National Institute for Health and Care Excellence

Draft for consultation

# End of life care for adults: service delivery

## [F] Evidence review: Advance Care Planning

*NICE guideline*

*Evidence review*

*April 2019*

*Draft for consultation*

*This evidence review was developed by the National Guideline Centre*

NICE accredited
www.nice.org.uk/accreditation

**Disclaimer**

The recommendations in this guideline represent the view of NICE, arrived at after careful consideration of the evidence available. When exercising their judgement, professionals are expected to take this guideline fully into account, alongside the individual needs, preferences and values of their patients or service users. The recommendations in this guideline are not mandatory and the guideline does not override the responsibility of healthcare professionals to make decisions appropriate to the circumstances of the individual patient, in consultation with the patient and, where appropriate, their carer or guardian.

Local commissioners and providers have a responsibility to enable the guideline to be applied when individual health professionals and their patients or service users wish to use it. They should do so in the context of local and national priorities for funding and developing services, and in light of their duties to have due regard to the need to eliminate unlawful discrimination, to advance equality of opportunity and to reduce health inequalities. Nothing in this guideline should be interpreted in a way that would be inconsistent with compliance with those duties.

NICE guidelines cover health and care in England. Decisions on how they apply in other UK countries are made by ministers in the Welsh Government, Scottish Government, and Northern Ireland Executive. All NICE guidance is subject to regular review and may be updated or withdrawn.

**Copyright**

© National Institute for Health and Care Excellence, 2017

**ISBN**

[add for final publication version only, delete this text for consultation version]

# Contents

# 1 Advance Care Planning

## 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<br>• Service models to facilitate or support ACP *versus* other service model to facilitate or support ACP<br>• Early service model to facilitate or support ACP *versus* late service model to facilitate or support ACP |
| **Outcomes** | CRITICAL<br>- Quality of life (Continuous)<br>- Preferred and actual place of death (Dichotomous)<br>- Preferred and actual place of care (Dichotomous)<br>IMPORTANT<br>- Length of survival (Dichotomous)<br>- Length of stay (Continuous)<br>- Hospitalisation (Dichotomous)<br>- Number of hospital visits (Dichotomous)<br>- Number of visits to accident and emergency (Dichotomous)<br>- Number of unscheduled admissions (Dichotomous)<br>- Use of community services (Dichotomous)<br>- Avoidable/inappropriate admissions to ICU (Dichotomous)<br>- Inappropriate attempt at cardiopulmonary resuscitation (Dichotomous)<br>- Staff satisfaction (Continuous)<br>- Patient/carer reported outcomes (satisfaction) (Continuous) |
| **Study design** | • Systematic reviews<br>• RCTs<br>• 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.<br>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)).<br>N=95<br>UK | Length of hospital stay<br>Preferred and actual place of death (preferred place of death – as far as next of kin was aware)<br>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.<br>N=98<br>UK | Length of hospital stay<br>Preferred and actual place of death (deaths at nursing home)<br>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.<br>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.<br>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 ≥ 5, range 0-15).<br>N=201 | QoL(SF 12)<br>Satisfaction (PSQ-18) | Cluster RCT of 16 residential care homes.<br>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).<br>N=33<br>UK | Carer QoL (EQ5D)<br>Carer satisfaction (LSQ; DSI; SWC-EOLCD)* | RCT<br>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.<br>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<br>(1 study1)<br>4-10 months | ⊕⊖⊖⊖<br>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<br>(1 study1)<br>4-10 months | ⊕⊖⊖⊖<br>VERY LOW[a,b,c] due to indirectness, imprecision | RR 1.15 (0.66 to 1.99) | 393 per 1000 | 59 more per 1000<br>(from 134 fewer to 389 more) |
| Number of residents wishing to die at hospice (next of kin opinion) | 79<br>(1 study1)<br>4-10 months | ⊕⊖⊖⊖<br>VERY LOW[a,b,c] due to indirectness, imprecision | RR 1.65 (0.59 to 4.63) | 143 per 1000 | 93 more per 1000<br>(from 59 fewer to 519 more) |
| Number of residents wishing to die at hospital (next of kin opinion) | 79<br>(1 study1)<br>4-10 months | ⊕⊖⊖⊖<br>VERY LOW[a,b,c] due to indirectness, imprecision | RR 0.6 (0.29 to 1.24) | 357 per 1000 | 143 fewer per 1000<br>(from 254 fewer to 86 more) |
| Number of residents wishing to die at care home (next of kin opinion) | 79<br>(1 study1)<br>4-10 months | ⊕⊖⊖⊖<br>VERY LOW[a,b,c] due to indirectness, imprecision | RR 0.55 (0.12 to 2.54) | 107 per 1000 | 48 fewer per 1000<br>(from 94 fewer to 165 more) |
| Number of residents wishing to die elsewhere (next of kin opinion) | 79<br>(1 study1)<br>4-10 months | ⊕⊖⊖⊖<br>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<br>(1 study1)<br>4-10 months | ⊕⊖⊖⊖<br>VERY LOW[a,b,c] due to indirectness, imprecision | RR 2.37 (0.72 to 7.83) | 86 per 1000 | 117 more per 1000<br>(from 24 fewer to 585 more) |
| Number of residents dying in hospice | 94 | ⊕⊖⊖⊖ | RR | | |

| 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) |
| | (1 study1)<br>4-10 months | VERY LOW[a,b,c] due to indirectness, imprecision | 2.37 (0.72 to 7.83) | 86 per 1000 | 117 more per 1000<br>(from 24 fewer to 585 more) |
| Number of residents dying in hospital | 94<br>(1 study1)<br>4-10 months | ⊕⊖⊖⊖<br>VERY LOW[a,b,c] due to indirectness, imprecision | RR 0.74 (0.53 to 1.04) | 686 per 1000 | 178 fewer per 1000<br>(from 322 fewer to 27 more) |
| Number of residents dying in care home | 94<br>(1 study1)<br>4-10 months | ⊕⊖⊖⊖<br>VERY LOW[a,b,c] due to indirectness, imprecision | RR 0.59 (0.18 to 1.91) | 143 per 1000 | 59 fewer per 1000<br>(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<br>(1 study1)<br>2 years | ⊕⊖⊖⊖<br>VERY LOW[a,b,c] due to indirectness, imprecision | RR 1.63 (1.05 to 2.51) | 467 per 1000 | 294 more per 1000<br>(from 23 more to 705 more) |
| Number of residents dying in hospital | 59 | ⊕⊖⊖⊖ | RR 0.45 | | |

| **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)** |
| | (1 study1)<br>2 years | VERY LOW[a,b,c]<br>due to indirectness, imprecision | (0.22 to 0.94) | 533 per 1000 | 293 fewer per 1000<br>(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**<br>Scale from: 0 to 100. | 160<br>(1 study)<br>12 months | ⊕⊕⊖⊖<br>**LOW**[a,b]<br>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<br>**2 lower**<br>(4.95 lower to 0.95 higher) |
| **SF_12 Mental component**<br>Scale from: 0 to 100. | 160<br>(1 study)<br>12 months | ⊕⊕⊖⊖<br>**LOW**[a,b]<br>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<br>**2 higher**<br>(1.55 lower to 5.55 higher) |
| **Patient Satisfaction (PSQ-18 _1subscale)**<br>Scale from: 1 to 5. | 160<br>(1 study)<br>12 months | ⊕⊕⊕⊖<br>**MODERATE**[a]<br>due to risk of bias | | The mean patient satisfaction (psq-18 _1subscale) | The mean patient satisfaction (psq-18 _1subscale) in the intervention groups was<br>**0 higher** |

| | | | | | |
|---|---|---|---|---|---|
| | | | | in the control groups was 4 | (0.23 lower to 0.23 higher) |
| [a] Downgraded by 1 increment for risk of bias<br>[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<br>(1 study)<br>6 months | ⊕⊖⊖⊖<br>VERY LOW[a,b]<br>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<br>(1 study)<br>6 months | ⊕⊖⊖⊖<br>VERY LOW[a,b]<br>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<br>(1 study)<br>6 months | ⊕⊖⊖⊖<br>VERY LOW[a,b]<br>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<br>(1 study)<br>6 months | ⊕⊕⊖⊖<br>LOW[a]<br>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<br>(1 study)<br>6 months | ⊕⊖⊖⊖<br>VERY LOW[a,b]<br>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<br>(1 study)<br>6 months | ⊕⊖⊖⊖<br>VERY LOW[a,b]<br>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<br>(1 study)<br>6 months | ⊕⊖⊖⊖<br>VERY LOW[a,b]<br>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<br>(1 study)<br>6 months | ⊕⊖⊖⊖<br>VERY LOW[a,b]<br>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<br>(1 study)<br>6 months | ⊕⊖⊖⊖<br>VERY LOW[a,b]<br>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<br>(1 study)<br>22 months | ⊕⊖⊖⊖<br>VERY LOW[a,b]<br>due to risk of bias, imprecision | The mean carers decision satisfaction at 6 weeks (DSI; range 10-50; high score indicates less satisfaction) in the control groups | 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) |
| | | | 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<br>(1 study)<br>6 months | ⊕⊖⊖⊖<br>VERY LOW[a,b]<br>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<br>(1 study)<br>6 months | ⊕⊕⊖⊖<br>LOW[a]<br>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<br>(1 study)<br>6 months | ⊕⊕⊖⊖<br>LOW[a]<br>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

One health economic study was identified with the relevant comparison and has been included in this review.[174] This is summarised in the health economic evidence profile below (Table 8) and the health economic evidence tables in Appendix F.

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

## 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: PCPDs: Identifying LTC residents with EoL goals and preferences for EPC (see Table 8) versus usual care**

| Study | Applicability | Limitations | Other comments | Incremental cost | Incremental effects | Cost-effectiveness | Uncertainty |
|---|---|---|---|---|---|---|---|
| Pham 2014[174] (UK) | Partially applicable[(a)] | Very Serious Limitations[(b)] | Economic Analysis: CUA<br>Study design: Probabilistic decision analytic Markov model (microsimulation )<br>Intervention: Patient Care Planning Decisions (PCPDs): Identifying LTC residents with EoL goals and preferences for EPC versus usual care (Please see Table 18) | Saves £15 | 0.01 more quality-adjusted life days | Intervention dominates usual care | A number of probabilistic and one-way sensitivity analyses conducted to explore key sources of variability and uncertainty in the simulated model.<br>The sensitivity analysis found that the results for Patient Care Planning Decisions (PCPDs): Identifying LTC residents with EoL goals and preferences for EPC versus usual care were uncertain and might change with additional data. |

*Abbreviations: PCPDs: patient care planning decision; LTC: long term care; EPC: early palliative care*

*(a) Not a UK study therefore study population and costs not directly applicable.*

*(b) 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.*

### 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 1.8 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 (was both more effective and less costly). This study was assessed as partially applicable with very serious limitations.

## 1.8 Recommendations

F1. Service providers should develop policies to ensure that advance care planning with adults who are approaching the end of their life is carried out.

F2. Service providers should develop processes to:

  - support carers and other people important to the person to be involved in advance care planning, if the person approaching the end of their life consents
  - take into account the views of carers and other people important to the person if the person approaching the end of their life lacks capacity to make decisions in line with the Mental Capacity Act 2005.

F3. For advice on supporting decision making, assessing mental capacity and advance care planning, see the NICE guideline on decision-making and mental capacity.

F4. For advice on starting advance care planning in adults who are at risk of a medical emergency, see the NICE guideline on emergency and acute medical care in over 16s: service delivery and organisation.

## 1.9 Rationale and impact

### 1.9.1 Why the committee made the recommendations

The evidence for advance care planning was unclear, although it did show some benefit in supporting people to stay in their preferred place of care. There was not enough evidence for the committee to recommend a specific service model for advance care planning. However, the committee agreed that advance care planning helps people to achieve the personalised care and support they want, and that processes should be in place to provide it to adults approaching the end of their life. The committee also felt that advance care planning should not be restricted to planning for possible future loss of mental capacity.

The evidence on barriers to care described how carers felt a lack of control and a lack of trust in health and social care practitioners, resulting in scepticism about the benefits of advance care planning. The committee agreed that better communication and processes to involve carers in advance care planning would help to address this

## 1.9.2 Impact of the recommendations on practice

The recommendations reflect good current practice available in some services, but there is variation in the timing and availability of advance care planning in different areas and for different patient groups.

Advance care planning supports adults approaching the end of their life to be cared for in their preferred place, which is often in the community. This may reduce the need for hospital services but increase demand for services in the community. The advance care plan documents the person's current, future and emergency needs, improving coordination of care across the multipractitioner team and should help avoid unnecessary hospital attendances and admissions.

## 1.9.3 The committee's discussion of the evidence

## 1.9.4 Interpreting the evidence

### 1.9.4.1 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.

### 1.9.4.2 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,

### 1.9.4.3 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).

### 1.9.5 Cost effectiveness and resource use

One 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 that the intervention saved £15 on average per person in the last year of life and lead to an increase of 0.01 more quality adjusted life days on average. The committee felt that as the study was not based on UK data, the results could not be generalised 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.

### 1.9.6 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<br>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 or reference (gold) standard | • No identified service model<br>• Other service model to facilitate or support ACP<br>• Early service model to facilitate or support ACP versus late |

| | | |
|---|---|---|
| | | service model to facilitate or support ACP |
| VII | Outcomes and prioritisation | CRITICAL<br>• Quality of life (Continuous)<br>• Preferred and actual place of death (Dichotomous)<br>• Preferred and actual place of care (Dichotomous)<br><br>IMPORTANT<br>• Length of survival (Dichotomous)<br>• Length of stay (Continuous)<br>• Hospitalisation (Dichotomous)<br>• Number of hospital visits (Dichotomous)<br>• Number of visits to accident and emergency (Dichotomous)<br>• Number of unscheduled admissions (Dichotomous)<br>• Use of community services (Dichotomous)<br>• Avoidable/inappropriate admissions to ICU (Dichotomous)<br>• Inappropriate attempt at cardiopulmonary resuscitation (Dichotomous)<br>Staff satisfaction (Continuous)<br>• Patient/carer reported outcomes (satisfaction) (Continuous) |
| VIII | Eligibility criteria – study design | • Systematic reviews<br>• RCTs<br>• Non-randomised comparative studies, including before and after studies. |
| IX | Other inclusion exclusion criteria | Exclusions:<br>• Children (17 years or younger)<br>• Studies will only be included if they reported one or more of the outcomes listed above<br>• Descriptive (non-comparative) studies will be excluded |
| X | Proposed sensitivity / subgroup analysis, or meta-regression | Subgroups to be analysed if heterogeneity found:<br>• Younger adults (aged 18-25)<br>• Frail elderly<br>• People with dementia<br>• People with hearing loss<br>• People with advanced heart and lung disease<br>• People in prisons<br>• Socioeconomic inequalities (people from lower income brackets)<br>• Homeless people/vulnerably housed<br>• Travellers<br>• People with learning difficulties<br>• People with disabilities<br>• People with mental health problems<br>• Migrant workers<br>• LGBT<br>• 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.<br>Review strategy/other analysis:<br>• Information on identification tools used as part of a service will be extracted.<br>• 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).<br>• GRADEpro was used to assess the quality of evidence for each outcome.<br>• Endnote was used for:<br>○ Bibliography, citations, sifting and reference management<br>• Evibase was used for<br>• 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)<br>Date: All years<br>Health economics search databases to be used: Medline, Embase, NHSEED, HTA<br>Date: Medline, Embase from 2014<br>NHSEED, HTA – All years<br>Language: Restrict to English only<br>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<br>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/<br>[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.<br>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.<br>• 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).<br>• 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.)<br>• 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.<br>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]<br>**Inclusion and exclusion criteria**<br>• 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.<br>• 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.<br>• If a study is rated as 'Partially applicable', with 'Potentially serious limitations' or both then there is discretion over whether it should be included.<br>**Where there is discretion**<br>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.<br>The health economist will be guided by the following hierarchies.<br>*Setting:*<br>• UK NHS (most applicable).<br>• OECD countries with predominantly public health insurance systems (for example, France, Germany, Sweden).<br>• OECD countries with predominantly private health insurance systems (for example, Switzerland).<br>• Studies set in non-OECD countries or in the USA will be excluded before being assessed for applicability and methodological limitations.<br>*Health economic study type:*<br>• Cost–utility analysis (most applicable).<br>• Other type of full economic evaluation (cost–benefit analysis, cost-effectiveness analysis, cost–consequences analysis).<br>• Comparative cost analysis.<br>• Non-comparative cost analyses including cost-of-illness studies will be excluded before being assessed for applicability and methodological limitations.<br>*Year of analysis:*<br>• The more recent the study, the more applicable it will be.<br>• 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'.<br>• 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:*<br>• 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<br>CENTRAL to Issue 1 of 12, January 2019<br>DARE, and NHSEED to Issue 2 of 4 2015<br>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 |
| 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 |

1 **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<br>Health economics studies<br>Health economics modelling studies<br>Quality of life studies |
| Embase | 2014 – 04 January 2019 | Exclusions<br>Health economics studies<br>Health economics modelling studies<br>Quality of life studies |
| Centre for Research and Dissemination (CRD) | HTA - Inception – 04 January 2019<br>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.**

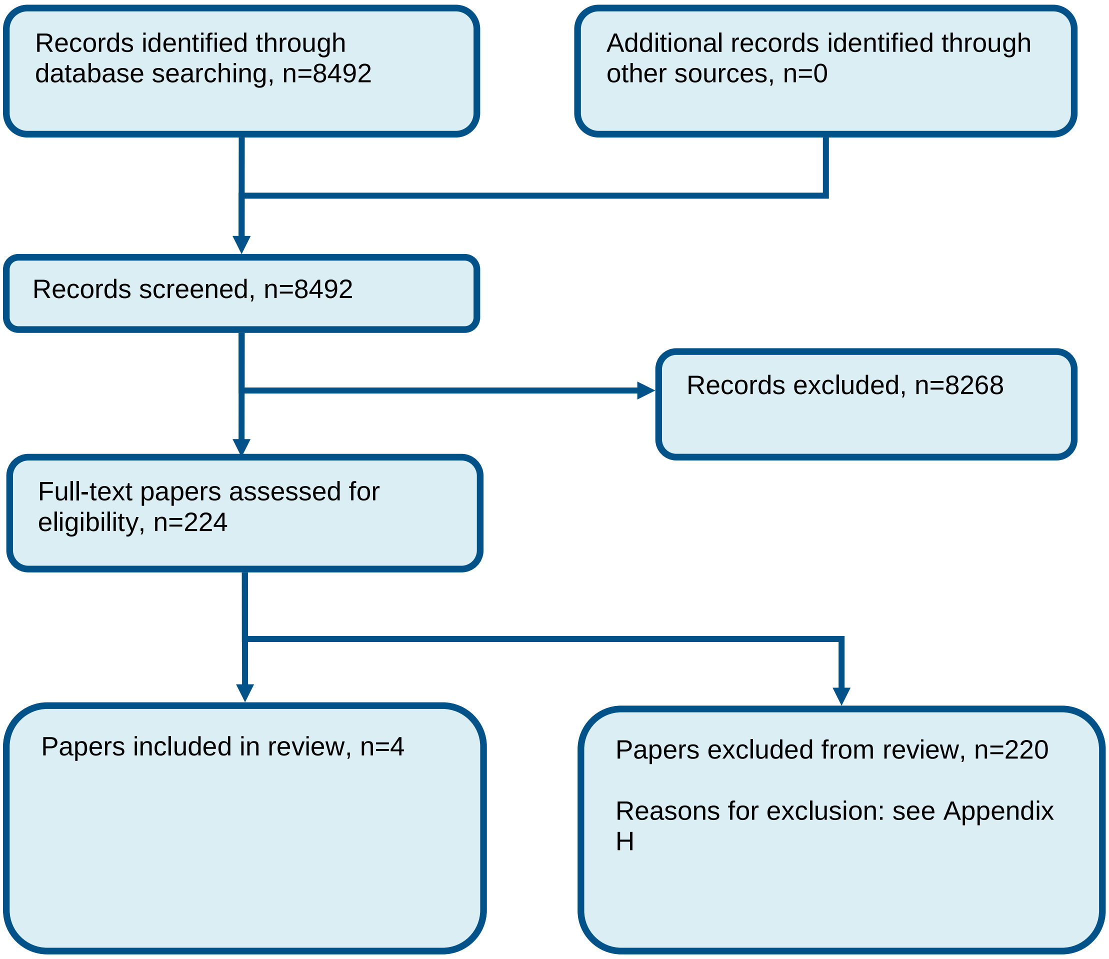
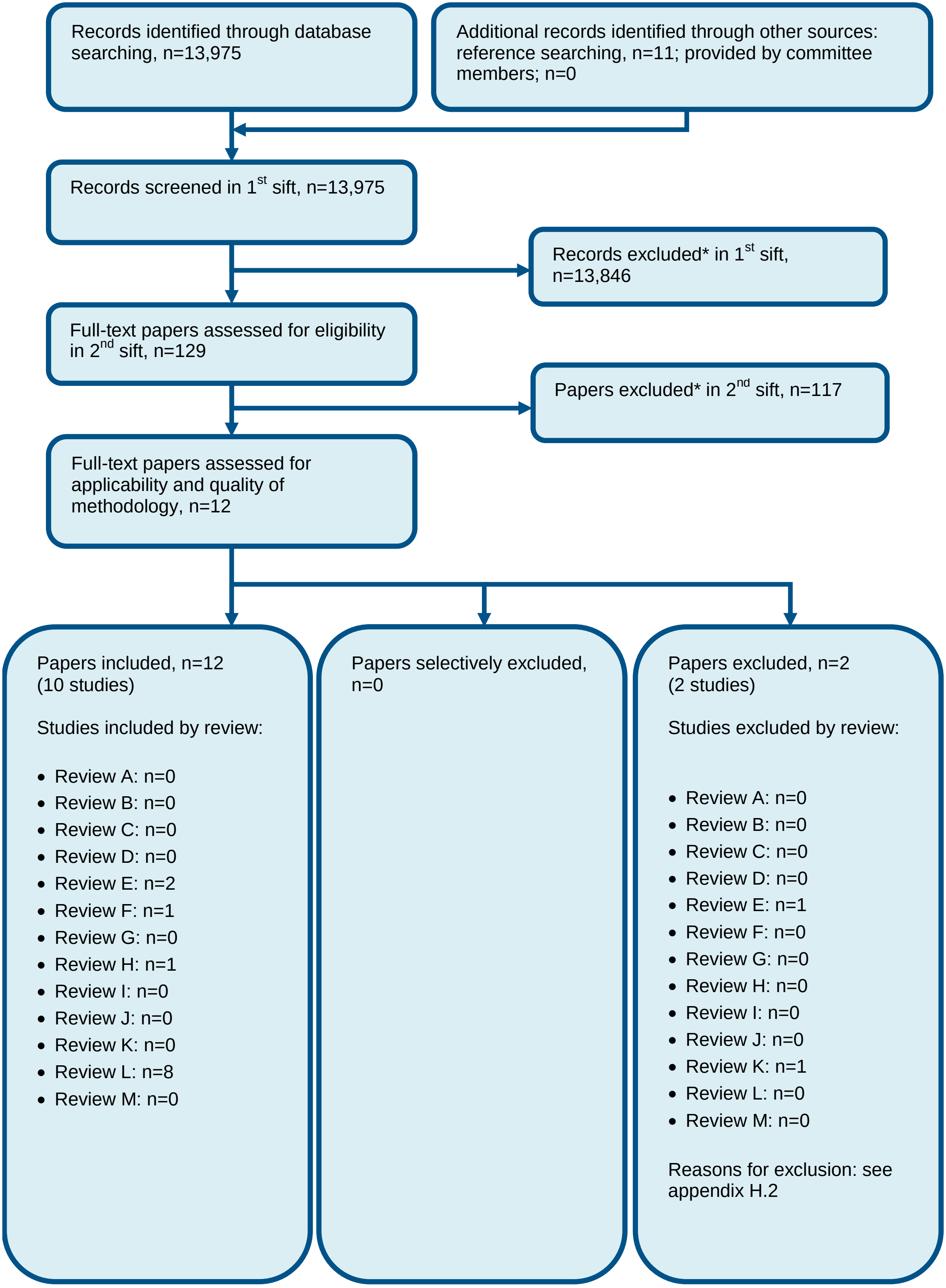


**Figure 2: Flow chart of health economic study selection for the guideline**



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

1

# 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.<br>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

<table>
<tr><td colspan="2">Group 1: 12/59, Group 2: 3/35<br>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<br>- Actual outcome for Adults (aged 18 years or over): Actual place of death - hospice<br>Group 1: 12/59, Group 2: 3/35<br>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<br>- Actual outcome for Adults (aged 18 years or over): Actual place of death - hospital<br>Group 1: 30/59, Group 2: 24/35<br>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<br>- Actual outcome for Adults (aged 18 years or over): Actual place of death - nursing home<br>Group 1: 5/59, Group 2: 5/35<br>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</td></tr>
<tr><td>Protocol outcomes not reported by the study</td><td>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</td></tr>
</table>

| **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<br>(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 SERVICE MODEL TO FACILITATE OR SUPPORT ACP<br>Protocol outcome 1: Length of stay<br>- 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));<br>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<br>Protocol outcome 2: Preferred and actual place of death<br>- Actual outcome for Adults (aged 18 years or over): Deaths in care home at 12 months; Group 1: 22/29, Group 2: 14/30<br>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<br>- Actual outcome for Adults (aged 18 years or over): Deaths in hospital at 12 months; Group 1: 7/29, Group 2: 16/30<br>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.<br>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 ; 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<br>(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.

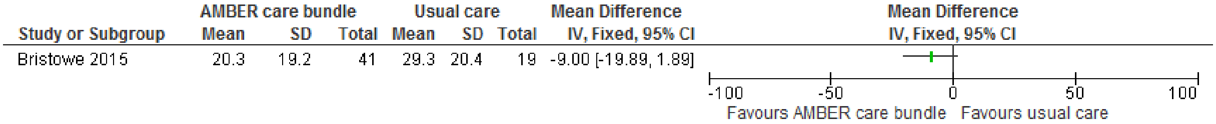
at 6 months; Group 1: mean 22.2 (SD 7.9); n=7, Group 2: mean 16.3 (SD 4.8); n=4; DSI 10-50 Top=High is poor outcome

| | |
|---|---|
| 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<br>- Actual outcome for Adults (aged 18 years or over): Decision satisfaction inventory (DSI) – range 10-50; high score indicates less satisfaction.<br><br>at Post-bereavement; Group 1: mean 28 (SD 7.2); n=4,<br>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<br>- 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.<br><br>Protocol outcome 4: Staff satisfaction<br>- 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.**<br><br>at Post-bereavement; Group 1: mean 27.6 (SD 8.5); n=4,<br>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

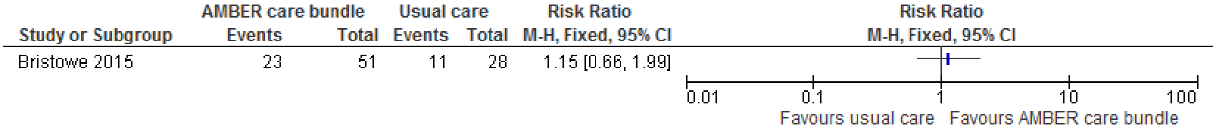
## E.1 AMBER care bundle versus usual care

### Figure 3: Length of hospital stay (days)



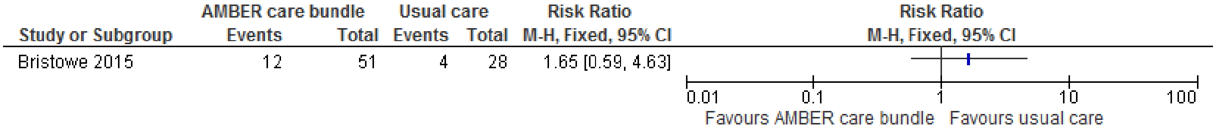
| | AMBER care bundle | | | Usual care | | | Mean Difference |
|---|---|---|---|---|---|---|---|
| Study or Subgroup | Mean | SD | Total | Mean | SD | Total | IV, Fixed, 95% CI |
| Bristowe 2015 | 20.3 | 19.2 | 41 | 29.3 | 20.4 | 19 | -9.00 [-19.89, 1.89] |

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



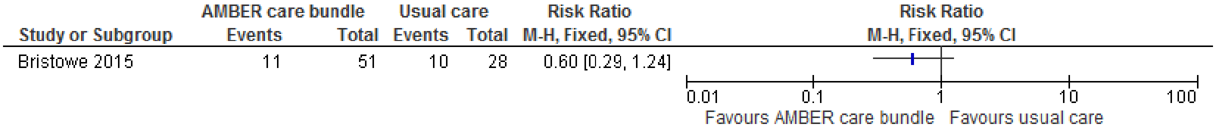
| | AMBER care bundle | | Usual care | | Risk Ratio |
|---|---|---|---|---|---|
| Study or Subgroup | Events | Total | Events | Total | M-H, Fixed, 95% CI |
| Bristowe 2015 | 23 | 51 | 11 | 28 | 1.15 [0.66, 1.99] |

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



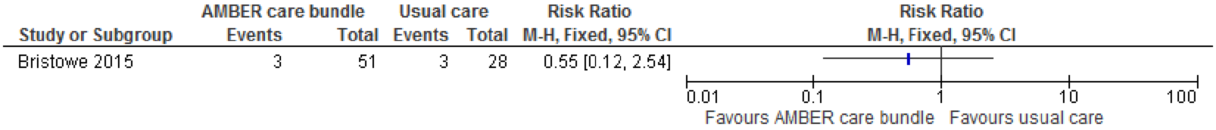
| | AMBER care bundle | | Usual care | | Risk Ratio |
|---|---|---|---|---|---|
| Study or Subgroup | Events | Total | Events | Total | M-H, Fixed, 95% CI |
| Bristowe 2015 | 12 | 51 | 4 | 28 | 1.65 [0.59, 4.63] |

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



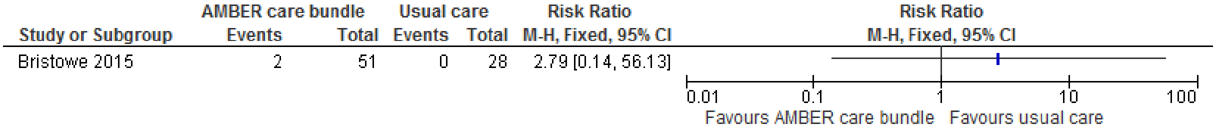
| | AMBER care bundle | | Usual care | | Risk Ratio |
|---|---|---|---|---|---|
| Study or Subgroup | Events | Total | Events | Total | M-H, Fixed, 95% CI |
| Bristowe 2015 | 11 | 51 | 10 | 28 | 0.60 [0.29, 1.24] |

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



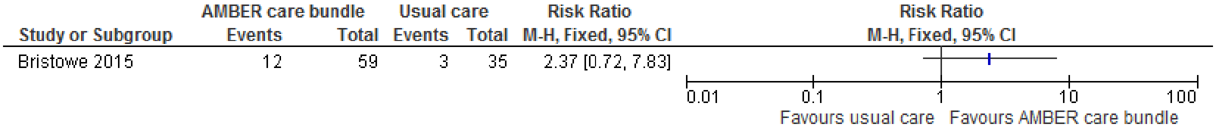
| | AMBER care bundle | | Usual care | | Risk Ratio |
|---|---|---|---|---|---|
| Study or Subgroup | Events | Total | Events | Total | M-H, Fixed, 95% CI |
| Bristowe 2015 | 3 | 51 | 3 | 28 | 0.55 [0.12, 2.54] |

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



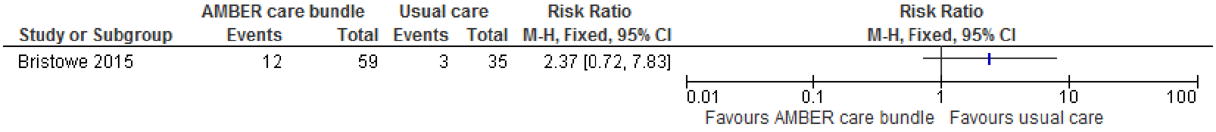
| | AMBER care bundle | | Usual care | | Risk Ratio |
|---|---|---|---|---|---|
| Study or Subgroup | Events | Total | Events | Total | M-H, Fixed, 95% CI |
| Bristowe 2015 | 2 | 51 | 0 | 28 | 2.79 [0.14, 56.13] |

### Figure 9: Number of residents dying in home



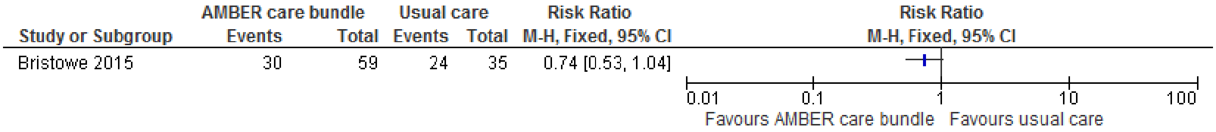
| | AMBER care bundle | | Usual care | | Risk Ratio |
|---|---|---|---|---|---|
| Study or Subgroup | Events | Total | Events | Total | M-H, Fixed, 95% CI |
| Bristowe 2015 | 12 | 59 | 3 | 35 | 2.37 [0.72, 7.83] |

### Figure 10: Number of residents dying in hospice



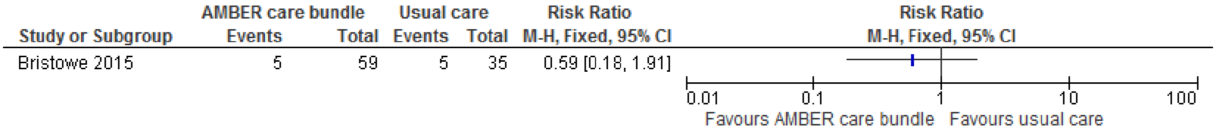
| Study or Subgroup | AMBER care bundle Events | AMBER care bundle Total | Usual care Events | Usual care Total | Risk Ratio M-H, Fixed, 95% CI |
|---|---|---|---|---|---|
| Bristowe 2015 | 12 | 59 | 3 | 35 | 2.37 [0.72, 7.83] |

### Figure 11: Number of residents dying in hospital



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

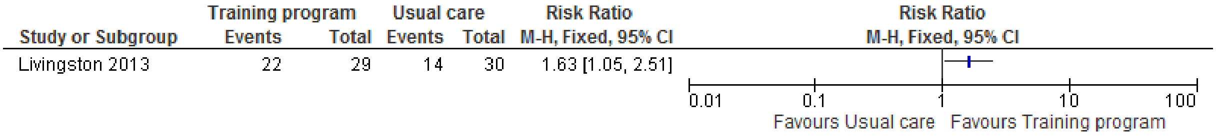
### Figure 12: Number of residents dying in care home



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

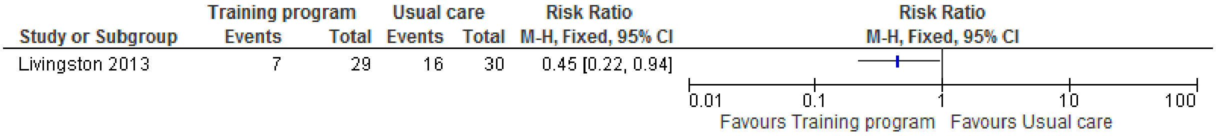
## E.2 Training program versus usual care

### Figure 13: Number of residents dying in care home



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

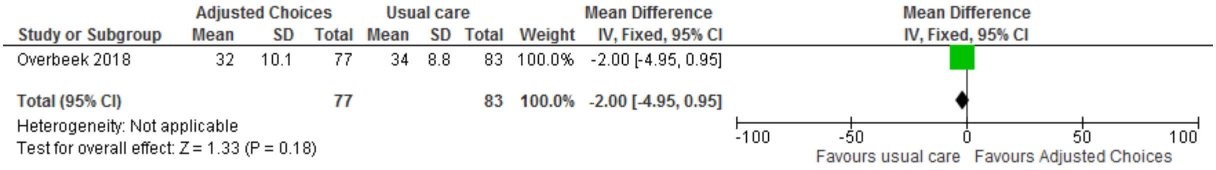
### Figure 14: Number of residents dying in hospital



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

## E.3 Adjusted Choices versus usual care

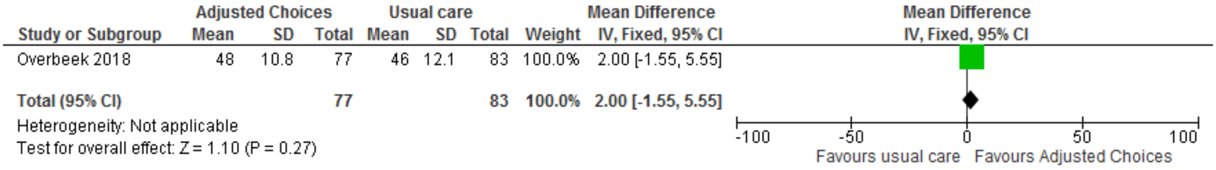
### Figure 15: Quality of life at 12 months (SF_12 Physical component score)



| Study or Subgroup | Adjusted Choices Mean | Adjusted Choices SD | Adjusted Choices Total | Usual care Mean | Usual care SD | Usual care Total | Weight | Mean Difference 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)

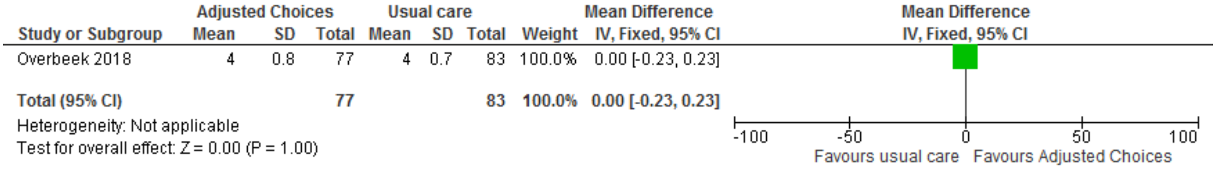
**Figure 16: Quality of life at 12 months (SF_12 Mental component score)**



| Study or Subgroup | Adjusted Choices Mean | SD | Total | Usual care Mean | SD | Total | Weight | Mean Difference 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)

**Figure 17: Patient Satisfaction (PSQ-18 1subscale)**

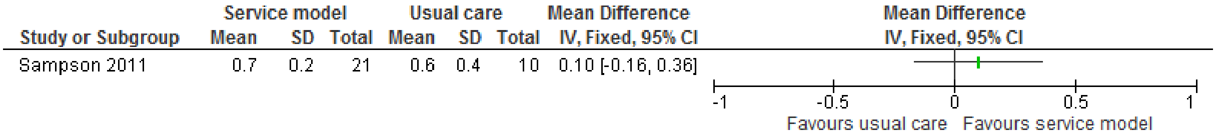


| Study or Subgroup | Adjusted Choices Mean | SD | Total | Usual care Mean | SD | Total | Weight | Mean Difference IV, Fixed, 95% CI |
|---|---|---|---|---|---|---|---|---|
| Overbeek 2018 | 4 | 0.8 | 77 | 4 | 0.7 | 83 | 100.0% | 0.00 [-0.23, 0.23] |
| **Total (95% CI)** | | | **77** | | | **83** | **100.0%**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

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

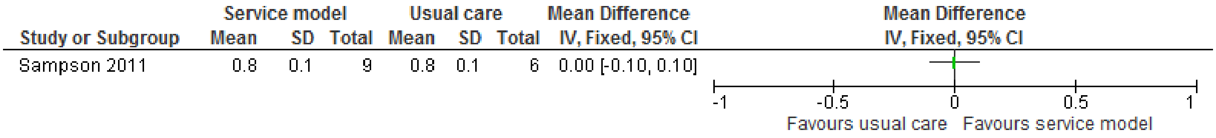
# E.4 Palliative assessment, carer consultation, ACP versus usual care

**Figure 18: Carers quality of life at baseline (EQ5D; scale 0-1, low score indicates poor health)**



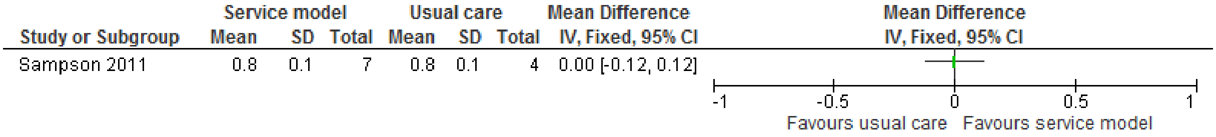
| Study or Subgroup | Service model Mean | SD | Total | Usual care Mean | SD | Total | Mean Difference IV, Fixed, 95% CI |
|---|---|---|---|---|---|---|---|
| Sampson 2011 | 0.7 | 0.2 | 21 | 0.6 | 0.4 | 10 | 0.10 [-0.16, 0.36] |

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



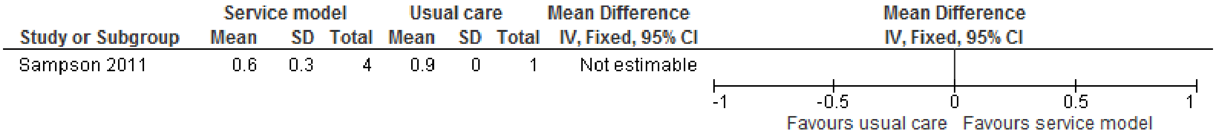
| Study or Subgroup | Service model Mean | SD | Total | Usual care Mean | SD | Total | Mean Difference IV, Fixed, 95% CI |
|---|---|---|---|---|---|---|---|
| Sampson 2011 | 0.8 | 0.1 | 9 | 0.8 | 0.1 | 6 | 0.00 [-0.10, 0.10] |

**Figure 20: Carers quality of life at 6 months (EQ5D; scale 0-1, low score indicates poor health)**



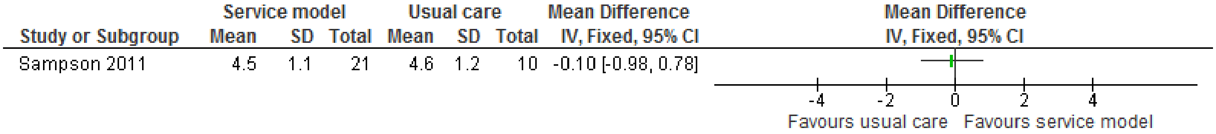
| Study or Subgroup | Service model Mean | SD | Total | Usual care Mean | SD | Total | Mean Difference IV, Fixed, 95% CI |
|---|---|---|---|---|---|---|---|
| Sampson 2011 | 0.8 | 0.1 | 7 | 0.8 | 0.1 | 4 | 0.00 [-0.12, 0.12] |

**Figure 21: Carers quality of life post bereavement (EQ5D; scale 0-1, low score indicates poor health)**



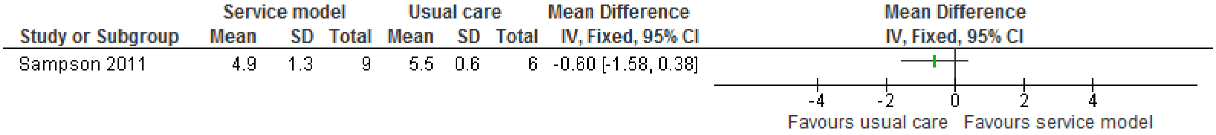
| Study or Subgroup | Service model Mean | SD | Total | Usual care Mean | SD | Total | Mean Difference IV, Fixed, 95% CI |
|---|---|---|---|---|---|---|---|
| Sampson 2011 | 0.6 | 0.3 | 4 | 0.9 | 0 | 1 | Not estimable |

Figure 22: Carers life satisfaction at baseline (LSQ; scale 0-7, high score indicates best possible outcome)



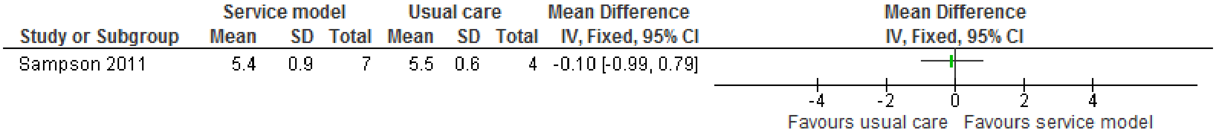
| Study or Subgroup | Service model Mean | SD | Total | Usual care Mean | SD | Total | Mean Difference IV, Fixed, 95% CI |
|---|---|---|---|---|---|---|---|
| Sampson 2011 | 4.5 | 1.1 | 21 | 4.6 | 1.2 | 10 | -0.10 [-0.98, 0.78] |

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



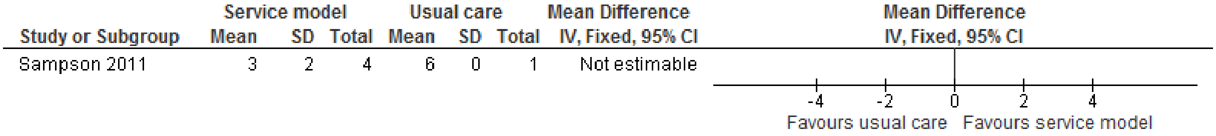
| Study or Subgroup | Service model Mean | SD | Total | Usual care Mean | SD | Total | Mean Difference IV, Fixed, 95% CI |
|---|---|---|---|---|---|---|---|
| Sampson 2011 | 4.9 | 1.3 | 9 | 5.5 | 0.6 | 6 | -0.60 [-1.58, 0.38] |

Figure 24: Carers life satisfaction at 6 months (LSQ; scale 0-7, high score indicates best possible outcome)



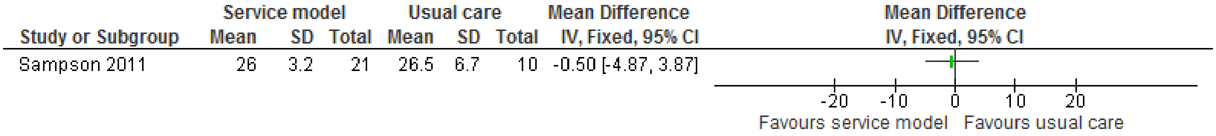
| Study or Subgroup | Service model Mean | SD | Total | Usual care Mean | SD | Total | Mean Difference IV, Fixed, 95% CI |
|---|---|---|---|---|---|---|---|
| Sampson 2011 | 5.4 | 0.9 | 7 | 5.5 | 0.6 | 4 | -0.10 [-0.99, 0.79] |

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



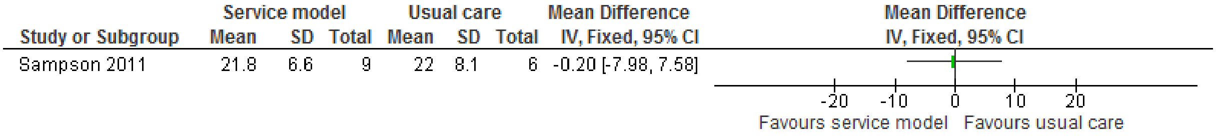
| Study or Subgroup | Service model Mean | SD | Total | Usual care Mean | SD | Total | Mean Difference IV, Fixed, 95% CI |
|---|---|---|---|---|---|---|---|
| Sampson 2011 | 3 | 2 | 4 | 6 | 0 | 1 | Not estimable |

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



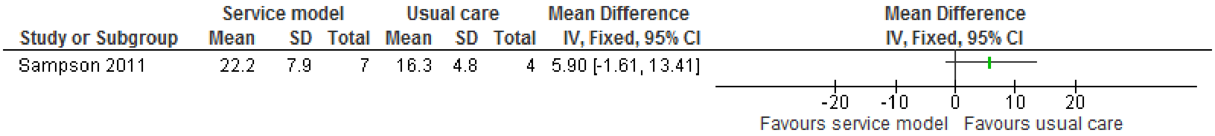
| Study or Subgroup | Service model Mean | SD | Total | Usual care Mean | SD | Total | Mean Difference IV, Fixed, 95% CI |
|---|---|---|---|---|---|---|---|
| Sampson 2011 | 26 | 3.2 | 21 | 26.5 | 6.7 | 10 | -0.50 [-4.87, 3.87] |

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



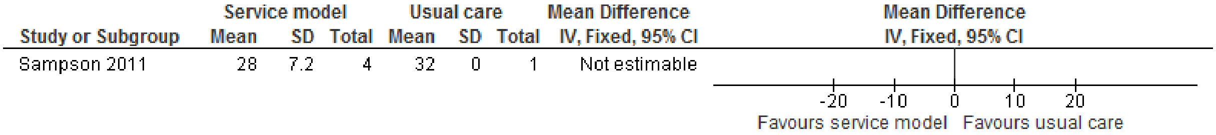
| Study or Subgroup | Service model Mean | SD | Total | Usual care Mean | SD | Total | Mean Difference IV, Fixed, 95% CI |
|---|---|---|---|---|---|---|---|
| Sampson 2011 | 21.8 | 6.6 | 9 | 22 | 8.1 | 6 | -0.20 [-7.98, 7.58] |

Figure 28: Carers decision satisfaction at 6 months (DSI; range 10-50; high score indicates less satisfaction)



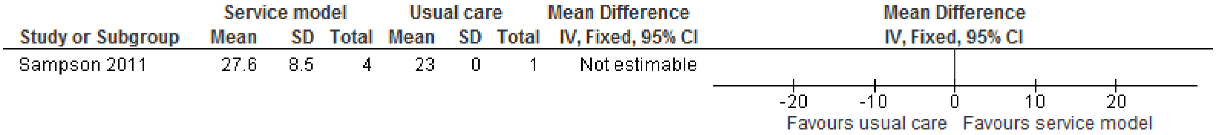
| Study or Subgroup | Service model Mean | SD | Total | Usual care Mean | SD | Total | Mean Difference IV, Fixed, 95% CI |
|---|---|---|---|---|---|---|---|
| Sampson 2011 | 22.2 | 7.9 | 7 | 16.3 | 4.8 | 4 | 5.90 [-1.61, 13.41] |

**Figure 29: Carers decision satisfaction post-bereavement (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 | 28 | 7.2 | 4 | 32 | 0 | 1 | Not estimable |

**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 Mean | SD | Total | Usual care Mean | SD | Total | Mean Difference IV, Fixed, 95% CI |
|---|---|---|---|---|---|---|---|
| Sampson 2011 | 27.6 | 8.5 | 4 | 23 | 0 | 1 | Not estimable |

# Appendix F: GRADE tables

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

| Quality assessment | | | | | | | No of patients | | Effect | | Quality | Importance |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| No of studies | 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 |
| **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) | - | ⊕OOO 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) | ⊕OOO 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) | ⊕OOO 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) | ⊕OOO 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) | ⊕OOO 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) | ⊕OOO 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) | ⊕OOO 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) | ⊕⊕OO 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) | ⊕⊕OO 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) | ⊕⊕⊕O MODERATE | IMPORTANT |

[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

| Quality assessment | | | | | | | No of patients | | Effect | | Quality | Importance |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| **No of studies** | **Design** | **Risk of bias** | **Inconsistency** | **Indirectness** | **Imprecision** | **Other considerations** | **Palliative assessment, carer consultation, ACP** | **Usual care** | **Relative (95% CI)** | **Absolute** | | |
| **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) | ⊕OOO 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) | ⊕OOO 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) | ⊕OOO 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] | ⊕⊕OO 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) | ⊕OOO 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 | very | no serious | no serious | no serious | none | 4 | 1 | - | MD 4.6 higher (0 to | ⊕⊕OO | IMPORTANT |

| | | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | trials | serious[a] | inconsistency | indirectness | imprecision | | | | | 0 higher)[3] | LOW | |

[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 economic evidence selection

| **Study** | **Pham 2014**[174] | | | |
|---|---|---|---|---|
| **Study details** | **Population & interventions** | **Costs** | **Health outcomes** | **Cost effectiveness** |
| **Economic analysis:** CUA[(a)]<br>**Study design:** Probabilistic decision analytic markov model (microsimulation)<br>**Approach to analysis:**<br>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.<br>Markov model used to simulate patterns of EOL care; related health care utilisation and recurrent events experienced (for example:  ED visits, | **Population:**<br>A cohort of Ontarian decedents (average age 72, approx. 50% female) and their primary informal caregivers (average age 56, approx. 68% female)<br>**Intervention 1:**<br>Usual care (see Table 18)<br>**Intervention 2:**<br>PTC: In-home (see Table 18)<br>**Intervention 3:**<br>PTC: Inpatient (see Table 18)<br>**Intervention 4:**<br>PTC: Comprehensive (see Table 18)<br>**Intervention 5:**<br>PCPDs: Identifying LTC residents with EoL goals and preferences for EPC (see Table 18)<br>**Intervention 6:**<br>PCPDs: Ethics consultation for ICU patients with treatment | **Total costs (mean per patient):**<br>Intervention 1: £28,065<br>Intervention 2: £25,588<br>Intervention 3: £27,145<br>Intervention 4: £28,360<br>Intervention 5: £28,051<br>Intervention 6: £28,018<br>Intervention 7: £28,096<br>Intervention 8: £30,733<br>Intervention 9: £28,175<br>Incremental (2−1): saves £2,477<br>Incremental (3−1): saves £920<br>Incremental (4−1): £295<br>Incremental (5−1): saves £15<br>Incremental (6−1): saves £48<br>Incremental (7−1): £31<br>Incremental (8−1): £2,668<br>Incremental (9−1): £110<br>(95% CI: NR; p=NR)<br>**Currency & cost year:** | **QALDs (mean total of patient and caregiver):**<br>Intervention 1: 518.53<br>Intervention 2: 519.00<br>Intervention 3: 518.80<br>Intervention 4: 521.18<br>Intervention 5: 518.54<br>Intervention 6: 518.63<br>Intervention 7: 519.02<br>Intervention 8: 522.16<br>Intervention 9: 519.35<br>Incremental (2−1): 0.47<br>Incremental (3-1): 0.27<br>Incremental (4-1): 2.65<br>Incremental (5-1): 0.01<br>Incremental (6-1): 0.10<br>Incremental (7-1): 0.49<br>Incremental (8-1): 3.63<br>Incremental (9-1): 0.82<br>(95% CI: NR; p=NR) | **ICER (Intervention 2 versus Intervention 1):**<br>Dominant<br>95% CI: NR<br>**ICER (Intervention 3 versus Intervention 1):**<br>Dominant<br>95% CI: NR<br>**ICER (Intervention 4 versus Intervention 1):**<br>£40,632.49 per QALY gained<br>95% CI: NR<br>**ICER (Intervention 5 versus Intervention 1):**<br>Dominant<br>95% CI: NR<br>**ICER (Intervention 6 versus Intervention 1):**<br>Dominant<br>95% CI: NR<br>**ICER (Intervention 7 versus Intervention 1):**<br>£23,092.97 per QALY gained<br>95% CI: NR<br>**ICER (Intervention 8 versus Intervention 1):**<br>£268,270.12 per QALY gained |

| | | | | |
|---|---|---|---|---|
| hospital admissions). 1-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<br>**Time horizon/Follow-up** 1 year<br>**Discounting:** Costs: 0%; Outcomes: 0% (Time horizon 1-year) | conflicts<br>(see Table 18)<br>**Intervention 7:**<br>PCPDs: Improving family conferences for relatives of patients dying in the ICU (see Table 18)<br>**Intervention 8:**<br>Multicomponent psycho-educational interventions for patients and families (see Table 18)<br>**Intervention 9:**<br>Supportive interventions for informal caregivers (see Table 18) | 2013 Canadian dollars (presented here as 2013 UK pounds(b))<br>**Cost components incorporated:**<br>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. | | 95% CI: NR<br>**ICER (Intervention 9 versus Intervention 1):**<br>£48,965.06 per QALY gained<br>95% CI: NR<br>**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.<br>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.*

(c) *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.*

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

(e) *Directly applicable / Partially applicable / Not applicable* *(f) 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 | 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 |
|---|---|---|---|
| | support to family physicians doing house calls or direct care | | |
| **Patient care planning decisions** | | | |
| PCPDs:<br>Identifying LTC residents with<br>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<br>in easily understood ethical terms with the involved parties (for example:, patients, family, attending physicians), facilitates communication, and explores ways to<br>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<br>Family conferences for relatives of<br>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 | Decedents with a palliative prognosis and their families | When a palliative prognosis is detected |

| Intervention | Description | Subgroup | Timing of Intervention |
|---|---|---|---|
| | sessions by phone with the patient and caregiver. The educational 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 H: Excluded studies

## H.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 |

## H.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

2. Abel J, Pring A, Rich A, Malik T, Verne J. The impact of advance care planning of place of death, a hospice retrospective cohort study. BMJ Supportive & Palliative Care. 2013; 3(2):168-73

3. Agar M, Beattie E, Luckett T, Phillips J, Luscombe G, Goodall S et al. Pragmatic cluster randomised controlled trial of facilitated family case conferencing compared with usual care for improving end of life care and outcomes in nursing home residents with advanced dementia and their families: the IDEAL study protocol. BMC Palliative Care. 2015; 14:63

4. Ahronheim JC, Morrison RS, Morris J, Baskin S, Meier DE. Palliative care in advanced dementia: A randomized controlled trial and descriptive analysis. Journal of Palliative Medicine. 2000; 3(3):265-73

5. Allen K, Hazelett S, Jarjoura D, Hua K, Wright K, Weinhardt J et al. A randomized trial testing the superiority of a postdischarge care management model for stroke survivors. Journal of Stroke and Cerebrovascular Diseases. 2009; 18(6):443-52

6. Allen KR, Hazelett SE, Radwany S, Ertle D, Fosnight SM, Moore PS. The Promoting Effective Advance Care for Elders (PEACE) randomized pilot study: Theoretical framework and study design. Population Health Management. 2012; 15(2):71-7

7. Allen M, Watts T. Promoting health and wellbeing at the end of life: The contribution of care pathways. International Journal of Palliative Nursing. 2012; 18(7):348-54

8. Allen SL, Davis KS, Rousseau PC, Iverson PJ, Mauldin PD, Moran WP. Advanced care directives: Overcoming the obstacles. Journal of Graduate Medical Education. 2015; 7(1):91-4

9. Almack K, Cox K, Moghaddam N. After you : conversations between patients and healthcare professionals in planning for end of life care. BMC Palliative Care. 2012; 11:15

10. Ampe S, Sevenants A, Coppens E, Spruytte N, Smets T, Declercq A et al. Study protocol for 'we decide': Implementation of advance care planning for nursing home residents with dementia. Journal of Advanced Nursing. 2015; 71(5):1156-68

11. Ampe S, Sevenants A, Smets T, Declercq A, Van Audenhove C. Advance care planning for nursing home residents with dementia: Influence of 'we DECide' on policy and practice. Patient Education and Counseling. 2016; 100(1):139-146

12. Ampe S, Sevenants A, Smets T, Declercq A, Van Audenhove C. Advance care planning for nursing home residents with dementia: Policy vs. practice. Journal of Advanced Nursing. 2016; 72(3):569-581

13. Amro OW, Ramasamy M, Strom JA, Weiner DE, Jaber BL. Nephrologist-facilitated advance care planning for hemodialysis patients: A quality improvement project. American Journal of Kidney Diseases. 2016; 68(1):103-9

14. Anonymous. A controlled trial to improve care for seriously ill hospitalized patients. The study to understand prognoses and preferences for outcomes and risks of treatments (SUPPORT). The SUPPORT Principal Investigators. JAMA. 1995; 274(20):1591-8

15. Anonymous. Challenges in implementing an advance care planning programme in long-term care. Nursing Older People. 2017; 29(3):13

16. Aslakson RA, Schuster AL, Reardon J, Lynch T, Suarez-Cuervo C, Miller JA et al. Promoting perioperative advance care planning: A systematic review of advance care planning decision aids. Journal of Comparative Effectiveness Research. 2015; 4(6):615-50

17. Auret K, Sinclair C, Averill B, Evans S. Advance care planning and end-of-life care in a network of rural Western Australian hospitals. Australian Journal of Rural Health. 2015; 23(4):195-200

18. Badger F, Clifford CHATK. An evaluation of the implementation of a programme to improve end-of-life care in nursing homes. Palliative Medicine. 2009; 23(6):502-11

19. Baidoobonso S. Patient care planning discussions for patients at the end-of-life: An evidence-based analysis. Ontario Health Technology Assessment Series. 2014; 14(19):1-72

20. Bailey FA, Williams BR, Woodby LL, Goode PS, Redden DT, Houston TK et al. Intervention to improve care at life's end in inpatient settings: The BEACON trial. Journal of General Internal Medicine. 2014; 29(6):836-43

21. Baker A, Leak P, Ritchie LD, Lee AJ, Fielding S. Anticipatory care planning and integration : A primary care pilot study aimed at reducing unplanned hospitalisation. British Journal of General Practice. 2012; 62(595):e113-e120

22. Becker CL, Arnold RM, Park SY, Rosenzweig M, Smith TJ, White DB et al. A cluster randomized trial of a primary palliative care intervention (CONNECT) for patients with advanced cancer: Protocol and key design considerations. Contemporary Clinical Trials. 2017; 54:98-104

23. Benham-Hutchins M, Kyba F. Promoting communication and documentation of advance care planning in long-term care facilities. Director. 2005; 13(1):10-2, 14-5

24. Bernacki R, Hutchings M, Vick J. Development of the Serious Illness Care Program : a randomised controlled trial of a palliative care communication intervention. BMJ Open. 2015; 5(10):e009032

25. Bigby C, Bowers B, Webber R. Planning and decision making about the future care of older group home residents and transition to residential aged care. Journal of Intellectual Disability Research. 2011; 55(8):777-89

26. Billings JA, Bernacki R. Strategic targeting of advance care planning interventions: The Goldilocks phenomenon. JAMA Internal Medicine. 2014; 174(4):620-4

27. Biondo PD, Lee LD, Davison SN, Simon JE, Advance Care Planning Collaborative R, Innovation Opportunities P. How healthcare systems evaluate their advance care planning initiatives: Results from a systematic review. Palliative Medicine. 2016; 30(8):720-9

28. Black K. Advance directive communication practices: Social workers' contributions to the interdisciplinary health care team. Social Work in Health Care. 2004; 40(3):39-55

29. Blackford J, Street A. Is an advance care planning model feasible in community palliative care? A multi-site action research approach. Journal of Advanced Nursing. 2012; 68(9):2021-2033

30. Boettcher I, Turner R, Briggs L. Telephonic advance care planning facilitated by health plan case managers. Palliative and Supportive Care. 2015; 13(3):795-800

31. Bookbinder M, Glajchen M, McHugh M, Higgins P, Budis J, Solomon N et al. Nurse practitioner-based models of specialist palliative care at home: Sustainability and evaluation of feasibility. Journal of Pain and Symptom Management. 2011; 41(1):25-34

32. Boorsma M, Hout HP, Frijters DH, Ribbe MW, Nijpels G. The cost-effectiveness of a new disease management model for frail elderly living in homes for the elderly,

design of a cluster randomized controlled clinical trial. BMC Health Services Research. 2008; 8:143

33. Bose-Brill S, Feeney M, Prater L, Miles L, Corbett A, Koesters S. Validation of a Novel Electronic Health Record Patient Portal Advance Care Planning Delivery System. Journal of Medical Internet Research. 2018; 20(6):e208

34. Bose-Brill S, Kretovics M, Ballenger T, Modan G, Lai A, Belanger L et al. Testing of a tethered personal health record framework for early end-of-life discussions. American Journal of Managed Care. 2016; 22(7):e258-e263

35. Bose-Brill S, Kretovics M, Ballenger T, Modan G, Lai A, Belanger L et al. Development of a tethered personal health record framework for early end-of-life discussions. American Journal of Managed Care. 2016; 22(6):412-8

36. Boyd K, Mason B, Kendall M, Barclay S, Chinn D, Thomas K et al. Advance care planning for cancer patients in primary care: a feasibility study. British Journal of General Practice. 2010; 60(581):e449-58

37. Bradley E, Walker L, Blechner B, Wetle T. Assessing capacity to participate in discussions of advance directives in nursing homes: Findings from a study of the patient self determination act. Journal of the American Geriatrics Society. 1997; 45(1):79-83

38. Bradley EH, Peiris V, Wetle T. Discussions about end-of-life care in nursing homes. Journal of the American Geriatrics Society. 1998; 46(10):1235-41

39. Bravo G, Arcand M, Blanchette D, Boire-Lavigne AM, Dubois MF, Guay M et al. Promoting advance planning for health care and research among older adults: A randomized controlled trial. BMC Medical Ethics. 2012; 13:1

40. Bravo G, Trottier L, Arcand M, Boire-Lavigne AM, Blanchette D, Dubois MF et al. Promoting advance care planning among community-based older adults: A randomized controlled trial. Patient Education and Counseling. 2016; 99(11):1785-1795

41. Brazil K, Carter G, Cardwell C, Clarke M, Hudson P, Froggatt K et al. Effectiveness of advance care planning with family carers in dementia nursing homes: A paired cluster randomized controlled trial. Palliative Medicine. 2017; Epublication

42. Brazil K, Carter G, Cardwell C, Clarke M, Hudson P, Froggatt K et al. Effectiveness of advance care planning with family carers in dementia nursing homes: a paired cluster randomized controlled trial. Palliative Medicine. 2018; 32(3):603-612

43. Briggs LA, Kirchhoff KT, Hammes BJ, Song MK, Colvin ER. Patient-centered advance care planning in special patient populations: A pilot study. Journal of professional nursing : official journal of the American Association of Colleges of Nursing. 2004; 20(1):47-58

44. Brinkman-Stoppelenburg A, Rietjens JA, van der Heide A. The effects of advance care planning on end-of-life care: A systematic review. Palliative Medicine. 2014; 28(8):1000-25

45. Bristowe K, Carey I, Hopper A, Shouls S, Prentice W, Caulkin R et al. Patient and carer experiences of clinical uncertainty and deterioration, in the face of limited reversibility: A comparative observational study of the AMBER care bundle. Palliative Medicine. 2015; 29(9):797-807

46. Bristowe K, Shepherd K, Bryan L, Brown H, Carey I, Matthews B et al. The development and piloting of the REnal specific Advanced Communication Training

(REACT) programme to improve Advance Care Planning for renal patients. Palliative Medicine. 2014; 28(4):360-6

47. Buchanan RJ, Bolin J, Wang S, Zhu L, Kim M. Urban/rural differences in decision making and the use of advance directives among nursing home residents at admission. Journal of Rural Health. 2004; 20(2):131-5

48. Buchanan RJ, Choi M, Wang S, Ju H. End-of-life care in nursing homes: Residents in hospice compared to other end-stage residents. Journal of Palliative Medicine. 2004; 7(2):221-32

49. Butler J, Binney Z, Kalogeropoulos A, Owen M, Clevenger C, Gunter D et al. Advance directives among hospitalized patients with heart failure. JACC Heart Failure. 2015; 3(2):112-21

50. Butler M, Ratner E, McCreedy E, Shippee N, Kane RL. Decision aids for advance care planning: An overview of the state of the science. Annals of Internal Medicine. 2014; 161(6):408-418

51. Cadigan RO, Grabowski DC, Givens JL, Mitchell SL. The quality of advanced dementia care in the nursing home: The role of special care units. Medical Care. 2012; 50(10):856-62

52. Caplan GA, Meller A, Squires B, Chan S, Willett W. Advance care planning and hospital in the nursing home. Age and Ageing. 2006; 35(6):581-5

53. Carey I, Shouls S, Bristowe K, Morris M, Briant L, Robinson C et al. Improving care for patients whose recovery is uncertain. The AMBER care bundle: Design and implementation. BMJ Supportive & Palliative Care. 2015; 5(1):12-8

54. Carrero Planes V, Navarro Sanz R, Serrano Font M. Advance care planning in patients with chronic disease and in need of palliative care. Medicina Paliativa. 2016; 23(1):32-41

55. Cartwright C, Montgomery J, Rhee J, Zwar N, Banbury A. Medical practitioners' knowledge and self-reported practices of substitute decision making and implementation of advance care plans. Internal Medicine Journal. 2014; 44(3):234-9

56. Castle NG, Mor V. Advance care planning in nursing homes: Pre- and post-Patient Self-Determination Act. Health Services Research. 1998; 33(1):101-24

57. Chan HY-L, Ng JS-C, Chan K-S, Ko P-S, Leung DY-P, Chan CW-H et al. Effects of a nurse-led post-discharge advance care planning programme for community-dwelling patients nearing the end of life and their family members: A randomised controlled trial. International Journal of Nursing Studies. 2018; 87:26

58. Chan HY, Pang SM. Let me talk--an advance care planning programme for frail nursing home residents. Journal of Clinical Nursing. 2010; 19(21-22):3073-84

59. Chan RJ, Webster J, Bowers A. End-of-life care pathways for improving outcomes in caring for the dying. Cochrane Database of Systematic Reviews 2016, Issue 2. Art. No.: CD008006. DOI: 10.1002/14651858.CD008006.pub4.

60. Chen CY, Thorsteinsdottir B, Cha SS, Hanson GJ, Peterson SM, Rahman PA et al. Health care outcomes and advance care planning in older adults who receive home-based palliative care: A pilot cohort study. Journal of Palliative Medicine. 2015; 18(1):38-44

61. Clark MA, Ott M, Rogers ML, Politi MC, Miller SC, Moynihan L et al. Advance care planning as a shared endeavor: Completion of ACP documents in a multidisciplinary cancer program. Psycho-Oncology. 2017; 26(1):67-73

62. Connolly J, Milligan S, Stevens E. Advance care planning in a community setting. Nursing Standard. 2015; 29(23):43-51

63. Coulter A, Entwistle VA, Eccles A, Ryan S, Shepperd S, Perera R. Personalised care planning for adults with chronic or long-term health conditions. Cochrane Database of Systematic Reviews 2015, Issue 3. Art. No.: CD010523. DOI: 10.1002/14651858.CD010523.pub2.

64. Counsell SR, Holder CM, Liebenauer LL, Palmer RM, Fortinsky RH, Kresevic DM et al. Effects of a multicomponent intervention on functional outcomes and process of care in hospitalized older patients: A randomized controlled trial of Acute Care for Elders (ACE) in a community hospital. Journal of the American Geriatrics Society. 2000; 48(12):1572-81

65. Courtright KR, Madden V, Gabler NB, Cooney E, Kim J, Herbst N et al. A Randomized Trial of Expanding Choice Sets to Motivate Advance Directive Completion. Medical Decision Making. 2016; 37(5):544-554

66. Curtis L, Burns A. Unit costs of health & social care 2016. Canterbury. University of Kent Personal Social Services Research Unit, 2016.

67. Danis M, Abernethy AP, Zafar SY, Samsa GP, Wolf SP, Howie L et al. A decision exercise to engage cancer patients and families in deliberation about Medicare coverage for advanced cancer care. BMC Health Services Research. 2014; 14:315

68. Dargin JM, Mackey CG, Lei Y, Liesching TN. Resource utilization and end-of-life care in a US hospital following medical emergency team-implemented do not resuscitate orders. Journal of Hospital Medicine. 2014; 9(6):372-378

69. Davison SN, Torgunrud C. The creation of an advance care planning process for patients with ESRD. American Journal of Kidney Diseases. 2007; 49(1):27-36

70. De Vleminck A, Houttekier D, Deliens L, Vander Stichele R, Pardon K. Development of a complex intervention to support the initiation of advance care planning by general practitioners in patients at risk of deteriorating or dying: A phase 0-1 study. BMC Palliative Care. 2016; 15 17

71. Detering K, Hancock A, Reade M. The impact of advance care planning on end of life care in elderly patients : randomised controlled trial. BMJ. 2010; 340(7751):c1345

72. Dickinson C, Bamford C, Exley C, Emmett C, Hughes J, Robinson L. Planning for tomorrow whilst living for today: The views of people with dementia and their families on advance care planning. International Psychogeriatrics. 2013; 25(12):2011-2021

73. Dionne-Odom JN, Sylvia Huang CH, Niranjan SJ, Williams CP, Bevis KS, Wallace AS et al. Implementation and Impact of Patient Lay Navigator-Led Advance Care Planning Conversations. Journal of Pain and Symptom Management. 2017; 53(4):682-692

74. Dixon J, Matosevic T, Knapp M. The economic evidence for advance care planning: Systematic review of evidence. Palliative Medicine. 2015; 29(10):869-884

75. Doorenbos AZ, Levy WC, Curtis JR, Dougherty CM. An intervention to enhance goals-of-care communication between heart failure patients and heart failure providers. Journal of Pain and Symptom Management. 2016; 52(3):353-360

76. Downar J, Rodin D, Barua R, Lejnieks B, Gudimella R, McCredie V et al. Rapid response teams, do not resuscitate orders, and potential opportunities to improve end-of-life care: A multicentre retrospective study. Journal of Critical Care. 2013; 28(4):498-503

77. Edwin AK, Johnson McGee S, Opare-Lokko EA, Gyakobo MK. A structured approach to end-of-life decision making improves quality of care for patients with terminal illness in a teaching hospital in Ghana. American Journal of Hospice & Palliative Medicine. 2016; 33(2):144-9

78. El-Jawahri A, Paasche-Orlow MK, Matlock D, Stevenson LW, Lewis EF, Stewart G et al. Randomized, controlled trial of an advance care planning video decision support tool for patients with advanced heart failure. Circulation. 2017; 134(1):52-60

79. El-Jawahri A, Podgurski LM, Eichler AF, Plotkin SR, Temel JS, Mitchell SL et al. Use of video to facilitate end-of-life discussions with patients with cancer: a randomized controlled trial. Journal of Clinical Oncology. 2010; 28(2):305-10

80. Epstein AS, O'Reilly EM, Shuk E, Romano D, Li Y, Breitbart W et al. A Randomized Trial of Acceptability and Effects of Values-Based Advance Care Planning in Outpatient Oncology: Person-Centered Oncologic Care and Choices. Journal of Pain and Symptom Management. 2018; 56(2):169-177.e1

81. Epstein AS, Volandes AE, Chen LY, Gary KA, Li Y, Agre P et al. A randomized controlled trial of a cardiopulmonary resuscitation video in advance care planning for progressive pancreas and hepatobiliary cancer patients. Journal of Palliative Medicine. 2014; 16(6):623-631

82. Evans R, Finucane A, Vanhegan L, Arnold E, Oxenham D. Do place-of-death preferences for patients receiving specialist palliative care change over time? International Journal of Palliative Nursing. 2014; 20(12):579-83

83. Fine RL, Yang Z, Spivey C, Boardman B, Courtney M. Early experience with digital advance care planning and directives, a novel consumer-driven program. Baylor University Medical Center Proceedings. 2016; 29(3):263-7

84. Fried TR, Gillick MR. Medical decision-making in the last six months of life: Choices about limitation of care. Journal of the American Geriatrics Society. 1994; 42(3):303-7

85. Garrido MM, Balboni TA, Maciejewski PK, Bao Y, Prigerson HG. Quality of life and cost of care at the end of life: The role of advance directives. Journal of Pain and Symptom Management. 2015; 49(5):828-835

86. General Medical Council. Treatment and care towards the end of life: good practice in decision making. London. General Medical Council, 2010. Available from: https://www.gmc-uk.org/End_of_life.pdf_32486688.pdf

87. Gilissen J, Pivodic L, Smets T, Gastmans C, Vander Stichele R, Deliens L et al. Preconditions for successful advance care planning in nursing homes: A systematic review. International Journal of Nursing Studies. 2017; 66:47-59

88. Glaudemans JJ, van Charante EPM, Willems DL. Advance care planning in primary care, only for severely ill patients? A structured review. Family Practice. 2015; 32(1):16-26

89. Go RS, Hammes BA, Lee JA, Mathiason MA. Advance directives among health care professionals at a community-based cancer center. Mayo Clinic Proceedings. 2007; 82(12):1487-90

90. Green MJ, Levi BH. Teaching advance care planning to medical students with a computer-based decision aid. Journal of cancer education : the official journal of the American Association for Cancer Education. 2011; 26(1):82-91

91. Green T, Gandhi S, Kleissen T, Simon J, Raffin-Bouchal S, Ryckborst K. Advance care planning in stroke: Influence of time on engagement in the process. Patient Preference and Adherence. 2014; 8:119-26

92. Grimaldo DA, Wiener-Kronish JP, Jurson T, Shaughnessy TE, Curtis JR, Liu LL. A randomized, controlled trial of advanced care planning discussions during preoperative evaluations. Anesthesiology. 2001; 95(1):43-50; discussion 5A

93. Hanson LC, Zimmerman S, Song MK, Lin FC, Rosemond C, Carey TS et al. Effect of the goals of care intervention for advanced dementia: a randomized clinical trial. JAMA Internal Medicine. 2017; 177(1):24-31

94. Happ MB, Capezuti E, Strumpf NE, Wagner L, Cunningham S, Evans L et al. Advance care planning and end-of-life care for hospitalized nursing home residents. Journal of the American Geriatrics Society. 2002; 50(5):829-35

95. Hendriks SA, Smalbrugge M, Hertogh C, van der Steen JT. Changes in care goals and treatment orders around the occurrence of health problems and hospital transfers in dementia: A prospective study. Journal of the American Geriatrics Society. 2017; 65(4):769-776

96. Hickman SE, Unroe KT, Ersek MT, Buente B, Nazir A, Sachs GA. An interim analysis of an advance care planning intervention in the nursing home setting. Journal of the American Geriatrics Society. 2016; 64(11):2385-2392

97. Hilgeman MM, Allen RS, Snow AL, Durkin DW, DeCoster J, Burgio LD. Preserving Identity and Planning for Advance Care (PIPAC): preliminary outcomes from a patient-centered intervention for individuals with mild dementia. Aging & Mental Health. 2014; 18(4):411-24

98. Hinderer KA, Lee MC. Assessing a nurse-led advance directive and advance care planning seminar. Applied Nursing Research. 2014; 27(1):84-6

99. Hing Wong A, Chin LE, Ping TL, Peng NK, Kun LS. Clinical impact of education provision on determining advance care planning decisions among end stage renal disease patients receiving regular hemodialysis in university Malaya medical centre. Indian Journal of Palliative Care. 2016; 22(4):437-445

100. Hogg K, Jenkins SMM. Medical anticipatory care plans in advanced heart failure prevent hospital re-admissions. European Heart Journal. 2012; 33(Suppl 1):483-484

101. Holland DE, Vanderboom CE, Dose AM, Ingram CJ, Delgado A, Austin CM et al. Nurse-led patient-centered advance care planning in primary care: A pilot study. Journal of Hospice and Palliative Nursing. 2017; 19(4):368-375

102. Holley JL. Advance care planning in elderly chronic dialysis patients. International Urology and Nephrology. 2003; 35(4):565-8

103. Houben CH, Spruit MA, Wouters EF, Janssen DJ. A randomised controlled trial on the efficacy of advance care planning on the quality of end-of-life care and communication in patients with COPD: The research protocol. BMJ Open. 2014; 4(1):e004465

104. Houben CHM, Spruit MA, Groenen MTJ, Wouters EFM, Janssen DJA. Efficacy of advance care planning: A systematic review and meta-analysis. Journal of the American Medical Directors Association. 2014; 15(7):477-489

105. Howard M, Bonham AJ, Heyland DK, Sudore R, Fassbender K, Robinson CA et al. Measuring engagement in advance care planning: A cross-sectional multicentre feasibility study. BMJ Open. 2016; 6(6):e010375

106. Huang C-HS, Crowther M, Allen RS, DeCoster J, Kim G, Azuero C et al. A pilot feasibility intervention to increase advance care planning among African Americans in the deep south. Journal of Palliative Medicine. 2016; 19(2):164-173

107. Huber MT, Highland JD, Krishnamoorthi VR, Tang JW. Utilizing the electronic health record to improve advance care planning: a systematic review. American Journal of Hospice & Palliative Medicine. 2017; Epublication

108. Hudson P, Collins A, Bostanci A, Willenberg L, Stepanov N, Philip J. Toward a systematic approach to assessment and care planning in palliative care: A practical review of clinical tools. Palliative and Supportive Care. 2016; 14(2):161-73

109. Hui E, Ma HM, Tang WH, Lai WS, Au KM, Leung MT et al. A new model for end-of-life care in nursing homes. Journal of the American Medical Directors Association. 2014; 15(4):287-9

110. In der Schmitten J, Rotharmel S, Mellert C, Rixen S, Hammes BJ, Briggs L et al. A complex regional intervention to implement advance care planning in one town's nursing homes: Protocol of a controlled inter-regional study. BMC Health Services Research. 2011; 11:14

111. Izumi S, Fromme EK. A model to promote clinicians' understanding of the continuum of advance care planning. Journal of Palliative Medicine. 2017; 20(3):220-221

112. Jacobsen J, Robinson E, Jackson VA, Meigs JB, Billings JA. Development of a cognitive model for advance care planning discussions: Results from a quality improvement initiative. Journal of Palliative Medicine. 2011; 14(3):331-336

113. Jain A, Corriveau S, Quinn K, Gardhouse A, Vegas DB, You JJ. Video decision aids to assist with advance care planning: A systematic review and meta-analysis. BMJ Open. 2015; 5(6):e007491

114. Janssen DJA, Spruit MA, Schols JMGA, Wouters EFM. A call for high-quality advance care planning in outpatients with severe COPD or chronic heart failure. Chest. 2011; 139(5):1081-1088

115. Jethwa KD, Onalaja O. Advance care planning and palliative medicine in advanced dementia: A literature review. BJPsych Bulletin. 2015; 39(2):74-8

116. Jones B, Appleton W, Heazlewood T, Ironside J, Dugdale P. Introduction of an advance care planning clinic in a regional care coordination service. World hospitals and health services : the official journal of the International Hospital Federation. 2015; 51(4):12-16

117. Jones DA, McIntyre T, Baldwin I, Mercer I, Kattula A, Bellomo R. The medical emergency team and end-of-life care: a pilot study. Critical Care and Resuscitation. 2007; 9(2):151-6

118. Kaambwa B, Ratcliffe J, Bradley SL, Masters S, Davies O, Whitehead C et al. Costs and advance directives at the end of life: a case of the 'Coaching Older Adults and Carers to have their preferences Heard (COACH)' trial. BMC Health Services Research. 15:545

119. Kalowes P. Improving end-of-life care prognostic discussions: role of advanced practice nurses. AACN Advanced Critical Care. 2015; 26(2):151-66

120. Karppinen H, Laakkonen ML, Strandberg TE, Tilvis RS, Pitkala KH. Living wills and end-of-life care of older people suffering from cardiovascular diseases: A ten-year follow-up. European Geriatric Medicine. 2014; 5(1):31-34

121. Khandelwal N, Benkeser DC, Coe NB, Curtis JR. Potential influence of advance care planning and palliative care consultation on ICU costs for patients with chronic and serious illness. Critical Care Medicine. 2016; 44(8):1474-81

122. Khandelwal N, Kross EK, Engelberg RA, Coe NB, Long AC, Curtis JR. Estimating the effect of palliative care interventions and advance care planning on ICU utilization: A systematic review. Critical Care Medicine. 2015; 43(5):1102-11

123. Kim J, Kim S, Shin MS, Jin JO, Kim Y, Lee MO. A context-oriented communication algorithm for advance care planning: A model to assist palliative care in heart failure. Journal of Cardiovascular Nursing. 2017; Epublication

124. Kinley J, Stone L, Butt A, Kenyon B, Lopes NS. Developing, implementing and sustaining an end-of-life care programme in residential care homes. International Journal of Palliative Nursing. 2017; 23(4):186-193

125. Kirchhoff KT, Hammes BJ, Kehl KA, Briggs LA, Brown RL. Effect of a disease-specific advance care planning intervention on end-of-life care. Journal of the American Geriatrics Society. 2012; 60(5):946-50

126. Klingler C, in der Schmitten J, Marckmann G. Does facilitated Advance Care Planning reduce the costs of care near the end of life? Systematic review and ethical considerations. Palliative Medicine. 2016; 30(5):423-33

127. Knott CI, Psirides AJ, Young PJ, Sim D. A retrospective cohort study of the effect of medical emergency teams on documentation of advance care directives. Critical Care and Resuscitation. 2011; 13(3):167-74

128. Ko E, Hohman M, Lee J, Ngo AN, Woodruff SI. Feasibility and acceptability of a brief motivational stage-tailored intervention to advance care planning: a pilot study. American Journal of Hospice & Palliative Medicine. 2016; 33(9):834-842

129. Kwak J, Ko E, Kramer BJ. Facilitating advance care planning with ethnically diverse groups of frail, low-income elders in the USA: Perspectives of care managers on challenges and recommendations. Health & Social Care in the Community. 2014; 22(2):169-177

130. Lawrence JF. The advance directive prevalence in long-term care: a comparison of relationships between a nurse practitioner healthcare model and a traditional healthcare model. Journal of the American Academy of Nurse Practitioners. 2009; 21(3):179-85

131. Leung AK, To MJ, Luong L, Vahabi ZS, Goncalves VL, Song J et al. The Effect of Advance Directive Completion on Hospital Care Among Chronically Homeless Persons: a Prospective Cohort Study. Journal of Urban Health. 2017; 94(1):43-53

132. Lewis E, Cardona-Morrell M, Ong KY, Trankle SA, Hillman K. Evidence still insufficient that advance care documentation leads to engagement of healthcare professionals in end-of-life discussions: A systematic review. Palliative Medicine. 2016; 30(9):807-24

133. Lewis M, Rand E, Mullaly E, Mellor D, Macfarlane S. Uptake of a newly implemented advance care planning program in a dementia diagnostic service. Age and Ageing. 2015; 44(6):1045-9

134. Lim CE, Ng RW, Cheng NC, Cigolini M, Kwok C, Brennan F. Advance care planning for haemodialysis patients. Cochrane Database of Systematic Reviews 2016, Issue 7. Art. No.: CD010737. DOI: 10.1002/14651858.CD010737.pub2.

135. Litzelman DK, Inui TS, Griffin WJ, Perkins A, Cottingham AH, Schmitt-Wendholt KM et al. Impact of community health workers on elderly patients' advance care planning and health care utilization: Moving the dial. Medical Care. 2017; 55(4):319-326

136. Litzelman DK, Inui TS, Schmitt-Wendholt KM, Perkins A, Griffin WJ, Cottingham AH et al. Clarifying values and preferences for care near the end of life: The role of a new lay workforce. Journal of Community Health. 2017; 42(5):926-934

137. Livingston G, Lewis-Holmes E, Pitfield C, Manela M, Chan D, Constant E et al. Improving the end-of-life for people with dementia living in a care home: An intervention study. International Psychogeriatrics. 2013; 25(11):1849-1858

138. Lord K, Livingston G, Cooper C. A systematic review of barriers and facilitators to and interventions for proxy decision-making by family carers of people with dementia. International Psychogeriatrics. 2015; 27(8):1301-12

139. Luckett T, Sellars M, Tieman J, Pollock CA, Silvester W, Butow PN et al. Advance care planning for adults with CKD: a systematic integrative review. American Journal of Kidney Diseases. 2014; 63(5):761-70

140. Lum HD, Jones J, Matlock DD, Glasgow RE, Lobo I, Levy CR et al. Advance care planning meets group medical visits: The feasibility of promoting conversations. Annals of Family Medicine. 2016; 14(2):125-32

141. Lum HD, Sudore RL, Matlock DD, Juarez-Colunga E, Jones J, Nowels M et al. A group visit initiative improves advance care planning documentation among older adults in primary care. Journal of the American Board of Family Medicine: JABFM. 2017; 30(4):480-490

142. Lustbader D, Pekmezaris R, Frankenthaler M, Walia R, Smith F, Hussain E et al. Palliative medicine consultation impacts DNR designation and length of stay for terminal medical MICU patients. Palliative and Supportive Care. 2011; 9(4):401-6

143. MacPherson A, Walshe C, O'Donnell V, Vyas A. The views of patients with severe chronic obstructive pulmonary disease on advance care planning: A qualitative study. Palliative Medicine. 2013; 27(3):265-72

144. Markham SA, Levi BH, Green MJ, Schubart JR. Use of a computer program for advance care planning with African American participants. Journal of the National Medical Association. 2015; 107(1):26-32

145. Martin MP, Ryan ME, Ballard J, Dolan E, Kennelly SM, McCormack PME. Impact of end of life care plans on nursing home residents. European Geriatric Medicine. 2010; 1:S121

146. Martin RS, Hayes B, Gregorevic K, Lim WK. The effects of advance care planning interventions on nursing home residents: A systematic review. Journal of the American Medical Directors Association. 2016; 17(4):284-93

147. McCorkle R, Jeon S, Ercolano E, Lazenby M, Reid A, Davies M et al. An advanced practice nurse coordinated multidisciplinary intervention for patients with late-stage cancer: A cluster randomized trial. Journal of Palliative Medicine. 2015; 18(11):962-9

148. Meehan KA. Advance directives: the clinical nurse specialist as a change agent. Clinical Nurse Specialist. 2009; 23(5):258-264

149. Meeussen K, Van den Block L, Echteld M, Bossuyt N, Bilsen J, Van Casteren V et al. Advance care planning in Belgium and The Netherlands: A nationwide retrospective study via sentinel networks of general practitioners. Journal of Pain and Symptom Management. 2011; 42(4):565-77

150. Metzger M, Song MK, Ward S, Chang PPY, Hanson LC, Lin FC. A randomized controlled pilot trial to improve advance care planning for LVAD patients and their surrogates. Heart and Lung. 2016; 45(3):186-92

151. Mitchell G, Zhang J, Burridge L, Senior H, Miller E, Young S et al. Case conferences between general practitioners and specialist teams to plan end of life care of people with end stage heart failure and lung disease: an exploratory pilot study. BMC Palliative Care. 2014; 13:24

152. Morrell ED, Brown BP, Qi R, Drabiak K, Helft PR. The do-not-resuscitate order: Associations with advance directives, physician specialty and documentation of discussion 15 years after the patient self-determination act. Journal of Medical Ethics. 2008; 34(9):642-7

153. Morrison RS, Chichin E, Carter J, Burack O, Lantz M, Meier DE. The effect of a social work intervention to enhance advance care planning documentation in the nursing home. Journal of the American Geriatrics Society. 2005; 53(2):290-4

154. Murray L, Butow PN. Advance care planning in motor neuron disease: A systematic review. Palliative and Supportive Care. 2016; 14(4):411-32

155. Nath SB, Hirschman KB, Lewis B, Strumpf NE. A place called LIFE: Exploring the advance care planning of African-American PACE enrollees. Social Work in Health Care. 2008; 47(3):277-292

156. Nathens AB, Rivara FP, Wang J, Mackenzie EJ, Jurkovich GJ. Variation in the rates of do not resuscitate orders after major trauma and the impact of intensive care unit environment. Journal of Trauma-Injury Infection & Critical Care. 2008; 64(1):81-8; discussion 88-91

157. National Institute for Health and Care Excellence. Developing NICE guidelines: the manual. London. National Institute for Health and Care Excellence, 2014. Available from: http://www.nice.org.uk/article/PMG20/chapter/1%20Introduction%20and%20overview

158. Nedjat-Haiem FR, Carrion IV, Gonzalez K, Quintana A, Ell K, O'Connell M et al. Implementing an advance care planning intervention in community settings with older latinos: A feasibility study. Journal of Palliative Medicine. 2017; 20(9):984-993

159. Nishie H, Mizobuchi S, Suzuki E, Sato K, Toda Y, Matsuoka J et al. Living will interest and preferred end-of-life care and death locations among Japanese adults 50 and over: a population-based survey. Acta Medica Okayama. 2014; 68(6):339-48

160. O'Sullivan R, Murphy A, O'Caoimh R, Cornally N, Svendrovski A, Daly B et al. Economic (gross cost) analysis of systematically implementing a programme of advance care planning in three Irish nursing homes. BMC Research Notes. 2016; 9:237

161. Obel J, Brockstein B, Marschke M, Robicsek A, Konchak C, Sefa M et al. Outpatient advance care planning for patients with metastatic cancer: A pilot quality improvement initiative. Journal of Palliative Medicine. 2014; 17(11):1231-7

162. Oczkowski SJ, Chung HO, Hanvey L, Mbuagbaw L, You JJ. Communication tools for end-of-life decision-making in ambulatory care settings: A systematic review and meta-analysis. PloS One. 2016; 11(4):e0150671

163. Olson KD, Harrison D, Hoverman JR, Arlen AG, Mikan SQ, Ash-Lee S. Systematic identification of metastatic population subsets for advance care planning (ACP) discussions: A scalable approach using electronic health record (EHR) technology. Journal of Clinical Oncology. 2013; 31(31 Suppl):243

164. Organisation for Economic Co-operation and Development (OECD). Purchasing power parities (PPP). 2017. Available from: https://data.oecd.org/conversion/purchasing-power-parities-ppp.htm Last accessed: 25/08/2017

165. Overbeek A, Korfage IJ, Jabbarian LJ, Billekens P, Hammes BJ, Polinder S et al. Advance Care Planning in Frail Older Adults: A Cluster Randomized Controlled Trial. Journal of the American Geriatrics Society. 2018; 66(6):1089-1095

166. Patrick DL, Pearlman RA, Starks HE, Cain KC, Cole WG, Uhlmann RF. Validation of preferences for life-sustaining treatment: Implications for advance care planning. Annals of Internal Medicine. 1997; 127(7):509-17

167. Pautex S, Gamondi C, Philippin Y, Gremaud G, Herrmann F, Camartin C et al. Advance directives and end-of-life decisions in Switzerland: role of patients, relatives and health professionals. BMJ Supportive & Palliative Care. 2015; Epublication

168. Pautex S, Herrmann FR, Zulian GB. Role of advance directives in palliative care units: A prospective study. Palliative Medicine. 2008; 22(7):835-41

169. Pearlman RA, Cain KC, Starks H, Cole WG, Uhlmann RF, Patrick DL. Preferences for life-sustaining treatments in advance care planning and surrogate decision making. Journal of Palliative Medicine. 2000; 3(1):37-48

170. Pearlman RA, Starks H, Cain KC, Cole WG. Improvements in advance care planning in the Veterans Affairs System: Results of a multifaceted intervention. Archives of Internal Medicine. 2005; 165(6):667-74

171. Pedraza SL, Culp S, Knestrick M, Falkenstine E, Moss AH. Association of Physician Orders for Life-Sustaining Treatment Form Use With End-of-Life Care Quality Metrics in Patients With Cancer. Journal of Oncology Practice. 2017; 13(10):e881-e888

172. Periyakoil VS, Neri E, Kraemer H. A randomized controlled trial comparing the Letter Project Advance Directive to Traditional Advance Directive. Journal of Palliative Medicine. 2017; 20(9):954-965

173. Perry E, Swartz J, Kelly G, Brown SL, Swartz RD. Palliative care in chronic kidney disease: Peer mentoring program personalizes advance directives discussions. Nephrology News and Issues. 2003; 17(8):28-31

174. Pham B, Krahn M. End-of-life care interventions: An economic analysis. Ontario Health Technology Assessment Series. 2014; 14(18):1-70

175. Pockett R, Walker E, Dave K. "Last orders": Dying in a hospital setting. Australian Social Work. 2010; 63(3):250-265

176. Radhakrishnan K, Van Scoy LJ, Jillapalli R, Saxena S, Kim MT. Community-based game intervention to improve South Asian Indian Americans' engagement with advanced care planning. Ethnicity and Health. 2017:1-19

177. Radwany SM, Hazelett SE, Allen KR, Kropp DJ, Ertle D, Albanese TH et al. Results of the promoting effective advance care planning for elders (PEACE) randomized pilot study. Population Health Management. 2014; 17(2):106-11

178. Ratner E, Norlander L, McSteen K. Death at home following a targeted advance-care planning process at home: The kitchen table discussion. Journal of the American Geriatrics Society. 2001; 49(6):778-81

179. Reinke LF, Feemster LC, McDowell J, Gunnink E, Tartaglione EV, Udris E et al. The long term impact of an end-of-life communication intervention among veterans with COPD. Heart and Lung. 2017; 46(1):30-34

180. Rhee JJ, Zwar NA, Kemp LA. Why are advance care planning decisions not implemented? Insights from interviews with Australian general practitioners. Journal of Palliative Medicine. 2013; 16(10):1197-1204

181. Robinson L, Bamford C, Beyer F, Clark A, Dickinson C, Emmet C et al. Patient preferences for future care--how can Advance Care Planning become embedded into dementia care: A study protocol. BMC Geriatrics. 2010; 10:2

182. Robinson L, Dickinson C, Bamford C, Clark A, Hughes J, Exley C. A qualitative study: Professionals' experiences of advance care planning in dementia and palliative care, 'a good idea in theory but ...'. Palliative Medicine. 2013; 27(5):401-8

183. Robinson L, Dickinson C, Rousseau N, Beyer F, Clark A, Hughes J et al. A systematic review of the effectiveness of advance care planning interventions for people with cognitive impairment and dementia. Age and Ageing. 2012; 41(2):263-9

184. Sadeghi B, Walling AM, Romano PS, Ahluwalia SC, Ong MK. A hospital-based advance care planning intervention for patients with heart failure: A feasibility study. Journal of Palliative Medicine. 2016; 19(4):451-5

185. Sampson EL, Jones L, Thuné-Boyle IC, Kukkastenvehmas R, King M, Leurent B et al. Palliative assessment and advance care planning in severe dementia: An exploratory randomized controlled trial of a complex intervention. Palliative Medicine. 2011; 25(3):197-209

186. Sander R. Planning end of life care. Nursing Older People. 2010; 22(5):13

187. Schaden E, Herczeg P, Hacker S, Schopper A, Krenn CG. The role of advance directives in end-of-life decisions in Austria: Survey of intensive care physicians. BMC Medical Ethics. 2010; 11:19

188. Schamp R, Tenkku L. Managed death in a PACE: Pathways in present and advance directives. Journal of the American Medical Directors Association. 2006; 7(6):339-44

189. Schellinger S, Sidebottom A, Briggs L. Disease specific advance care planning for heart failure patients: Implementation in a large health system. Journal of Palliative Medicine. 2011; 14(11):1224-1230

190. Schenker Y, White D, Rosenzweig M, Chu E, Moore C, Ellis P et al. Care management by oncology nurses to address palliative care needs: A pilot trial to assess feasibility, acceptability, and perceived effectiveness of the CONNECT intervention. Journal of Palliative Medicine. 2015; 18(3):232-240

191. Schmidt RJ, Weaner BB, Long D. The power of advance care planning in promoting hospice and out-of-hospital death in a dialysis unit. Journal of Palliative Medicine. 2015; 18(1):62-66

192. Schofield G, Kreeger L, Meyer M, Swann D, Wijeratne A, Wood J et al. Implementation of a quality improvement programme to support advance care planning in five hospitals across a health region. BMJ Supportive & Palliative Care. 2015; 5(1):91-4

193. Schwartz CE, Wheeler HB, Hammes B, Basque N, Edmunds J, Reed G et al. Early intervention in planning end-of-life care with ambulatory geriatric patients: Results of a pilot trial. Archives of Internal Medicine. 2002; 162(14):1611-8

194. Scott IA, Rajakaruna N, Shah D, Miller L, Reymond E, Daly M. Normalising advance care planning in a general medicine service of a tertiary hospital: an exploratory study. Australian Health Review. 2015; Epublication

195. Seal M. Patient advocacy and advance care planning in the acute hospital setting. Australian Journal of Advanced Nursing. 2007; 24(4):29-36

196. Sellars M, Detering KM, Silvester W. Current advance care planning practice in the Australian community: An online survey of home care package case managers and service managers Knowledge, education and training. BMC Palliative Care. 2015; 14:15

197. Sharp T, Moran E, Kuhn I, Barclay S. Do the elderly have a voice? Advance care planning discussions with frail and older individuals: A systematic literature review and narrative synthesis. British Journal of General Practice. 2013; 63(615):e657-e668

198. Sinclair C, Auret KA, Evans SF, Williamson F, Dormer S, Wilkinson A et al. Advance care planning uptake among patients with severe lung disease: A randomised patient preference trial of a nurse-led, facilitated advance care planning intervention. BMJ Open. 2017; 7(2):e013415

199. Smith RL, Hayashi VN, Lee YI, Navarro-Mariazeta L, Felner K. The medical emergency team call: A sentinel event that triggers goals of care discussion. Critical Care Medicine. 2014; 42(2):322-7

200. Song J, Ratner ER, Wall MM, Bartels DM, Ulvestad N, Petroskas D et al. Effect of an end-of-life planning intervention on the completion of advance directives in homeless persons: A randomized trial. Annals of Internal Medicine. 2010; 153(2):76-84

201. Song MK, Kirchhoff KT, Douglas J, Ward S, Hammes B. A randomized, controlled trial to improve advance care planning among patients undergoing cardiac surgery. Medical Care. 2005; 43(10):1049-53

202. Song MK, Ward SE. Making visible a theory-guided advance care planning intervention. Journal of Nursing Scholarship. 2015; 47(5):389-96

203. Splendore E, Grant C. A nurse practitioner-led community workshop: Increasing adult participation in advance care planning. Journal of the American Association of Nurse Practitioners. 2017; 29(9):535-542

204. Stein GL, Fineberg IC. Advance care planning in the USA and UK: A comparative analysis of policy, implementation and the social work role. British Journal of Social Work. 2013; 43(2):233-248

205. Sudore RL, Boscardin J, Feuz MA, McMahan RD, Katen MT, Barnes DE. Effect of the PREPARE website vs an easy-to-read advance directive on advance care planning documentation and engagement among veterans: A randomized clinical trial. JAMA Internal Medicine. 2017; 177(8):1102-1109

206. Sumalinog R, Harrington K, Dosani N, Hwang SW. Advance care planning, palliative care, and end-of-life care interventions for homeless people: A systematic review. Palliative Medicine. 2016; 31(2):109-119

207. Sung HC, Wang SC, Fan SY, Lin CY. Advance Care Planning Program and the Knowledge and Attitude Concerning Palliative Care. Clinical Gerontologist. 2017; Epublication

208. Tan A, Seah A, Chua G, Lim TK, Phua J. Impact of a palliative care initiative on end-of-life care in the general wards: A before-and-after study. Palliative Medicine. 2014; 28(1):34-41

209. Tan HM, Lee SF, O'Connor MM, Peters L, Komesaroff PA. A case study approach to investigating end-of-life decision making in an acute health service. Australian Health Review. 2013; 37(1):93-97

210. Teno J, Lynn J, Connors AF, Jr., Wenger N, Phillips RS, Alzola C et al. The illusion of end-of-life resource savings with advance directives. SUPPORT Investigators. Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment. Journal of the American Geriatrics Society. 1997; 45(4):513-8

211. Teno J, Lynn J, Wenger N, Phillips RS, Murphy DP, Connors AF et al. Advance directives for seriously ill hospitalized patients: Effectiveness with the patient self-determination act and the SUPPORT intervention. SUPPORT Investigators. Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment. Journal of the American Geriatrics Society. 1997; 45(4):500-7

212. Teno JM, Branco KJ, Mor V, Phillips CD, Hawes C, Morris J et al. Changes in advance care planning in nursing homes before and after the patient Self-Determination Act: Report of a 10-state survey. Journal of the American Geriatrics Society. 1997; 45(8):939-44

213. Thoonsen B, Groot M, Verhagen S, van Weel C, Vissers K, Engels Y. Timely identification of palliative patients and anticipatory care planning by GPs: Practical application of tools and a training programme. BMC Palliative Care. 2016; 15:39

214. Turley M, Wang S, Meng D, Kanter M, Garrido T. Impact of a care directives activity tab in the electronic health record on documentation of advance care planning. Permanente Journal. 2016; 20(2):43-8

215. Van Scoy LJ, Reading JM, Hopkins M, Smith B, Dillon J, Green MJ et al. Community Game Day: Using an end-of-life conversation game to encourage advance care planning. Journal of Pain and Symptom Management. 2017; 54(5):680-691

216. Vander Laan KJ. Deciding to engage in advance care planning: a comparison of participants' experiences. Michigan State University. 2007. Ph.D.

217. Vandervoort A, Houttekier D, Vander Stichele R, van der Steen JT, Van den Block L. Quality of dying in nursing home residents dying with dementia: does advanced care planning matter? A nationwide postmortem study. PloS One. 2014; 9(3):e91130

218. Verreault R, Arcand M, Misson L, Durand PJ, Kroger E, Aubin M et al. Quasi-experimental evaluation of a multifaceted intervention to improve quality of end-of-life care and quality of dying for patients with advanced dementia in long-term care institutions. Palliative Medicine. 2018; 32(3):613-621

219. Vogel RI, Petzel SV, Cragg J, McClellan M, Chan D, Dickson E et al. Development and pilot of an advance care planning website for women with ovarian cancer: A randomized controlled trial. Gynecologic Oncology. 2013; 131(2):430-436

220. Volandes AE, Mitchell SL, Gillick MR, Chang Y, Paasche-Orlow MK. Using video images to improve the accuracy of surrogate decision-making: A randomized controlled trial. Journal of the American Medical Directors Association. 2009; 10(8):575-80

221. Volandes AE, Paasche-Orlow MK, Barry MJ, Gillick MR, Minaker KL, Chang Y et al. Video decision support tool for advance care planning in dementia: randomised controlled trial. BMJ. 2009; 338:b2159

222. Volandes AE, Paasche-Orlow MK, Davis AD, Eubanks R, El-Jawahri A, Seitz R. Use of video decision aids to promote advance care planning in Hilo, Hawai'i. Journal of General Internal Medicine. 2016; 31(9):1035-40

223. Voss H, Vogel A, Wagemans AM, Francke AL, Metsemakers JF, Courtens AM et al. Advance care planning in palliative care for people with intellectual disabilities: a systematic review. Journal of Pain and Symptom Management. 2017; Epublication

224. Walczak A, Butow PN, Bu S, Clayton JM. A systematic review of evidence for end-of-life communication interventions: Who do they target, how are they structured and do they work? Patient Education and Counseling. 2016; 99(1):3-16

225. Walczak A, Butow PN, Tattersall MH, Davidson PM, Young J, Epstein RM et al. Encouraging early discussion of life expectancy and end-of-life care: A randomised controlled trial of a nurse-led communication support program for patients and caregivers. International Journal of Nursing Studies. 2017; 67:31-40

226. Walczak A, Mazer B, Butow PN, Tattersall MH, Clayton JM, Davidson PM et al. A question prompt list for patients with advanced cancer in the final year of life: Development and cross-cultural evaluation. Palliative Medicine. 2013; 27(8):779-88

227. Weathers E, O'Caoimh R, Cornally N, Fitzgerald C, Kearns T, Coffey A et al. Advance care planning: A systematic review of randomised controlled trials conducted with older adults. Maturitas. 2016; 91:101-9

228. Weinick RM, Wilcox SR, Park ER, Griffey RT, Weissman JS. Use of advance directives for nursing home residents in the emergency department. American Journal of Hospice & Palliative Medicine. 2008; 25(3):179-83

229. Wrigley H, Standerwick L, Chan T, Ghosh S, Simon J. Patient acceptance of advance care planning guidebook distribution at hospital admission. Journal of Palliative Medicine. 2016; 19(7):690-1

230. Yamada R, Galecki AT, Goold SD, Hogikyan RV. A multimedia intervention on cardiopulmonary resuscitation and advance directives. Journal of General Internal Medicine. 1999; 14(9):559-63

231. Young Y, Nakashima T, Hsu WH. Are hospital/ED transfers less likely among nursing home residents with Do-Not-Hospitalize orders? Journal of the American Medical Directors Association. 2017; 18(5):438-441