1: mean 21.8 (SD 6.6); n=9, Group 2: mean 22 (SD 8.1); n=6; DSI 10-50 Top=High is poor outcome
Risk of bias: All domain - Very high, Selection - High, Blinding - High, Incomplete outcome data - Low, Outcome reporting - Low, Measurement - Low, Crossover - Low; Indirectness of outcome: No indirectness
- Actual outcome for Adults (aged 18 years or over): Decision satisfaction inventory (DSI) – range 10-50; high score indicates less satisfaction.

at 6 months; Group 1: mean 22.2 (SD 7.9); n=7, Group 2: mean 16.3 (SD 4.8); n=4; DSI 10-50 Top=High is poor outcome
Risk of bias: All domain - Very high, Selection - High, Blinding - High, Incomplete outcome data - Low, Outcome reporting - Low, Measurement - Low, Crossover - Low;

Indirectness of outcome: No indirectness
- Actual outcome for Adults (aged 18 years or over): Decision satisfaction inventory (DSI) – range 10-50; high score indicates less satisfaction.

 at Post-bereavement; Group 1: mean 28 (SD 7.2); n=4,
Risk of bias: All domain - Very high, Selection - High, Blinding - High, Incomplete outcome data - Low, Outcome reporting - Low, Measurement - Low, Crossover - Low;
Indirectness of outcome: No indirectness
- Actual outcome for Adults (aged 18 years or over): Satisfaction with end of life care in advanced dementia (SWC-EOLCD) – range 10-40; high score indicates greater satisfaction.

Protocol outcome 4: Staff satisfaction
- Actual outcome for Adults (aged 18 years or over): Satisfaction with end of life care in advanced dementia (SWC-EOLCD) – range 10-40; high score indicates greater satisfaction. Comments: **Measures satisfaction with end of life care in dementia.**

 at Post-bereavement; Group 1: mean 27.6 (SD 8.5); n=4,
Risk of bias: All domain - Very high, Selection - High, Blinding - High, Incomplete outcome data - Low, Outcome reporting - Low, Measurement - Low, Crossover - Low;
Indirectness of outcome: No indirectness

Protocol outcomes not reported by the study	Hospitalisation ; Number of hospital visits ; Number of visits to accident and emergency ; Number of unscheduled admissions ; Use of community services ; Preferred and actual place of death ; Length of survival ; Avoidable/inappropriate admissions to ICU ; Inappropriate attempts at cardiopulmonary resuscitation ; Patient/carer reported outcomes (satisfaction) ; Preferred and actual place of care ; Length of stay

Appendix E: Forest plots

E.1 AMBER care bundle versus usual care

Figure 3: Length of hospital stay (days)

Figure 4:   Number of residents wishing to die at home (next of kin opinion)

Figure 5:   Number of residents wishing to die at hospice (next of kin opinion)
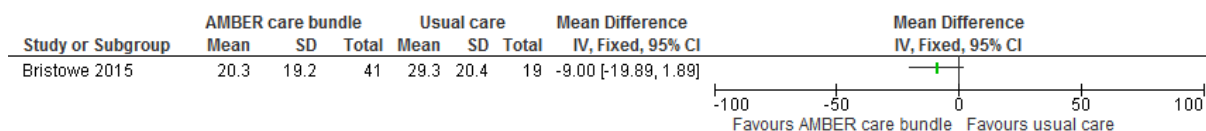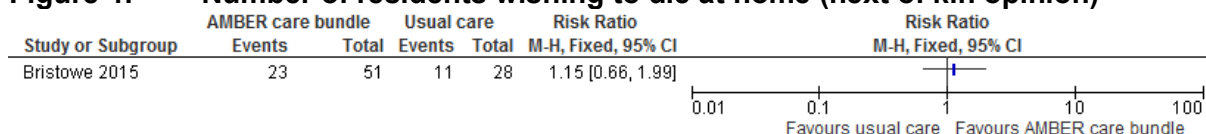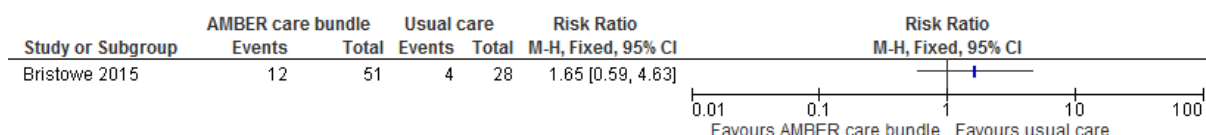

Figure 6:   Number of residents wishing to die at hospital (next of kin opinion)
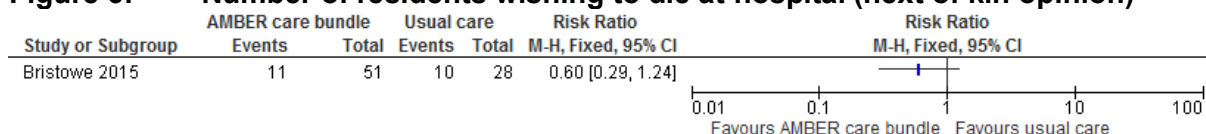

Figure 7:   Number of residents wishing to die at care home (next of kin opinion)
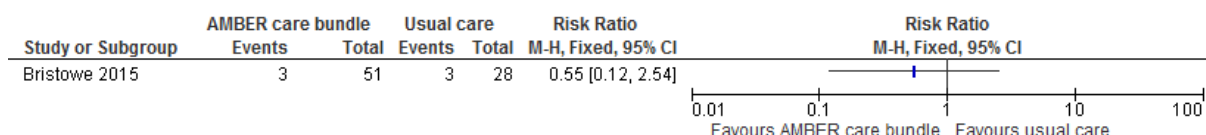

Figure 8:   Number of residents wishing to die elsewhere (next of kin opinion)
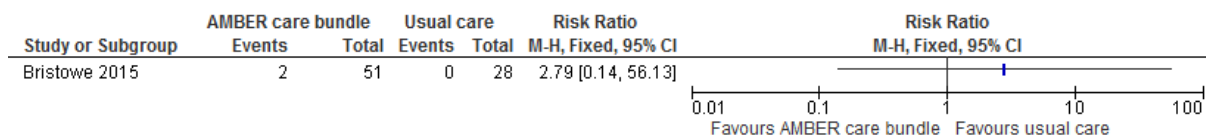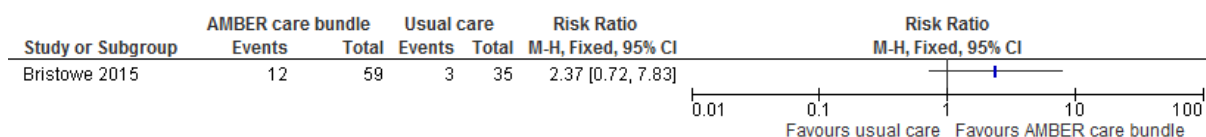

Figure 9:   Number of residents dying in home

Figure 10:   Number of residents dying in hospice

	AMBER care bundle		Usual care		Risk Ratio	Risk Ratio
Study or Subgroup	Events	Total	Events	Total	M-H, Fixed, 95% CI	M-H, Fixed, 95% CI
Bristowe 2015	12	59	3	35	2.37 [0.72, 7.83]	

Favours AMBER care bundle   Favours usual care
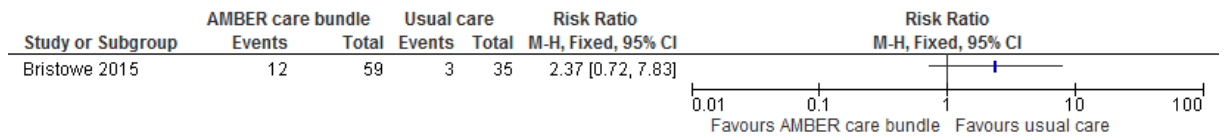
Figure 11:   Number of residents dying in hospital

	AMBER care bundle		Usual care		Risk Ratio	Risk Ratio
Study or Subgroup	Events	Total	Events	Total	M-H, Fixed, 95% CI	M-H, Fixed, 95% CI
Bristowe 2015	30	59	24	35	0.74 [0.53, 1.04]	

Favours AMBER care bundle   Favours usual care
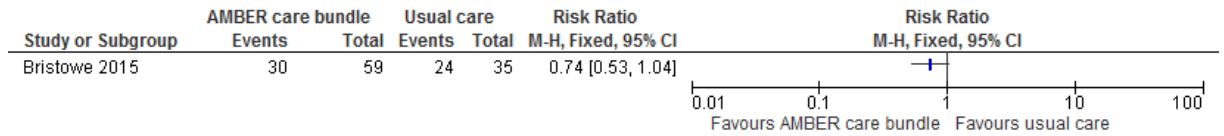
Figure 12:   Number of residents dying in care home

	AMBER care bundle		Usual care		Risk Ratio	Risk Ratio
Study or Subgroup	Events	Total	Events	Total	M-H, Fixed, 95% CI	M-H, Fixed, 95% CI
Bristowe 2015	5	59	5	35	0.59 [0.18, 1.91]	

Favours AMBER care bundle   Favours usual care
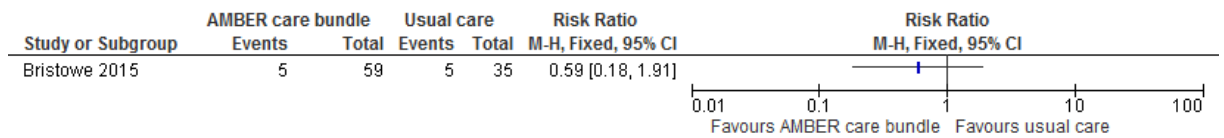
E.2   Training program versus usual care

Figure 13:   Number of residents dying in care home

	Training program		Usual care		Risk Ratio	Risk Ratio
Study or Subgroup	Events	Total	Events	Total	M-H, Fixed, 95% CI	M-H, Fixed, 95% CI
Livingston 2013	22	29	14	30	1.63 [1.05, 2.51]	

Favours Usual care   Favours Training program
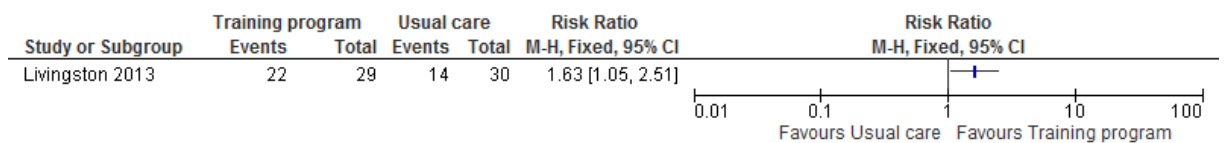
Figure 14:   Number of residents dying in hospital

	Training program		Usual care		Risk Ratio	Risk Ratio
Study or Subgroup	Events	Total	Events	Total	M-H, Fixed, 95% CI	M-H, Fixed, 95% CI
Livingston 2013	7	29	16	30	0.45 [0.22, 0.94]	

Favours Training program   Favours Usual care
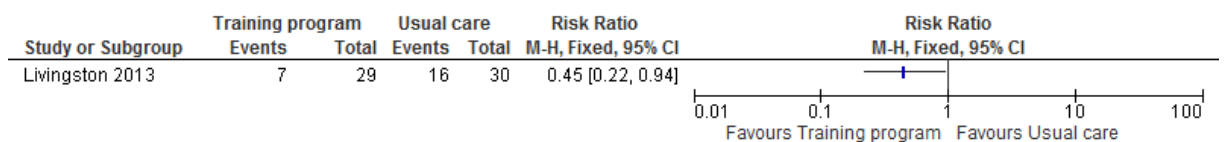
E.3   Adjusted Choices versus usual care

Figure 15:   Quality of life at 12 months (SF_12 Physical component score)

	Adjusted Choices			Usual care				Mean Difference	Mean Difference
Study or Subgroup	Mean	SD	Total	Mean	SD	Total	Weight	IV, Fixed, 95% CI	IV, Fixed, 95% CI
Overbeek 2018	32	10.1	77	34	8.8	83	100.0%	-2.00 [-4.95, 0.95]	
Total (95% CI)			77			83	100.0%	-2.00 [-4.95, 0.95]	

Heterogeneity: Not applicable
Test for overall effect: Z = 1.33 (P = 0.18)

Favours usual care   Favours Adjusted Choices
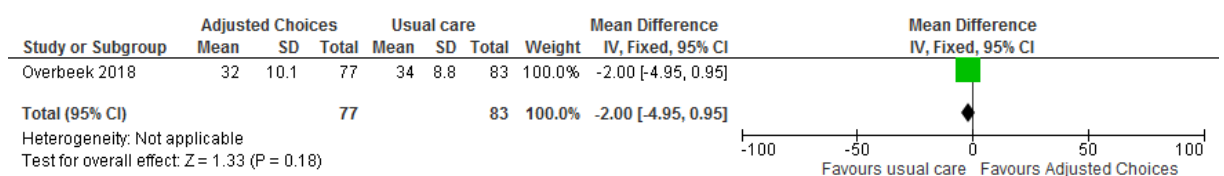
Figure 16: Quality of life at 12 months (SF_12 Mental component score)

| Study or Subgroup | Adjusted Choices | | | Usual care | | | | Mean Difference | Mean Difference |
	Mean	SD	Total	Mean	SD	Total	Weight	IV, Fixed, 95% CI	IV, Fixed, 95% CI
Overbeek 2018	48	10.8	77	46	12.1	83	100.0%	2.00 [-1.55, 5.55]	
Total (95% CI)			**77**			**83**	**100.0%**	**2.00 [-1.55, 5.55]**	

Heterogeneity: Not applicable
Test for overall effect: Z = 1.10 (P = 0.27)

-100 -50 0 50 100
Favours usual care Favours Adjusted Choices
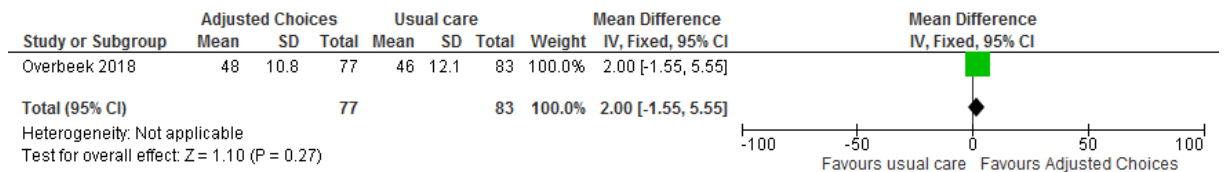
Figure 17:   Patient Satisfaction (PSQ-18 1subscale)

| Study or Subgroup | Adjusted Choices | | | Usual care | | | | Mean Difference | Mean Difference |
	Mean	SD	Total	Mean	SD	Total	Weight	IV, Fixed, 95% CI	IV, Fixed, 95% CI
Overbeek 2018	4	0.8	77	4	0.7	83	100.0%	0.00 [-0.23, 0.23]	
Total (95% CI)			**77**			**83**	**100.0%**	**0.00 [-0.23, 0.23]**	

Heterogeneity: Not applicable
Test for overall effect: Z = 0.00 (P = 1.00)

-100 -50 0 50 100
Favours usual care Favours Adjusted Choices
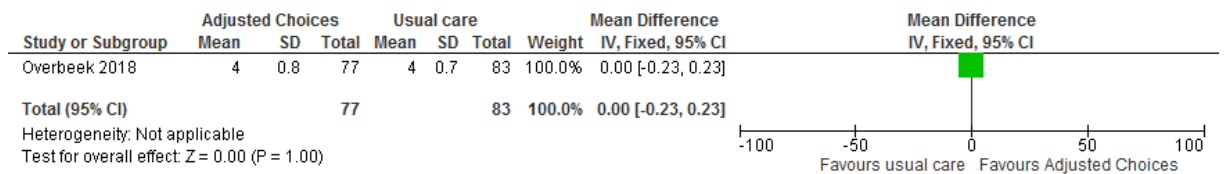
E.4 Palliative assessment, carer consultation, ACP versus usual care

Figure 18:   Carers quality of life at baseline (EQ5D; scale 0-1, low score indicates poor health)
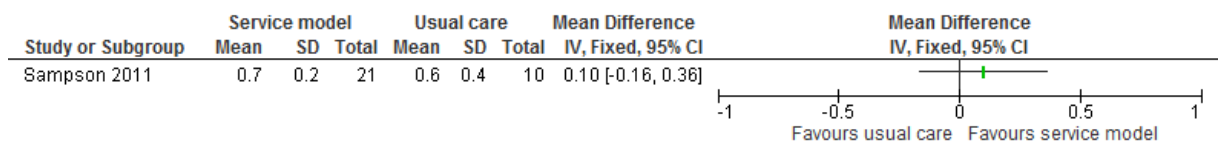
| Study or Subgroup | Service model | | | Usual care | | | Mean Difference | Mean Difference |
	Mean	SD	Total	Mean	SD	Total	IV, Fixed, 95% CI	IV, Fixed, 95% CI
Sampson 2011	0.7	0.2	21	0.6	0.4	10	0.10 [-0.16, 0.36]	

-1 -0.5 0 0.5 1
Favours usual care Favours service model

Figure 19:   Carers quality of life at 6 weeks (EQ5D; scale 0-1, low score indicates poor health)

| Study or Subgroup | Service model | | | Usual care | | | Mean Difference | Mean Difference |
	Mean	SD	Total	Mean	SD	Total	IV, Fixed, 95% CI	IV, Fixed, 95% CI
Sampson 2011	0.8	0.1	9	0.8	0.1	6	0.00 [-0.10, 0.10]	

-1 -0.5 0 0.5 1
Favours usual care Favours service model
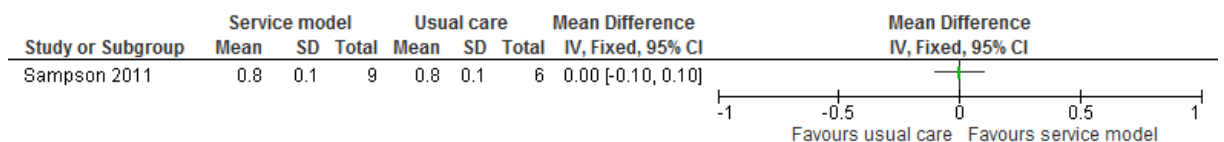
Figure 20:   Carers quality of life at 6 months (EQ5D; scale 0-1, low score indicates poor health)

| Study or Subgroup | Service model | | | Usual care | | | Mean Difference | Mean Difference |
	Mean	SD	Total	Mean	SD	Total	IV, Fixed, 95% CI	IV, Fixed, 95% CI
Sampson 2011	0.8	0.1	7	0.8	0.1	4	0.00 [-0.12, 0.12]	

-1 -0.5 0 0.5 1
Favours usual care Favours service model
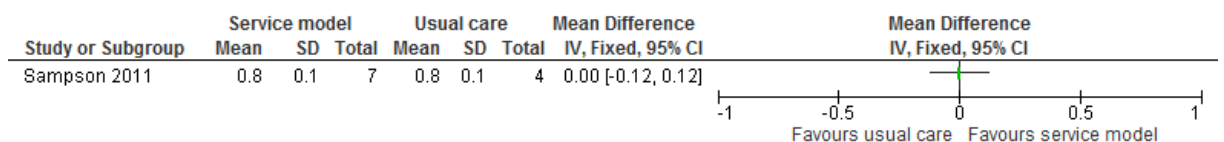
Figure 21:   Carers quality of life post bereavement (EQ5D; scale 0-1, low score indicates poor health)

| Study or Subgroup | Service model | | | Usual care | | | Mean Difference | Mean Difference |
	Mean	SD	Total	Mean	SD	Total	IV, Fixed, 95% CI	IV, Fixed, 95% CI
Sampson 2011	0.6	0.3	4	0.9	0	1	Not estimable	

-1 -0.5 0 0.5 1
Favours usual care Favours service model
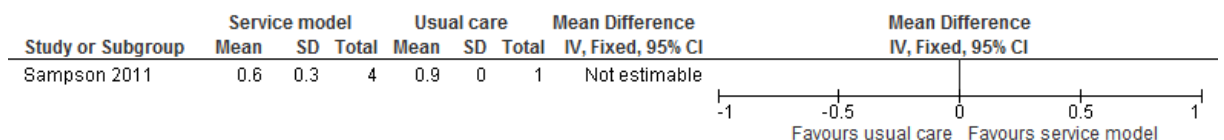
Figure 22:   **Carers life satisfaction at baseline (LSQ; scale 0-7, high score indicates best possible outcome)**

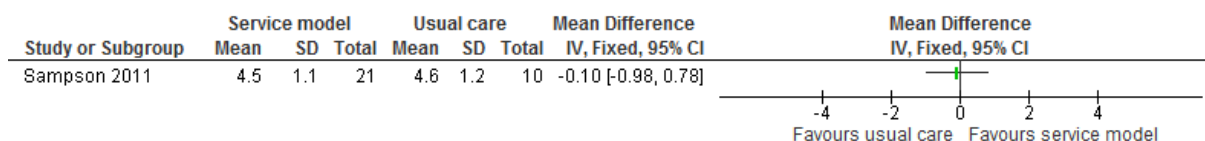| Study or Subgroup	Service model Mean	SD	Total	Usual care Mean	SD	Total	Mean Difference IV, Fixed, 95% CI
Sampson 2011	4.5	1.1	21	4.6	1.2	10	-0.10 [-0.98, 0.78]

Mean Difference IV, Fixed, 95% CI
Favours usual care   Favours service model

Figure 23:   **Carers life satisfaction at 6 weeks (LSQ; scale 0-7, high score indicates best possible outcome)**

Study or Subgroup	Service model Mean	SD	Total	Usual care Mean	SD	Total	Mean Difference IV, Fixed, 95% CI
Sampson 2011	4.9	1.3	9	5.5	0.6	6	-0.60 [-1.58, 0.38]

Mean Difference IV, Fixed, 95% CI
Favours usual care   Favours service model
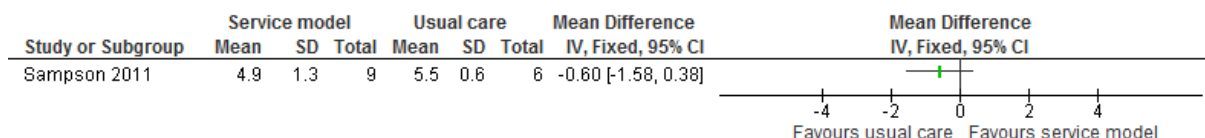
Figure 24:   **Carers life satisfaction at 6 months (LSQ; scale 0-7, high score indicates best possible outcome)**

Study or Subgroup	Service model Mean	SD	Total	Usual care Mean	SD	Total	Mean Difference IV, Fixed, 95% CI
Sampson 2011	5.4	0.9	7	5.5	0.6	4	-0.10 [-0.99, 0.79]

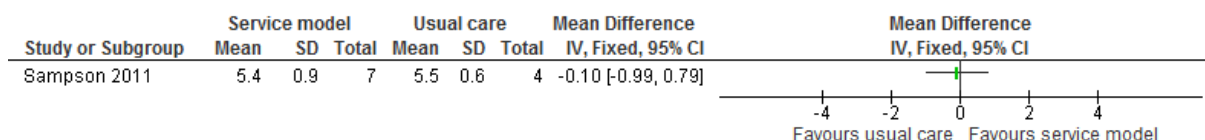Mean Difference IV, Fixed, 95% CI
Favours usual care   Favours service model

Figure 25:   **Carers life satisfaction post-bereavement (LSQ; scale 0-7, high score indicates best possible outcome)**

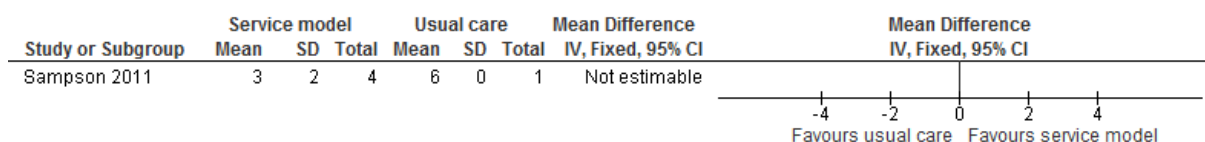| Study or Subgroup	Service model Mean	SD	Total	Usual care Mean	SD	Total	Mean Difference IV, Fixed, 95% CI
Sampson 2011	3	2	4	6	0	1	Not estimable

Mean Difference IV, Fixed, 95% CI
Favours usual care   Favours service model

Figure 26:   **Carers decision satisfaction at baseline (DSI; range 10-50; high score indicates less satisfaction)**

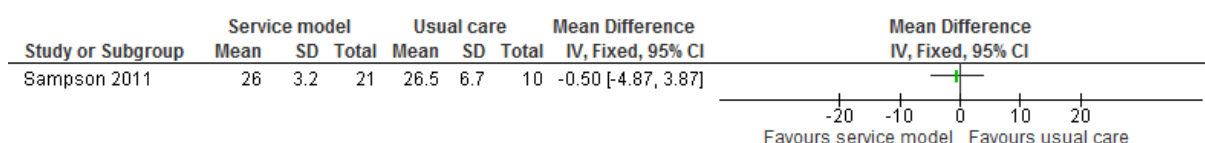| Study or Subgroup	Service model Mean	SD	Total	Usual care Mean	SD	Total	Mean Difference IV, Fixed, 95% CI
Sampson 2011	26	3.2	21	26.5	6.7	10	-0.50 [-4.87, 3.87]

Mean Difference IV, Fixed, 95% CI
Favours service model   Favours usual care

Figure 27:   **Carers decision satisfaction at 6 weeks (DSI; range 10-50; high score indicates less satisfaction)**

Study or Subgroup	Service model Mean	SD	Total	Usual care Mean	SD	Total	Mean Difference IV, Fixed, 95% CI
Sampson 2011	21.8	6.6	9	22	8.1	6	-0.20 [-7.98, 7.58]

Mean Difference IV, Fixed, 95% CI
Favours service model   Favours usual care
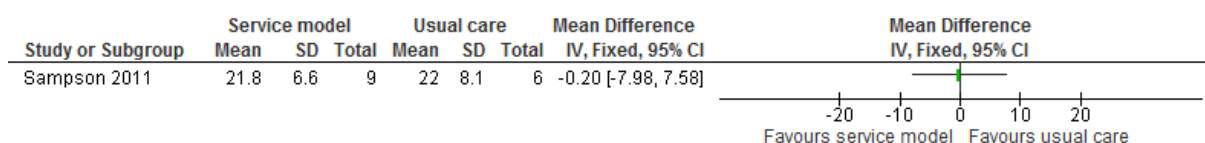
Figure 28:   **Carers decision satisfaction at 6 months (DSI; range 10-50; high score indicates less satisfaction)**

| Study or Subgroup | Service model | | | Usual care | | | Mean Difference | Mean Difference |
	Mean	SD	Total	Mean	SD	Total	IV, Fixed, 95% CI	IV, Fixed, 95% CI
Sampson 2011	22.2	7.9	7	16.3	4.8	4	5.90 [-1.61, 13.41]	

-20   -10   0   10   20
Favours service model   Favours usual care
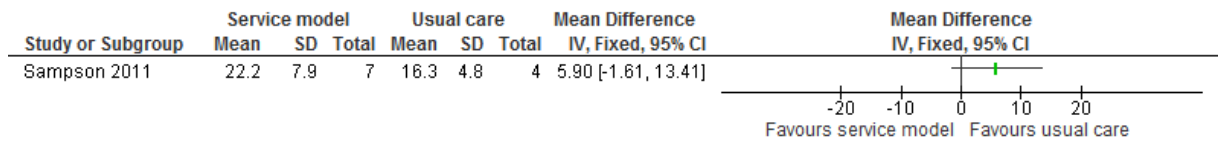
Figure 29: **Carers decision satisfaction post-bereavement (DSI; range 10-50; high score indicates less satisfaction)**

| Study or Subgroup | Service model | | | Usual care | | | Mean Difference | Mean Difference |
	Mean	SD	Total	Mean	SD	Total	IV, Fixed, 95% CI	IV, Fixed, 95% CI
Sampson 2011	28	7.2	4	32	0	1	Not estimable	

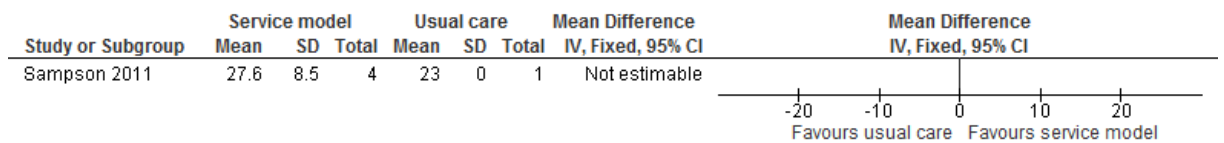-20   -10   0   10   20
Favours service model   Favours usual care
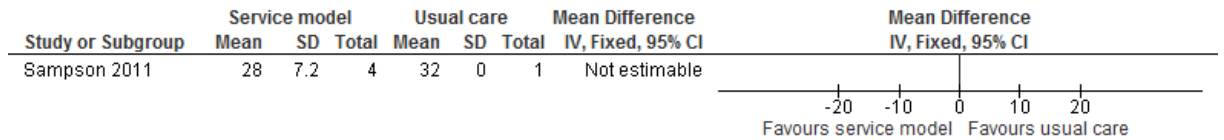
Figure 30: **Carers satisfaction with end of life care post-bereavement (SWC-EOLCD; range 10-40; high score indicates greater satisfaction)**

| Study or Subgroup | Service model | | | Usual care | | | Mean Difference | Mean Difference |
	Mean	SD	Total	Mean	SD	Total	IV, Fixed, 95% CI	IV, Fixed, 95% CI
Sampson 2011	27.6	8.5	4	23	0	1	Not estimable	

-20   -10   0   10   20
Favours usual care   Favours service model

Appendix F: GRADE tables

Table 14: **Clinical evidence profile: AMBER care bundle versus usual care**

No of studies	Quality assessment						No of patients		Effect		Quality	Importance
	Design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations	AMBER care bundle	Usual care	Relative (95% CI)	Absolute		
Length of hospital stay (days) (follow-up 4-10 months; Better indicated by lower values)												
1	observational studies[a]	no serious risk of bias	no serious inconsistency	no serious indirectness	very serious	none	41	19	-	MD 9 lower (19.89 lower to 1.89 higher)	⊕OOO VERY LOW	IMPORTANT
Number of residents wishing to die at home (next of kin opinion) (follow-up 4-10 months)												
1	observational studies[a]	no serious risk of bias	no serious inconsistency	serious[b]	very serious[3]	none	23/51 (45.1%)	11/28 (39.3%)	RR 1.15 (0.66 to 1.99)	59 more per 1000 (from 134 fewer to 389 more)	⊕OOO VERY LOW	CRITICAL
Number of residents wishing to die at hospice (next of kin opinion) (follow-up 4-10 months)												
1	observational studies[a]	no serious risk of bias	no serious inconsistency	serious[b]	very serious[c]	none	12/51 (23.5%)	4/28 (14.3%)	RR 1.65 (0.59 to 4.63)	93 more per 1000 (from 59 fewer to 519 more)	⊕OOO VERY LOW	CRITICAL
Number of residents wishing to die at hospital (next of kin opinion) (follow-up 4-10 months)												
1	observational studies[a]	no serious risk of bias	no serious inconsistency	serious[b]	serious[c]	none	11/51 (21.6%)	10/28 (35.7%)	RR 0.6 (0.29 to 1.24)	143 fewer per 1000 (from 254 fewer to 86 more)	⊕OOO VERY LOW	CRITICAL
Number of residents wishing to die at care home (next of kin opinion) (follow-up 4-10 months)												
1	observational studies[a]	no serious risk of bias	no serious inconsistency	serious[b]	very serious[c]	none	3/51 (5.9%)	3/28 (10.7%)	RR 0.55 (0.12 to 2.54)	48 fewer per 1000 (from 94 fewer to 165 more)	⊕OOO VERY LOW	CRITICAL

No of studies	Design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations			Relative (95% CI)	Absolute	Quality	Importance
Number of residents wishing to die elsewhere (next of kin opinion) (follow-up 4-10 months)												
1	observational studies[a]	no serious risk of bias	no serious inconsistency	serious[b]	very serious[c]	none	2/51 (3.9%)	0/28 (0%)	RR 2.79 (0.14 to 56.13)	-	⊕◯◯◯ VERY LOW	CRITICAL
Number of residents dying in home (follow-up 4-10 months)												
1	observational studies[a]	no serious risk of bias	no serious inconsistency	serious[b]	very serious[c]	none	12/59 (20.3%)	3/35 (8.6%)	RR 2.37 (0.72 to 7.83)	117 more per 1000 (from 24 fewer to 585 more)	⊕◯◯◯ VERY LOW	CRITICAL
Number of residents dying in hospice (follow-up 4-10 months)												
1	observational studies[a]	no serious risk of bias	no serious inconsistency	serious[b]	very serious[c]	none	12/59 (20.3%)	3/35 (8.6%)	RR 2.37 (0.72 to 7.83)	117 more per 1000 (from 24 fewer to 585 more)	⊕◯◯◯ VERY LOW	CRITICAL
Number of residents dying in hospital (follow-up 4-10 months)												
1	observational studies[a]	no serious risk of bias	no serious inconsistency	serious[b]	serious[c]	none	30/59 (50.8%)	24/35 (68.6%)	RR 0.74 (0.53 to 1.04)	178 fewer per 1000 (from 322 fewer to 27 more)	⊕◯◯◯ VERY LOW	CRITICAL
Number of residents dying in care home (follow-up 4-10 months)												
1	observational studies[a]	no serious risk of bias	no serious inconsistency	serious[b]	very serious[c]	none	5/59 (8.5%)	5/35 (14.3%)	RR 0.59 (0.18 to 1.91)	59 fewer per 1000 (from 117 fewer to 130 more)	⊕◯◯◯ VERY LOW	CRITICAL

[a] Downgraded by 2 increments if the majority of the evidence was from studies with observational/non-randomised study design. 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 or 2 increments because the majority of the evidence had indirect outcomes
[c] Downgraded by 1 increment if the confidence interval crossed 1 MID or by 2 increments if the confidence interval crossed both MIDs

Table 15: **Clinical evidence profile: Training program versus usual care**

	Quality assessment						No of patients		Effect		Quality	Importance
No of studies	Design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations	Training program	Usual care	Relative (95% CI)	Absolute		

Number of residents dying in care home (follow-up mean 2 years)

1	observational studies[a]	no serious risk of bias	no serious inconsistency	serious[b]	serious[c]	none	22/29 (75.9%)	14/30 (46.7%)	RR 1.63 (1.05 to 2.51)	294 more per 1000 (from 23 more to 705 more)	⊕○○○ VERY LOW	CRITICAL

Number of residents dying in hospital (follow-up mean 2 years)

1	observational studies[a]	no serious risk of bias	no serious inconsistency	serious[b]	serious[c]	none	7/29 (24.1%)	16/30 (53.3%)	RR 0.45 (0.22 to 0.94)	293 fewer per 1000 (from 32 fewer to 416 fewer)	⊕○○○ VERY LOW	CRITICAL

[a] Downgraded by 2 increments if the majority of the evidence was from studies with observational/non-randomised study design. 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 or 2 increments because the majority of the evidence had indirect outcomes
[c] Downgraded by 1 increment if the confidence interval crossed 1 MID or by 2 increments if the confidence interval crossed both MIDs

Table 16: Clinical evidence profile: Adjusted Choices versus Usual care

Quality assessment							No of patients		Effect		Quality	Importance
No of studies	Design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations	Adjusted Choices	Usual care	Relative (95% CI)	Absolute		
SF_12 Physical component (follow-up 12 months; range of scores: 0-100; Better indicated by higher values)												
1	randomised trials	Serious[a]	no serious inconsistency	no serious indirectness	Serious[b]	none	77	83	-	MD 2 lower (4.95 lower to 0.95 higher)	⊕⊕○○ LOW	CRITICAL
SF_12 Mental component (follow-up 12 months; range of scores: 0-100; Better indicated by higher values)												
1	randomised trials	Serious[a]	no serious inconsistency	no serious indirectness	Serious[b]	none	77	83	-	MD 2 higher (1.55 lower to 5.55 higher)	⊕⊕○○ LOW	CRITICAL
Patient Satisfaction (PSQ-18 _1subscale) (follow-up 12 months; range of scores: 1-5; Better indicated by higher values)												
1	randomised trials	Serious[a]	no serious inconsistency	no serious indirectness	no serious imprecision	none	77	83	-	MD 0 higher (0.23 lower to 0.23 higher)	⊕⊕⊕○ MODERATE	IMPORTANT

74

a Downgraded by 1 increment for risk of bias
b Downgraded by 1 increment if the confidence interval crossed by 1 MID

Table 17:   Clinical evidence profile: Training program versus usual care

No of studies	Design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations	Palliative assessment, carer consultation, ACP	Usual care	Relative (95% CI)	Absolute	Quality	Importance
			Quality assessment				**No of patients**		**Effect**			
Carers quality of life at baseline (EQ5D; scale 0-1, low score indicates poor health) (follow-up mean 6 months; Better indicated by higher values)												
1	randomised trials	very serious[a]	no serious inconsistency	no serious indirectness	very serious[b]	none	21	10	-	MD 0.1 higher (0.16 lower to 0.36 higher)	⊕○○○ VERY LOW	CRITICAL
Carers quality of life at 6 weeks (EQ5D; scale 0-1, low score indicates poor health) (follow-up mean 6 months; Better indicated by higher values)												
1	randomised trials	very serious[a]	no serious inconsistency	no serious indirectness	very serious[b]	none	9	6	-	MD 0 higher (0.1 lower to 0.1 higher)	⊕○○○ VERY LOW	CRITICAL
Carers quality of life at 6 months (EQ5D; scale 0-1, low score indicates poor health) (follow-up mean 6 months; Better indicated by higher values)												
1	randomised trials	very serious[a]	no serious inconsistency	no serious indirectness	very serious[b]	none	7	4	-	MD 0 higher (0.12 lower to 0.12 higher)	⊕○○○ VERY LOW	CRITICAL
Carers quality of life at post-bereavement (EQ5D; scale 0-1, low score indicates poor health) (follow-up mean 6 months; Better indicated by higher values)												
1	randomised trials	very serious[a]	no serious inconsistency	no serious indirectness	no serious imprecision	none	4	1	-	MD 0.3 lower (0 to 0 higher)[3]	⊕⊕○○ LOW	CRITICAL
Carers life satisfaction at baseline (LSQ; scale 0-7, high score indicates best possible outcome) (follow-up mean 6 months; Better indicated by higher values)												
1	randomised trials	very serious[a]	no serious inconsistency	no serious indirectness	very serious[b]	none	21	10	-	MD 0.1 lower (0.98 lower to 0.78 higher)	⊕○○○ VERY LOW	IMPORTANT

Carers life satisfaction at 6 weeks (LSQ; scale 0-7, high score indicates best possible outcome) (follow-up mean 6 months; Better indicated by higher values)

1	randomised trials	very serious[a]	no serious inconsistency	no serious indirectness	serious[b]	none	9	6	-	MD 0.6 lower (1.58 lower to 0.38 higher)	⊕OOO VERY LOW	IMPORTANT

Carers life satisfaction at 6 months (LSQ; scale 0-7, high score indicates best possible outcome) (follow-up mean 6 months; Better indicated by higher values)

1	randomised trials	very serious[a]	no serious inconsistency	no serious indirectness	very serious[b]	none	7	4	-	MD 0.1 lower (0.99 lower to 0.79 higher)	⊕OOO VERY LOW	IMPORTANT

Carers life satisfaction at post-bereavement (LSQ; scale 0-7, high score indicates best possible outcome) (follow-up mean 6 months; Better indicated by higher values)

1	randomised trials	very serious[a]	no serious inconsistency	no serious indirectness	very serious[b]	none	4	1	-	MD 3 lower (0 to 0 higher)[3]	⊕OOO VERY LOW	IMPORTANT

Carers decision satisfaction at baseline (DSI; range 10-50; high score indicates less satisfaction) (follow-up mean 6 months; Better indicated by lower values)

1	randomised trials	very serious[a]	no serious inconsistency	no serious indirectness	very serious[b]	none	21	10	-	MD 0.5 lower (4.86 lower to 3.86 higher)	⊕OOO VERY LOW	IMPORTANT

Carers decision satisfaction at 6 weeks (DSI; range 10-50; high score indicates less satisfaction) (follow-up mean 22 months; Better indicated by lower values)

1	randomised trials	very serious[a]	no serious inconsistency	no serious indirectness	very serious[b]	none	9	6	-	MD 0.2 lower (7.98 lower to 7.58 higher)	⊕OOO VERY LOW	IMPORTANT

Carers decision satisfaction at 6 months (DSI; range 10-50; high score indicates less satisfaction) (follow-up mean 6 months; Better indicated by lower values)

1	randomised trials	very serious[a]	no serious inconsistency	no serious indirectness	very serious[b]	none	7	4	-	MD 5.9 higher (1.61 lower to 13.41 higher)	⊕OOO VERY LOW	IMPORTANT

Carers decision satisfaction at post-bereavement (DSI; range 10-50; high score indicates less satisfaction) (follow-up mean 6 months; Better indicated by lower values)

1	randomised trials	very serious[a]	no serious inconsistency	no serious indirectness	no serious imprecision	none	4	1	-	MD 4 lower (0 to 0 higher)[3]	⊕⊕OO LOW	IMPORTANT

Carers satisfaction with end of life care at post-bereavement (SWC-EOLCD; range 10-40; high score indicates greater satisfaction) (follow-up mean 6 months; Better indicated by higher values)

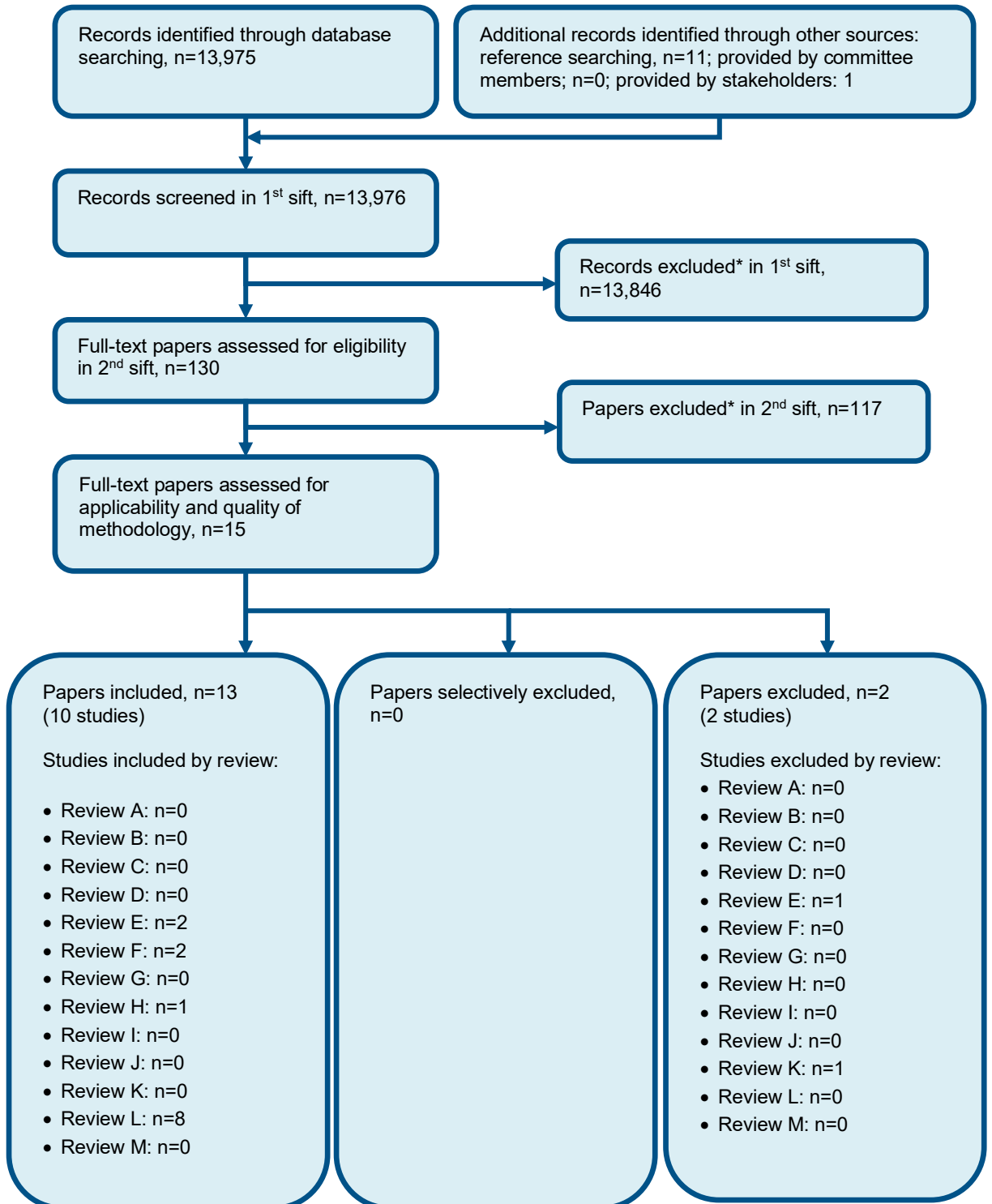| 1	randomised trials	very serious[a]	no serious inconsistency	no serious indirectness	no serious imprecision	none	4	1	-	MD 4.6 higher (0 to 0 higher)[3]	⊕⊕OO LOW	IMPORTANT

[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
[c] Not estimable

Appendix G: Health economics study selection

Figure 31: **Flow chart of health economic study selection for the guideline**

```
┌─────────────────────────────────┐   ┌─────────────────────────────────────────┐
│ Records identified through       │   │ Additional records identified through     │
│ database searching, n=13,975     │   │ other sources: reference searching, n=11; │
│                                  │   │ provided by committee members; n=0;       │
│                                  │   │ provided by stakeholders: 1               │
└─────────────────────────────────┘   └─────────────────────────────────────────┘
                    │                                    │
                    ▼◄───────────────────────────────────┘
┌─────────────────────────────────┐
│ Records screened in 1st sift,    │
│ n=13,976                         │          ┌─────────────────────────────┐
└─────────────────────────────────┘          │ Records excluded* in 1st     │
                    │───────────────────────► │ sift, n=13,846               │
                    ▼                          └─────────────────────────────┘
┌─────────────────────────────────┐
│ Full-text papers assessed for    │
│ eligibility in 2nd sift, n=130   │          ┌─────────────────────────────┐
└─────────────────────────────────┘          │ Papers excluded* in 2nd      │
                    │───────────────────────► │ sift, n=117                  │
                    ▼                          └─────────────────────────────┘
┌─────────────────────────────────┐
│ Full-text papers assessed for    │
│ applicability and quality of      │
│ methodology, n=15                │
└─────────────────────────────────┘
```

Papers included, n=13 (10 studies)	Papers selectively excluded, n=0	Papers excluded, n=2 (2 studies)
Studies included by review:		Studies excluded by review:
• Review A: n=0		• Review A: n=0
• Review B: n=0		• Review B: n=0
• Review C: n=0		• Review C: n=0
• Review D: n=0		• Review D: n=0
• Review E: n=2		• Review E: n=1
• Review F: n=2		• Review F: n=0
• Review G: n=0		• Review G: n=0
• Review H: n=1		• Review H: n=0
• Review I: n=0		• Review I: n=0
• Review J: n=0		• Review J: n=0
• Review K: n=0		• Review K: n=1
• Review L: n=8		• Review L: n=0
• Review M: n=0		• Review M: n=0

* Non-relevant population, intervention, comparison, design or setting; non-English language

Appendix H: Health economic evidence selection

Study	Overbeek el al. 2019{3558}			
Study details	**Population & interventions**	**Costs**	**Health outcomes**	**Cost effectiveness**
Economic analysis: CCA [(a)] **Study design:** RCT Within-trial analysis **Approach to analysis:** Analysis of the total costs for the interventions, multiplied by the individual level healthcare use and costs (obtained within trial), to get the costs per group. The QoL measured via SF-12 was reported but not used in the analysis. **Perspective:** Netherlands healthcare **Time horizon/Follow-up:** 12 months **Discounting:** n/a	**Population:** Adults living at home or in residential care homes or receiving home care aged 75 years and older and frail (Tilburg Frailty Index > 5, range 0-15). **Patient characteristics:** N: 201 Mean age: 86 years (SD: 5.5) Male intervention 1: 28% Male intervention 2: 32% **Intervention 1:** Usual care: No identified service model to facilitate or support ACP **Intervention 2:** ACP: based on Respecting Choices ACP facilitator training, education materials, and tools. The program involves trained facilitators who assist individuals in exploring the understanding of their illness reflecting on goals, values, and beliefs; discussing healthcare preferences and appointing a	**Total costs (mean per patient):** [(b)] Intervention 1: £31,985 Intervention 2: £24,048 Incremental (2−1): Saves £7,937 (95% CI: NR; p=NR) **Intervention costs (fixed + variable) (mean per patient):** [(c)] £259 **Total medical care costs (mean per patient):** Intervention 1: £1,930 Intervention 2: £2,038 Incremental (2−1): £108 (95% CI: NR; p=0.36) **Total costs of inpatient days in residential care homes (mean per patient):** Intervention 1: £23,441 Intervention 2: £14,951 Incremental (2−1): Saves £8,490 (95% CI: NR; p=NR) **Total costs of home care (mean per patient):** Intervention 1: £6,614 Intervention 2: £6,800 Incremental (2−1): £186 (95% CI: NR; p=NR) **Currency & cost year:**	**SF-12 physical component score:** Intervention 1: Baseline: 33 Follow-up: 34 Change: 1 Intervention 2: Baseline: 31 Follow-up: 32 Change: 1 Incremental (2−1): 0 (95% CI: NR; p=NR) **SF-12 mental component score:** Intervention 1: Baseline: 50 Follow-up: 46 Change: 4 Intervention 2: Baseline: 52 Follow-up: 48 Change: 4 Incremental (2−1): no change (95% CI: NR; p=NR)	**Overall** Since there was no difference in health outcomes, ACP dominates (based on total costs). **Analysis of uncertainty:** Statistical analyses were conducted according to the intention-to-treat principle, using chi-square tests and analysis of variance (ANOVA). Costs of medical care was compared using multilevel analyses, adjusting for clustering effects at residential care home level and differences in demographics.

| | surrogate decision-maker (modified for Dutch context). Nurses trained to deliver the intervention. Three day training. The intervention had 3 core elements; information provision through leaflets; facilitated ACP conversations based on scripted interview cards; and completion of an advance directive, including appointment of a surrogate decision- maker. | 2014 Dutch Euros (presented here as 2014 UK pounds[d]) **Cost components incorporated:** (1) costs of medical care including hospital care (ED visits, hospital stays, ICU care, diagnostic procedures [e.g. blood transfusion or CT scan], medical interventions [e.g. surgery or cardiopulmonary resuscitation] and medication, (2) costs of inpatient days in residential care homes including nursing and/or medical care, residential care housing and daytime activities and (3) costs of home care including nursing care and domestic help. | | |

Data sources

Health outcomes: From Trial registration number; NTR4454 – See Overbeek (2018){3533}.. **Quality-of-life weights:** N/A. N/A. **Cost sources:** The cost of the ACP programme was determined by micro-costing. Medical care: Multiplying the volumes of medical care use with the corresponding cost prices. Hospital care: calculation of hospital care, diagnostic procedures and medical interventions, charges were used as a proxy for real costs. A 'fee-for-service' system is available in the Netherlands for the remuneration of diagnostic procedures and medical interventions. Medication use: The average cost prices per day were used. Only expensive medication, operationalised as a cost price of >€10 per day, was considered in the analysis. Inpatient care: Costs of inpatient days in residential care homes and costs of home care were estimated as real, basic costs per day or per hour, respectively, using detailed administrative information from the care organisation. Costs of medical care were calculated by multiplying the volumes of medical care use with the corresponding cost prices. For the calculation of hospital care, diagnostic procedures and medical interventions, charges were used as a proxy for real costs. Costs of residential care were from care organisation.

Comments

Source of funding: Netherlands Organisation for Health Research and Development project 837001009. **Limitations:** Not UK NHS perspective, not clear if all costs would fall within an NHS and personal social services perspective, no QALYs. Charges used as a proxy for costs. No sensitivity analysis **Other:**

Overall applicability:[e] *Partially applicable*   **Overall quality:**[f] *Potentially serious limitations*

Abbreviations: ACP=Advanced care planning; CCA= cost–consequences analysis; 95% CI= 95% confidence interval; CT=computed tomography; ED=emergency department; ICU=intensive care unit; N/A= not applicable; NR= not reported; pa= probabilistic analysis; QoL= quality of life; RCT=randomised controlled trial; SF= short form

(a) Overbeek et al 2018{3533}., report quality of life using the SF-12 and satisfaction (PSQ-18) questionnaire.
(b) This was calculated per patient by adding the costs of; intervention, the average medical care costs, use and costs of inpatient and residential settings and home care total costs.
(c) The cost was calculated per patient by dividing the total ACP programme fixed costs (£18,786) by the number of participants who received the ACP (n=97) added to the variable cost of ACP (£66).
(d) Converted using 2014 purchasing power parities{OECDPPP}
(e) Directly applicable / Partially applicable / Not applicable
(f) Minor limitations / Potentially serious limitations / Very serious limitations

Study	Pham 2014[174]			
Study details	**Population & interventions**	**Costs**	**Health outcomes**	**Cost effectiveness**
Economic analysis: CUA[(a)] **Study design:** Probabilistic decision analytic markov model (microsimulation) **Approach to analysis:** Each intervention was compared to usual care as the interventions were not considered mutually exclusive; could be used in combination to improve the quality of EOL care. Pathways generated (with associated health outcomes and costs) for each patient in cohort (microsimulation) and averages derived from sum of simulated data. Markov model used to simulate patterns of EOL care; related health care utilisation and recurrent events experienced (for example: ED visits, hospital admissions). 1-	**Population:** A cohort of Ontarian decedents (average age 72, approx. 50% female) and their primary informal caregivers (average age 56, approx. 68% female) **Intervention 1:** Usual care (see Table 18) **Intervention 2:** PTC: In-home (see Table 18) **Intervention 3:** PTC: Inpatient (see Table 18) **Intervention 4:** PTC: Comprehensive (see Table 18) **Intervention 5:** PCPDs: Identifying LTC residents with EoL goals and preferences for EPC (see Table 18) **Intervention 6:** PCPDs: Ethics consultation for ICU patients with treatment conflicts	**Total costs (mean per patient):** Intervention 1: £28,065 Intervention 2: £25,588 Intervention 3: £27,145 Intervention 4: £28,360 Intervention 5: £28,051 Intervention 6: £28,018 Intervention 7: £28,096 Intervention 8: £30,733 Intervention 9: £28,175 Incremental (2−1): saves £2,477 Incremental (3−1): saves £920 Incremental (4−1): £295 Incremental (5−1): saves £15 Incremental (6−1): saves £48 Incremental (7−1): £31 Incremental (8−1): £2,668 Incremental (9−1): £110 (95% CI: NR; p=NR) **Currency & cost year:**	**QALDs (mean total of patient and caregiver):** Intervention 1: 518.53 Intervention 2: 519.00 Intervention 3: 518.80 Intervention 4: 521.18 Intervention 5: 518.54 Intervention 6: 518.63 Intervention 7: 519.02 Intervention 8: 522.16 Intervention 9: 519.35 Incremental (2−1): 0.47 Incremental (3-1): 0.27 Incremental (4-1): 2.65 Incremental (5-1): 0.01 Incremental (6-1): 0.10 Incremental (7-1): 0.49 Incremental (8-1): 3.63 Incremental (9-1): 0.82 (95% CI: NR; p=NR)	**ICER (Intervention 2 versus Intervention 1):** Dominant 95% CI: NR **ICER (Intervention 3 versus Intervention 1):** Dominant 95% CI: NR **ICER (Intervention 4 versus Intervention 1):** £40,632.49 per QALY gained 95% CI: NR **ICER (Intervention 5 versus Intervention 1):** Dominant 95% CI: NR **ICER (Intervention 6 versus Intervention 1):** Dominant 95% CI: NR **ICER (Intervention 7 versus Intervention 1):** £23,092.97 per QALY gained 95% CI: NR **ICER (Intervention 8 versus Intervention 1):** £268,270.12 per QALY gained 95% CI: NR

day cycle length with simulation starting at 1st day of last year of life, tracking daily events for the following 365 days. Model accounted for a proportion of patients who were designated with a palliative prognosis before last year of life. On any day, simulated patients could begin receiving home care services, be admitted to LTC, visit the ED, or be admitted to hospital. Simulated patients with a palliative prognosis could receive a combination of acute or palliative services at home, in LTC, or in hospital. All decedents assumed to die on the 365th day. **Perspective:** Ontario Ministry of Health and Long-Term Care **Time horizon/Follow-up** 1 year **Discounting:** Costs: 0%; Outcomes: 0% (Time horizon 1-year)	(see Table 18) **Intervention 7:** PCPDs: Improving family conferences for relatives of patients dying in the ICU (see Table 18) **Intervention 8:** Multicomponent psycho-educational interventions for patients and families (see Table 18) **Intervention 9:** Supportive interventions for informal caregivers (see Table 18)	2013 Canadian dollars (presented here as 2013 UK pounds[b]) **Cost components incorporated:** Time specific daily healthcare costs in the last year of life (ED visit, Hospital care, Home care, LTC, Rehabilitation, Outpatient visit, Physician, Drugs/devices, other); Other daily healthcare costs in the last year of life (ICU stay, CCC stay, Non-home hospice stay, ALC, PWC stay); resources required to deliver the interventions and their associated costs.		**ICER (Intervention 9 versus Intervention 1):** £48,965.06 per QALY gained 95% CI: NR **Analysis of uncertainty:** A number of probabilistic and one-way sensitivity analyses conducted to explore key sources of variability and uncertainty in the simulated model. Model calibration (via visual inspection) was performed to ensure model projections were consistent with observed data for the HQO ICES and OHRI ICES cohorts. The sensitivity analysis found that the results were uncertain for interventions 2, 3, 4, 5, 6, 7, 8 and 9 and might change with additional data.

Data sources

Data was obtained from two EoL cohorts for tracked patterns of care and health care resource utilisation in 12 months before death from linked administration databases at ICES. One cohort consisted of 265,284 Ontario decedents from January 1 2007 to December 31 2009 referred to as the HQO ICES cohort. The other cohort consisted of 175,478 Ontarian decedents from April 1 2010 to March 31 2012, referred to as the OHRI ICES cohort. **Health outcomes:**

Natural history (proportion of patients with a palliative prognosis) was derived using the OHRI ICES summary data. Summary data from the ICES cohorts were used to quantify patterns of EoL care practice in Ontario. Usual care included some provision of services related to the intervention strategies. Monthly data from the HQO ICES cohort were used to estimate daily transition rates. Effectiveness evidence for in-home palliative care team was derived from an RCT comparing the intervention to a control group, in the analysis this was assumed to the the same as the usual care strategy. For all interventions the summary estimates of effectiveness were derived using data from RCTs obtained through SRs of the literature; where appropriate pooled effects were calculated using a random effects approach. **Quality-of-life weights:** Pooled effect size from 3 RCTs using HRQOL scale specific to EOL (Functional Assessment of Chronic Illness Therapy – Spiritual Well-Being, scale) was estimated for comprehensive palliative care team. Assumption was made that generic instruments (EQ-5D) would be less responsive by a relative reduction of 0.8 therefore effect size was converted by multiplying by the reduction factor. Absolute QALY weight change scores were estimated by multiplying by an assumed standard deviation of 0.18. The absolute QALY weight change score was applied to the QALY weights of patients with a palliative prognosis during their hospital days and post discharge days. Duration effect of QALY weight change scores was three months; as summary data for HQO ICES cohort indicated patients were identified with a palliative prognosis approximately 3 months prior to death. Literature searches conducted to obtain decrements in QALY weights for patients with acute conditions that required ED visits, hospital days, ICU days. QALY weight decrements also estimated for caregivers. **Cost sources:** HQO ICES cohort was used to calculate the time specific healthcare costs in the last year of life. A combination of sources including data from the HQO ICES cohort, input from a local CCC facility and the central east residential hospice working group were used to cost the other daily costs in the last year of life. A combination of sources including data from 11 teams in Ontario (Lukas et. al 2013), HQO expert panel, published inputs and inputs from 6 RCTs included in a systematic review were used to estimate the resource use required for the included interventions. Unit costs of staff sourced from CFNU, CIHI and expert opinion.

Comments

Source of funding: Health Quality Ontario **Applicability:** Not a UK study therefore study population and costs not directly appropriate. Not all the interventions in the model were appropriate for the guideline. **Limitations:** Model assumes that last year of life is known which does not reflect reality. Model assumes that interventions do not affect survival time which does not reflect reality. Model assumes that a palliative prognosis can be determined by resource use of patients therefore doesn't account for patients with a terminal illness who do not receive EOL care services in the last year of life, it is not clear how this effects the cost effectiveness results. Cost effectiveness results for in-home palliative care are subject to EOL care in the control group of the RCT study being the same as the usual care strategy; this is unlikely to be true. The model does not explicitly take into account that some of the interventions are currently provided as part of usual care therefore it is likely that the treatment effects are overestimated. Estimating the intervention effect on HRQOL as well as decrements in QALY weights through downstream resource use risks the possibility of double counting. **Other:**

Overall applicability: Partially applicable[c]   **Overall quality: Potentially serious limitations**[d]

Abbreviations: ALC: alternate level of care; CCC: complex continuing care; CFNU: Canadian Federation of Nurses Unions; CIHI: Canadian Institute for Health Information; CEA: cost-effectiveness analysis; 95% CI: 95% confidence interval; CUA: cost–utility analysis; da: deterministic analysis; ED: emergency department; EOL: end of life; EQ-5D: Euroqol 5 dimensions (scale: 0.0 [death] to 1.0 [full health], negative values mean worse than death); EPC: early palliative care; HQO: Health quality Ontario; ICER: incremental cost-effectiveness ratio; ICES: Institute for Clinical Evaluative Sciences; ICU: intensive care unit; LTC: Long term care; NR: not reported; OHRI: Ottawa hospital research institute; pa: probabilistic analysis; QALD: quality-adjusted life day; QALYs: quality-adjusted life years; PCPDs: patient care planning decisions; PCT: palliative care team; PCW: palliative care ward.

(g) *The primary analysis in the study was a CEA and the CUA was conducted as a sensitivity analysis. Only the CUA has been extracted as considered most relevant according to the NICE reference case.*

(h) *Converted using 2013 purchasing power parities[164]*

(i) *Directly applicable / Partially applicable / Not applicable*

(j) *Minor limitations / Potentially serious limitations / Very serious limitations*

Table 18: Interventions, subgroups and timing of intervention strategies

Intervention	Description	Subgroup	Timing of Intervention
Usual Care	Current patterns of EoL care; decedents were identified with a palliative prognosis if they received at least 1 palliative care service (for example: physician billing for palliative consultation)	All decedents (with and without a palliative prognosis in their last year of life); the former received additional interventions listed below	Current patterns of EoL care observed from linked health administrative databases at ICES
Palliative care team			
PTC: In-home	An inter-professional core team that coordinates and delivers palliative services in the home, including the patient and family, a physician, nurse, social worker, and other team members (for example: a bioethicist, a chaplain)	Decedents with a palliative prognosis who received home care	When a palliative prognosis is detected in a decedent receiving home care
PTC: Inpatient	A team that includes a palliative care physician, a nurse, a hospital social worker, and a chaplain. The team assesses the needs of patients with respect to symptom management, psychosocial and spiritual support, and EoL care planning, and provides care and support for patients and informal caregivers	Decedents with a palliative prognosis who received inpatient care	When a palliative prognosis is detected in a decedent receiving hospital care
PTC: Comprehensive	A team with an outpatient clinic and an inpatient consultant team. The core intervention includes consultation and follow-up in the clinic by a physician and a nurse. The team communicates with family physicians. Home care physicians from the team provide back-up support to family physicians doing house calls or direct care	Decedents with a palliative prognosis who received home care or inpatient care	When a palliative prognosis is detected in a decedent receiving home care or hospital care

Intervention	Description	Subgroup	Timing of Intervention
Patient care planning decisions			
PCPDs: Identifying LTC residents with EoL goals and preferences for EPC	A structured interview is used to identify LTC residents with a palliative prognosis. Residents' physicians are notified and asked to authorize a visit by a member of an in-home palliative care team	Decedents with a palliative prognosis in LTC	When a palliative prognosis is detected in a LTC resident
PCPDs: Ethics consultation for ICU patients with treatment conflicts	ICU nurses identify ICU patients with treatment conflicts that could lead to incompatible courses of action. An ethics consultant discusses the conflicts in easily understood ethical terms with the involved parties (for example:, patients, family, attending physicians), facilitates communication, and explores ways to address and resolve the conflicts	Decedents admitted to ICU in the last month of life	When treatment conflicts are identified by ICU nurses
PCPDs: Improving Family conferences for relatives of patients dying in the ICU	A proactive EoL conference involving the ICU team members caring for the patient and family and a brochure to facilitate communication during the conference. The aim of the family conference is to lessen the effects of bereavement for caregivers	Decedents in the ICU and their families	Last ICU stay
Educational Interventions for Patients and Caregivers			
Multicomponent psycho-educational interventions for patients and families	Education is delivered by APNs with palliative care specialty training. The APNs conduct 4 initial structured educational and problem-solving sessions by phone with the patient and caregiver. The educational	Decedents with a palliative prognosis and their families	When a palliative prognosis is detected

Intervention	Description	Subgroup	Timing of Intervention
	approach is designed to encourage patient activation, self-management, and empowerment. The APNs also conduct monthly telephone follow-up until the patient dies		
Supportive Interventions for Informal Caregivers			
Supportive interventions for Informal caregivers	Direct support for caregivers (for example: breaks from caregiving), increasing coping skills (for example: by providing programs that develop problem-solving) and enhancing well-being (for example; by providing counselling, relaxation or psychotherapy)	Caregivers of decedents with a palliative prognosis	When a palliative prognosis is detected

Appendix I: Excluded studies

I.1 Excluded clinical studies

Table 19:   Studies excluded from the clinical review

Reference	Reason for exclusion
Aasmul 2018[1]	No outcomes
Abel 2013[2]	Inappropriate comparison
Agar 2015 [3]	Inappropriate study design
Ahronheim 2000[4]	Inappropriate intervention
Allen 2009[5]	Inappropriate population
Allen 2012[7]	Inappropriate study design
Allen 2012[6]	Inappropriate study design
Allen 2015[8]	Inappropriate population
Almack 2012[9]	Inappropriate study design
Ampe 2015[10]	Inappropriate intervention
Ampe 2016[12]	Inappropriate intervention
Ampe 2016[11]	Inappropriate study design
Amro 2016[13]	Inappropriate comparison
Anon 1995[14]	Inappropriate intervention
Anonymous 2017[15]	inappropriate study design
Aslakson 2015[16]	SR not relevant to pico
Auret 2015[17]	Inappropriate study design
Badger 2009[18]	Inappropriate population
Baidoobonso 2014[19]	SR not relevant to PICO
Bailey 2014[20]	Inappropriate intervention
Baker 2012[21]	Inappropriate population
Becker 2017[22]	Inappropriate study design
Benham-Hutchins 2005[23]	Inappropriate study design
Bernacki 2015[24]	Inappropriate study design and intervention
Bigby 2011[25]	Inappropriate study design
Billings 2014[26]	Inappropriate study design

Reference	Reason for exclusion
Biondo 2016[27]	SR not relevant to pico
Black 2004[28]	Inappropriate study design
Blackford 2012[29]	Inappropriate intervention and study design
Boettcher 2015[30]	Inappropriate population
Bookbinder 2011[31]	No relevant outcome
Boorsma 2008[32]	Inappropriate study design
Bose-Brill 2016[34]	Inappropriate population
Bose-Brill 2016[35]	Inappropriate study design
Bose- Brill 2018 [33]	Inappropriate population
Boyd 2010[36]	Inappropriate study design
Bradley 1997[37]	Inappropriate population and study design
Bradley 1998[38]	Inappropriate population
Bravo 2012[39]	Inappropriate population
Bravo 2016[40]	Inappropriate population
Brazil 2017[41]	Not review population
Brazil 2018[42]	Not review population
Briggs 2004[43]	No relevant outcome
Brinkman-Stoppelenburg 2014[44]	SR not relevant PICO
Bristowe 2014[46]	Inappropriate intervention
Buchanan 2004[48]	Inappropriate comparison
Buchanan 2004[47]	Inappropriate comparison
Butler 2014[50]	Inappropriate study design
Butler 2015[49]	Inappropriate study design
Cadigan 2012[51]	Inappropriate study design
Caplan 2006[52]	Inappropriate intervention
Carey 2015[53]	Inappropriate study design
Carrero Planes 2016[54]	Not in English
Cartwright 2014[55]	Inappropriate study design
Castle 1998[56]	Inappropriate intervention

Reference	Reason for exclusion
Chan 2010[58]	Inappropriate population
Chan 2016[59]	SR not relevant to PICO
Chan 2018[57]	No outcomes
Chen 2015[60]	Inappropriate comparison
Clark 2017[61]	Inappropriate study design
Connolly 2015[62]	Inappropriate study design (abstract only) and intervention
Coulter 2015[63]	Inappropriate comparison
Counsell 2000[64]	Inappropriate population
Courtright 2016[65]	Inappropriate comparison
Danis 2014[67]	Inappropriate intervention
Dargin 2014[68]	Inappropriate intervention
Davison 2007[69]	Inappropriate study design
De Vleminck 2016[70]	Inappropriate study design
Detering 2010[71]	Inappropriate comparison
Dickinson 2013[72]	Inappropriate study design
Dionne-Odom 2017[73]	Not review population
Dixon 2015[74]	No relevant outcome
Doorenbos 2016[75]	Not review population
Downar 2013[76]	Inappropriate study design
Edwin 2016[77]	inappropriate intervention
El-Jawahri 2010[79]	Inappropriate intervention
El-Jawahri 2017[78]	Inappropriate intervention
Epstein 2014[81]	Inappropriate intervention
Epstein 2018[80]	Inappropriate intervention
Evans 2014[82]	Inappropriate study design
Fine 2016[83]	Inappropriate study design
Fried 1994[84]	Inappropriate study design
Garrido 2015[85]	Inappropriate comparison
Gilissen 2017[87]	Inappropriate study design and intervention
Glaudemans 2015[88]	SR not relevant to PICO

Reference	Reason for exclusion
Go 2007[89]	Inappropriate study design
Green 2011[90]	Inappropriate population
Green 2014[91]	Inappropriate study design
Grimaldo 2001[92]	Inappropriate population
Hanson 2017[93]	Inappropriate intervention
Happ 2002[94]	Inappropriate study design and population
Hendriks 2017[95]	Not review population and not our outcomes
Hickman 2016[96]	Inappropriate population
Hilgeman 2014[97]	Inappropriate population
Hinderer 2014[98]	Inappropriate study design
Hing Wong 2016[99]	inappropriate study design
Hogg 2012[100]	Inappropriate study design (abstract only)
Holland 2017[101]	Inappropriate intervention
Holley 2003[102]	Inappropriate study design
Houben 2014[104]	SR not relevant PICO
Houben 2014[103]	Inappropriate study design
Howard 2016[105]	Inappropriate study design
Huang 2016[106]	Inappropriate population
Huber 2017[107]	Inappropriate intervention
Hudson 2016[108]	Inappropriate study design
Hui 2014[109]	Inappropriate study design
In der Schmitten 2011[110]	Inappropriate population
Izumi 2017[111]	Inappropriate study design
Jacobsen 2011[112]	No relevant outcome
Jain 2015[113]	Inappropriate intervention
Janssen 2011[114]	Inappropriate population
Jethwa 2015[115]	SR not relevant to PICO
Jones 2007[117]	Inappropriate study design
Jones 2015[116]	No relevant outcome
Kaambwa [118]	Inappropriate population and intervention

Reference	Reason for exclusion
Kalowes 2015[119]	Inappropriate study design
Karppinen 2014[120]	Inappropriate intervention
Khandelwal 2015[122]	SR not relevant to PICO
Khandelwal 2016[121]	Inappropriate study design
Kim 2017[123]	Inappropriate study design
Kinley 2017[124]	Inappropriate study design and intervention
Kirchhoff 2012[125]	Inappropriate comparison
Klingler 2016[126]	inappropriate outcomes
Knott 2011[127]	Inappropriate population
Ko 2016[128]	Inappropriate population and intervention
Kwak 2014[129]	Inappropriate study design
Lawrence 2009[130]	Inappropriate population
Leung 2017[131]	Not review population
Lewis 2015[133]	Inappropriate study design
Lewis 2016[132]	Study designs and inappropriate interventions
Lim 2016[134]	SR not relevant to PICO
Litzelman 2017[135]	Inappropriate population
Litzelman 2017[136]	inappropriate intervention
Lord 2015[138]	SR not relevant to PICO
Luckett 2014[139]	SR not relevant to PICO
Lum 2016[140]	Inappropriate study design
Lum 2017[141]	Not review population
Lustbader 2011[142]	Inappropriate intervention
MacPherson 2013[143]	Inappropriate study design
Markham 2015[144]	Inappropriate population
Martin 2010[145]	Inappropriate study design
Martin 2016[146]	SR not relevant to PICO
McCorkle 2015[147]	Inappropriate intervention
Meehan 2009[148]	Inappropriate study design
Meeussen 2011[149]	Inappropriate study design

Reference	Reason for exclusion
Metzger 2016[150]	Inappropriate population
Mitchell 2014[151]	Inappropriate intervention
Morrell 2008[152]	Inappropriate comparison
Morrison 2005[153]	Inappropriate population
Murray 2016[154]	SR not relevant to pico
Nath 2008[155]	Inappropriate study design
Nathens 2008[156]	Inappropriate study design
Nedjat-Haiem 2017[158]	Inappropaite study design
Nishie 2014[159]	Inappropriate comparison
Obel 2014[161]	Inappropriate study design
Oczkowski 2016[162]	SR not relevant to PICO
Olson 2013[163]	Inappropriate study design (abstract only)
O'Sullivan 2016[160]	inappropriate intervention
Patrick 1997[166]	Inappropriate population
Pautex 2008[168]	Inappropriate comparison
Pautex 2015[167]	Inappropriate study design
Pearlman 2000[169]	Inappropriate study design
Pearlman 2005[170]	Inappropriate population
Pedraza 2017[171]	Unable to locate
Periyakoil 2017[172]	inappropriate intervention
Perry 2003[173]	Inappropriate study design
Pockett 2010[175]	Inappropriate study design
Radhakrishnan 2017[176]	Not review population
Radwany 2014[177]	Inappropriate population
Ratner 2001[178]	Inappropriate study design
Reinke 2017[179]	inappropriate intervention
Rhee 2013[180]	Inappropriate study design
Robinson 2010[181]	Inappropriate study design
Robinson 2012[183]	Inappropriate comparison
Robinson 2013[182]	Inappropriate study design

Reference	Reason for exclusion
Sadeghi 2016[184]	Inappropriate study design
Sander 2010[186]	inappropriate study design
Schaden 2010[187]	Inappropriate study design
Schamp 2006[188]	Inappropriate intervention
Schellinger 2011[189]	Inappropriate study design
Schenker 2015[190]	inappropriate study design
Schmidt 2015[191]	Inappropriate comparison
Schofield 2015[192]	Inappropriate study design
Schwartz 2002[193]	Inappropriate population
Scott 2015[194]	No relevant outcome
Seal 2007[195]	No relevant outcome
Sellars 2015[196]	Inappropriate population and intervention
Sharp 2013[197]	Inappropriate study design
Sinclair 2017[198]	No relevant outcome
Smith 2014[199]	Inappropriate intervention
Song 2005[201]	Inappropriate population
Song 2010[200]	Inappropriate population
Song 2015[202]	Inappropriate study design
Splendore 2017[203]	Not review population
Stein 2013[204]	Inappropriate study design
Sudore 2017[205]	Inappropriate study design
Sumalinog 2016[206]	SR not relevant to PICO
Sung 2017[207]	not review populatioon
Tan 2013[209]	Inappropriate study design
Tan 2014[208]	No relevant outcome
Teno 1997[212]	Inappropriate comparison
Teno 1997[210]	Inappropriate intervention
Teno 1997[211]	No relevant outcome
Thoonsen 2016[213]	Inappropriate study design
Turley 2016[214]	Not review population and inappropriate intervention

Reference	Reason for exclusion
Van Scoy 2017[215]	inappropriate intervention
Vander Laan 2007[216]	Non-free PhD
Vandervoort 2014[217]	Inappropriate comparison
Verreault 2018[218]	Inappropriate intervention
Vogel 2013[219]	Inappropriate intervention
Volandes 2009[221]	Inappropriate intervention
Volandes 2009[220]	Inappropriate intervention
Volandes 2016[222]	Inappropriate intervention
Voss 2017[223]	Inappropriate population and intervention
Walczak 2013[226]	Inappropriate study design
Walczak 2016[224]	SR not relevant to PICO
Walczak 2017[225]	Inappropriate intervention
Weathers 2016[227]	Inappropriate population
Weinick 2008[228]	Inappropriate study design
Wrigley 2016[229]	Inappropriate study design
Yamada 1999[230]	Inappropriate intervention
Young 2017[231]	Inappropriate study design

I.2 Excluded health economic studies

Table 20:   Studies excluded from the health economic review

Reference	Reason for exclusion
Kaambwa 2015[118]	This study was assessed as not applicable as the population in the study was not strictly an end of life population.

1.   Aasmul I, Husebo BS, Sampson EL, Flo E. Advance Care Planning in Nursing Homes - Improving the Communication Among Patient, Family, and Staff: Results From a Cluster Randomized Controlled Trial (COSMOS). Frontiers in Psychology. 2018; 9:2284

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