National Institute for Health and Care Excellence

Draft for consultation

End of life care for adults: service delivery

[A] Evidence review: what are the best service models to support the identification of people who may be entering the last year of life?

NICE guideline

Evidence review

April 2019

Draft for consultation

This evidence review was developed by the National Guideline Centre

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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.

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1 Identification of people who may be in their last year of life and their carers

1.1 Review question: What are the best service models to support the identification of people who may be entering the last year of life?

1.2 Introduction

There are wide ranging benefits to be gained from identifying people who may be nearing the end of life. Following effective identification, time can then be given to allow patients, and those important to them, to re-align their priorities for care. This can facilitate the delivery of health and social care interventions that are targeted to ensure patients' priorities are recognised and, where possible, met. Reducing the burden of treatments that may be unnecessary and minimising the risk of inappropriate hospital admission are potential benefits to be gained from effective identification of this cohort.[66]

Prognostication for individual patients is a recognised challenge for healthcare professionals, due in part to the implications of the decisions being made and the inherent uncertainty in the outcomes for individual patients.[49] A variety of tools and approaches have been developed in an attempt to augment what could be seen as a 'typical' intuitive approach.[56] The accuracy of tools which attempt to identify dying patients was not part of the guideline scope. This review seeks to explore the evidence for service delivery models which can best support the identification of people who may be in 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 18 or over) with progressive life-limiting conditions thought to be entering the last year of life. • Carers, or those important to, adults (aged 18 or over) with progressive life-limiting conditions thought to be entering the last year of life. • Carers (under 18 years old) of adults (aged 18 or over) with progressive life-limiting conditions thought to be entering the last year of life
Interventions	• Methods, systems or policies to support identification of people who may be entering the last year of life and/or their carers: for example: ○ Proactive care ○ Centralised records ○ Gold standard framework ○ AMBER care bundle ○ Electronic discharge notifications ○ Video-conferencing ○ Multidisciplinary meetings ○ Virtual hospital/ward rounds ○ Established routines for handovers and exchange of information
Comparisons	• Combination of methods, systems or policies to support identification of people who may be entering the last year of life, or their carers

	• To each other • No established method to support identification
Outcomes	CRITICAL • Quality of life of person in their last year of life (Continuous) • Quality of life of carer of (or person important to) the person in their last year of life (Continuous) • Preferred and actual place of death (Dichotomous) • Preferred and actual place of care (Dichotomous) • Longevity of carer (Continuous) IMPORTANT • Length of stay (Continuous) • Length of survival (Continuous) • Hospitalisation (Dichotomous) • Number of hospital visits (Dichotomous) • Number of visits to accident and emergency (Dichotomous) • Number of unscheduled admissions (Dichotomous) • Use of community services (Dichotomous) • Avoidable/inappropriate admissions to ICU (Dichotomous) • Inappropriate attempts at cardiopulmonary resuscitation (Dichotomous) • Staff satisfaction (Continuous) • Patient/carer reported outcomes (satisfaction) (Continuous) • Carer health (for example: GP visits, mental health, school/work attendance) (Continuous/Dichotomous)
Study design	• Systematic reviews • RCTs • Non-randomised comparative studies, including before and after studies and interrupted-time-series

1.4 Clinical evidence

1.4.1 Included studies

A search was conducted for randomised or non-randomised comparative studies on service models to support the identification of people who may be entering the last year of life.

One clinical study (Campbell 2004)[13] was identified for this review.

1.4.2 Excluded studies

See the excluded studies list in Appendix G.

1.4.3 Summary of clinical studies included in the evidence review

Table 2: Summary of studies included in the evidence review

Study	Intervention and comparison	Population	Outcomes	Comments
Campbell 2004[13]	• Intervention: Proactive case-finding. Patients were screened daily for meeting the study criteria. Patients were identified and the	Patients with advanced-stage dementia in a medical	• Length of hospital stay • Length of MICU stay • Discharged to	Non-randomised comparative study

Study	Intervention and comparison	Population	Outcomes	Comments
	patient's surrogate or guardian was contacted for a meeting, and the patient's prognosis was communicated and clarified as needed. A change of treatment goals to focus on comfort-oriented care was recommended and ventilation withdrawal. • Comparison: No established method to support identification.	intensive care unit (MICU) N=52 USA	another hospital	

1 See Appendix D for full evidence tables.

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1.4.4 Quality assessment of clinical studies included in the evidence review

Table 3: Clinical evidence summary: Proactive case-finding versus no intervention

Outcomes	No of Participants (studies) Follow up	Quality of the evidence (GRADE)	Relative effect (95% CI)	Anticipated absolute effects	
				Risk with No intervention	Risk difference with Proactive case-finding (95% CI)
Length of stay (days)	52 (1 study)	⨁⊖⊖⊖ VERY LOW[a,b] due to risk of bias, imprecision	-	-	The mean length of hospital stay (days) in the intervention groups was 4.7 lower (8.87 to 0.53 lower)
Length of stay in MICU (days)	52 (1 study)	⨁⊖⊖⊖ VERY LOW[a,b] due to risk of bias, imprecision	-	-	The mean length of stay in MICU (days) in the intervention groups was 3.3 lower (5.46 to 1.14 lower)
Discharged to another hospital	52 (1 study)	⨁⊖⊖⊖ VERY LOW[a,b] due to risk of bias, imprecision	Peto OR 7.39 (0.15 to 372.38)	0 per 1000	40 higher (from 60 lower to 140 higher)

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

See Appendix F for full GRADE tables.

1.5 Economic evidence

1.5.1 Included studies

No relevant health economic studies were identified.

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 C.

1.6 Resource costs

Recommendations made based on this review (see section 1.8) are not expected to have a substantial impact on resources.

1.7 Evidence statements

1.7.1 Clinical evidence statements

Proactive case-finding versus no intervention

One study compared the proactive case-finding to no intervention. There was a clinically important benefit for the proactive case-finding for length of stay in hospital and in MICU (n=52; very low quality), but a clinically important benefit for no intervention for discharge to another hospital (n=52; very low quality).

1.7.2 Health economic evidence statements

- No relevant economic evaluations were identified.

1.8 Recommendations

A1. People managing services should develop systems to identify adults who are likely to be approaching the end of their life. This will enable health and social care practitioners to start discussions about advance care planning and provide the support needed to help people stay in their preferred place of care.

A.2 Health and social care practitioners should identify carers and other people important to adults who are likely to be approaching the end of their life.

1.8.1 Rationale and impact

Why the committee made the recommendations

Although the evidence was limited, the committee agreed that identifying adults who may be approaching the end of their life supports health and social care practitioners to start discussions about advance care planning. This should provide the person near the end of life the support that they may need now or later on to help them stay in their preferred place of care. It also gives them time to consider and re-evaluate their needs with their health and social care practitioners.

The committee wanted to emphasise the importance of identifying people systematically. There are already some systems in use for identifying people approaching the end of their life (for example, the Gold Standards Framework, Amber Care Bundle, Supportive and Palliative Care Indicators Tool (SPICT)). However, there were no studies comparing and evaluating their effectiveness in service delivery so the committee could not recommend a particular system.

The committee agreed that the use of a shared coordination of care system would improve coordination of care between all health and social care practitioners involved in a person's care and in turn improve service delivery.

Impact of the recommendations on practice

The recommendations reflect current good practice available in some services, but there is variation in how and when people are identified across different patient groups and settings. The recommendations are expected to increase the number of people identified. However, this is not likely to have a significant resource impact because early identification will ensure that people approaching the end of their life will receive the appropriate care and their carers will receive support, which will help to avoid unnecessary hospital admissions.

Full details of the evidence and the committee's discussion are in evidence review C: barriers to accessing end of life care services, evidence review H: carer support services and evidence review I: information sharing in the project documents.

1.9 The Committee's discussion of the evidence

1.9.1 Interpreting the evidence

1.9.1.1 The outcomes that matter most

The committee identified quality of life, preferred place of care and death, and longevity of carer as the critical outcomes for identifying people who may be in their last year of life. The following outcomes were identified as important: 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.

No evidence was found for the following outcomes: quality of life, preferred place of care and death, length of survival and longevity of carer as the critical outcomes for identifying people in their who may be in the last year of life, 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.

1.9.1.2 The quality of the evidence

One non-randomised study comparing pro-active case-finding to no intervention was identified. There was no evidence found for proactive care, centralised records, gold standard framework, AMBER care bundle, electronic discharge notifications, video-conferencing, multi-disciplinary meetings, virtual hospital/ward rounds and established routines for handovers and exchange of information.. Evidence was available evaluating the accuracy of various tools but these studies did not compare different service delivery models.

The evidence was very low quality due to high risk of bias and imprecision. It was a non-randomised study with few participants. The Committee agreed that this study lacked direct relevance, as it was a different healthcare system and ICU outreach in UK already includes this type of intervention.

1.9.1.3 Benefits and harms

Length of stay in hospital and length of stay in MICU were lower in the pro-active case-finding group. The number of people discharged to another hospital was higher, but this was based on only more individual. The outcome 'discharged to another hospital 'was included as a proxy for the outcome hospitalisation, the Committee clarified that this would be a benefit in this evidence as it was discharge to a community hospital.

The Committee agreed that although the study met the protocol the setting was not directly relevant to the NHS and the quality of the evidence was too low for them to be confident in basing a recommendation for proactive case finding. The Committee made a consensus based recommendation based on their clinical experience that early identification can support people in making decisions about their priorities for care.

The Committee recommended that all NHS commissioned services should have a system in place that would identify people who may be in their last year of life. The identification and documentation of people who may be in their last year of life is helpful to service planners for commissioning future services for people in the last year of life. Timely identification is required to ensure people's needs are met at the end of life (for example, being cared for in the place they want to). The Committee agreed it was important that information should be shared between services. This would enable people to have access to appropriate well-coordinated care.

1.9.2 Cost effectiveness and resource use

"The national primary care snapshot audit in End of Life Care 2010/11 of the provision of EoLC based on use of Palliative Care/GSF Registers in primary care for 502 GP practices in 15 PCTs and 7,200 case notes, over a two-month period found 27% of people who died were included on the palliative care register and of these 23% had a non-cancer diagnosis. Most significantly though it found that those people included on the palliative care register were more likely to receive well-co-ordinated care (for example handover to out-of-hours, anticipatory prescribing) and more likely to have been offered an advance care planning discussion and to die in their preferred place of choice."[73]

It is anticipated that 20% of deaths are unpredictable and people who die in these circumstances could not have been identified as approaching the end of life. However, it is clear that the majority of people dying from predictable causes are also not being appropriately identified as approaching the end of life. This can have significant consequences for patients. Unidentified people will not receive appropriate holistic needs assessments to determine what services and care they would benefit from, and this in turn will lead to their needs not being adequately met by the health and social care services. Unidentified people would be likely to experience a lower quality of life than if they had been identified and offered access to services to support their needs. Poor identification can also have significant financial consequences for the NHS, as early identification of people who may be in the last year of life can reduce the costs of end of life service provision, for example by ensuing necessary services are in place to avoid costly emergency admissions to hospital.

Currently, the majority of carers who are caring for someone that is in the last year of life are not identified as being a carer by the health and/or social services, and therefore do not receive access to services to support them in their caring role. Identifying a carer should trigger a referral for a carer assessment for which they are legally entitled to. Identifying carers means they can be referred to carer support services, ensuring their own needs can

be met and enabling them to be adequately equipped, skilled and informed, to care for someone outside of hospital. These support services could reduce avoidable hospital admissions and improve quality of life and health outcomes for both the carer and the person in the last year of life.

Increasing the number of people that are identified either as carers or those likely to be in the last year of life will have a mixed effect on costs to the NHS. Increased identification will increase the number of people who are offered access to carer support services, supportive care, palliative care or end of life care services therefore will increase the demand for these services. This will increase costs but is fundamental to good end of life care. However, some of the services could decrease the probability and frequency that people in the last year of life are admitted to hospital and could increase the chance and length of time that they can be cared for in their preferred place of choice which could in turn, decrease costs to the NHS.

No health economic studies were identified for inclusion in this review and the one clinical study that was included was not considered relevant to base recommendations on. The committee considered the costs to the NHS when formulating the consensus recommendations however, due to wide scale national variation and uncertainty in effect that increasing identification will have on costs (as highlighted above) they could not estimate how the recommendations they have made on identification will affect NHS costs. The cost implications of the recommendations will depend on the local processes currently in existence or that they decide to establish in order to adequately identify and record people thought to be in the last year of their life and, if applicable, their carers.

1.9.3 Other factors the committee took into account

No evidence was identified to evaluate the effectiveness of systems that are currently used in practice to identify people who are likely to be in the last year of life, the Committee agreed it was important to note that there are systems in place but could not recommend any one system. They are aware of systems, for example the Gold Standards Framework, Amber Care Bundle, Supportive and Palliative Care Indicators Tool (SPICT).

The committee discussed and acknowledged the negative connotations the term register can have and the perceived stigma attached to being placed on a register. They noted that a register can of benefit to commissioners in making future planning decisions about services.

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Appendices

Appendix A: Review protocols

Table 4: Review protocol for what are the best service models to support the identification of people who may be entering the last year of life

Question number: 1

Relevant section of Scope: Service organisation that supports the identification of people thought to be entering the last year of life.

ID	Field	Content
I	Review question	What are the best service models to support the identification of people who may be entering the last year of life
II	Type of review question	Intervention review. 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 the identification of people who might be entering the last year of life and/or their carers (or those important to them)
IV	Eligibility criteria – population / disease / condition / issue / domain	Adults (aged 18 or over) with progressive life-limiting conditions thought to be entering the last year of life and/or their carers (or those important to them); Carers of those (or those important to) adults (aged 18 or over) with progressive life-limiting conditions thought to be entering the last years of life; Carers (aged under 18) of adults (aged 18 or over) with progressive life-limiting conditions thought to be entering the last year of life.
V	Eligibility criteria – intervention(s) / exposure(s) / prognostic factor(s)	Methods, systems or policies to support identification of people who may be entering the last year of life and/or their carers: for example, • Proactive care • Centralised records • Gold standard framework • AMBER care bundle • Electronic discharge notifications • Video-conferencing • Multidisciplinary meetings • Virtual hospital/ward rounds Established routines for handovers and exchange of information
VI	Eligibility criteria – comparator(s) / control or reference (gold) standard	• Combination of methods, systems or policies to support identification of people who may be entering the last year of life, or their carers • To each other • No established method to support identification
VII	Outcomes and	CRITICAL

	prioritisation	• Quality of life of person in their last year of life (Continuous) • Quality of life of carer of (or person important to) the person in their last year of life (Continuous) • Preferred and actual place of death (Dichotomous) • Preferred and actual place of care (Dichotomous) • Longevity of carer (Continuous) IMPORTANT • Length of stay (Continuous) • Length of survival (Continuous) • Hospitalisation (Dichotomous) • Number of hospital visits (Dichotomous) • Number of visits to accident and emergency (Dichotomous) • Number of unscheduled admissions (Dichotomous) • Use of community services (Dichotomous) • Avoidable/inappropriate admissions to ICU (Dichotomous) • Inappropriate attempts at cardiopulmonary resuscitation (Dichotomous) • Staff satisfaction (Continuous) • Patient/carer reported outcomes (satisfaction) (Continuous) • Carer health (for example: GP visits, mental health, school/work attendance) (Continuous/Dichotomous)
VIII	Eligibility criteria – study design	• Systematic reviews • RCTs • Non-randomised comparative studies, including before and after studies and interrupted-time-series
IX	Other inclusion exclusion criteria	• Children and young people (17 years or younger) in their last year of life • Studies will only be included if they reported one of more of the outcomes listed above • Descriptive (non-comparative) studies will be excluded
X	Proposed sensitivity / subgroup analysis, or meta-regression	Not applicable.
XI	Selection process – duplicate screening / selection / analysis	Quality assurance will be undertaken by a senior research fellow prior to completion. Review strategy/other analysis: • Information on identification tools used as part of a service will be extracted. • Due to the expected complexity of the service models implemented in the studies, studies will be reported separately if necessary. In such case, studies on the populations included in the subgroup list will be highlighted to the Committee and will be considered when making the recommendations
XII	Data management (software)	• Pairwise meta-analyses were performed using Cochrane Review Manager (RevMan5). • GRADEpro was used to assess the quality of evidence for each outcome. • Endnote was used for: ○ Bibliography, citations, sifting and reference management • Evibase was used for

		○ Data extraction and quality assessment / critical appraisal
XIII	Information sources – databases and dates	Clinical search databases to be used: Medline, Embase, Cochrane Library, Current Nursing and Allied Health Literature (CINAHL), PsycINFO, Healthcare Management Information Consortium (HMIC), Social Policy and Practice (SSP), Applied Social Sciences Index and Abstracts (ASSIA) Date: All years Health economics search databases to be used: Medline, Embase, NHSEED, HTA Date: Medline, Embase from 2014 NHSEED, HTA – All years Language: Restrict to English only
XIV	Identify if an update	Not applicable.
XV	Author contacts	
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 append ices 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 H (health economic evidence tables).
XX	Methods for assessing bias at outcome / study level	Standard study checklists were used to critically appraise individual studies. For details please see section 6.2 of Developing NICE guidelines: the manual The risk of bias across all available evidence was evaluated for each outcome using an adaptation of the 'Grading of Recommendations Assessment, Development and Evaluation (GRADE) toolbox' developed by the international GRADE working group http://www.gradeworkinggroup.org/
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. [Consider exploring publication bias for review questions where it may be more common, such as pharmacological questions, certain disease areas. Describe any steps taken to mitigate against publication bias, such as examining trial registries.]
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	A multidisciplinary committee (https://www.nice.org.uk/guidance/indevelopment/gid-

	guarantor	cgwave0799/documents) developed the evidence review. The committee was convened by the National Guideline Centre (NGC) and chaired by Mark in line with section 3 of Developing NICE guidelines: the manual. Staff from NGC undertook systematic literature searches, appraised the evidence, conducted meta-analysis and cost-effectiveness analysis where appropriate, and drafted the evidence review in collaboration with the committee. For details please see Developing NICE guidelines: the manual.
XXVII	Sources of funding / support	NGC is funded by NICE and hosted by the Royal College of Physicians.
XXVIII	Name of sponsor	NGC is funded by NICE and hosted by the Royal College of Physicians.
XXIX	Roles of sponsor	NICE funds NGC to develop guidelines for those working in the NHS, public health and social care in England.
XXX	PROSPERO registration number	Not registered

1

2 **Table 5: Health economic review protocol**

Review question	All questions – health economic evidence
Objectives	To identify health economic studies relevant to any of the review questions.
Search criteria	Populations, interventions and comparators must be as specified in the clinical review protocol above. Studies must be of a relevant health economic study design (cost–utility analysis, cost-effectiveness analysis, cost–benefit analysis, cost–consequences analysis, comparative cost analysis). Studies must not be a letter, editorial or commentary, or a review of health economic evaluations. (Recent reviews will be ordered although not reviewed. The bibliographies will be checked for relevant studies, which will then be ordered.) Unpublished reports will not be considered unless submitted as part of a call for evidence. Studies must be in English.
Search strategy	A health economic study search will be undertaken using population-specific terms and a health economic study filter – see Appendix G [in the Full guideline]
Review strategy	Studies not meeting any of the search criteria above will be excluded. Studies published before 2007, abstract-only studies and studies from non-OECD countries or the USA will also be excluded. Each remaining study will be assessed for applicability and methodological limitations using the NICE economic evaluation checklist which can be found in Appendix H of Developing NICE guidelines: the manual (2014).[67] Inclusion and exclusion criteria If a study is rated as both 'Directly applicable' and with 'Minor limitations' then it will be included in the guideline. A health economic evidence table will be completed and it will be included in the health economic evidence profile. If a study is rated as either 'Not applicable' or with 'Very serious limitations' then it will usually be excluded from the guideline. If it is excluded then a health economic evidence table will not be completed and it will not be included in the health economic evidence profile. If a study is rated as 'Partially applicable', with 'Potentially serious limitations' or both then there is discretion over whether it should be included.

Review question	All questions – health economic evidence
	Where there is discretion The health economist will make a decision based on the relative applicability and quality of the available evidence for that question, in discussion with the guideline committee if required. The ultimate aim is to include health economic studies that are helpful for decision-making in the context of the guideline and the current NHS setting. If several studies are considered of sufficiently high applicability and methodological quality that they could all be included, then the health economist, in discussion with the committee if required, may decide to include only the most applicable studies and to selectively exclude the remaining studies. All studies excluded on the basis of applicability or methodological limitations will be listed with explanation as excluded health economic studies in Appendix M. The health economist will be guided by the following hierarchies. Setting: UK NHS (most applicable). OECD countries with predominantly public health insurance systems (for example, France, Germany, Sweden). OECD countries with predominantly private health insurance systems (for example, Switzerland). Studies set in non-OECD countries or in the USA will be excluded before being assessed for applicability and methodological limitations. Health economic study type: Cost–utility analysis (most applicable). Other type of full economic evaluation (cost–benefit analysis, cost-effectiveness analysis, cost–consequences analysis). Comparative cost analysis. Non-comparative cost analyses including cost-of-illness studies will be excluded before being assessed for applicability and methodological limitations. Year of analysis: The more recent the study, the more applicable it will be. Studies published in 2007 or later but that depend on unit costs and resource data entirely or predominantly from before 2007 will be rated as ‘Not applicable’. Studies published before 2007 will be excluded before being assessed for applicability and methodological limitations. Quality and relevance of effectiveness data used in the health economic analysis: The more closely the clinical effectiveness data used in the health economic analysis match with the outcomes of the studies included in the clinical review the more useful the analysis will be for decision-making in the guideline.

1

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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 6: Database date parameters and filters used

Database	Dates searched	Search filter used
Medline (Ovid)	1946 – 04 January 2019	Exclusions
Embase (Ovid)	1974 – 04 January 2019	Exclusions
The Cochrane Library (Wiley)	Cochrane Reviews to Issue 1 of 12, January 2019 CENTRAL to Issue 1 of 12, January 2019 DARE, and NHSEED to Issue 2 of 4 2015 HTA to Issue 4 of 4 2016	None
CINAHL, Current Nursing and Allied Health Literature (EBSCO)	Inception – 04 January 2019	Limiters - English Language; Exclude MEDLINE records; Publication Type: Clinical Trial, Journal Article, Meta Analysis, Randomized Controlled Trial, Systematic Review: Age Groups: All Adult; Language: English
PsycINFO (ProQuest)	Inception – 04 January 2019	Study type
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.	(commission* adj2 (support* or service* or model*)).ti,ab.
51.	((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.
52.	Critical Pathways/
53.	((critical or clinic* or service* or care) adj2 path*).ti,ab.
54.	Patient Care Bundles/
55.	(care adj2 (bundle* or service* or package* or standard*)).ti,ab.
56.	or/50-55
57.	(assess* or criteria* or predict* or recogni* or identif* or refer*).ti,ab.
58.	49 and 56 and 57
59.	gold standard*.ti,ab.
60.	49 and 59
61.	(amber adj2 bundle).ti,ab.
62.	58 or 60 or 61
63.	patient care team/
64.	interdisciplinary communication/
65.	(((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.
66.	(((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.
67.	(key adj2 work*).ti,ab.
68.	((healthcare or care) adj2 (lead or leader or leads or facilitat*)).ti,ab.
69.	((healthcare or care) adj1 profession*).ti,ab.
70.	*Case Management/
71.	(case adj2 manage*).ti,ab.
72.	(co-ordinator* or coordinator* or coordinate* or co-ordinate*).ti,ab.
73.	Or/63-72
74.	"referral and consultation"/
75.	(referral* or referred or referring or refer or refers or consult*).ti,ab.
76.	(recommend* or direct*).ti,ab.
77.	or/74-76
78.	exp Advance Care Planning/
79.	(advance* adj2 (plan* or decision* or directive*)).ti,ab.
80.	living will*.ti,ab.
81.	or/78-80
82.	Caregivers/
83.	Spouses/
84.	Family/
85.	(spouse* or wife or wives or husband* or carer* or caregiver* or care giver* or significant other* or friend* or partner* or family or families or individual* or sibling* or

	brother* or sister* or relative or relatives or mothers* or daughters* or father* or son or sons or uncle* or aunt* or grand mother* or grandmother* or grandfather* or grand father* or aunt* or uncle* or cousin* or niece* or nephew*).ti,ab.
86.	Or/82-85
87.	((replacement or break* or holiday* or respite) adj3 (care* or service*)).ti,ab.
88.	((communit* or support* or psychosocial* or psycholog*) adj3 (service* or group* or system*)).ti,ab.
89.	((group* or support* or psychosocial* or psycholog*) adj3 (selfhelp or self help or therap*)).ti,ab.
90.	((psychosocial* or psycholog*) adj2 support*).ti,ab.
91.	Self-Help Groups/
92.	exp social support/
93.	Counseling/
94.	(counseling or counselling*).ti,ab.
95.	(buddy* or buddies).ti,ab.
96.	((health* or medical*) adj2 check*).ti,ab.
97.	((spouse* or wife or wives or husband* or carer* or caregiver* or care giver* or significant other* or friend* or partner* or family or families or individual* or sibling* or brother* or sister* or relative or relatives or mothers* or daughters* or father* or son or sons or uncle* or aunt* or grand mother* or grandmother* or grandfather* or grand father* or aunt* or uncle* or cousin* or niece* or nephew*) adj3 (education or educate or educating or information or literature or leaflet* or booklet* or pamphlet* or website* or knowledge)).ti,ab.
98.	or/87-97
99.	49 and 86 and 98
100.	49 and (73 or 77 or 81)
101.	62 or 99 or 100

1 **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.	(commission* adj2 (support* or service* or model*)).ti,ab.
49.	((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.
50.	*Clinical Pathway/
51.	((critical or clinic* or service* or care) adj2 path*).ti,ab.
52.	*Care Bundle/
53.	(care adj2 (bundle* or service* or package* or standard*)).ti,ab.
54.	or/48-53
55.	(assess* or criteria* or predict* or recogni* or identif* or refer*).ti,ab.
56.	47 and 54 and 55
57.	gold standard*.ti,ab.
58.	47 and 57
59.	(amber adj2 bundle).ti,ab.
60.	56 or 58 or 59
61.	interdisciplinary communication/
62.	patient care team*.ti,ab.
63.	(((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.
64.	(((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.
65.	(key adj2 work*).ti,ab.
66.	((healthcare or care) adj2 (lead or leader or leads or facilitat*)).ti,ab.
67.	((healthcare or care) adj1 profession*).ti,ab.
68.	*Case Management/
69.	(case adj2 manage*).ti,ab.
70.	(co-ordinator* or coordinator* or coordinate* or co-ordinate*).ti,ab.
71.	Or/61-70
72.	exp patient referral/
73.	(referral* or referred or referring or refer or refers or consult*).ti,ab.
74.	(recommend* or direct*).ti,ab.
75.	or/72-74
76.	(advance* adj2 (plan* or decision* or directive*)).ti,ab.
77.	living will*.ti,ab.
78.	76 or 77
79.	*Caregiver/
80.	*Spouse/
81.	*Family/
82.	(spouse* or wife or wives or husband* or carer* or caregiver* or care giver* or significant other* or friend* or partner* or family or families or individual* or sibling* or brother* or sister* or relative or relatives or mothers* or daughters* or father* or son or sons or uncle* or aunt* or grand mother* or grandmother* or grandfather* or grand father* or aunt* or uncle* or cousin* or niece* or nephew*).ti,ab.
83.	Or/79-82
84.	((replacement or break* or holiday* or respite) adj3 (care* or service*)).ti,ab.
85.	((communit* or support* or psychosocial* or psycholog*) adj3 (service* or group* or system*)).ti,ab.
86.	((group* or support* or psychosocial* or psycholog*) adj3 (selfhelp or self help or therap*)).ti,ab.
87.	((psychosocial* or psycholog*) adj2 support*).ti,ab.
88.	*Self-Help/
89.	*Social support/
90.	*Counseling/
91.	(counseling or counselling*).ti,ab.
92.	(buddy* or buddies).ti,ab.
93.	((health* or medical*) adj2 check*).ti,ab.
94.	((spouse* or wife or wives or husband* or carer* or caregiver* or care giver* or significant other* or friend* or partner* or family or families or individual* or sibling* or brother* or sister* or relative or relatives or mothers* or daughters* or father* or son or sons or uncle* or aunt* or grand mother* or grandmother* or grandfather* or grand father* or aunt* or uncle* or cousin* or niece* or nephew*) adj3 (education or educate or educating or information or literature or leaflet* or booklet* or pamphlet* or website*

	or knowledge)).ti,ab.
95.	or/84-94
96.	47 and 83 and 95
97.	47 and (71 or 75 or 78)
98.	60 or 96 and 97

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.	(commission* near/2 (support* or service* or model*)):ti,ab
#29.	((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
#30.	MeSH descriptor: [Critical Pathways] explode all trees
#31.	((critical or clinic* or service* or care) near/2 path*):ti,ab
#32.	MeSH descriptor: [Patient Care Bundles] explode all trees
#33.	(care near/2 (bundle* or service* or package* or standard*)):ti,ab
#34.	(or #28-#33)
#35.	(assess* or criteria* or predict* or recogni* or identif* or refer*):ti,ab
#36.	#27 and #34 and #35
#37.	gold standard*:ti,ab

#38.	#27 and #37
#39.	(amber near/2 bundle):ti,ab
#40.	#36 or #38 or #39
#41.	MeSH descriptor: [Patient Care Team] explode all trees
#42.	MeSH descriptor: [Interdisciplinary Communication] explode all trees
#43.	(((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
#44.	((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
#45.	(key near/2 work*):ti,ab
#46.	((healthcare or care) near/2 (lead or leader or leads or facilitat*)):ti,ab
#47.	((healthcare or care) near/1 profession*):ti,ab
#48.	MeSH descriptor: [Case Management] this term only
#49.	(case near/2 manage*):ti,ab
#50.	(co-ordinator* or coordinator* or coordinate* or co-ordinate*):ti,ab
#51.	(or #41-#50)
#52.	MeSH descriptor: [Referral and Consultation] explode all trees
#53.	(referral* or referred or referring or refer or refers or consult*):ti,ab
#54.	(recommend* or direct*):ti,ab
#55.	(or #52-#53)
#56.	MeSH descriptor: [Advance Care Planning] explode all trees
#57.	(advance* near/2 (plan* or decision* or directive*)):ti,ab
#58.	living will*:ti,ab
#59.	(or #56-#58)
#60.	MeSH descriptor: [Caregivers] this term only
#61.	MeSH descriptor: [Spouses] this term only
#62.	MeSH descriptor: [Family] this term only
#63.	(spouse* or wife or wives or husband* or carer* or caregiver* or care giver* or significant other* or friend* or partner* or family or families or individual* or sibling* or brother* or sister* or relative or relatives or mothers* or daughters* or father* or son or sons or uncle* or aunt* or grand mother* or grandmother* or grandfather* or grand father* or aunt* or uncle* or cousin* or niece* or nephew*):ti,ab
#64.	(or #60-#63)
#65.	((replacement or break* or holiday* or respite) near/3 (care* or service*)):ti,ab
#66.	((communit* or support* or psychosocial* or psycholog*) near/3 (service* or group* or system*)):ti,ab
#67.	((group* or support* or psychosocial* or psycholog*) near/3 (selfhelp or self help or therap*)):ti,ab
#68.	((psychosocial* or psycholog*) near/2 support*):ti,ab
#69.	MeSH descriptor: [Self-Help Groups] this term only
#70.	MeSH descriptor: [Social Support] explode all trees
#71.	MeSH descriptor: [Counseling] this term only
#72.	(counseling or counselling*):ti,ab
#73.	(buddy* or buddies):ti,ab

#74.	(health or medical*) near/3 check*:ti,ab
#75.	(spouse* or wife or wives or husband* or carer* or caregiver* or care giver* or significant other* or friend* or partner* or family or families or individual* or sibling* or brother* or sister* or relative or relatives or mothers* or daughters* or father* or son or sons or uncle* or aunt* or grand mother* or grandmother* or grandfather* or grand father* or aunt* or uncle* or cousin* or niece* or nephew*) near/3 (education or educate or educating or information or literature or leaflet* or booklet* or pamphlet* or website* or knowledge):ti,ab
#76.	(or #65-#75)
#77.	#27 and #64 and #76
#78.	#27 and (#51 or #55 or #59)
#79.	#40 or #77 or #78

1 **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.	TI advance* AND TI (plan* or decision* or directive*)
S33.	AB advance* AND AB (plan* or decision* or directive*)

S34.	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 OR S32 OR S33
S35.	TI commission* AND TI ((support* or service* or model*))
S36.	AB commission* AND AB ((support* or service* or model*))
S37.	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*)
S38.	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*)
S39.	TI (critical or clinic* or service* or care) AND TI path*
S40.	AB (critical or clinic* or service* or care) AND AB path*
S41.	TI care AND TI (bundle* or service* or package* or standard*)
S42.	AB care AND AB (bundle* or service* or package* or standard*)
S43.	S35 OR S36 OR S37 OR S38 OR S39 OR S40 OR S41 OR S42
S44.	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*)
S45.	S34 AND S43 AND S44
S46.	TI gold standard* OR AB gold standard*
S47.	S34 AND S46
S48.	TI amber AND TI bundle
S49.	AB amber AND AB bundle
S50.	S48 OR S49
S51.	S45 OR S47 OR S50
S52.	(MH "Multidisciplinary Care Team+")
S53.	MDT OR IDT
S54.	((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*))
S55.	((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*))
S56.	TI (key n2 work*) OR AB (key n2 work*)
S57.	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*)))
S58.	TI (((healthcare or care) n1 profession*)) OR AB (((healthcare or care) n1 profession*))
S59.	MH Case Management
S60.	TI (case n2 manage*) OR AB (case n2 manage*)
S61.	TI ((co-ordinator* or coordinator* or coordinate* or co-ordinate*)*)) OR AB ((co-ordinator* or coordinator* or coordinate* or co-ordinate*))
S62.	S52 OR S53 OR S54 OR S55 OR S56 OR S57 OR S58 OR S59 OR S60 OR S61
S63.	(MH "Referral and Consultation+")
S64.	TI (referral* or referred or referring or refer or refers or consult*) OR AB (referral* or referred or referring or refer or refers or consult*)

S65.	TI (recommend* or direct*) OR AB (recommend* or direct*)
S66.	S63 OR S64 OR S65
S67.	TI advance* AND TI (plan* or decision* or directive*)
S68.	AB advance* AND AB (plan* or decision* or directive*)
S69.	S67 OR S68
S70.	S34 AND (S62 OR S66 OR S69)
S71.	S51 or S70

1 **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

2 **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/1-8
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

1 **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)

2 **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 7: Database date parameters and filters used

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

Medline (Ovid) search terms

1.	Palliative care/
2.	Terminal care/
3.	Hospice care/
4.	palliat*.ti,ab.
5.	Terminally Ill/
6.	((terminal* or long term or longterm) adj2 (care* or caring or ill*)).ti,ab.
7.	((dying or terminal) adj (phase* or stage*)).ti,ab.
8.	life limit*.ti,ab.
9.	Nursing Homes/
10.	((care or nursing) adj2 (home or homes)).ti,ab.
11.	Respite Care/
12.	((respite or day) adj2 (care or caring)).ti,ab.
13.	Hospices/
14.	hospice*.ti,ab.

15.	exp Advance Care Planning/
16.	(advance* adj2 (plan* or decision* or directive*)).ti,ab.
17.	living will*.ti,ab.
18.	*Patient care planning/
19.	*"Continuity of Patient Care"/
20.	((advance* or patient*) adj3 (care or caring) adj3 (continu* or plan*)).ti,ab.
21.	*Attitude to Death/
22.	(attitude* adj3 (death* or dying*)).ti,ab.
23.	*Physician-Patient Relations/
24.	*Long-Term Care/
25.	*"Delivery of Health Care"/
26.	(end adj2 life).ti,ab.
27.	EOLC.ti,ab.
28.	((last or final) adj2 (year or month*) adj2 life).ti,ab.
29.	((dying or death) adj2 (patient* or person* or people or care or caring)).ti,ab.
30.	or/1-29
31.	letter/
32.	editorial/
33.	news/
34.	exp historical article/
35.	Anecdotes as Topic/
36.	comment/
37.	case report/
38.	(letter or comment*).ti.
39.	or/31-38
40.	randomized controlled trial/ or random*.ti,ab.
41.	39 not 40
42.	animals/ not humans/
43.	exp Animals, Laboratory/
44.	exp Animal Experimentation/
45.	exp Models, Animal/
46.	exp Rodentia/
47.	(rat or rats or mouse or mice).ti.
48.	or/41-47
49.	30 not 48
50.	limit 49 to English language
51.	(exp child/ or exp pediatrics/ or exp infant/) not (exp adolescent/ or exp adult/ or exp middle age/ or exp aged/)
52.	50 not 51
53.	economics/
54.	value of life/
55.	exp "costs and cost analysis"/
56.	exp Economics, Hospital/
57.	exp Economics, medical/
58.	Economics, nursing/

59.	economics, pharmaceutical/
60.	exp "Fees and Charges"/
61.	exp budgets/
62.	budget*.ti,ab.
63.	cost*.ti.
64.	(economic* or pharmaco?economic*).ti.
65.	(price* or pricing*).ti,ab.
66.	(cost* adj2 (effectiv* or utilit* or benefit* or minimi* or unit* or estimat* or variable*)).ab.
67.	(financ* or fee or fees).ti,ab.
68.	(value adj2 (money or monetary)).ti,ab.
69.	or/53-68
70.	exp models, economic/
71.	*Models, Theoretical/
72.	*Models, Organizational/
73.	markov chains/
74.	monte carlo method/
75.	exp Decision Theory/
76.	(markov* or monte carlo).ti,ab.
77.	econom* model*.ti,ab.
78.	(decision* adj2 (tree* or analy* or model*)).ti,ab.
79.	or/70-78
80.	quality-adjusted life years/
81.	sickness impact profile/
82.	(quality adj2 (wellbeing or well being)).ti,ab.
83.	sickness impact profile.ti,ab.
84.	disability adjusted life.ti,ab.
85.	(qal* or qtime* or qwb* or daly*).ti,ab.
86.	(euroqol* or eq5d* or eq 5*).ti,ab.
87.	(qol* or hql* or hqol* or h qol* or hrqol* or hr qol*).ti,ab.
88.	(health utility* or utility score* or disutilit* or utility value*).ti,ab.
89.	(hui or hui1 or hui2 or hui3).ti,ab.
90.	(health* year* equivalent* or hye or hyes).ti,ab.
91.	discrete choice*.ti,ab.
92.	rosser.ti,ab.
93.	(willingness to pay or time tradeoff or time trade off or tto or standard gamble*).ti,ab.
94.	(sf36* or sf 36* or short form 36* or shortform 36* or shortform36*).ti,ab.
95.	(sf20 or sf 20 or short form 20 or shortform 20 or shortform20).ti,ab.
96.	(sf12* or sf 12* or short form 12* or shortform 12* or shortform12*).ti,ab.
97.	(sf8* or sf 8* or short form 8* or shortform 8* or shortform8*).ti,ab.
98.	(sf6* or sf 6* or short form 6* or shortform 6* or shortform6*).ti,ab.
99.	or/80-98
100.	52 and (69 or 79 or 99)

1 **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)

1 **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

1

Appendix C: Clinical evidence selection

Figure 1: Flow chart of clinical study selection for the review of what are the best service models to support the identification of people who may be entering the last year of life?

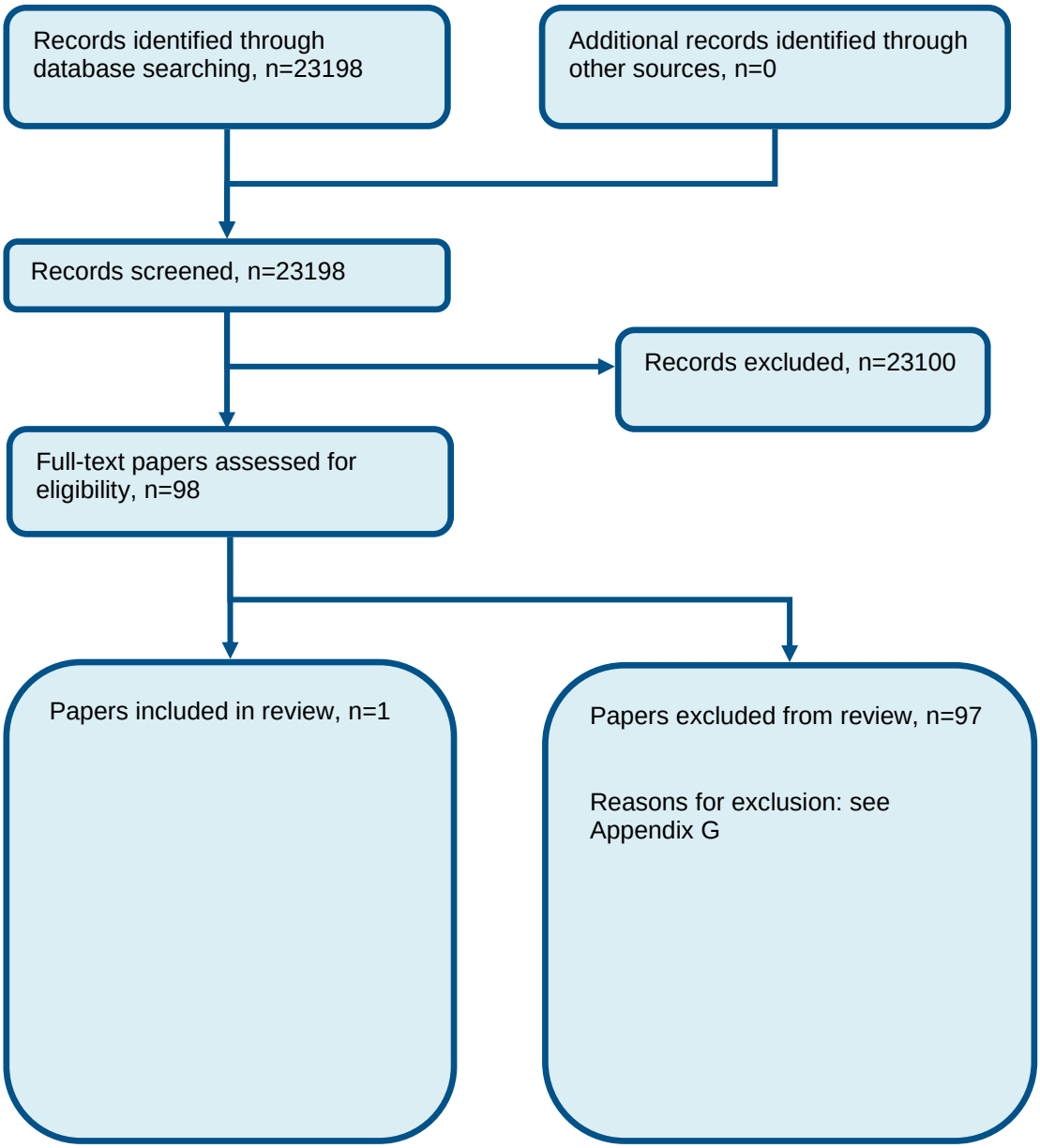
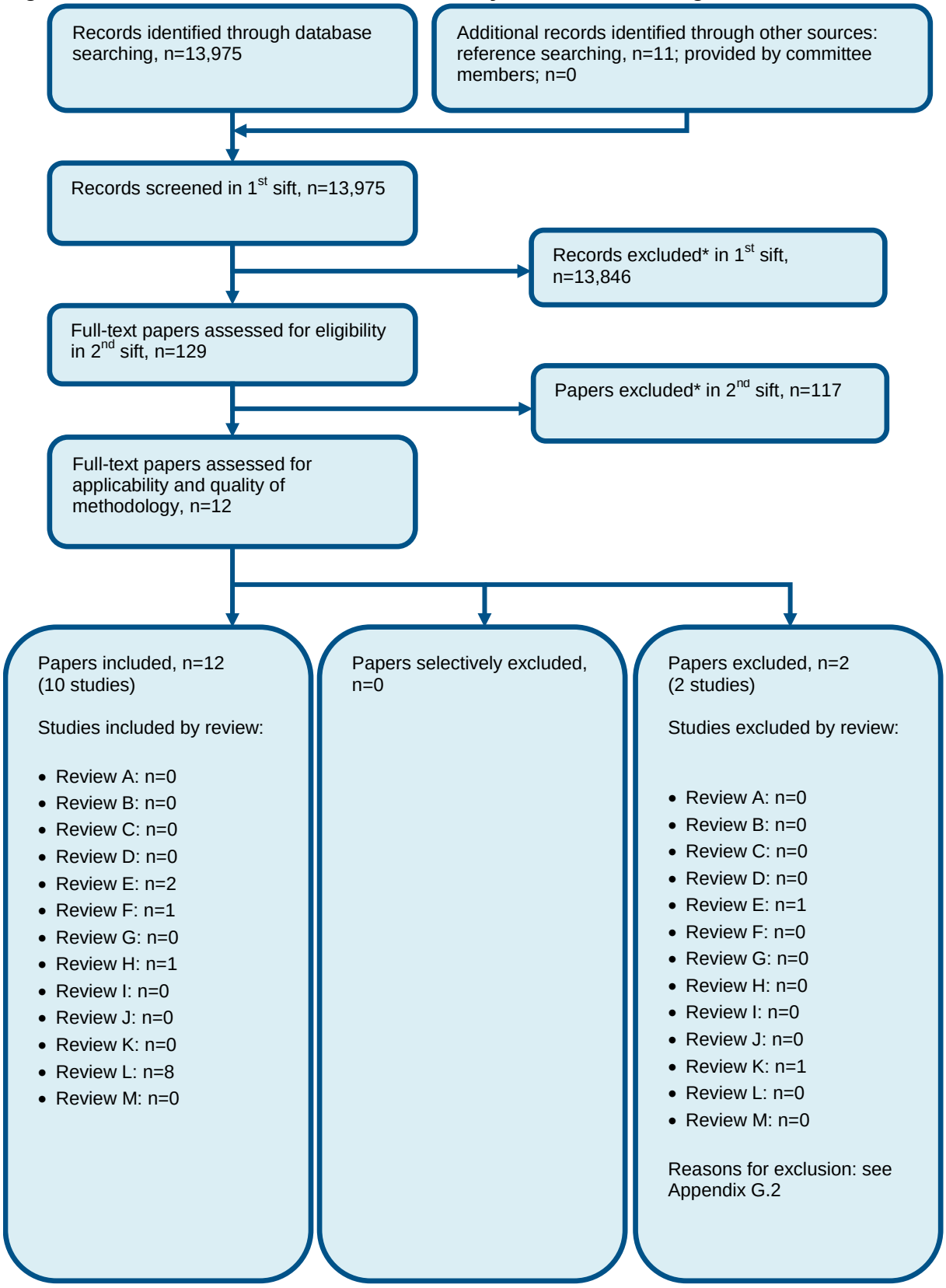


Figure 2: Flow chart of health economic study selection for the guideline



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

1

Appendix D: Clinical evidence tables

Study	Campbell 2004[13]
Study type	Non-randomised comparative study
Number of studies (number of participants)	1 (n=52)
Countries and setting	Conducted in USA; Setting: Detroit Receiving Hospital medical ICU
Line of therapy	Not applicable
Duration of study	Patients enrolled prospectively from August 14, 1999 to March 11, 2001 and retrospective control records from July 1, 1998 to June 30, 1999
Method of assessment of guideline condition	Adequate method of assessment/diagnosis
Stratum	Adults (aged 18 or over) at end of life: All were elderly at the end of life
Subgroup analysis within study	Not applicable
Inclusion criteria	Patients with advanced-stage dementia with pre-hospital functional status including factors consistent with late stage disease, such as being bed-bound, largely non-verbal, incontinent, and unable to self-nourish or nourished by tube (Functional Assessment Staging and the National Hospice Organisation Guidelines).
Exclusion criteria	Not reported
Recruitment/selection of patients	Retrospective chart analysis: patients with dementia were identified by a medical records search using an initial coding system and proactive interventions: members of the palliative care service of Detroit Receiving Hospital screened the MICU census daily for any patient meeting the study criteria
Age, gender and ethnicity	Age - Mean (SD): Intervention group: 80.8 (1.4); Control group: 81.2 (2.1). Gender (M:F): Not reported. Ethnicity: Not reported
Further population details	1. Frail elderly: 2. Homeless people/vulnerably housed: 3. LGBT: 4. Migrant workers: 5. People from ethnic minorities: 6. People in prisons: 7. People in whom life-prolonging therapies are still an active option: 8. People with dementia: 9. People with disabilities: 10. People with hearing loss: 11. People with learning difficulties: 2. People with mental health problems: 13. Socioeconomic inequalities: 14. Travellers: 15. Younger adults:
Indirectness of population	No indirectness
Interventions	(n=26) Intervention 1: Methods, systems or policies to support identification of people who may be entering the last year of life and/or their carers - Proactive care. Patients were screened daily for meeting the study

Study	Campbell 2004[13]
	criteria with the following aims: a) early involvement of the palliative care service in the process of communicating prognostic news to the family; b) assistance in identifying the patient's advance directives or preferences for end-of-life care, if any; c) assistance with the discussion of the treatment options with patients' surrogates; d) implementation of palliative care strategies when treatment goals changed to "comfort measures only"; and e) provision of consultation and education to the primary team regarding palliative care strategies. Patients were identified and the patient's surrogate or guardian was contacted for a meeting, and the patient's prognosis was communicated and clarified as needed. A change of treatment goals to a focus on comfort-oriented care was recommended and ventilation withdrawal. Duration Not reported. Concurrent medication/care: Not reported. (n=26) Intervention 2: No established method to support identification - No method. Patients were identified by medical records using an initial coding system that included any of the following variables in combination with ICU: age >80 years, dementia and decubitus ulcers. From this initial coding, research assistants reviewed the medical record to identify factors for subject inclusion. Documentation of pre-hospital functional status was found in the history and physical exam, the nursing functional assessment, and materials sent from the nursing home for those patients admitted from a facility. Duration Not reported. Concurrent medication/care: Not reported
Funding	Funding not stated

RESULTS (NUMBERS ANALYSED) AND RISK OF BIAS FOR COMPARISON: PROACTIVE CARE versus NO METHOD

Protocol outcome 1: Length of stay
- Actual outcome for Adults (aged 18 or over) at end of life: Hospital length of stay; Group 1: mean 7.4 Days (SD 7.14); n=26, Group 2: mean 12.1 Days (SD 8.16); n=26
Risk of bias: All domain - Very high, Selection - Very high, Blinding - Low, Incomplete outcome data - Low, Outcome reporting - Low, Measurement - Low, Crossover - Low, Subgroups - Low; Indirectness of outcome: No indirectness
- Actual outcome for Adults (aged 18 or over) at end of life: MICU length of stay; Group 1: mean 3.5 Days (SD 2.55); n=26, Group 2: mean 6.8 Days (SD 5); n=26
Risk of bias: All domain - Very high, Selection - Very high, Blinding - Low, Incomplete outcome data - Low, Outcome reporting - Low, Measurement - Low, Crossover - Low, Subgroups - Low; Indirectness of outcome: No indirectness

Protocol outcome 2: Hospitalisation
- Actual outcome for Adults (aged 18 or over) at end of life: Discharge outcome – to another hospital; Group 1: 1/26, Group 2: 0/26

Study	Campbell 2004[13]
Risk of bias: Risk of bias: All domain - Very high, Selection - Very high, Blinding - Low, Incomplete outcome data - Low, Outcome reporting - Low, Measurement - Low, Crossover - Low, Subgroups - Low; Indirectness of outcome: No indirectness	
Protocol outcomes not reported by the study	Quality of life of person in their last year of life; Quality of life of carer of (or person important to) the person in their last year of life; Preferred and actual place of death; Preferred and actual place of care; Length of survival; Longevity of care; Number of hospital visits; Number of visits to accident and emergency; Number of unscheduled admissions; Use of community services at; Avoidable/inappropriate admissions to ICU; Inappropriate attempts at cardiopulmonary resuscitation; Staff satisfaction; Patient/carer reported outcomes (satisfaction); Carer health (for example: GP visits, mental health, school/work attendance).

Appendix E: Forest plots

E.1 Proactive case-finding versus no intervention

Figure 3: Proactive case-finding versus no intervention in end of life care: length of stay in hospital (days)

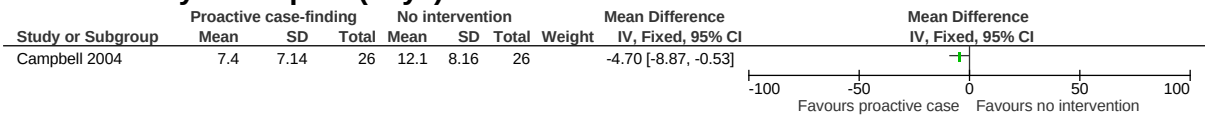


Figure 4: Proactive case-finding versus no intervention in end of life care: length of MICU stay (days)

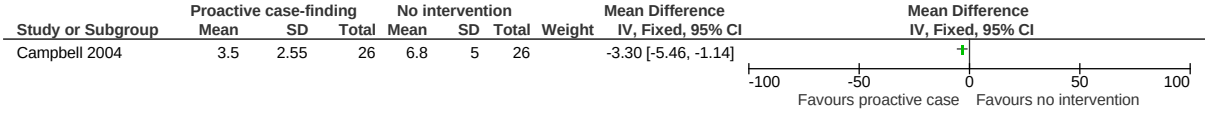
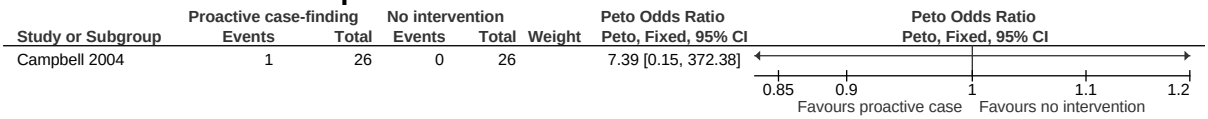


Figure 5: Proactive case-finding versus no intervention in end of life care: discharge to another hospital



Appendix F: GRADE tables

Table 8: Clinical evidence profile: Proactive case-finding versus no intervention

Quality assessment							No of patients		Effect		Quality	Importance
No of studies	Design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations	Proactive case-finding	No intervention	Relative (95% CI)	Absolute		
Length of stay (days) (Better indicated by lower values)												
1	observational studies	very serious[a]	no serious inconsistency	no serious indirectness	serious[b]	none	26	26	-	MD 4.7 lower (8.87 to 0.53 lower)	⊕OOO VERY LOW	IMPORTANT
Length of stay in MICU (days) (Better indicated by lower values)												
1	observational studies	very serious[a]	no serious inconsistency	no serious indirectness	serious[b]	none	26	26	-	MD 3.3 lower (5.46 to 1.14 lower)	⊕OOO VERY LOW	IMPORTANT
Discharged to another hospital												
1	observational studies	very serious[a]	no serious inconsistency	no serious indirectness	very serious[b]	none	1/26 (3.8%)	0%	Peto OR (7.39 (0.15 to 372.38)	40 higher (60 lower to 140 higher)	⊕OOO VERY LOW	IMPORTANT

a Downgraded by 1 increment if the majority of the evidence was at high risk of bias, and downgraded by 2 increments if the majority of the evidence was at very high risk of bias

b Downgraded by 1 increment if the confidence interval crossed one MID or by 2 increments if the confidence interval crossed both MIDs

Appendix G: Excluded studies

G.1 Excluded clinical studies

Table 9: Studies excluded from the clinical review

Reference	Reason for exclusion
Adelson 2017[1]	Inappropriate intervention
Ahmed 2015[2]	Inappropriate intervention
Amass 2006[3]	Inappropriate study design
Amblas-Novellas 2016[4]	Inappropriate study design
Amro 2016[5]	Inappropriate comparison
Autor 2013[6]	Inappropriate intervention
Baba 2015[7]	Inappropriate intervention
Beernaert 2014[8]	Inappropriate study design
Begum 2013[9]	Inappropriate study design and intervention
Bennett 2000[10]	Inappropriate study design
Boyd 2010[11]	Inappropriate study design
Broom 2012[12]	Inappropriate study design
Carduff 2016[14]	Inappropriate study design and intervention
Carey 2015[15]	Inappropriate study design
Chan 2012[16]	Inappropriate intervention
Chang 2015[17]	Inappropriate intervention
Chen 2017[18]	Inappropriate intervention
Clark 2016[19]	Inappropriate study design
Clarkson 2013[20]	Inappropriate study design
Cotogni 2017[21]	Inappropriate intervention
Dalgaard 2010[22]	Inappropriate study design
Davis 2015[23]	Inappropriate study design and intervention
Dhiliwal 2016[24]	Inappropriate intervention
Downar 2017[25]	Inappropriate intervention
Evans 2016[26]	Inappropriate intervention
Fenning 2012[27]	Inappropriate intervention
Feyi 2015[28]	Inappropriate intervention
Fromme 2010[29]	Inappropriate intervention
Glajchen 2011[30]	Inappropriate intervention
Glare 2001[31]	Inappropriate intervention
Goodlin 2004[32]	Inappropriate intervention
Grbich 2005[33]	Inappropriate intervention
Greiner 2003[34]	Unable to locate
Gwilliam 2013[35]	Inappropriate study design and intervention
Haga 2012[36]	Inappropriate intervention
Hamano 2015[37]	Inappropriate intervention
Harrison 2012[38]	Inappropriate study design and intervention

Reference	Reason for exclusion
Haydar 2017[39]	Not review population
Hornbrook 2013[40]	Inappropriate intervention
Hosie 2014[41]	Inappropriate study design
Hui 2016[42]	Inappropriate study design
Iwashyna 2001[43]	Unable to locate
Janssen 2012[44]	Inappropriate intervention
Jenko 2015[45]	Inappropriate intervention
Johnson 2012[47]	Inappropriate study design
Johnston 1998[48]	Inappropriate comparison
Kennedy 2014[49]	Inappropriate population
Kristjanson 2005[50]	Inappropriate study design
Kuhn 2012[51]	Inappropriate study design
Ledoux 2015[52]	Not relevant to PICO
Leysen 2015[53]	Inappropriate study design and intervention
Llobera 2000[54]	Inappropriate study design and intervention
Lynn 2000[55]	Inappropriate study design
Maquire 2013[57]	Inappropriate intervention
Marcucci 2016[58]	Inappropriate study design
Mason 2015[59]	Inappropriate comparison
Meffert 2016[60]	Inappropriate intervention and comparison
Mierendorf 2014[61]	Inappropriate study design
Milnes 2015[62]	Inappropriate intervention
Mittman 2018{Mittmann, 2018 #3553}	Conference abstract
Moretti 2016[64]	Inappropriate intervention
Moretti 2016[63]	Unable to locate
Morita 2008[65]	Inappropriate study design and intervention
Norton 2007[68]	Not relevant to PICO
O'Callaghan 2014[69]	Inappropriate study design
O'Mahony 2005[70]	Inappropriate intervention
Philip 2010[71]	Inappropriate interventions
Phua 2016[72]	Inappropriate study design (abstract)
Rainone 2007[74]	Inappropriate study design and intervention
Reynolds 2010[46]	Inappropriate study design
Riggs 2016[75]	Inappropriate intervention
Rocque 2015[76]	Inappropriate intervention
Rojas 2016[77]	Inappropriate study design
Schenker 2014[78]	Inappropriate study design
Schofield 2006[79]	Not relevant to PICO
Seow 2009[80]	Inappropriate study design
Sharpe 2016[81]	Inappropriate study design
Shaw 2010[82]	Inappropriate intervention
Silvester 2014[83]	Inappropriate study design and intervention
Slaven 2007[84]	Inappropriate intervention
Smith 2016[86]	Inappropriate study design
Smith 2017[85]	Inappropriate intervention

Reference	Reason for exclusion
Strupp 2015[87]	Inappropriate study design and intervention
Szekendi 2017[88]	Inappropriate intervention
Takahashi 2012[89]	Inappropriate intervention
Thoonsen 2016[90]	Inappropriate study design
Trueman 2011[91]	Inappropriate study design and intervention
Vanbutsele 2015[92]	Inappropriate study design
Van der Plas 2018{van der Plas, 2018 #3524}	Inappropriate study population
Villa 2015[93]	Inappropriate intervention
Vrijmoeth 2016[94]	Inappropriate study design
Waller 2012[95]	Inappropriate intervention
Walshe 2008[96]	Inappropriate study design
White 2016[98]	Inappropriate study design and intervention
White 2017[97]	Inappropriate intervention
Yamada 2017[99]	Inappropriate study design
Zare 2011[100]	Inappropriate intervention

G.2 Excluded economic studies

There were no excluded economic studies for this review.