National Institute for Health and Care Excellence

Draft for consultation

End of life care for adults service delivery

[J] Evidence review: service provision: identifying the need for additional services; timing and frequency of review of services

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.

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 All NICE guidance is subject to regular review and may be updated or withdrawn.

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1.1 Review question 1: What is the best method/service to review service provision and identify when additional services may be required in people thought to be entering their last year of life?

1.2 Review question 2: When and how frequently should service need provision be reviewed in people thought to be in their last year of life?

1.3 Introduction

It is well recognised that planning services with people in the last year of life and their carers is key to a good outcome at the end of life. The identification of additional services that may be required or indeed discontinued should be based on a holistic needs assessment that is responsive to change as things change. It is reasonable to assume that needs between people vary widely and generalisations cannot be made.

Too many services involved can be as problematic as too few. It is just as important to review when existing services are no longer required. Patient's needs and the needs of their carer's/loved ones may differ in intensity at different times, and need to be assessed separately.

Additional services are those required in addition to the core palliative care services provided in any particular location. For people at home, core palliative care is provided by the general practice team, and community nursing as required. In acute hospital, core palliative care is provided by the ward-based health and social care team.

The additional services that may be required range widely, from additional nursing, social care, and allied health professional support, to welfare and benefits advice, specialist palliative care, spiritual care and other specialist support for example heart failure nurse, community diabetes, dementia nursing support, and specialist psychological support. Service configurations may also vary widely, for example allied health professionals may provide services from services based within general practice, community nursing or hospice/community specialist palliative care. Eligibility and discharge criteria for additional services should be available, and based on current level of need identified through a holistic care assessment.

1.4 PICO table

For full details see the review protocol in appendix A.

Table 1: PICO characteristics of review question 1

Population	Adults (aged over 18 or over) with progressive life-limiting conditions thought to be entering the last year of life.
Interventions	• Method/service to review service provision and identify when additional

	services may be required in people thought to be entering their last year of life Combinations of methods/services to review service provision and identify when additional services may be required in people thought to be entering their last year of life
Comparisons	• To each other • No standardised method/service to review service provision and identify when additional services may be required
Outcomes	CRITICAL - Quality of life (Continuous) - Preferred and actual place of death (Dichotomous) - Preferred and actual place of care (Dichotomous) - Length of survival (Continuous) IMPORTANT - Length of survival (Continuous) - Length of stay (Continuous) - Hospitalisation (Dichotomous) - Number of hospital visits (Continuous/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)
Study design	• Systematic reviews • RCTs • Non-randomised comparative studies, including before and after studies and interrupted-time series

Table 2: PICO characteristics of review question 2

Population	Adults (aged over 18 or over) with progressive life-limiting conditions thought to be entering the last year of life.
Interventions	Timing/frequency to review service provision in people thought to be entering their last year of life
Comparisons	• To each other • No standardised timing/frequency to review service provision
Outcomes	CRITICAL - Quality of life (Continuous) - Preferred and actual place of death (Dichotomous) - Preferred and actual place of care (Dichotomous) IMPORTANT - Length of survival (Continuous) - Length of stay (Continuous) - Hospitalisation (Dichotomous) - Number of hospital visits (Continuous/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)
Study design	• Systematic reviews • RCTs • Non-randomised comparative studies, including before and after studies and

interrupted-time series

1.5 Clinical evidence

1.5.1 Included studies

A search was conducted for randomised trials or non-randomised comparative studies on service models (or service components) enabling the identification of the need for additional services, and the timing and frequency of review of service provision for people in their last year of life.

No relevant clinical studies were identified for this review.

1.5.2 Excluded studies

See the excluded studies list in appendix H.

1.6 Economic evidence

1.6.1 Included studies

No relevant health economic studies were identified.

1.6.2 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.

1.6.3 Unit costs

Table 3 reports the unit cost of staff time for some health care professionals who may undertake a review of a person's holistic needs with the person in the last year of life, to determine whether they require any changes to the end-of-life care services they receive. The cost of patient contact as opposed to per working hour has been reported where available.

Table 3: UK costs of staff time for health care professionals who might undertake reviews of a person's end-of-life care needs

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

Staff Member	Unit Cost of Staff Time[(a)]
Social Worker (adult services)	£55 per hour of client-related work

(a) Source: Curtis (2016)[1]
(b) Please see Curtis (2016)[1] for details of the health care professionals included in this category by band. Examples include: Physiotherapists, Occupational therapists, Counsellors, Pharmacists.

1.7 Resource costs

Recommendations made based on this review (see section 1.9) are not expected to have a substantial impact on resources.

1.8 Evidence statements

1.8.1 Clinical evidence statements

No relevant published evidence was identified.

1.8.2 Health economic evidence statements

No relevant economic evaluations were identified.

1.9 Recommendations

J1. For advice on reducing treatment burden and reviewing medicines and other treatments see the NICE guidelines on multimorbidity and medicines optimisation.

J2. Develop policies for reviewing treatment across specialities to meet the changing needs of adults approaching the end of their life and to reduce the burden of unhelpful treatments.

J3. The lead healthcare professional for the person's care in each care setting should discuss all existing treatment plans with the person approaching the end of their life and, with the person's consent, their carers and other people important to them. This should include discussing:

- any changes that could optimise care and improve their quality of life (for example, reducing the number of unnecessary routine appointments, organising appointments close to the person's home, starting new treatments or stopping unhelpful treatments)
- community support available to help with their treatment.

1.9.1 Research recommendations

The Committee considered the following topic for research in this area:

RR3. Planned regular community-based reviews

What are the benefits of planned regular community-based reviews versus as required review of non-cancer patients in last year of life?

Why this is important

There is little relevant research evidence for the optimum frequency of review of patients with progressive non-cancer conditions who have entered the last year of life. Many of the studies attempted in this area have been conducted in other countries where the healthcare systems are very different from the UK. ‘Usual care’ for non-cancer conditions tends to provide

demand-led review by specialists and primary care staff. This may be appropriate if patients are well supported at home or in care settings, but could lead to unrecognised deterioration in symptoms or functioning; and place people at risk of crises and unplanned hospital admissions if they are living alone and/or with little professional support. A policy of regular planned reviews of patients in their usual place of residence could improve symptom management, maintain better level of functioning, prevent crises and may pre-empt emergency hospital visits and admission; but conversely they could impose unnecessary burdens on the patient, family and the healthcare system. This research would study non-cancer patients receiving usual care (with or without any concurrent specialist level care), and assess their outcomes against different levels of frequency of planned specialist reviews in the community. Please see Appendix I for further details.

1.10 Rationale and impact

1.10.1 Why the committee made the recommendations

There was no evidence identified on how and when to carry out an initial review of service provision for people in the last year of life. However, the committee agreed that it was important for all lead healthcare professionals responsible for the person's care to review and discuss the person's current care needs with them. In particular, they discussed identifying services that may be needed or could be stopped, and acknowledged that the involvement of too many services can be as problematic as too few. The committee also agreed that adapting care pathways for managing comorbidities in the last year of life would help ensure that the right care is provided at the right time.

To encourage more research in this area, a research recommendation was also developed for the area of Early review of service provision and referral to additional specialist palliative care services, this can be found in Chapter B, the evidence review on early versus late referral).

1.10.2 Impact of the recommendations on practice

The recommendations reflect current good practice available in some services, but there is variation nationally. Reviewing current treatment of people in the last year of life means appropriate care will be given and may reduce the burden of unnecessary appointments and treatments.

Further details of the evidence and the committee's discussions can be found in evidence review D: the care coordinator and lead health professional.

1.11 The committee's discussion of the evidence

1.11.1 Interpreting the evidence

The committee identified quality of life, preferred place of care and preferred place of death as the critical outcomes. The following outcomes were identified as important for decision making and focus on the impact and use of health resources as well as the impact on the patient; length of survival, length of hospital stay, hospitalisation, number of hospital visits, number of visits to accident and emergency , number of unscheduled admissions , use of community services, avoidable/inappropriate admissions to ICU, inappropriate attempts at cardiopulmonary resuscitation and staff , patient and carer satisfaction.

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

No relevant clinical studies were identified; therefore no evidence was available for any of these outcomes.

1.11.1.1 The quality of the evidence

No relevant clinical studies were identified for this review.

1.11.1.2 Benefits and harms

No relevant clinical studies were identified for this review. However, the Committee felt that a consensus recommendation in this area was warranted as it is important that people receive the right care at the right time. If care is not reviewed then people may stay on treatments that are unnecessary and not receive the ones that are now needed

The Committee agreed to recommend that the needs of people in the last year of life should be assessed when required, for example at transition points. End of life treatment and care issues should be discussed whenever people wish to do so, and the timing of discussion should take into account the person's current communication ability, cognitive status and mental capacity. The Committee also agreed to formulate a research recommendation to encourage further research regarding the modality, timing and frequency of review of service provision in people in the last year of life.

1.11.2 Cost effectiveness and resource use

Most End of Life care services are provided to help improve the quality of care and maintain quality of life of people thought to be nearing the end of life. Some of the services provided may also reduce costs to the NHS, for example, by reducing the number of inappropriate emergency admissions or reducing the proportion of deaths occurring in hospitals. In order to provide the level of services that meet the needs of a patient, the patient's needs must be assessed; ideally through a holistic needs assessment. Patient's needs are likely to vary over the duration of their last year of life. To ensure the levels of services provided continuously meet the needs of the patient their needs will need to be regularly reviewed. How often their needs are reviewed will depend on how quickly the needs of the patient change over time.

Determining the interval between reassessment of patient and carer needs requires careful consideration. Reviewing too early could mean that a patient's needs have not changed and therefore reviewing their services is an inefficient use of their time, and service resources. Reviewing too late could mean that the patient and their family have been struggling with unmet needs, and possibly needing to access care in an unplanned, and therefore inefficient, way. To ensure that patient and NHS resources are used as efficiently as possible, it would seem appropriate to determine when to review patients' needs on a patient by patient basis, tailoring the service delivery to meet the individual needs of the patient.

The committee discussed the balance of when to review services and the feeling from the group was that currently it is much more likely that patient needs and services are not reviewed enough and leading to unmet needs of patients. Although theoretically patients could be reviewed too often, in reality this rarely happens.

No economic evidence was identified therefore it was not possible to determine the cost effectiveness of reviewing patients' needs for any time intervals. However, the committee considered cost effectiveness when making their consensus recommendations. Instead of selecting a timespan for how often needs should be reviewed, the committee felt it would be a better and more cost effective use of resources for patients to have assessments of their needs only when required, for example at periods of transition.

1.11.3 Other factors the committee took into account

The Committee acknowledged that for some conditions the identification of transition points at which to review service provision could be difficult, for example in people with dementia and frailty. They were aware of national tools for the identification of transition point specific for palliative care, for example OACC and GSF. However they expressed their concern on the absence of published research on the impact of these tools on service provision.

The Committee stressed that patients may not initiate discussions about end of life care ,dying and their concerns, often expecting the clinicians to raise these issues first.

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Appendices

Appendix A: Review protocols

Table 4: Review protocol for what is the best method/service to review service provision and identify when additional services may be required in people thought to be entering their last year of life?

Question number: Q5

Relevant section of Scope:

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.

ID	Field	Content
I	Review question	What is the best method/service to review service provision and identify when additional services may be required in people thought to be entering their last year of life?
II	Type of review question	Intervention A review of health economic evidence related to the same review question was conducted in parallel with this review. For details see the health economic review protocol for this NICE guideline.
III	Objective of the review	To identify the best method/service to review service provision and identify when additional services may be required in people thought to be entering their last year of life
IV	Eligibility criteria – population / disease / condition / issue / domain	Adults (aged over 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)	• Method/service to review service provision and identify when additional services may be required in people thought to be entering their last year of life
VI	Eligibility criteria – comparator(s) / control or reference (gold) standard	• Combinations of methods/services to review service provision and identify when additional services may be required in people thought to be entering their last year of life • To each other • No standardized method/service to review service provision

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

	duplicate screening / selection / analysis	• 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
XIII	Information sources – databases and dates	Clinical search databases to be used: Medline, Embase, Cochrane Library, Current Nursing and Allied Health Literature (CINAHL), PsycINFO, Healthcare Management Information Consortium (HMIC), Social Policy and Practice (SSP), Applied Social Sciences Index and Abstracts (ASSIA) Date: All years Health economics search databases to be used: Medline, Embase, NHSEED, HTA Date: Medline, Embase from 2014 NHSEED, HTA – All years Language: Restrict to English only A call for evidence was also conducted.
XIV	Identify if an update	Not applicable
XV	Author contacts	https://www.nice.org.uk/guidance/indevelopment/gid-cgwave0799
XVI	Highlight if amendment to previous protocol	For details please see section 4.5 of Developing NICE guidelines: the manual.
XVII	Search strategy – for one database	For details please see appendix B
XVIII	Data collection process – forms / duplicate	A standardised evidence table format will be used, and published as appendix D of the evidence report.
XIX	Data items – define all variables to be collected	For details please see evidence tables in Appendix D (clinical evidence tables) or G (health economic evidence tables).
XX	Methods for assessing bias at outcome / study level	Standard study checklists were used to critically appraise individual studies. For details please see section 6.2 of Developing NICE guidelines: the manual The risk of bias across all available evidence was evaluated for each outcome using an adaptation of the 'Grading of Recommendations Assessment, Development and Evaluation (GRADE) toolbox' developed by the international GRADE working group http://www.gradeworkinggroup.org/ [Please document any deviations/alternative approach when GRADE isn't used or if a modified GRADE approach has been used for non-intervention or non-comparative studies.]
XXI	Criteria for	For details please see section 6.4 of Developing NICE

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

Table 5: Review protocol for when and how frequently should service need provision be reviewed in people thought to be in their last year of life?

Question number: Q7

Relevant section of Scope:

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.]

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ID	Field	Content
I	Review question	When and how frequently should service need provision be reviewed in people thought to be in their last year of life?:
II	Type of review question	Intervention A review of health economic evidence related to the same review question was conducted in parallel with this review. For details see the health economic review protocol for this NICE guideline.
III	Objective of the review	To identify the best timing or frequency to review service provision in people thought to be entering their last year of life
IV	Eligibility criteria – population / disease / condition / issue / domain	Adults (aged over 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)	• Timing/frequency to review service provision in people thought to be entering their last year of life
VI	Eligibility criteria – comparator(s) / control or reference (gold) standard	• To each other • No standardized timing/frequency to review service provision
VII	Outcomes and prioritisation	CRITICAL • Quality of life (Continuous) • Preferred and actual place of death (Dichotomous) • Preferred and actual place of care (Dichotomous) • Length of survival (Dichotomous) IMPORTANT • Length of stay (Continuous) • Hospitalisation (Dichotomous) • Number of hospital visits (Dichotomous) • Number of visits to accident and emergency (Dichotomous) • Number of unscheduled admissions (Dichotomous) • Use of community services (Dichotomous) • Avoidable/inappropriate admissions to ICU (Dichotomous) • Inappropriate attempt at cardiopulmonary resuscitation (Dichotomous) Staff satisfaction (Continuous) • Patient/carer reported outcomes (satisfaction) (Continuous)
VIII	Eligibility criteria – study design	• Systematic reviews • RCTs • Non-randomised comparative studies, including before and after studies.
IX	Other inclusion	

	exclusion criteria	Exclusions: • Children (17 years or younger) • Studies will only be included if they reported one or more of the outcomes listed above • Descriptive (non-comparative) studies will be excluded
X	Proposed sensitivity / subgroup analysis, or meta-regression	Subgroups to be analysed if heterogeneity found: • Younger adults (aged 18-25) • Frail elderly • People with dementia • People with hearing loss • People with advanced heart and lung disease • People in prisons • Socioeconomic inequalities (people from lower income brackets) • Homeless people/vulnerably housed • Travellers • People with learning difficulties • People with disabilities • People with mental health problems • Migrant workers • LGBT • People in whom life-prolonging therapies are still an active option
XI	Selection process – duplicate screening / selection / analysis	• 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 citations and bibliographies
XIII	Information sources – databases and dates	Databases: Medline, Embase, The Cochrane LIbrary Date limits for search: all years Language: English only A call for evidence was also conducted.
XIV	Identify if an update	Not applicable
XV	Author contacts	https://www.nice.org.uk/guidance/indevelopment/gid-cgwave0799
XVI	Highlight if amendment to previous protocol	For details please see section 4.5 of Developing NICE guidelines: the manual.
XVII	Search strategy – for one database	For details please see appendix B
XVIII	Data collection process – forms /	A standardised evidence table format will be used, and published as appendix D of the evidence report.

	duplicate	
XIX	Data items – define all variables to be collected	For details please see evidence tables in Appendix D (clinical evidence tables) or G (health economic evidence tables).
XX	Methods for assessing bias at outcome / study level	Standard study checklists were used to critically appraise individual studies. For details please see section 6.2 of Developing NICE guidelines: the manual The risk of bias across all available evidence was evaluated for each outcome using an adaptation of the 'Grading of Recommendations Assessment, Development and Evaluation (GRADE) toolbox' developed by the international GRADE working group http://www.gradeworkinggroup.org/ [Please document any deviations/alternative approach when GRADE isn't used or if a modified GRADE approach has been used for non-intervention or non-comparative studies.]
XXI	Criteria for quantitative synthesis	For details please see section 6.4 of Developing NICE guidelines: the manual.
XXII	Methods for quantitative analysis – combining studies and exploring (in)consistency	For details please see the separate Methods report for this guideline.
XXIII	Meta-bias assessment – publication bias, selective reporting bias	For details please see section 6.2 of Developing NICE guidelines: the manual. [Consider exploring publication bias for review questions where it may be more common, such as pharmacological questions and 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 guarantor	A multidisciplinary committee [https://www.nice.org.uk/guidance/indevelopment/gid-cgwave0799] developed the evidence review. The committee was convened by the National Guideline Centre (NGC) and chaired by Mark Thomas in line with section 3 of Developing NICE guidelines: the manual. Staff from NGC undertook systematic literature searches, appraised the evidence, conducted meta-analysis and cost-effectiveness analysis where appropriate, and drafted the evidence review in collaboration with the committee. For details please see Developing NICE guidelines: the manual.
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XXX	PROSPERO registration number	Not registered

1 **Table 6: Health economic review protocol**

Review question	All questions – health economic evidence
Objective	To identify health economic studies relevant to any of the review questions.

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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 A.
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).[7] **Inclusion and exclusion criteria** • If a study is rated as both 'Directly applicable' and with 'Minor limitations' then it will be included in the guideline. A health economic evidence table will be completed and it will be included in the health economic evidence profile. • If a study is rated as either 'Not applicable' or with 'Very serious limitations' then it will usually be excluded from the guideline. If it is excluded then a health economic evidence table will not be completed and it will not be included in the health economic evidence profile. • If a study is rated as 'Partially applicable', with 'Potentially serious limitations' or both then there is discretion over whether it should be included. **Where there is discretion** The health economist will make a decision based on the relative applicability and quality of the available evidence for that question, in discussion with the guideline committee if required. The ultimate aim is to include health economic studies that are helpful for decision-making in the context of the guideline and the current NHS setting. If several studies are considered of sufficiently high applicability and methodological quality that they could all be included, then the health economist, in discussion with the committee if required, may decide to include only the most applicable studies and to selectively exclude the remaining studies. All studies excluded on the basis of applicability or methodological limitations will be listed with explanation as excluded health economic studies in appendix M. The health economist will be guided by the following hierarchies. *Setting:* • UK NHS (most applicable). • OECD countries with predominantly public health insurance systems (for example, France, Germany, Sweden). • OECD countries with predominantly private health insurance systems (for example, Switzerland). • Studies set in non-OECD countries or in the USA will be excluded before being assessed for applicability and methodological limitations. *Health economic study type:* • Cost–utility analysis (most applicable).

	• Other type of full economic evaluation (cost–benefit analysis, cost-effectiveness analysis, cost–consequences analysis). • Comparative cost analysis. • Non-comparative cost analyses including cost-of-illness studies will be excluded before being assessed for applicability and methodological limitations. *Year of analysis:* • The more recent the study, the more applicable it will be. • Studies published in 2007 or later but that depend on unit costs and resource data entirely or predominantly from before 2007 will be rated as 'Not applicable'. • Studies published before 2007 will be excluded before being assessed for applicability and methodological limitations. *Quality and relevance of effectiveness data used in the health economic analysis:* • The more closely the clinical effectiveness data used in the health economic analysis match with the outcomes of the studies included in the clinical review the more useful the analysis will be for decision-making in the guideline.

Appendix B: Literature search strategies

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

For more detailed information, please see the Methodology Review.

B.1 Clinical search literature search strategy

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

Table 7: 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

Database	Dates searched	Search filter used
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

1

2

3

4 **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.	(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.
54.	52 and 53
55.	(commission* adj2 (support* or service* or model*)).ti,ab.
56.	((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.
57.	Critical Pathways/
58.	((critical or clinic* or service* or care) adj2 path*).ti,ab.
59.	Patient Care Bundles/
60.	(care adj2 (bundle* or service* or package* or standard*)).ti,ab.
61.	or/55-60
62.	(assess* or criteria* or predict* or recogni* or identif* or refer*).ti,ab.
63.	52 and 61 and 62
64.	gold standard*.ti,ab.
65.	52 and 64

66.	(amber adj2 bundle).ti,ab.
67.	63 or 65 or 66
68.	patient care team/
69.	interdisciplinary communication/
70.	(((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.
71.	(((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.
72.	(key adj2 work*).ti,ab.
73.	((healthcare or care) adj2 (lead or leader or leads or facilitat*)).ti,ab.
74.	((healthcare or care) adj1 profession*).ti,ab.
75.	*Case Management/
76.	(case adj2 manage*).ti,ab.
77.	(co-ordinator* or coordinator* or coordinate* or co-ordinate*).ti,ab.
78.	Or/68-77
79.	Social Welfare/ec, ed, es, eh, ma, st, sn, td [Economics, Education, Ethics, Ethnology, Manpower, Standards, Statistics & Numerical Data, Trends]
80.	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]
81.	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]
82.	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]
83.	Telemedicine/ec, es, ma, mt, og, st, sn, td, ut [Economics, Ethics, Manpower, Methods, Organization & Administration, Standards, Statistics & Numerical Data, Trends, Utilization]
84.	exp remote consultation/
85.	*telemedicine/ or *telepathology/ or *teleradiology/ or *telerehabilitation/
86.	(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.
87.	((tele* or remote) adj2 consult*).ti,ab.
88.	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]
89.	(mobile adj2 (health or care) adj2 unit*).ti,ab.
90.	(hospital-based home care or HBHC or hospital-based hospice care or acute hospital care).ti,ab.
91.	(hospital adj3 (domicil* or home)).ti,ab.
92.	home hospitali*ation.ti,ab.
93.	exp Home Care Agencies/
94.	(social adj (welfare or care)).ti,ab.

95.	(nurs* adj4 (home-visit* or home visit* or home-based or home based)).ti,ab.
96.	((district* or communit* or home or visit*) adj nurs*).ti,ab.
97.	(community adj2 (health care or healthcare or nursing or nurse*)).ti,ab.
98.	((hospitali*ation* or admission* or readmission* or admit*) adj3 (reduc* or avoid* or prevent* or inappropiate or increase* or risk*)).ti,ab.
99.	Or/78-98
100.	*"Continuity of Patient Care"/
101.	*Aftercare/ or *Patient discharge/ or *Patient handoff/ or *Patient transfer/ or *Transitional care/
102.	Patient Discharge Summaries/
103.	((patient* or person* or people or nursing* or clinic*) adj (discharg* or handover* or hand* over* or handoff* or hand off* or signout* or sign* out* or signover* or sign* over*)).ti,ab.
104.	((care or caring or serv*) adj2 (continu* or change* or transition* or transfer*)).ti,ab.
105.	(discharg* adj2 (facilitat* or rapid* or pathway* or path way* or plan* or program*)).ti,ab.
106.	Or/100-105
107.	(advance* adj2 (plan* or decision* or directive*)).ti,ab.
108.	living will*.ti,ab.
109.	Or/107-108
110.	*Caregiver/
111.	*Spouse/
112.	*Family/
113.	(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.
114.	Or/110-113
115.	((replacement or break* or holiday* or respite) adj3 (care* or service*)).ti,ab.
116.	((communit* or support* or psychosocial* or psycholog*) adj3 (service* or group* or system*)).ti,ab.
117.	((group* or support* or psychosocial* or psycholog*) adj3 (selfhelp or self help or therap*)).ti,ab.
118.	((psychosocial* or psycholog*) adj2 support*).ti,ab.
119.	*Self-Help/
120.	*Social support/
121.	*Counseling/
122.	(counseling or counselling*).ti,ab.
123.	(buddy* or buddies).ti,ab.
124.	((health* or medical*) adj2 check*).ti,ab.
125.	((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.
126.	Or/115-125
127.	52 and 114 and 126

128.	52 and (78 or 99 or 106 or 109)
129.	54 or 67 or 127 or 128

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.	(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.
51.	49 and 50
52.	(commission* adj2 (support* or service* or model*)).ti,ab.
53.	((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.
54.	*Clinical Pathway/
55.	((critical or clinic* or service* or care) adj2 path*).ti,ab.
56.	*Care Bundle/
57.	(care adj2 (bundle* or service* or package* or standard*)).ti,ab.
58.	or/52-57
59.	(assess* or criteria* or predict* or recogni* or identif* or refer*).ti,ab.
60.	49 and 58 and 59
61.	gold standard*.ti,ab.
62.	49 and 61
63.	(amber adj2 bundle).ti,ab.
64.	60 or 62 or 63
65.	interdisciplinary communication/
66.	patient care team*.ti,ab.
67.	(((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.
68.	(((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.
69.	(key adj2 work*).ti,ab.
70.	((healthcare or care) adj2 (lead or leader or leads or facilitat*)).ti,ab.
71.	((healthcare or care) adj1 profession*).ti,ab.
72.	*Case Management/
73.	(case adj2 manage*).ti,ab.
74.	(co-ordinator* or coordinator* or coordinate* or co-ordinate*).ti,ab.
75.	Or/65-74
76.	*social welfare/
77.	*community health nursing/ or *community care/
78.	*senior center/

79.	*telemedicine/ or *telehealth/
80.	*teleconsultation/
81.	(telehealth or tele health or virtual hospital* or helpline* or help line* or rapid response team* or mobile health unit*).ti,ab.
82.	*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/
83.	*health care personnel/ or *health auxiliary/ or *nursing home personnel/
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 adj2 (health or care) adj2 unit*).ti,ab.
87.	(hospital-based home care or HBHC or hospital-based hospice care or acute hospital care).ti,ab.
88.	(hospital adj3 (domicil* or home)).ti,ab.
89.	home hospitali*ation.ti,ab.
90.	(social adj (welfare or care)).ti,ab.
91.	(nurs* adj4 (home-visit* or home visit* or home-based or home based)).ti,ab.
92.	((district* or communit* or home or visit*) adj nurs*).ti,ab.
93.	(community adj2 (health care or healthcare or nursing or nurse*)).ti,ab.
94.	((hospitali*ation* or admission* or readmission* or admit*) adj3 (reduc* or avoid* or prevent* or inappropiate or increase* or risk*)).ti,ab.
95.	Or/76-94
96.	*patient care/ or *case management/ or *patient care planning/ or *rapid response team/
97.	*aftercare/
98.	*hospital discharge/
99.	*clinical handover/
100.	*transitional care/
101.	*patient care planning/
102.	*medical record/
103.	((patient* or person* or people or nursing* or clinic*) adj (discharg* or handover* or hand* over* or handoff* or hand off* or signout* or sign* out* or signover* or sign* over*)).ti,ab.
104.	((care or caring or serv*) adj2 (continu* or change* or transition* or transfer*)).ti,ab.
105.	(discharg* adj2 (facilitat* or rapid* or pathway* or path way* or plan* or program*)).ti,ab.
106.	Or/96-105
107.	(advance* adj2 (plan* or decision* or directive*)).ti,ab.
108.	living will*.ti,ab.
109.	Or/107-108
110.	*Caregiver/
111.	*Spouse/
112.	*Family/
113.	(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.
114.	Or/110-113
115.	((replacement or break* or holiday* or respite) adj3 (care* or service*)).ti,ab.
116.	((communit* or support* or psychosocial* or psycholog*) adj3 (service* or group* or system*)).ti,ab.
117.	((group* or support* or psychosocial* or psycholog*) adj3 (selfhelp or self help or therap*)).ti,ab.
118.	((psychosocial* or psycholog*) adj2 support*).ti,ab.
119.	*Self-Help/
120.	*Social support/
121.	*Counseling/
122.	(counseling or counselling*).ti,ab.
123.	(buddy* or buddies).ti,ab.
124.	((health* or medical*) adj2 check*).ti,ab.
125.	((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.
126.	or/115-125
127.	49 and 114 and 126
128.	49 and (75 or 95 or 106 or 109)
129.	51 or 64 or 127 or 128

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.	MeSH descriptor: [Advance Care Planning] explode all trees
#28.	(advance* near/2 (plan* or decision* or directive*)):ti,ab
#29.	(or #1-#28)
#30.	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
#31.	#29 and #30
#32.	(commission* near/2 (support* or service* or model*)):ti,ab
#33.	((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
#34.	MeSH descriptor: [Critical Pathways] explode all trees
#35.	((critical or clinic* or service* or care) near/2 path*):ti,ab
#36.	MeSH descriptor: [Patient Care Bundles] explode all trees
#37.	(care near/2 (bundle* or service* or package* or standard*)):ti,ab
#38.	(or #34-#37)
#39.	(assess* or criteria* or predict* or recogni* or identif* or refer*):ti,ab
#40.	#29 and #38 and #39
#41.	gold standard*:ti,ab
#42.	#29 and #41
#43.	(amber near/2 bundle):ti,ab
#44.	#40 or #43 or #43
#45.	MeSH descriptor: [Patient Care Team] explode all trees
#46.	MeSH descriptor: [Interdisciplinary Communication] explode all trees
#47.	(((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
#48.	((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
#49.	(key near/2 work*):ti,ab
#50.	((healthcare or care) near/2 (lead or leader or leads or facilitat*)):ti,ab
#51.	((healthcare or care) near/1 profession*):ti,ab
#52.	MeSH descriptor: [Case Management] this term only
#53.	(case near/2 manage*):ti,ab
#54.	(co-ordinator* or coordinator* or coordinate* or co-ordinate*):ti,ab
#55.	(or #45-#54)
#56.	MeSH descriptor: [Social Welfare] explode all trees
#57.	MeSH descriptor: [Charities] explode all trees
#58.	MeSH descriptor: [Adult Day Care Centers] explode all trees
#59.	MeSH descriptor: [Community Health Nursing] explode all trees

#60.	MeSH descriptor: [Home Care Services] explode all trees
#61.	MeSH descriptor: [Senior Centers] explode all trees
#62.	MeSH descriptor: [Telemedicine] this term only
#63.	MeSH descriptor: [Remote Consultation] explode all trees
#64.	(telehealth or tele health or virtual hospital* or helpline* or help line* or rapid response team*):ti,ab
#65.	MeSH descriptor: [Mobile Health Units] explode all trees
#66.	((community based or community dwelling home or rural) near/3 (care or health care or healthcare)):ti,ab
#67.	(hospital-based home care or HBHC or hospital-based hospice care or acute hospital care):ti,ab
#68.	((hospitali*ation* or admission* or readmission* or admit*) near/3 (reduc* or avoid* or prevent* or inappropiate or increase* or risk*)):ti,ab
#69.	(home based versus hospital based):ti,ab
#70.	(hospital near/3 (domicil* or home)):ti,ab
#71.	(home hospitali*ation):ti,ab
#72.	MeSH descriptor: [Home Care Services, Hospital-Based] explode all trees
#73.	MeSH descriptor: [Home Health Nursing] explode all trees
#74.	MeSH descriptor: [Homemaker Services] explode all trees
#75.	MeSH descriptor: [Home Care Agencies] explode all trees
#76.	MeSH descriptor: [Home Health Aides] explode all trees
#77.	(social care):ti,ab
#78.	MeSH descriptor: [Nurses, Community Health] explode all trees
#79.	(nurs* near/4 (home-visit* or home visit* or home-based or home based)):ti,ab
#80.	((district* or communit* or home or visit*) near nurs*):ti,ab
#81.	(Or #56-#80)
#82.	MeSH descriptor: [Continuity of Patient Care] this term only
#83.	MeSH descriptor: [Aftercare] this term only
#84.	MeSH descriptor: [Patient Discharge] this term only
#85.	MeSH descriptor: [Patient Handoff] this term only
#86.	MeSH descriptor: [Patient Transfer] this term only
#87.	MeSH descriptor: [Transitional Care] this term only
#88.	MeSH descriptor: [Patient Discharge Summaries] this term only
#89.	((patient* or person* or people or nursing* or clinic*) near (discharg* or handover* or hand* over* or handoff* or hand off* or signout* or sign* out* or signover* or sign* over*)):ti,ab
#90.	((care or caring or serv*) near/2 (continu* or change* or transition* or transfer*)):ti,ab
#91.	(discharg* near/2 (facilitat* or rapid* or pathway* or path way* or plan* or program*)):ti,ab
#92.	(or #82-#90)
#93.	MeSH descriptor: [Advance Care Planning] explode all trees
#94.	(advance* near/2 (plan* or decision* or directive*)):ti,ab
#95.	living will*:ti,ab
#96.	(or #93-#95)
#97.	MeSH descriptor: [Caregivers] this term only
#98.	MeSH descriptor: [Spouses] this term only
#99.	MeSH descriptor: [Family] this term only

#100.	(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
#101.	(or #97-#100)
#102.	((replacement or break* or holiday* or respite) near/3 (care* or service*)):ti,ab
#103.	((communit* or support* or psychosocial* or psycholog*) near/3 (service* or group* or system*)):ti,ab
#104.	((group* or support* or psychosocial* or psycholog*) near/3 (selfhelp or self help or therap*)):ti,ab
#105.	((psychosocial* or psycholog*) near/2 support*):ti,ab
#106.	MeSH descriptor: [Self-Help Groups] this term only
#107.	MeSH descriptor: [Social Support] explode all trees
#108.	MeSH descriptor: [Counseling] this term only
#109.	(counseling or counselling*):ti,ab
#110.	(buddy* or buddies):ti,ab
#111.	(health or medical*) near/3 check*:ti,ab
#112.	(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
#113.	(or #102-#112)
#114.	29 and 101 and 113
#115.	#29 and (#55 or #81 or #92 or #96)
#116.	#31 or #44 or #114 or #115

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 "Continuity of Patient Care")
S21.	TI (advance* or patient*) AND TI (care or caring) AND TI (continu* or plan*)
S22.	AB (advance* or patient*) AND AB (care or caring) AND AB (continu* or plan*)
S23.	MH Attitude to Death
S24.	TI attitude* AND TI (death* or dying)
S25.	AB attitude* AND AB (death* or dying)
S26.	MH Physician-Patient Relations
S27.	(MH "Long Term Care")
S28.	(MH "Health Care Delivery")
S29.	TI end AND TI life OR AB end AND AB life
S30.	TI EOLC OR AB EOLC
S31.	TI (last or final) AND TI (year or month) AND TI life
S32.	AB (last or final) AND AB (year or month) AND AB life
S33.	TI (dying or death) AND TI (patient* or person* or people or care or caring)
S34.	AB (dying or death) AND AB (patient* or person* or people or care or caring)
S35.	(MH "Advance Care Planning")
S36.	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 OR S34 OR S35
S37.	TX service* AND TX (provision* or deliver* or addition* or method* or time* or timing or frequent* or frequenc* or review* or ident* or assess*)
S38.	AB service* AND AB (provision* or deliver* or addition* or method* or time* or timing or frequent* or frequenc* or review* or ident* or assess*)
S39.	S37 OR S38
S40.	TI commission* AND TI ((support* or service* or model*))
S41.	AB commission* AND AB ((support* or service* or model*))
S42.	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*)
S43.	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*)
S44.	TI (critical or clinic* or service* or care) AND TI path*
S45.	AB (critical or clinic* or service* or care) AND AB path*
S46.	TI care AND TI (bundle* or service* or package* or standard*)
S47.	AB care AND AB (bundle* or service* or package* or standard*)
S48.	S40 OR S41 OR S42 OR S43 OR S44 OR S45 OR S46 OR S47
S49.	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*)
S50.	S36 AND S48 AND S49
S51.	TI gold standard* OR AB gold standard*
S52.	S36 AND S51
S53.	TI amber AND TI bundle
S54.	AB amber AND AB bundle
S55.	S53 OR S54
S56.	S48 OR S50 OR S55

S57.	(MH "Multidisciplinary Care Team+")
S58.	MDT OR IDT
S59.	((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*))
S60.	((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*))
S61.	TI (key n2 work*) OR AB (key n2 work*)
S62.	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*)))
S63.	TI (((healthcare or care) n1 profession*)) OR AB (((healthcare or care) n1 profession*))
S64.	MH Case Management
S65.	TI (case n2 manage*) OR AB (case n2 manage*)
S66.	TI ((co-ordinator* or coordinator* or coordinate* or co-ordinate*)*)) OR AB ((co-ordinator* or coordinator* or coordinate* or co-ordinate*))
S67.	S57 OR S58 OR S59 OR S60 OR S61 OR S62 OR S63 OR S64 OR S65 OR S66
S68.	(MM "Social Welfare")
S69.	(MH "Charities")
S70.	(MM "Adult Day Center (Saba CCC)") OR (MM "Housing for the Elderly") OR (MM "Older Adult Care (Saba CCC)")
S71.	(MH "Community Health Nursing+") OR (MM "Community Health Centers")
S72.	(MH "Home Health Care+") OR (MM "Home Health Aides") OR (MM "Home Health Care Information Systems") OR (MM "Home Health Aide Service (Saba CCC)")
S73.	(MM "Housing for the Elderly") OR (MM "Rural Health Centers") OR (MM "Community Health Centers")
S74.	(MH "Telemedicine+") OR (MH "Telehealth+")
S75.	(MM "Remote Consultation") OR (MM "Telephone Consultation (Iowa NIC)") OR (MM "Services for Australian Rural and Remote Allied Health")
S76.	telehealth or tele health or virtual hospital* or helpline* or help line* or rapid response team* or senior center*
S77.	(MM "Rural Health Personnel") OR (MM "Mobile Health Units")
S78.	remote consultation
S79.	((community based or community dwelling home or rural) n3 (care or health care or healthcare))
S80.	hospital-based home care or HBHC or hospital-based hospice care or acute hospital care
S81.	((hospitali?ation* or admission* or readmission* or admit*) n3 (reduc* or avoid* or prevent* or inappropiate or increase* or risk*))
S82.	home based versus hospital based
S83.	(hospital n3 (domicil* or home))
S84.	home hospitali?ation
S85.	home care service*
S86.	(MM "Home Health Agencies") OR (MM "Nursing Home Personnel")
S87.	(MM "Homemaker Services") OR (MM "Health Services for the Aged")
S88.	(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")
S89.	social care
S90.	(MM "Hospitals, Community")
S91.	(MM "Home Nursing") OR (MM "Home Nursing, Professional")
S92.	(nurs* n4 (home-visit* or home visit* or home-based or home based))
S93.	((district* or communit* or home or visit*) n nurs*)
S94.	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 OR S82 OR S83 OR S84 OR S85 OR S86 OR S87 OR S88 OR S89 OR S90 OR S91 OR S92 OR S93
S95.	MH Continuity of Patient Care OR MH Aftercare OR MH Patient discharge OR MH Patient handoff OR MH Patient transfer OR MH Transitional care
S96.	(MM "Discharge Planning") OR (MM "Patient Discharge Summaries")
S97.	TI (((patient* or person* or people or nursing* or clinic*)) AND TX ((discharg* or handover* or hand* over* or handoff* or hand off* or signout* or sign* out* or signover* or sign* over*))
S98.	AB (((patient* or person* or people or nursing* or clinic*)) AND AB ((discharg* or handover* or hand* over* or handoff* or hand off* or signout* or sign* out* or signover* or sign* over*))
S99.	AB ((care or caring or serv*)) AND AB ((continu* or change* or transition* or transfer*))
S100.	TI ((care or caring or serv*)) AND TI ((continu* or change* or transition* or transfer*))
S101.	TI discharg* AND TI (facilitat* or rapid* or pathway* or path way* or plan* or program*))
S102.	AB discharg* AND AB (facilitat* or rapid* or pathway* or path way* or plan* or program*))
S103.	S95 OR S96 OR S97 OR S98 OR S99 OR S100 OR S101 OR S102
S104.	TI advance* AND TI (plan* or decision* or directive*)
S105.	AB advance* AND AB (plan* or decision* or directive*)
S106.	S104 OR S105
S107.	S36 AND (S67 OR S94 OR S103 OR S106)
S108.	S39 OR S56 OR S107

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

1 **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

2 **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 8: 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 – 204 January 2019	Exclusions Health economics studies Health economics modelling

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

1 **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

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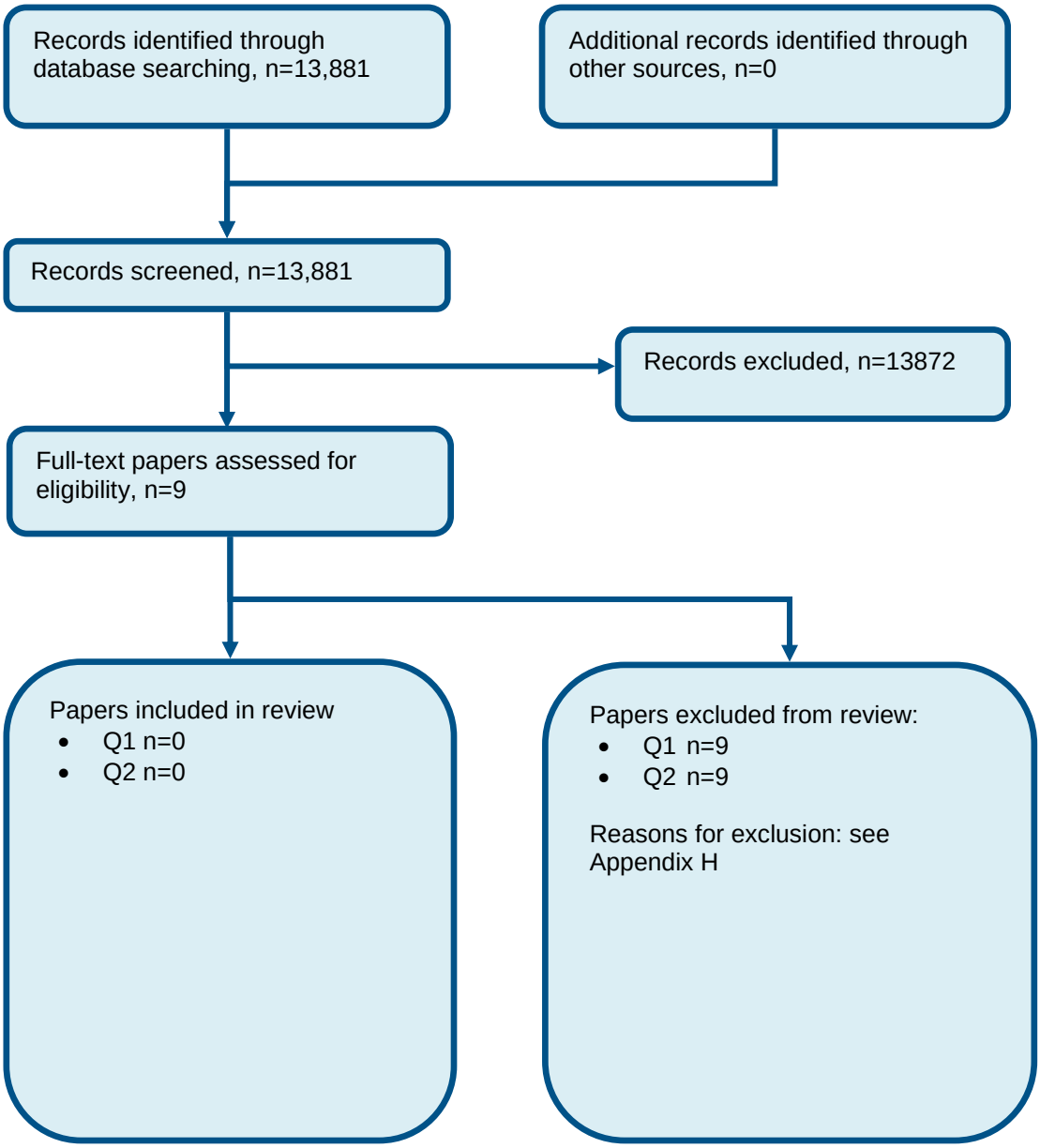
Appendix C: Clinical evidence selection

Figure 1: Flow chart of clinical study selection for the review of review of service provision



Appendix D: Clinical evidence tables

None.

Appendix E: Forest plots

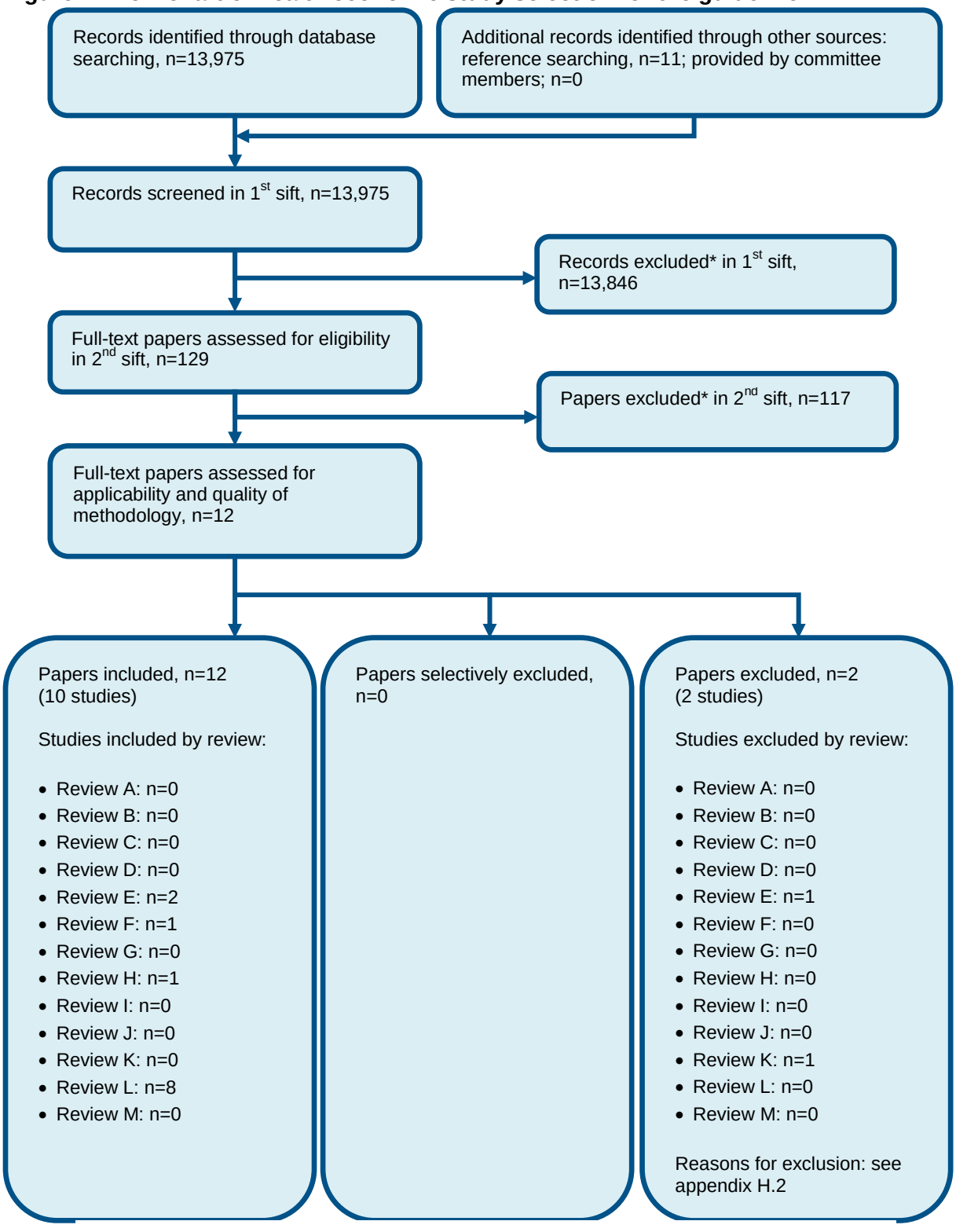
None.

Appendix F: GRADE tables

None.

Appendix G: Health economic evidence selection

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



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

Appendix H: Excluded studies

H.1 Excluded clinical studies

Table 9: Studies excluded from the clinical review

Study	Exclusion reason
Edwards 2013[2]	Inappropriate study design
Hu 2014[3]	Inappropriate study design
Jacob 2010[4]	Not review population. Inappropriate study design
Lam 2017[5]	Inappropriate study design
Miller 2017[6]	Inappropriate comparison
Schenker 2017[8]	Inappropriate study design
White 2002[9]	Inappropriate study design
Wilson 2017[10]	Not review population
Yilmaz 2005[11]	Not review population. Inappropriate study design

H.2 Excluded health economic studies

No economic studies were excluded for this review.

Appendix I: Research recommendations

RR3 What are the benefits of planned regular community-based reviews versus as required review of non-cancer patients in last year of life?

Why this is important

There is little relevant research evidence for the optimum frequency of review of patients with progressive non-cancer conditions who have entered the last year of life. Many of the studies attempted in this area have been conducted in other countries where the healthcare systems are very different from the UK. 'Usual care' for non-cancer conditions tends to provide demand-led review by specialists and primary care staff. This may be appropriate if patients are well supported at home or in care settings, but could lead to unrecognised deterioration in symptoms or functioning; and place people at risk of crises and unplanned hospital admissions if they are living alone and/or with little professional support. A policy of regular planned reviews of patients in their usual place of residence could improve symptom management, maintain better level of functioning, prevent crises and may pre-empt emergency hospital visits and admission; but conversely they could impose unnecessary burdens on the patient, family and the healthcare system. This research would study non-cancer patients receiving usual care (with or without any concurrent specialist level care), and assess their outcomes against different levels of frequency of planned specialist reviews in the community.

PICO question	**What are the benefits of planned regular reviews versus as required review of non-cancer patients in last year of life?** Population: People entering the last year of life with a chronic progressive disease such as COPD, renal failure or dementia. For example in COPD after first respiratory crisis requiring non-invasive ventilation; or in CRF after first course of haemodialysis; or soon after diagnosis with dementia whilst person still has capacity to consent. Intervention(s): A standardised holistic needs assessment tool validated for non-cancer patients, after identification of entering last year of life and repeated at pre-determined points in the disease process. The HNA should be followed by a consultation with a disease-specific specialist and/or a

	specialist palliative care professional. The frequency of HNAs should be set at appropriate rates for different disease groups and reflecting prognostic information, for example, they may need to become more frequent as disease progresses. Comparison: Same populations but not offered HNA or referral to disease-specific specialist and/or SPC at first identification of entering last year of life, being followed up at usual care intervals by usual healthcare professionals. Outcome(s): Benefits of planned regular assessments in terms of (a) identification of health, social care and other needs which require additional specific interventions by current professionals/practitioners or by referral to new staff; (b) improvement in symptom management, functioning and quality of life; (c) avoidance of crises; (d) reduction in unplanned hospital visits and admissions; (e) survival; (f) carer experience. The research could help to identify triggers in disease processes when holistic needs assessment and SPC input are most effective.
Importance to patients or the population	Patients with cancer are already recommended to have holistic needs assessments from diagnosis and at key points in their illness. They are also referred, to varying extents, to SPC teams in hospitals or community during the last year of life. This research would bring new evidence to the larger group of people who in the last year of life, who have non-cancer conditions and often multimorbidity. Because of the potentially large numbers and impact on the NHS, it is important to know how often such patients should be assessed and reviewed by SPC services.
Relevance to NICE guidance	Relevant to future updates of NICE End of Life Care Service Delivery guideline, and NICE guidelines for specific chronic diseases, which have been lacking on evidence for this question.
Relevance to the NHS	Optimisation of NHS-funded community-based services for non-cancer conditions; optimal use of current resources and allocation of future resources; identification of potential future extended role for hospice community-based services; improving education and training of community staff, effective use of resources and enable more effective individual case management.
National priorities	The research could help to deliver the priorities of the NHS programme for improving end of life care for people with all conditions. It could also support existing and future national

	service frameworks for specific diseases.
Current evidence base	Many of the studies carried out in this area have been conducted in other countries where the healthcare systems are very different from the UK. There was also little evidence found for holistic needs assessment and review of non-cancer patients as opposed to those with cancer.
Equality	There is inequality in access to some services for end of life care between people with a cancer diagnosis and those with a non-cancer diagnosis which may result in similar disease progression and symptoms, for example comparing lung cancer and chronic respiratory disease. Many people in the last year of life have physical disabilities and cognitive impairments which restrict their ability to attend hospitals for secondary care review. This research may help people with non-cancer conditions access to DS1500 or other benefits.
Study design	This should be a primary research study with a prospective design, comparing people with have a HNA followed up by specialist level review, and further assessments and reviews, to a matched population who have usual care. The design could be a RCT or carefully controlled case-matched parallel cohort study. Randomisation could be at cluster (for example, GP practice) or individual patient level. Both quantitative and qualitative methodologies could be used, using a nested approach. An in-built feasibility study with clear criteria for progression to a larger RCT or cohort study should be included.
Feasibility	The intervention may carry significant NHS research support costs because of the need for additional assessments and specialist reviews. However the study may point to future NHS savings if unplanned secondary level care is avoided. Ethical constraints include the need to obtain and maintain consent from patients who may have deteriorating mental capacity.
Other comments	As well as NIHR, disease-specific charities such as British Heart Foundation, British Lung Foundation, Motor Neurone Disease Association may be interested to fund a study in their populations.
Importance	High: the research is essential to inform future updates of key recommendations in the guideline.

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