National Institute for Health and Care Excellence

Final

End of life care for adults: service delivery

[I] Evidence review: Information sharing

NICE guideline NG142

Evidence review

October 2019

Final

Developed by the National Guideline Centre, hosted by the Royal College of Physicians

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.

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1 Information sharing

1.1 Review question: What are the best ways to share information within multiprofessional teams, between multiprofessional teams and between multiprofessional teams and services to ensure continuity of care for people who are in their last year of life?

1.2 Introduction

People in the last year of life are likely to be involved in meeting and dealing with a wide range of health and social care professionals in order to meet their needs. This will result in data being held at various organisations and different sectors, thus causing burden for patients and their carers. Errors in duplication of information can occur, but more importantly the lack of access to relevant information such as advance care plans, can cause distress and harm.

Data protection governance is a necessity but it should not be a barrier to sharing data across different organisations. The access to the right information at the right time by the right person can make it much easier to provide high quality care to the patient including following their previously expressed wishes where appropriate. It can also make the experience more positive for their carers and people important to them.

The sharing of information has to be across health, social care and third sector organisations and this presents a major challenge. The development and use of electronic co-ordination systems (such as EPaCCS (Electronic Palliative Care Coordination Systems)) which use a minimum data set to be shared electronically across all organisations caring for the patient is a move towards doing this.

1.3 PICO table

For full details see the review protocol in Appendix A.

Table 1: PICO characteristics of review question

Population	Adults (aged 18 or over) with progressive life-limiting conditions thought to be entering the last year of life.
Interventions	• Models of information sharing within MPTs • Models of information sharing between MPTs • Models of information sharing between MPTs and other services Examples of models of information sharing include: • Proactive follow-up of patients after significant health events, or in people with changing/deteriorating health status • Patient-held information • Advanced care planning documentation • Electronic systems • Discharge forms • Out of hours forms
Comparisons	• To each other • No standardized model of information sharing (usual care)

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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 (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.

1.4 Clinical evidence

Included studies

A search was conducted for randomised trials and non-randomised comparative studies on the effectiveness of models of information sharing within multiprofessional teams, between multiprofessional teams and between multiprofessional teams and services to ensure continuity of care for people in their last year of life.

Two studies were included in the review; [19] [52] these are summarised in Table 2 below. These studies both compared models of information sharing between multiprofessional teams and services. No evidence was found on models of information sharing within multiprofessional teams or between multiprofessional teams.

Evidence from these studies is summarised in the clinical evidence summary below (Table 3). See also the study selection flow chart in Appendix B, forest plots in Appendix D, study evidence tables in Appendix E, GRADE tables in Appendix G and excluded studies list in Appendix H.

Excluded studies

See the excluded studies list in Appendix I.

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Summary of clinical studies included in the evidence review

Table 2: Summary of studies included in the evidence review

Study	Intervention and comparison	Population	Outcomes	Comments
Cornbleet 2002[19]	Model of information sharing between MPTs and services - Patient-held information (paper record). The 'Newcastle record' Usual care (no details)	People with advanced cancer and palliative care needs; people with a diagnosis of cancer aged >18 years, attending an oncology out-patient clinic or receiving hospice home care or day care; prognosis of at least 6 months Follow up 4-6 months N=231 UK	Patient reported outcomes (satisfaction)*	People in whom life-prolonging therapies are still an active option. Maximum life expectancy not stated. Background care not stated. Usual care not described
Latimer 1998[52]	Model of information sharing between MPTs and services - Patient-held information (paper record). Patient Care Travelling Record© (PCTR) Usual care	People accessing palliative care team services; expected prognosis of at least 2 months Follow up 2 months N=46 Canada	Patient reported outcomes (satisfaction – General satisfaction questionnaire)	Maximum life expectancy not stated. Background care not stated

*Satisfaction outcomes: mix of open and closed questions with responses in the form of 5-point Likert scales ranging from very satisfied to very dis-satisfied, or 4-point scales ranging from very well informed to not informed at all.

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Quality assessment of clinical studies included in the evidence review

Table 3: Clinical evidence summary: Model of information sharing between multiprofessional teams and services (Patient-held information – the Newcastle record) versus usual care

Outcomes	No of Participants (studies) Follow up	Quality of the evidence (GRADE)	Relative effect (95% CI)	Anticipated absolute effects	
				Risk with Usual care	Risk difference with Information sharing between MPTs and services (95% CI)
Satisfaction with communication between GP and hospital doctors (GP kept very well informed about illness)	148 (1 study) 4-6 months	⨁⨁⊖⊖ LOW[a] due to risk of bias	RR 0.98 (0.79 to 1.21)	697 per 1000	14 fewer per 1000 (from 146 fewer to 146 more)
Satisfaction with communication between GP and hospital doctors (GP kept very well informed about problems)	143 (1 study) 4-6 months	⨁⨁⊖⊖ LOW[a] due to risk of bias	RR 0.99 (0.81 to 1.22)	716 per 1000	7 fewer per 1000 (from 136 fewer to 158 more)
Satisfaction with communication between GP and hospital doctors (GP kept very well informed about treatment)	139 (1 study) 4-6 months	⨁⊖⊖⊖ VERY LOW[a,b] due to risk of bias, imprecision	RR 1.02 (0.82 to 1.27)	690 per 1000	14 more per 1000 (from 124 fewer to 186 more)
Satisfaction with information exchange between hospital staff (informing each other very well about illness)	144 (1 study) 4-6 months	⨁⊖⊖⊖ VERY LOW[a,b] due to risk of bias, imprecision	RR 0.89 (0.69 to 1.14)	671 per 1000	74 fewer per 1000 (from 208 fewer to 94 more)
Satisfaction with information exchange between hospital staff (informing each other very well about problems)	140 (1 study) 4-6 months	⨁⊖⊖⊖ VERY LOW[a,b] due to risk of bias, imprecision	RR 0.9 (0.7 to 1.14)	687 per 1000	69 fewer per 1000 (from 206 fewer to 96 more)

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Outcomes	No of Participants (studies) Follow up	Quality of the evidence (GRADE)	Relative effect (95% CI)	Anticipated absolute effects	
				Risk with Usual care	Risk difference with Information sharing between MPTs and services (95% CI)
Satisfaction with information exchange between hospital staff (informing each other very well about treatment)	137 (1 study) 4-5 months	⨁⨁⨀⨀ LOW[a] due to risk of bias	RR 0.97 (0.76 to 1.23)	662 per 1000	20 fewer per 1000 (from 159 fewer to 152 more)
Satisfaction with information from GP (very satisfied with information from GP)	173 (1 study) 4-6 months	⨁⨀⨀⨀ VERY LOW[a,b] due to risk of bias, imprecision	RR 1.21 (0.99 to 1.48)	628 per 1000	132 more per 1000 (from 6 fewer to 301 more)
Satisfaction with information from out-patient doctor (very satisfied with information provided)	164 (1 study) 4-6 months	⨁⨀⨀⨀ VERY LOW[a,b] due to risk of bias, imprecision	RR 1.07 (0.89 to 1.28)	721 per 1000	50 more per 1000 (from 79 fewer to 202 more)

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

Table 4: Clinical evidence summary: Model of information sharing between multiprofessional teams and services (Patient-held information – the Patient care travelling record) versus usual care

Outcomes	No of Participants (studies) Follow up	Quality of the evidence (GRADE)	Anticipated absolute effects	
			Risk with Usual care	Risk difference with Information sharing between MPTs and services (95% CI)
Satisfaction at 2 months Scale from: 0 to 5, higher is better.	21 (1 study) 2 months	⨁⨀⨀⨀ VERY LOW[a,b] due to risk of bias, imprecision	The mean satisfaction at 2 months in the control groups was 3.94	The mean satisfaction at 2 months in the intervention groups was 0.31 lower (1.05 lower to 0.43 higher)

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Outcomes	No of Participants (studies) Follow up	Quality of the evidence (GRADE)	Anticipated absolute effects	
			Risk with Usual care	Risk difference with Information sharing between MPTs and services (95% CI)

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

See Appendix F for full GRADE tables.

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1.5 Economic evidence

Included studies

No relevant health economic studies were identified.

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 Resource costs

Recommendations made based on this review (see section **Error! Reference source not found.**) are not expected to have a substantial impact on resources.

1.7 Evidence statements

Clinical evidence statements

Model of information sharing between multiprofessional teams and services (Patient-held information – the Newcastle record) versus usual care

One study compared a model of information sharing between multiprofessional teams and services (patient-held information, the Newcastle record) versus usual care. The evidence showed no clinically important difference in patients' satisfaction with communication between GP and hospital doctors (about illness, problems and treatment), with information exchange between hospital staff (about illness, problems and treatment) and with information from out-patient doctors (range from n=137-164; low to very low quality). There was evidence of clinically important benefit of information sharing for patients' satisfaction with information from their GP (n=173; very low quality).

Model of information sharing between multiprofessional teams and services (Patient-held information – the Patient care travelling record) versus usual care

One study compared a model of information sharing between multiprofessional teams and services (patient-held information, the Patient care travelling record) versus usual care. There was no evidence of clinically important difference in patients' satisfaction between the two groups (n=21; very low quality).

Health economic evidence statements

- No relevant economic evaluations were identified.

1.8 The committee's discussion of the evidence

Interpreting the evidence

The outcomes that matter most

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

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

No evidence was found on models of information sharing within multiprofessional teams or between multiprofessional teams.

There was no evidence relative to the critical outcomes of quality of life, preferred and actual place of care and death.

For the important outcomes, two studies reported patients' satisfaction. There was no evidence on any of the other important outcomes of length of survival, length of 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 satisfaction.

The quality of the evidence

The quality of the evidence ranged from very low to low. This was due to selection and performance bias, resulting in a high risk of bias rating, and imprecision.. The committee commented on the methodological issue of measuring satisfaction in end of life care, which can prove challenging as people are often either very dissatisfied or very satisfied this might polarise results. The measurement of satisfaction is further complicated by the fact that often papers do not report whether the care people received matched their expectations.

For both studies included in the review, the components of usual care were not described in detail and it was difficult to understand how the intervention was different. The maximum life expectancy of participants was also not stated, however, the Committee agreed that based on the characteristics reported in the studies, the population met the protocol criteria for inclusion in both cases.

The Committee noted that one of the studies included a population of people in whom life-prolonging therapies are still an active option and took this into consideration when assessing the evidence.

Benefits and harms

The Committee noted the evidence was limited, of low quality and only included patient satisfaction outcomes. They observed there was no clinically important difference in satisfaction between the groups where care included a standardised method to share information between MDT and services.

The Committee also noted that both studies examined paper record and notes as models of information sharing. The Committee acknowledged that these type of information sharing records were popular some years ago, but their use has been increasingly reduced since the introduction of IT-based systems (for example, EPaCCS and CANISC). The Committee discussed the variation in the implementation of digital systems across the UK and that these systems are not yet mandatory.

The Committee agreed they were not confident in making an evidence-based recommendation on what system to use. However, a consensus based recommendation on information sharing between organisations and services for people in the last year of life would be important, as this is fundamental to providing well-coordinated care and likely to

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improve care and health outcomes. The Committee agreed that commissioners and local planners of services should consider having a standardised information sharing system that can be accessed by the health and social care professional involved in the care of the person in their last year of life.

The Committee agreed the system should be digital, examples are EPaCCS or CANISC, which are currently used in some areas of England and Wales. Electronic information sharing has the benefit of being easily accessible to more than one user at a time and in different locations. Records can also be updated easily an the most up to date information is then easily communicated. The Committee also emphasised the importance of patients' consent to information sharing and access to the information shared on the system.

While the Committee could not recommend what information should be recorded they agreed that it was important to make a consensus recommendation that once people are identified as being in the last year of life they should be added to an end of life care register and this information shared with other health and social care professionals involved in their care. This documentation is fundamental to ensuring people in the last year of life and their carers begin to receive appropriate support (see review on identification). In order to facilitate this, the Committee recommended a process should be in place to ensure this happens.

Cost effectiveness and resource use

No relevant economic evaluations were identified to determine the cost effectiveness of different methods of information sharing.

The committee discussed different methods and concluded that low cost methods of information sharing, such as patient held records, would be likely to reduce costs by reducing the duplication of tasks by numerous health care professionals without the need for significant upfront investment but that other more electronic methods of information sharing (such as EPaCCS) would require upfront investment in IT infrastructure and training to ensure all health care providers are able to easily access the electronic forms, however the committee thought that they would also be likely to reduce costs in the long term; although there is currently no evidence to support this.

The committee agreed that good information sharing between healthcare professionals and healthcare settings contributes towards delivering well-coordinated high quality care and reduces duplications of tasks which is currently very common. For this reason the committee recommended that commissioners, local planners and co-ordinators of health services consider having local standardised electronic information sharing systems.

Other factors the committee took into account

The Health and Social Care (Safety and Quality) Act 2015[43] introduces a new legal duty requiring health and adult social care bodies to share information where this will facilitate care for an individual. This guidance note explains what this new legislation requires and provides a clear message that subject to the preferences of the individuals concerned, sharing for the care of individuals is a requirement, not an option.

The Committee noted it would be desirable for a system to be in place where the care plan sits with the patient (and can be accessed/updated electronically by the patient), but this is not currently achieved in clinical practice.

It was also noted that a limitation of implementing EPaCCS is that they are large datasets which can be off-putting for some health care staff.

The Committee was aware of the ReSPECT (Recommended summary Plan for Emergency Care and Treatment) form (recently released in March 2017), a paper based and patient-held tool providing joint information on DNACPR and ACP for people at the end of life.

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Appendices

Appendix A: Review protocols

Table 5: Review protocol for what are the best ways to share information within multiprofessional teams, between multi-profesional teams and between multiprofessional teams and services to ensure continuity of care for people who are in their last year of life?

Question number: Q8

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

[First, fourth and fifth columns to be deleted in versions for public consultation and publication, with column 3 widened to fill page. Field names are based on PRISMA-P.]

ID	Field	Content
I	Review question	What are the best ways to share information within multiprofessional teams, between multiprofessional teams and between multiprofessional teams and services to ensure continuity of care for people who are 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 ways to share information within multiprofessional teams, between multiprofessional teams and between multiprofessional teams and services to ensure continuity of care for people who are in their last year of life
IV	Eligibility criteria – population / disease / condition / issue / domain	Adults (aged 18 or over) with progressive life-limiting conditions thought to be entering the last year of life.
V	Eligibility criteria – intervention(s) / exposure(s) / prognostic factor(s)	• Information sharing within MDTs • Information sharing between MDTs • Information sharing between MDTs and services
VI	Eligibility criteria – comparator(s) / control or reference (gold) standard	• Model of information sharing within MDTs • To each other • No standardized model of information sharing (usual care) • Model of information sharing between MDTs • To each other • No standardized model of information sharing (usual care)

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		• Model of information sharing between MDTs and other services • To each other • No standardized model of information sharing (usual care) Examples of models of information sharing include: • Proactive follow-up of patients after significant health events, or in people with changing/deteriorating health status • Patient-held information • Advanced care planning documentation • Electronic systems • Discharge forms • Out of hours forms
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 (Continuous) • 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

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		• 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	• Quality assurance will be undertaken by a senior research fellow prior to completion. • Review strategy/other analysis: • Information on identification tools used as part of a service will be extracted. • Due to the expected complexity of the service models implemented in the studies, studies will be reported separately if necessary. In such case, studies on the populations included in the subgroup list will be highlighted to the Committee and will be considered when making the recommendations
XII	Data management (software)	• Pairwise meta-analyses were performed using Cochrane Review Manager (RevMan5). • GRADEpro was used to assess the quality of evidence for each outcome. • Endnote was used for: ○ Bibliography, citations, sifting and reference management • Evibase was used for • Data extraction and quality assessment / critical appraisal
XIII	Information sources – databases and dates	Clinical search databases to be used: Medline, Embase, Cochrane Library, Current Nursing and Allied Health Literature (CINAHL), PsycINFO, Healthcare Management Information Consortium (HMIC), Social Policy and Practice (SSP), Applied Social Sciences Index and Abstracts (ASSIA) Date: All years Health economics search databases to be used: Medline, Embase, NHSEED, HTA Date: Medline, Embase from 2014 NHSEED, HTA – All years Language: Restrict to English only A call for evidence was also conducted.
XIV	Identify if an update	Not applicable
XV	Author contacts	https://www.nice.org.uk/guidance/indevelopment/gid-cgwave0799

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XVI	Highlight if amendment to previous protocol	For details please see section 4.5 of Developing NICE guidelines: the manual.
XVII	Search strategy – for one database	For details please see Appendix B
XVIII	Data collection process – forms / duplicate	A standardised evidence table format will be used, and published as Appendix D of the evidence report.
XIX	Data items – define all variables to be collected	For details please see evidence tables in Appendix D (clinical evidence tables) or G (health economic evidence tables).
XX	Methods for assessing bias at outcome / study level	Standard study checklists were used to critically appraise individual studies. For details please see section 6.2 of Developing NICE guidelines: the manual The risk of bias across all available evidence was evaluated for each outcome using an adaptation of the 'Grading of Recommendations Assessment, Development and Evaluation (GRADE) toolbox' developed by the international GRADE working group http://www.gradeworkinggroup.org/ [Please document any deviations/alternative approach when GRADE isn't used or if a modified GRADE approach has been used for non-intervention or non-comparative studies.]
XXI	Criteria for quantitative synthesis	For details please see section 6.4 of Developing NICE guidelines: the manual.
XXII	Methods for quantitative analysis – combining studies and exploring (in)consistency	For details please see the separate Methods report for this guideline.
XXIII	Meta-bias assessment – publication bias, selective reporting bias	For details please see section 6.2 of Developing NICE guidelines: the manual. [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.

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XXX	PROSPERO registration number	Not registered

Table 6: Health economic review protocol

Review question	All questions – health economic evidence
Objectives	To identify health economic studies relevant to any of the review questions.
Search criteria	• Populations, interventions and comparators must be as specified in the clinical review protocol above. • Studies must be of a relevant health economic study design (cost–utility analysis, cost-effectiveness analysis, cost–benefit analysis, cost–consequences analysis, comparative cost analysis). • Studies must not be a letter, editorial or commentary, or a review of health economic evaluations. (Recent reviews will be ordered although not reviewed. The bibliographies will be checked for relevant studies, which will then be ordered.) • Unpublished reports will not be considered unless submitted as part of a call for evidence. • Studies must be in English.
Search strategy	A health economic study search will be undertaken using population-specific terms and a health economic study filter – see Appendix G
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).[72] **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:*

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	• 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	None

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Database	Dates searched	Search filter used
	CENTRAL to Issue 1 of 12, January 2019 DARE, and NHSEED to Issue 2 of 4 2015 HTA to Issue 4 of 4 2016	
CINAHL, Current Nursing and Allied Health Literature (EBSCO)	Inception – 04 January 2019	Limiters - English Language; Exclude MEDLINE records; Publication Type: Clinical Trial, Journal Article, Meta Analysis, Randomized Controlled Trial, Systematic Review: Age Groups: All Adult; Language: English
PsycINFO (ProQuest)	Inception – 04 January 2019	Study type
HMIC. Healthcare Management Information Consortium (Ovid)	1979 – 04 January 2019	Exclusions
SPP, Social Policy and Practice	1981 – 04 January 2019	Study types
ASSIA, Applied Social Sciences Index and Abstracts (ProQuest)	1987 – 04 January 2019	None

Medline (Ovid) search terms

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

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

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	round* or panel* or forum* or fora or communicat* or collaborat* or relat*)) or MDT or IDT).ti,ab.
54.	((interdisciplinary or multidisciplinary or combin* or inter disciplinary or multi disciplinary or interprofessional or multiprofessional or inter professional or multi professional) adj2 (work* or team* or care or ward#)).ti,ab.
55.	(key adj2 work*).ti,ab.
56.	((healthcare or care) adj2 (lead or leader or leads or facilitat*)).ti,ab.
57.	((healthcare or care) adj1 profession*).ti,ab.
58.	*Case Management/
59.	(case adj2 manage*).ti,ab.
60.	(co-ordinator* or coordinator* or coordinate* or co-ordinate*).ti,ab.
61.	Or/51-60
62.	interdisciplinary communication/
63.	exp Communication Barriers/
64.	(communicat* or discuss* or speak* or talk* or convers* or contact).ti,ab.
65.	((handover or hand over or share or shared or sharing or transfer*) adj3 information*).ti,ab.
66.	(followup or follow up).ti,ab.
67.	(palliativ* adj2 (care or caring)).ti,ab.
68.	Or/62-67
69.	49 and 61 and 68
70.	Social Welfare/ec, ed, es, eh, ma, st, sn, td [Economics, Education, Ethics, Ethnology, Manpower, Standards, Statistics & Numerical Data, Trends]
71.	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]
72.	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]
73.	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]
74.	Telemedicine/ec, es, ma, mt, og, st, sn, td, ut [Economics, Ethics, Manpower, Methods, Organization & Administration, Standards, Statistics & Numerical Data, Trends, Utilization]
75.	exp remote consultation/
76.	*telemedicine/ or *telepathology/ or *teleradiology/ or *telerehabilitation/
77.	(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.
78.	((tele* or remote) adj2 consult*).ti,ab.
79.	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]
80.	(mobile adj2 (health or care) adj2 unit*).ti,ab.
81.	(hospital-based home care or HBHC or hospital-based hospice care or acute hospital care).ti,ab.
82.	(hospital adj3 (domicil* or home)).ti,ab.
83.	home hospitali*ation.ti,ab.
84.	exp Home Care Agencies/

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85.	(social adj (welfare or care)).ti,ab.
86.	(nurs* adj4 (home-visit* or home visit* or home-based or home based)).ti,ab.
87.	((district* or communit* or home or visit*) adj nurs*).ti,ab.
88.	(community adj2 (health care or healthcare or nursing or nurse*)).ti,ab.
89.	((hospitali*ation* or admission* or readmission* or admit*) adj3 (reduc* or avoid* or prevent* or inappropiate or increase* or risk*)).ti,ab.
90.	Or/70-89
91.	*"Continuity of Patient Care"/
92.	*Aftercare/ or *Patient discharge/ or *Patient handoff/ or *Patient transfer/ or *Transitional care/
93.	Patient Discharge Summaries/
94.	((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.
95.	((care or caring or serv*) adj2 (continu* or change* or transition* or transfer*)).ti,ab.
96.	(discharg* adj2 (facilitat* or rapid* or pathway* or path way* or plan* or program*)).ti,ab.
97.	Or/91-96
98.	After-Hours Care/
99.	((morning* or evening* or weekday or weekend* or 7 day or seven day or seven-day or after-hour* or 24 hour* or 24hour* or twenty-four-hour* or out-of-hour* or 9-5 or Monday-Friday or Saturday or Sunday) adj3 (service* or access* or availab* or hour* or appointment* or care or caring or palliativ* or pharmacy* or telephone* or advic* or advis* or consult* or support* or nurs* or speciali* or physician* or doctor* or expert* or professional* or paramedic* or general practioner* or GP* or social worker* or case worker* or ambulance* or health worker* or physiotherapist* or therapist*)).ti,ab.
100.	rapid response.ti,ab.
101.	Hospital Rapid Response Team/
102.	(critical care adj2 outreach).ti,ab.
103.	medical emergency team*.ti,ab.
104.	(hospital* adj2 home*).ti,ab.
105.	hospital at night.ti,ab.
106.	("NHS 111" or "NHS 24" or "NHS Direct").ti,ab.
107.	exp telemedicine/
108.	(telehealth* or tele-health* or telemedicine* or tele-medicine* or teleconsult* or tele-consult* or tele-monitor* or telemonitor* or telemanag* or tele-manag* or telepharm* or tele-pharm* or telenurs* or tele-nurs* or tele-homecare or telehomecare or tele-support or telesupport or mobile health or ehealth or e-health or mhealth or m-health).ti,ab.
109.	hotlines/
110.	(hotline* or helpline* or help-line* or call cent* or call service*).ti,ab.
111.	((email* or e-mail* or telephone* or phone* or video*) adj3 (servic* or advic* or advis* or consult* or support* or care* or caring* or appoint*)).ti,ab.
112.	Or/98-111
113.	Caregivers/
114.	Spouses/
115.	Family/
116.	(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

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	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.
117.	Or/113-116
118.	((replacement or break* or holiday* or respite) adj3 (care* or service*)).ti,ab.
119.	((communit* or support* or psychosocial* or psycholog*) adj3 (service* or group* or system*)).ti,ab.
120.	((group* or support* or psychosocial* or psycholog*) adj3 (selfhelp or self help or therap*)).ti,ab.
121.	((psychosocial* or psycholog*) adj2 support*).ti,ab.
122.	Self-Help Groups/
123.	exp social support/
124.	Counseling/
125.	(counseling or counselling*).ti,ab.
126.	(buddy* or buddies).ti,ab.
127.	((health* or medical*) adj2 check*).ti,ab.
128.	((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.
129.	or/118-127
130.	49 and 117 and 129
131.	(commission* adj2 (support* or service* or model*)).ti,ab.
132.	((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.
133.	Critical Pathways/
134.	((critical or clinic* or service* or care) adj2 path*).ti,ab.
135.	Patient Care Bundles/
136.	(care adj2 (bundle* or service* or package* or standard*)).ti,ab.
137.	or/131-136
138.	(assess* or criteria* or predict* or recogni* or identif* or refer*).ti,ab.
139.	49 and 137 and 138
140.	gold standard*.ti,ab.
141.	49 and 140
142.	(amber adj2 bundle).ti,ab.
143.	139 or 141 or 142
144.	"referral and consultation"/
145.	(referral* or referred or referring or refer or refers or consult*).ti,ab.
146.	(recommend* or direct*).ti,ab.
147.	Or/144-146
148.	49 and (90 or 97 or 112 or 147)
149.	69 or 130 or 143 or 148

Embase (Ovid) search terms

1.	*Palliative therapy/
2.	*Terminal care/

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3.	*Hospice care/
4.	palliat*.ti,ab.
5.	*Terminally ill patient/
6.	((terminal* or long term or longterm) adj2 (care* or caring or ill*)).ti,ab.
7.	((dying or terminal) adj (phase* or stage*)).ti,ab.
8.	life limit*.ti,ab.
9.	*Nursing home/
10.	((care or nursing) adj2 (home or homes)).ti,ab.
11.	*Respite Care/
12.	((respite or day) adj2 (care or caring)).ti,ab.
13.	*Hospice/
14.	hospice*.ti,ab.
15.	*Patient care planning/
16.	((advance* or patient*) adj3 (care or caring) adj3 (continu* or plan*)).ti,ab.
17.	*Patient care/
18.	*Attitude to Death/
19.	(attitude* adj3 (death* or dying*)).ti,ab.
20.	*Doctor patient relation/
21.	*Long term care/
22.	*Health care delivery/
23.	(end adj2 life).ti,ab.
24.	EOLC.ti,ab.
25.	((last or final) adj2 (year or month*) adj2 life).ti,ab.
26.	((dying or death) adj2 (patient* or person* or people or care or caring)).ti,ab.
27.	or/1-26
28.	letter.pt. or letter/
29.	note.pt.
30.	editorial.pt.
31.	case report/ or case study/
32.	(letter or comment*).ti.
33.	or/28-32
34.	randomized controlled trial/ or random*.ti,ab.
35.	33 not 34
36.	animal/ not human/
37.	nonhuman/
38.	exp Animal Experiment/
39.	exp Experimental Animal/
40.	animal model/
41.	exp Rodent/
42.	(rat or rats or mouse or mice).ti.
43.	or/35-42
44.	27 not 43
45.	(exp child/ or exp pediatrics/ or exp infant/) not (exp adolescent/ or exp adult/ or exp middle age/ or exp aged/)
46.	44 not 45

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47.	limit 46 to English language
48.	interdisciplinary communication/
49.	patient care team*.ti,ab.
50.	(((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.
51.	(((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.
52.	(key adj2 work*).ti,ab.
53.	((healthcare or care) adj2 (lead or leader or leads or facilitat*)).ti,ab.
54.	((healthcare or care) adj1 profession*).ti,ab.
55.	*Case Management/
56.	(case adj2 manage*).ti,ab.
57.	(co-ordinator* or coordinator* or coordinate* or co-ordinate*).ti,ab.
58.	(palliativ* adj2 (care or caring)).ti,ab.
59.	Or/49-58
60.	interdisciplinary communication/
61.	(communicat* or discuss* or speak* or talk* or convers* or contact).ti,ab.
62.	((handover or hand over or share or shared or sharing or transfer*) adj3 information*).ti,ab.
63.	(followup or follow up).ti,ab.
64.	Or/60-63
65.	47 and 59 and 64
66.	*Caregiver/
67.	*Spouse/
68.	*Family/
69.	(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.
70.	Or/66-69
71.	((replacement or break* or holiday* or respite) adj3 (care* or service*)).ti,ab.
72.	((communit* or support* or psychosocial* or psycholog*) adj3 (service* or group* or system*)).ti,ab.
73.	((group* or support* or psychosocial* or psycholog*) adj3 (selfhelp or self help or therap*)).ti,ab.
74.	((psychosocial* or psycholog*) adj2 support*).ti,ab.
75.	*Self-Help/
76.	*Social support/
77.	*Counseling/
78.	(counseling or counselling*).ti,ab.
79.	(buddy* or buddies).ti,ab.
80.	((health* or medical*) adj2 check*).ti,ab.

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81.	((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.
82.	or/71-81
83.	47 and 70 and 82
84.	*social welfare/
85.	*community health nursing/ or *community care/
86.	*senior center/
87.	*telemedicine/ or *telehealth/
88.	*teleconsultation/
89.	(telehealth or tele health or virtual hospital* or helpline* or help line* or rapid response team* or mobile health unit*).ti,ab.
90.	*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/
91.	*health care personnel/ or *health auxiliary/ or *nursing home personnel/
92.	(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.
93.	((tele* or remote) adj2 consult*).ti,ab.
94.	(mobile adj2 (health or care) adj2 unit*).ti,ab.
95.	(hospital-based home care or HBHC or hospital-based hospice care or acute hospital care).ti,ab.
96.	(hospital adj3 (domicil* or home)).ti,ab.
97.	home hospitali*ation.ti,ab.
98.	(social adj (welfare or care)).ti,ab.
99.	(nurs* adj4 (home-visit* or home visit* or home-based or home based)).ti,ab.
100.	((district* or communit* or home or visit*) adj nurs*).ti,ab.
101.	(community adj2 (health care or healthcare or nursing or nurse*)).ti,ab.
102.	((hospitali*ation* or admission* or readmission* or admit*) adj3 (reduc* or avoid* or prevent* or inappropiate or increase* or risk*)).ti,ab.
103.	Or/84-102
104.	*patient care/ or *case management/ or *patient care planning/ or *rapid response team/
105.	*aftercare/
106.	*hospital discharge/
107.	*clinical handover/
108.	*transitional care/
109.	*patient care planning/
110.	*medical record/
111.	((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.
112.	((care or caring or serv*) adj2 (continu* or change* or transition* or transfer*)).ti,ab.
113.	(discharg* adj2 (facilitat* or rapid* or pathway* or path way* or plan* or program*)).ti,ab.

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114.	Or/104-113
115.	(after hours care or after-hours care).ti,ab.
116.	((morning* or evening* or weekday or weekend* or 7 day or seven day or seven-day or after-hour* or 24 hour* or 24hour* or twenty-four-hour* or out-of-hour* or 9-5 or Monday-Friday or Saturday or Sunday) adj3 (service* or access* or availab* or hour* or appointment* or care or caring or palliativ* or pharmacy* or telephone* or advic* or advis* or consult* or support* or nurs* or speciali* or physician* or doctor* or expert* or professional* or paramedic* or general practioner* or GP* or social worker* or case worker* or ambulance* or health worker* or physiotherapist* or therapist*)).ti,ab.
117.	rapid response.ti,ab.
118.	rapid response team/
119.	(critical care adj2 outreach).ti,ab.
120.	medical emergency team*.ti,ab.
121.	(hospital* adj2 home*).ti,ab.
122.	hospital at night.ti,ab.
123.	("NHS 111" or "NHS 24" or "NHS Direct").ti,ab.
124.	exp telehealth/
125.	(telehealth* or tele-health* or telemedicine* or tele-medicine* or teleconsult* or tele-consult* or tele-monitor* or telemonitor* or telemanag* or tele-manag* or telepharm* or tele-pharm* or telenurs* or tele-nurs* or tele-homecare or telehomecare or tele-support or telesupport or mobile health or ehealth or e-health or mhealth or m-health).ti,ab.
126.	telephone/
127.	(hotline* or helpline* or help-line* or call cent* or call service*).ti,ab.
128.	((email* or e-mail* or telephone* or phone* or video*) adj3 (servic* or advic* or advis* or consult* or support* or care* or caring* or appoint*)).ti,ab.
129.	or/115-128
130.	(commission* adj2 (support* or service* or model*)).ti,ab.
131.	((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.
132.	*Clinical Pathway/
133.	((critical or clinic* or service* or care) adj2 path*).ti,ab.
134.	*Care Bundle/
135.	(care adj2 (bundle* or service* or package* or standard*)).ti,ab.
136.	or/130-135
137.	(assess* or criteria* or predict* or recogni* or identif* or refer*).ti,ab.
138.	47 and 136 and 137
139.	gold standard*.ti,ab.
140.	47 and 139
141.	(amber adj2 bundle).ti,ab.
142.	138 or 140 or 141
143.	exp patient referral/
144.	(referral* or referred or referring or refer or refers or consult*).ti,ab.
145.	(recommend* or direct*).ti,ab.
146.	Or/143-145
147.	47 and (103 or 114 or 129 or 146)
148.	65 or 93 or 142 or 147

Cochrane Library (Wiley) search terms

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#1.	MeSH descriptor: [Palliative Care] this term only
#2.	MeSH descriptor: [Terminal Care] this term only
#3.	MeSH descriptor: [Hospice Care] this term only
#4.	palliat*:ti,ab
#5.	MeSH descriptor: [Terminally Ill] this term only
#6.	((terminal* or long term or longterm) near/2 (care* or caring or ill*)):ti,ab
#7.	((dying or terminal) near (phase* or stage*)):ti,ab
#8.	life limit*:ti,ab
#9.	MeSH descriptor: [Nursing Homes] explode all trees
#10.	((care or nursing) near/2 (home or homes)):ti,ab
#11.	MeSH descriptor: [Respite Care] this term only
#12.	((respite or day) near/2 (care or caring)):ti,ab
#13.	MeSH descriptor: [Hospices] this term only
#14.	hospice*:ti,ab
#15.	MeSH descriptor: [Patient Care Planning] this term only
#16.	MeSH descriptor: [Continuity of Patient Care] this term only
#17.	((advance* or patient*) near/3 (care or caring) near/3 (continu* or plan*)):ti,ab
#18.	MeSH descriptor: [Attitude to Death] explode all trees
#19.	(attitude* near/3 (death* or dying*)):ti,ab
#20.	MeSH descriptor: [Physician-Patient Relations] this term only
#21.	MeSH descriptor: [Long-Term Care] this term only
#22.	MeSH descriptor: [Delivery of Health Care] this term only
#23.	(end near/2 life):ti,ab
#24.	EOLC:ti,ab
#25.	((last or final) near/2 (year or month*) near/2 life):ti,ab
#26.	((dying or death) near/2 (patient* or person* or people or care or caring)):ti,ab
#27.	(or #1-#26)
#28.	MeSH descriptor: [Patient Care Team] explode all trees
#29.	MeSH descriptor: [Interdisciplinary Communication] explode all trees
#30.	(((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
#31.	((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
#32.	(key near/2 work*):ti,ab
#33.	((healthcare or care) near/2 (lead or leader or leads or facilitat*)):ti,ab
#34.	((healthcare or care) near/1 profession*):ti,ab
#35.	MeSH descriptor: [Case Management] this term only
#36.	(case near/2 manage*):ti,ab
#37.	(co-ordinator* or coordinator* or coordinate* or co-ordinate*):ti,ab
#38.	palliativ* near/2 (care or caring)):ti,ab
#39.	(or #28-#38)
#40.	MeSH descriptor: [Interdisciplinary Communication] explode all trees

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#41.	MeSH descriptor: [Communication Barriers] explode all trees
#42.	(communicat* or discuss* or speak* or talk* or convers* or contact):ti,ab
#43.	((handover or hand over or share or shared or sharing or transfer*) near/3 information*):ti,ab
#44.	(followup or follow up):ti,ab
#45.	(or #40-44)
#46.	#27 and #39 and #45
#47.	MeSH descriptor: [Caregivers] this term only
#48.	MeSH descriptor: [Spouses] this term only
#49.	MeSH descriptor: [Family] this term only
#50.	(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
#51.	(or #47-50)
#52.	((replacement or break* or holiday* or respite) near/3 (care* or service*)):ti,ab
#53.	((communit* or support* or psychosocial* or psycholog*) near/3 (service* or group* or system*)):ti,ab
#54.	((group* or support* or psychosocial* or psycholog*) near/3 (selfhelp or self help or therap*)):ti,ab
#55.	((psychosocial* or psycholog*) near/2 support*):ti,ab
#56.	MeSH descriptor: [Self-Help Groups] this term only
#57.	MeSH descriptor: [Social Support] explode all trees
#58.	MeSH descriptor: [Counseling] this term only
#59.	(counseling or counselling*):ti,ab
#60.	(buddy* or buddies):ti,ab
#61.	(health or medical*) near/3 check*:ti,ab
#62.	(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
#63.	(or #52-#62)
#64.	#27 and #51 and #63
#65.	MeSH descriptor: [Social Welfare] explode all trees
#66.	MeSH descriptor: [Charities] explode all trees
#67.	MeSH descriptor: [Adult Day Care Centers] explode all trees
#68.	MeSH descriptor: [Community Health Nursing] explode all trees
#69.	MeSH descriptor: [Home Care Services] explode all trees
#70.	MeSH descriptor: [Senior Centers] explode all trees
#71.	MeSH descriptor: [Telemedicine] this term only
#72.	MeSH descriptor: [Remote Consultation] explode all trees
#73.	(telehealth or tele health or virtual hospital* or helpline* or help line* or rapid response team*):ti,ab
#74.	MeSH descriptor: [Mobile Health Units] explode all trees

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#75.	((community based or community dwelling home or rural) near/3 (care or health care or healthcare)):ti,ab
#76.	(hospital-based home care or HBHC or hospital-based hospice care or acute hospital care):ti,ab
#77.	((hospitali*ation* or admission* or readmission* or admit*) near/3 (reduc* or avoid* or prevent* or inappropiate or increase* or risk*)):ti,ab
#78.	(home based versus hospital based):ti,ab
#79.	(hospital near/3 (domicil* or home)):ti,ab
#80.	(home hospitali*ation):ti,ab
#81.	MeSH descriptor: [Home Care Services, Hospital-Based] explode all trees
#82.	MeSH descriptor: [Home Health Nursing] explode all trees
#83.	MeSH descriptor: [Homemaker Services] explode all trees
#84.	MeSH descriptor: [Home Care Agencies] explode all trees
#85.	MeSH descriptor: [Home Health Aides] explode all trees
#86.	(social care):ti,ab
#87.	MeSH descriptor: [Nurses, Community Health] explode all trees
#88.	(nurs* near/4 (home-visit* or home visit* or home-based or home based)):ti,ab
#89.	((district* or communit* or home or visit*) near nurs*):ti,ab
#90.	(Or #65-#89)
#91.	MeSH descriptor: [Continuity of Patient Care] this term only
#92.	MeSH descriptor: [Aftercare] this term only
#93.	MeSH descriptor: [Patient Discharge] this term only
#94.	MeSH descriptor: [Patient Handoff] this term only
#95.	MeSH descriptor: [Patient Transfer] this term only
#96.	MeSH descriptor: [Transitional Care] this term only
#97.	MeSH descriptor: [Patient Discharge Summaries] this term only
#98.	((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
#99.	((care or caring or serv*) near/2 (continu* or change* or transition* or transfer*)):ti,ab
#100.	(discharg* near/2 (facilitat* or rapid* or pathway* or path way* or plan* or program*)):ti,ab
#101.	(or #91-#100)
#102.	MeSH descriptor: [After-Hours Care] explode all trees
#103.	((morning* or evening* or weekday or weekend* or 7 day or seven day or seven-day or after-hour* or 24 hour* or 24hour* or twenty-four-hour* or out-of-hour* or 9-5 or Monday-Friday or Saturday or Sunday) near/3 (service* or access* or availab* or hour* or appointment* or care or caring or palliativ* or pharmacy* or telephone* or advic* or advis* or consult* or support* or nurs* or speciali* or physician* or doctor* or expert* or professional* or paramedic* or general practioner* or GP* or social worker* or case worker* or ambulance* or health worker* or physiotherapist* or therapist*)):ti,ab
#104.	rapid next response:ti,ab
#105.	MeSH descriptor: [Hospital Rapid Response Team] explode all trees
#106.	medical next emergency next team*:ti,ab
#107.	(hospital* near/2 home*):ti,ab
#108.	hospital next at next night:ti,ab
#109.	(NHS next (111 or 24 or direct)):ti,ab
#110.	MeSH descriptor: [Telemedicine] this term only

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#111.	(telehealth* or tele-health* or telemedicine* or tele-medicine* or teleconsult* or tele-consult* or tele-monitor* or telemonitor* or telemanag* or tele-manag* or telepharm* or tele-pharm* or telenurs* or tele-nurs* or tele-homecare or telehomecare or tele-support or telesupport or mobile health or ehealth or e-health or mhealth or m-health):ti,ab
#112.	MeSH descriptor: [Hotlines] explode all trees
#113.	(hotline* or helpline* or help-line* or call cent* or call service*):ti,ab
#114.	((email* or e-mail* or telephone* or phone* or video*) near/3 (servic* or advic* or advis* or consult* or support* or care* or caring* or appoint*)):ti,ab
#115.	(or #102-#114)
#116.	(commission* near/2 (support* or service* or model*)):ti,ab
#117.	((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
#118.	MeSH descriptor: [Critical Pathways] explode all trees
#119.	((critical or clinic* or service* or care) near/2 path*):ti,ab
#120.	MeSH descriptor: [Patient Care Bundles] explode all trees
#121.	(care near/2 (bundle* or service* or package* or standard*)):ti,ab
#122.	(or #116-#121)
#123.	(assess* or criteria* or predict* or recogni* or identif* or refer*):ti,ab
#124.	#27 and #122 and #123
#125.	gold standard*:ti,ab
#126.	#27 and #125
#127.	(amber near/2 bundle):ti,ab
#128.	MeSH descriptor: [Referral and Consultation] explode all trees
#129.	#124 or #126 or #127
#130.	(referral* or referred or referring or refer or refers or consult*):ti,ab
#131.	(recommend* or direct*):ti,ab
#132.	(or #128-#131)
#133.	#27 and (#90 or #101 or #115 or #132)
#134.	#46 or #64 or #129 or #133

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)

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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.	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
S36.	(MH "Multidisciplinary Care Team+")
S37.	MDT OR IDT
S38.	((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*))
S39.	((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*))
S40.	S36 OR S37 OR S38 OR S39
S41.	S35 AND S40
S42.	TI (key n2 work*) OR AB (key n2 work*)
S43.	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*)))
S44.	TI (((healthcare or care) n1 profession*)) OR AB (((healthcare or care) n1 profession*))
S45.	MH Case Management
S46.	TI (case n2 manage*) OR AB (case n2 manage*)
S47.	TI ((co-ordinator* or coordinator* or coordinate* or co-ordinate*)*)) OR AB ((co-ordinator* or coordinator* or coordinate* or co-ordinate*))
S48.	S42 OR S43 OR S44 OR S45 OR S46 OR S47
S49.	S35 and S48
S50.	S49 not S41
S51.	S41 OR S49

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S52.	TX ((palliativ* n2 (care or caring))) OR AB ((palliativ* n2 (care or caring)))
S53.	(MH "Communication+")
S54.	TI ((communicat* or discuss* or speak* or talk* or convers* or contact)) OR AB ((communicat* or discuss* or speak* or talk* or convers* or contact))
S55.	TI (((handover or hand over or share or shared or sharing or transfer*) n3 information*)) OR AB (((handover or hand over or share or shared or sharing or transfer*) n3 information*))
S56.	TI ((followup or follow up)) OR AB ((followup or follow up).ti,ab.)
S57.	S53 OR S54 OR S55 OR S56
S58.	S49 NOT S41
S59.	S40 OR S48 OR S52
S60.	S35 AND S59 AND S57
S61.	S60 not S41
S62.	S58 OR S61
S63.	(MM "Social Welfare")
S64.	(MH "Charities")
S65.	(MM "Adult Day Center (Saba CCC)") OR (MM "Housing for the Elderly") OR (MM "Older Adult Care (Saba CCC)")
S66.	(MH "Community Health Nursing+") OR (MM "Community Health Centers")
S67.	(MH "Home Health Care+") OR (MM "Home Health Aides") OR (MM "Home Health Care Information Systems") OR (MM "Home Health Aide Service (Saba CCC)")
S68.	(MM "Housing for the Elderly") OR (MM "Rural Health Centers") OR (MM "Community Health Centers")
S69.	(MH "Telemedicine+") OR (MH "Telehealth+")
S70.	(MM "Remote Consultation") OR (MM "Telephone Consultation (Iowa NIC)") OR (MM "Services for Australian Rural and Remote Allied Health")
S71.	telehealth or tele health or virtual hospital* or helpline* or help line* or rapid response team* or senior center*
S72.	(MM "Rural Health Personnel") OR (MM "Mobile Health Units")
S73.	remote consultation
S74.	((community based or community dwelling home or rural) n3 (care or health care or healthcare))
S75.	hospital-based home care or HBHC or hospital-based hospice care or acute hospital care
S76.	((hospitali?ation* or admission* or readmission* or admit*) n3 (reduc* or avoid* or prevent* or inappropiate or increase* or risk*))
S77.	home based versus hospital based
S78.	(hospital n3 (domicil* or home))
S79.	home hospitali?ation
S80.	home care service*
S81.	(MM "Home Health Agencies") OR (MM "Nursing Home Personnel")
S82.	(MM "Homemaker Services") OR (MM "Health Services for the Aged")
S83.	(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")
S84.	social care
S85.	(MM "Hospitals, Community")
S86.	(MM "Home Nursing") OR (MM "Home Nursing, Professional")
S87.	(nurs* n4 (home-visit* or home visit* or home-based or home based))

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S88.	((district* or communit* or home or visit*) n nurs*)
S89.	S63 OR S64 OR S65 OR S66 OR S67 OR S68 OR S69 OR S70 OR S71 OR S72 OR S73 OR S74 OR S75 OR S76 OR S77 OR S78 OR S79 OR S80 OR S81 OR S82 OR S83 OR S84 OR S85 OR S86 OR S87 OR S88
S90.	MH Continuity of Patient Care OR MH Aftercare OR MH Patient discharge OR MH Patient handoff OR MH Patient transfer OR MH Transitional care
S91.	(MM "Discharge Planning") OR (MM "Patient Discharge Summaries")
S92.	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*))
S93.	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*))
S94.	AB ((care or caring or serv*)) AND AB ((continu* or change* or transition* or transfer*))
S95.	TI ((care or caring or serv*)) AND TI ((continu* or change* or transition* or transfer*))
S96.	TI discharg* AND TI (facilitat* or rapid* or pathway* or path way* or plan* or program*))
S97.	AB discharg* AND AB (facilitat* or rapid* or pathway* or path way* or plan* or program*))
S98.	S90 OR S91 OR S92 OR S93 OR S94 OR S95 OR S96 OR S97
S99.	out of hours care
S100.	((morning* or evening* or weekday or weekend* or 7 day or seven day or seven-day or after-hour* or 24 hour* or 24hour* or twenty-four-hour* or out-of-hour* or 9-5 or Monday-Friday or Saturday or Sunday) n3 (service* or access* or availab* or hour* or appointment* or care or caring or palliativ* or pharmacy* or telephone* or advic* or advis* or consult* or support* or nurs* or speciali* or physician* or doctor* or expert* or professional* or paramedic* or general practioner* or GP* or social worker* or case worker* or ambulance* or health worker* or physiotherapist* or therapist*))
S101.	rapid response
S102.	(critical care n2 outreach) OR medical emergency team* OR (hospital* n2 home*) OR hospital at night
S103.	NHS 111 OR NHS 24 OR NHS Direct
S104.	(MH "Telemedicine") OR (MH "Telehealth")
S105.	(telehealth* or tele-health* or telemedicine* or tele-medicine* or teleconsult* or tele-consult* or tele-monitor* or telemonitor* or telemanag* or tele-manag* or telepharm* or tele-pharm* or telenurs* or tele-nurs* or tele-homecare or telehomecare or tele-support or telesupport or mobile health or ehealth or e-health or mhealth or m-health)
S106.	(MH "Telephone Information Services")
S107.	(hotline* or helpline* or help-line* or call cent* or call service*)
S108.	((email* or e-mail* or telephone* or phone* or video*) n3 (servic* or advic* or advis* or consult* or support* or care* or caring* or appoint*))
S109.	S99 OR S100 OR S101 OR S102 OR S103 OR S104 OR S105 OR S106 OR S107 OR S108
S110.	TI commission* AND TI ((support* or service* or model*))
S111.	AB commission* AND AB ((support* or service* or model*))
S112.	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*)
S113.	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*)
S114.	TI (critical or clinic* or service* or care) AND TI path*

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S115.	AB (critical or clinic* or service* or care) AND AB path*
S116.	TI care AND TI (bundle* or service* or package* or standard*)
S117.	AB care AND AB (bundle* or service* or package* or standard*)
S118.	S110 OR S111 OR S112 OR S113 OR S114 OR S115 OR S116 OR S117
S119.	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*)
S120.	S35 AND S118 AND S119
S121.	TI gold standard* OR AB gold standard*
S122.	S35 AND S121
S123.	TI amber AND TI bundle
S124.	AB amber AND AB bundle
S125.	S123 OR S124
S126.	S120 OR S122 OR S125
S127.	(MH "Referral and Consultation+")
S128.	TI (referral* or referred or referring or refer or refers or consult*) OR AB (referral* or referred or referring or refer or refers or consult*)
S129.	TI (recommend* or direct*) OR AB (recommend* or direct*)
S130.	S127 OR S128 OR S129
S131.	S35 AND (89 OR 98 OR 109 OR 130)
S132.	S62 OR S126 OR S131

PsycINFO (ProQuest) search terms

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

HMIC (Ovid) search terms

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

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

SPP (Ovid) search terms

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

ASSIA (ProQuest) search terms

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

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	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 – 04 January 2019	Exclusions Health economics studies Health economics modelling studies Quality of life studies
Centre for Research and Dissemination (CRD)	HTA - Inception – 04 January 2019 NHSEED - Inception to March 2015	None

Medline (Ovid) search terms

1.	Palliative care/

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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/

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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.

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

Embase (Ovid) search terms

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

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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/

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

NHS EED and HTA (CRD) search terms

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

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#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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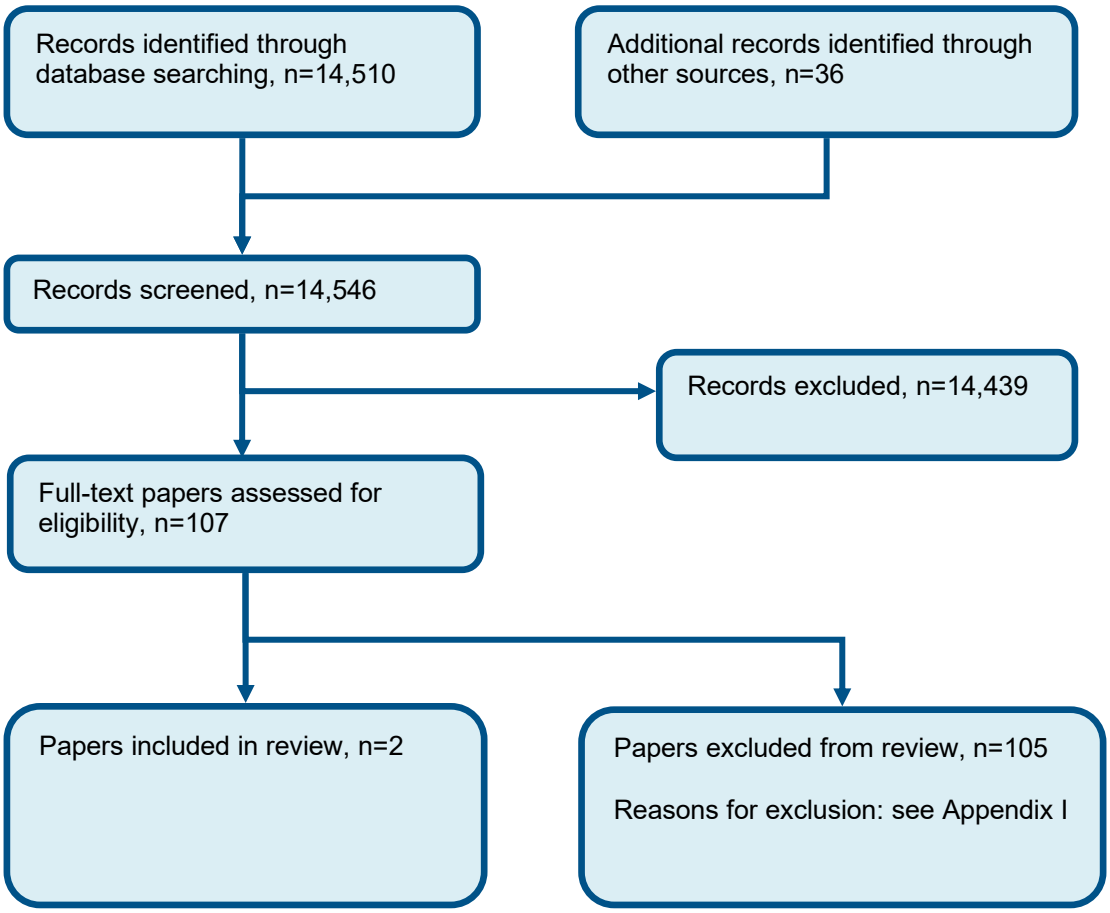
Appendix C: Clinical evidence selection

Figure 1: Flow chart of clinical study selection for the review of information sharing



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Appendix D: Clinical evidence tables

Study	Cornbleet 2002[19]
Study type	RCT (Patient randomised; Parallel)
Number of studies (number of participants)	1 (n=244)
Countries and setting	Conducted in United Kingdom; Setting: Out-patient oncology centres in Glasgow and Edinburgh, hospice home-care services across the central belt in Scotland
Line of therapy	Not applicable
Duration of study	Follow up (post intervention): 4-6 months for patients; 14 months for health professionals
Method of assessment of guideline condition	Unclear method of assessment/diagnosis
Stratum	Adults (aged 18 years or over)
Subgroup analysis within study	Not applicable
Inclusion criteria	People with a diagnosis of cancer aged >18 years, attending an oncology out-patient clinic or receiving hospice home care or day care; prognosis of at least 6 months; able to read English.
Exclusion criteria	Psychological condition or sensory impairment such that an interview would either be unwise or impossible
Recruitment/selection of patients	Eligible patients were identified by a member of clinic or home-care staff
Age, gender and ethnicity	Age - Mean (SD): intervention group 58(12), control group 60.3(14.1). Ethnicity: Not stated
Further population details	1. Any specific population: Any specific population (People in whom life-prolonging therapies are still an active option).
Extra comments	People with advanced cancer and palliative care needs. Current treatment in intervention and control groups, respectively: surgery 1, 4; radiotherapy 18, 12; chemotherapy 39, 41; other drug treatment 27, 33; symptomatic treatment 38, 37.
Indirectness of population	Serious indirectness: Maximum life expectancy not stated - however this study has been included as the population was people with advanced cancer and palliative care needs
Interventions	(n=117) Intervention 1: Model of information sharing between MDTs and services - Patient-held information. The 'Newcastle record': a loose-leaf, soft-covered booklet containing separate sections for personal details, 'what I have been told', personal diary, shared care notes, blood test results, useful telephone numbers and special treatment. People received the record by their interviewer or the referring health professional at the next meeting. They were advised to bring it whenever they attended hospital/hospice/GP surgery and to

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Study	Cornbleet 2002[19]
	present it to any health professionals coming into their own home. Duration 4-6 months for patients; 14 months for health professionals. Concurrent medication/care: Not stated. (n=114) Intervention 2: Usual care. Usual care - not described. Duration 4-6 months for patients; 14 months for health professionals. Concurrent medication/care: Not stated
Funding	Funding not stated

RESULTS (NUMBERS ANALYSED) AND RISK OF BIAS FOR COMPARISON: PATIENT-HELD INFORMATION (NEWCASTLE RECORD) versus USUAL CARE

Protocol outcome 1: Patient/carer reported outcomes (satisfaction). Note: mix of open and closed questions with responses in the form of 5-point Likert scales ranging from very satisfied to very dissatisfied, or 4-point scales ranging from very well informed to not informed at all.
- Actual outcome for Adults (aged 18 years or over): Satisfaction with information from GP at 4 months (very satisfied with information from GP); Group 1: 60/79, Group 2: 59/94; Risk of bias: All domain - Very high, Selection - High, Blinding - High, Incomplete outcome data - High, Outcome reporting - Low, Measurement - Low, Crossover - Low, Subgroups - Low, Indirectness of outcome: No indirectness ; Group 1 Number missing: 38; Group 2 Number missing: 20

- Actual outcome for Adults (aged 18 years or over): Satisfaction with information from out-patient doctor at 4 months (very satisfied with information provided); Group 1: 60/78, Group 2: 62/86; Risk of bias: All domain - Very high, Selection - High, Blinding - High, Incomplete outcome data - High, Outcome reporting - Low, Measurement - Low, Crossover - Low, Subgroups - Low, Indirectness of outcome: No indirectness; Group 1 Number missing: 38; Group 2 Number missing: 20

- Actual outcome for Adults (aged 18 years or over): Satisfaction with information exchange between hospital staff (informing each other very well about illness) at 4 months; Group 1: 44/74, Group 2: 47/70; Risk of bias: All domain - Very high, Selection - High, Blinding - High, Incomplete outcome data - High, Outcome reporting - Low, Measurement - Low, Crossover - Low, Subgroups - Low, Indirectness of outcome: No indirectness ; Group 1 Number missing: 43; Group 2 Number missing: 44

- Actual outcome for Adults (aged 18 years or over): Satisfaction with information exchange between hospital staff (informing each other very well about treatment) at 4 months; Group 1: 46/72, Group 2: 43/65; Risk of bias: All domain - Very high, Selection - High, Blinding - High, Incomplete outcome data - High, Outcome reporting - Low, Measurement - Low, Crossover - Low, Subgroups - Low, Indirectness of outcome: No indirectness ; Group 1 Number missing: 45; Group 2 Number missing: 49

- Actual outcome for Adults (aged 18 years or over): Satisfaction with information exchange between hospital staff (informing each other very well about problems) at 4 months; Group 1: 45/73, Group 2: 46/67; Risk of bias: All domain - Very high, Selection - High, Blinding - High, Incomplete outcome data - High, Outcome reporting - Low, Measurement - Low, Crossover - Low, Subgroups - Low, Indirectness of outcome: No indirectness ; Group 1 Number missing: 44; Group 2 Number missing: 47

Study	Cornbleet 2002[19]
- Actual outcome for Adults (aged 18 years or over): Satisfaction with communication between GP and hospital doctors (GP very well informed about illness) at 4 months; Group 1: 49/72, Group 2: 53/76; Risk of bias: All domain - Very high, Selection - High, Blinding - High, Incomplete outcome data - High, Outcome reporting - Low, Measurement - Low, Crossover - Low, Subgroups - Low, Indirectness of outcome: No indirectness ; Group 1 Number missing: 45; Group 2 Number missing: 38 - Actual outcome for Adults (aged 18 years or over): Satisfaction with communication between GP and hospital doctors (GP very well informed about treatment) at 4 months; Group 1: 48/68, Group 2: 49/71; Risk of bias: All domain - Very high, Selection - High, Blinding - High, Incomplete outcome data - High, Outcome reporting - Low, Measurement - Low, Crossover - Low, Subgroups - Low, Indirectness of outcome: No indirectness ; Group 1 Number missing: 49; Group 2 Number missing: 43 - Actual outcome for Adults (aged 18 years or over): Satisfaction with communication between GP and hospital doctors (GP very well informed about problems) at 4 months; Group 1: 49/69, Group 2: 53/74; Risk of bias: All domain - Very high, Selection - High, Blinding - High, Incomplete outcome data - High, Outcome reporting - Low, Measurement - Low, Crossover - Low, Subgroups - Low, Indirectness of outcome: No indirectness ; Group 1 Number missing: 48; Group 2 Number missing: 40	
Protocol outcomes not reported by the study	Quality of life; Hospitalisation; Number of hospital visits; Number of visits to accident and emergency; Number of unscheduled admissions; Use of community services; Preferred and actual place of death; Length of survival; Staff satisfaction; Avoidable/inappropriate admissions to ICU; Inappropriate resuscitation; Preferred and actual place of care at Define; Length of stay

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Study	Latimer 1998[52]
Study type	RCT (Patient randomised; Parallel)
Number of studies (number of participants)	1 (n=46)
Countries and setting	Conducted in Canada; Setting: Hamilton Civic Hospitals Palliative Care Team
Line of therapy	Not applicable
Duration of study	Intervention + follow up: 8 weeks
Method of assessment of guideline condition	Unclear method of assessment/diagnosis
Stratum	Adults (aged 18 years or over)
Subgroup analysis within study	Not applicable
Inclusion criteria	Knowledge of diagnosis, goals of treatment and prognosis; prognosis estimated to be 2 months or more; physical and emotional status assessed as sufficiently stable to participate in the study; 18 years of age or older; able to read and write English; and ability to consent to participate in the trial.
Exclusion criteria	Not stated
Recruitment/selection of patients	All patients under the services of the palliative care team
Age, gender and ethnicity	Age - Mean (SD): 54.6 (11.5). Gender (M:F): not stated. Ethnicity: not stated
Further population details	1. Any specific population: Not applicable
Extra comments	Baseline satisfaction, mean (SD) in the intervention and control group, respectively: 3.48 (0.9), 3.64 (1.0).
Indirectness of population	Serious indirectness: Not clearly stated if people were in their last year of life; this study was nevertheless included as 18/46 (40%) people enrolled died within 2 months of follow-up, giving an indication of the severity of conditions of patients in the population sample.
Interventions	(n=22) Intervention 1: Model of information sharing between MDTs and services - Patient-held information. Patient care travelling record© (PCTR): a tool to convey important clinical information about the palliative care patient. A folded 6-sided document providing the names of the health care team members involved in ongoing care patient's next of kin and contact person for care, power of attorney for personal care, most responsible physician and pharmacy, patient's diagnosis, health-care problems, hospital admissions, and medications being taken, patient's and family's understanding of the illness and care plans (including treatment decisions such as no CPR, use of IV fluids and antibiotics and the patient's wishes regarding admission to hospital), a chart of suggested therapies for symptom control that is clearly labelled 'for nurses and doctors'. The record was completed by the palliative care nurse or physician, and the material recorded was reviewed with the patient and their family or primary caregiver. The patients and their caregiver were instructed to show the record to all health professional encountered in the home, clinic, emergency room, office, hospital or other settings. They were to request that the record be updated when changes were made.

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	The use of the record was in the patient's control, with the assistance of the family. The record was reviewed at each visit to the palliative care clinic to monitor its utilisation by others and its current accuracy. . Duration 8 weeks. Concurrent medication/care: not stated (n=24) Intervention 2: Usual care. The control group was asked to complete the questionnaires at the same intervals as the experimental group, but were not given the travelling record to use. They were provided with the usual list of their medications and approach to care that would be provided in palliative care service. Duration 8 weeks. Concurrent medication/care: not stated
Funding	Academic or government funding (This study was supported by a research grant from the Hamilton Civic Hospitals)
RESULTS (NUMBERS ANALYSED) AND RISK OF BIAS FOR COMPARISON: PATIENT-HELD INFORMATION (PATIENT CARE TRAVELLING RECORD) versus USUAL CARE Protocol outcome 1: Patient/carer reported outcomes (satisfaction) - Actual outcome for Adults (aged 18 years or over): Level of satisfaction (1-5) at 2 months; Group 1: mean 3.63 (SD 1.1); n=12, Group 2: mean 3.94 (SD 0.6); n=9; General Satisfaction Questionnaire 0-5 Top=High is good outcome; Risk of bias: All domain - Very high, Selection - High, Blinding - High, Incomplete outcome data - High, Outcome reporting - Low, Measurement - Low, Crossover - Low; Indirectness of outcome: No indirectness ; Group 1 Number missing: 10; Group 2 Number missing: 15	
Protocol outcomes not reported by the study	Quality of life; Hospitalisation; Number of hospital visits; Number of visits to accident and emergency; Number of unscheduled admissions; Use of community services; Preferred and actual place of death; Length of survival; Staff satisfaction; Avoidable/inappropriate admissions to ICU; Inappropriate resuscitation at Define; Preferred and actual place of care; Length of stay

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Appendix E: Forest plots

E.1 Model of information sharing between multiprofessional teams and services versus usual care

E.1.1 Patient-held information (The Newcastle Record) versus usual care

Figure 2: Patient reported outcome – satisfaction (people satisfied with communication between GP and hospital doctors about illness) at 4-6 months

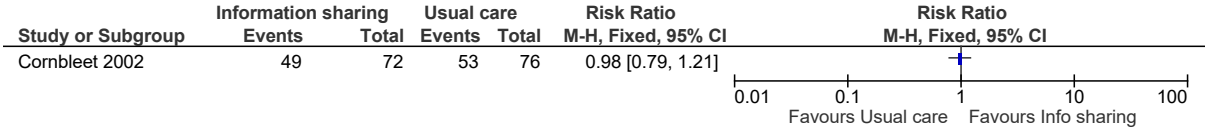

Figure 3: Patient reported outcome – satisfaction (people satisfied with communication between GP and hospital doctors about problems) at 4-6 months

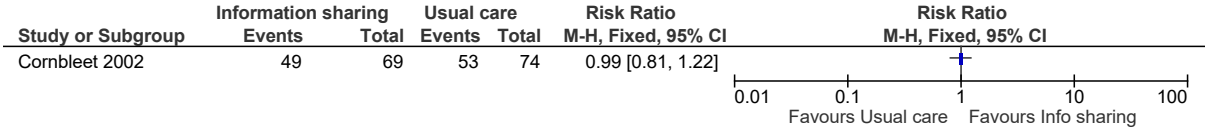

Figure 4: Patient reported outcome – satisfaction (people satisfied with communication between GP and hospital doctors about treatment) at 4-6 months

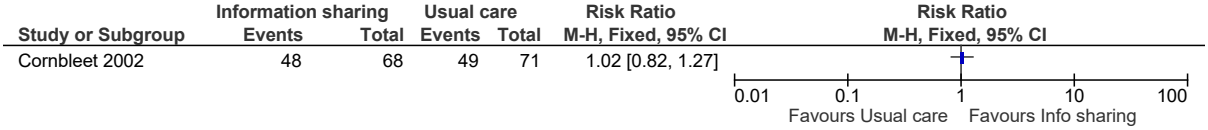

Figure 5: Patient reported outcome – satisfaction (people satisfied with information exchange between hospital staff about illness) at 4-6 months

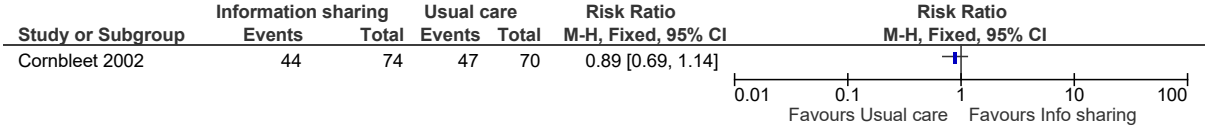

Figure 6: Patient reported outcome – satisfaction (people satisfied with information exchange between hospital staff about problems) at 4-6 months

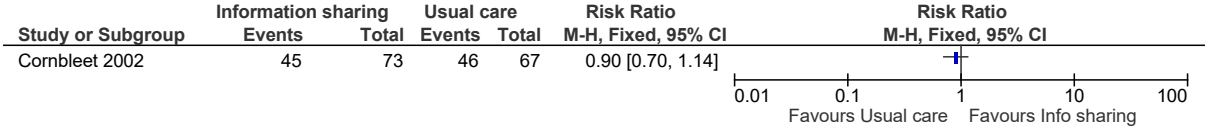

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Figure 7: Patient reported outcome – satisfaction (people satisfied with information exchange between hospital staff about treatment) at 4-6 months

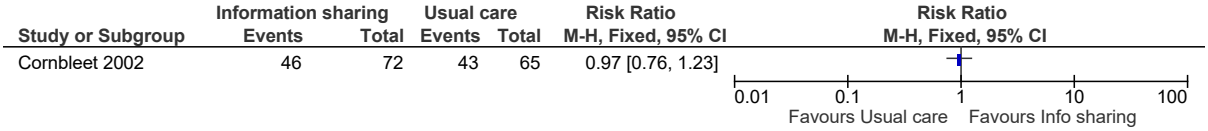


Figure 8: Patient reported outcome – satisfaction (people satisfied with information from GP) at 4-6 months

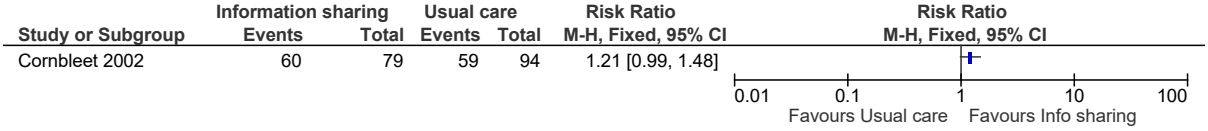
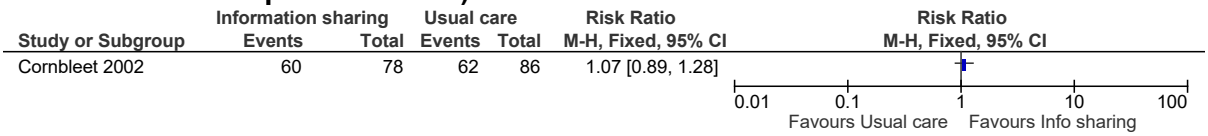
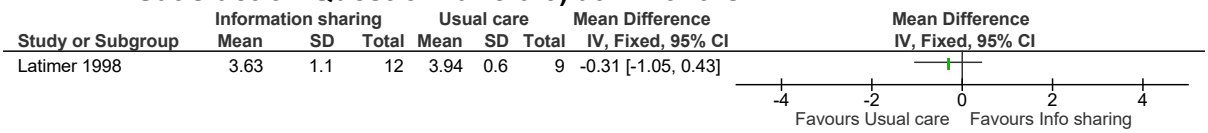


Figure 9: Patient reported outcome – satisfaction (people satisfied with information from out-patient doctor) at 4-6 months



E.1.2 Patient-held information (Patient care travelling record) versus usual care (Latimer 1998)

Figure 10: Patient reported outcome – satisfaction (satisfaction, General Satisfaction Questionnaire 0-5) at 2 months



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Appendix F: GRADE tables

Table 9: Clinical evidence profile: Model of information sharing between multiprofessional teams and services (Patient-held information – the Newcastle record) versus usual care

Quality assessment							No of patients		Effect		Quality	Importance
No of studies	Design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations	Information sharing between MDTs and services	Usual care	Relative (95% CI)	Absolute		
Satisfaction with communication between GP and hospital doctors (GP kept very well informed about illness) (follow-up 4-6 months)												
1	randomised trials	very serious[a]	no serious inconsistency	no serious indirectness	no serious imprecision	none	49/72 (68.1%)	53/76 (69.7%)	RR 0.98 (0.79 to 1.21)	14 fewer per 1000 (from 146 fewer to 146 more)	⊕⊕OO LOW	IMPORTANT
Satisfaction with communication between GP and hospital doctors (GP kept very well informed about problems) (follow-up 4-6 months)												
1	randomised trials	very serious[a]	no serious inconsistency	no serious indirectness	no serious imprecision	none	49/69 (71%)	53/74 (71.6%)	RR 0.99 (0.81 to 1.22)	7 fewer per 1000 (from 136 fewer to 158 more)	⊕⊕OO LOW	IMPORTANT
Satisfaction with communication between GP and hospital doctors (GP kept very well informed about treatment) (follow-up 4-6 months)												
1	randomised trials	very serious[a]	no serious inconsistency	no serious indirectness	serious[b]	none	48/68 (70.6%)	49/71 (69%)	RR 1.02 (0.82 to 1.27)	14 more per 1000 (from 124 fewer to 186 more)	⊕OOO VERY LOW	IMPORTANT
Satisfaction with information exchange between hospital staff (informing each other very well about illness) (follow-up 4-6 months)												
1	randomised trials	very serious[a]	no serious inconsistency	no serious indirectness	serious[b]	none	44/74 (59.5%)	47/70 (67.1%)	RR 0.89 (0.69 to 1.14)	74 fewer per 1000 (from 208 fewer to 94 more)	⊕OOO VERY LOW	IMPORTANT
Satisfaction with information exchange between hospital staff (informing each other very well about problems) (follow-up 4-6 months)												

1	randomised trials	very serious[a]	no serious inconsistency	no serious indirectness	serious[b]	none	45/73 (61.6%)	46/67 (68.7%)	RR 0.9 (0.7 to 1.14)	69 fewer per 1000 (from 206 fewer to 96 more)	⊕OOO VERY LOW	IMPORTANT
Satisfaction with information exchange between hospital staff (informing each other very well about treatment) (follow-up 4-5 months)												
1	randomised trials	very serious[a]	no serious inconsistency	no serious indirectness	no serious imprecision	none	46/72 (63.9%)	43/65 (66.2%)	RR 0.97 (0.76 to 1.23)	20 fewer per 1000 (from 159 fewer to 152 more)	⊕⊕OO LOW	IMPORTANT
Satisfaction with information from GP (very satisfied with information from GP) (follow-up 4-6 months)												
1	randomised trials	very serious[a]	no serious inconsistency	no serious indirectness	serious[b]	none	60/79 (75.9%)	59/94 (62.8%)	RR 1.21 (0.99 to 1.48)	132 more per 1000 (from 6 fewer to 301 more)	⊕OOO VERY LOW	IMPORTANT
Satisfaction with information from out-patient doctor (very satisfied with information provided) (follow-up 4-6 months)												
1	randomised trials	very serious[a]	no serious inconsistency	no serious indirectness	serious[b]	none	60/78 (76.9%)	62/86 (72.1%)	RR 1.07 (0.89 to 1.28)	50 more per 1000 (from 79 fewer to 202 more)	⊕OOO VERY LOW	IMPORTANT

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

Table 10: Clinical evidence profile: Model of information sharing between multiprofessional teams and services (Patient-held information – Patient care travelling record) versus usual care

Quality assessment							No of patients		Effect		Quality	Importance
No of studies	**Design**	**Risk of bias**	**Inconsistency**	**Indirectness**	**Imprecision**	**Other considerations**	**Information sharing between MDTs and services**	**Usual care**	**Relative (95% CI)**	**Absolute**		
Satisfaction at 2 months (follow-up 2 months; range of scores: 0-5; Better indicated by higher values)												

1	randomised trials	very serious[a]	no serious inconsistency	no serious indirectness	very serious[b]	none	12	9	-	MD 0.31 lower (1.05 lower to 0.43 higher)	⊕OOO VERY LOW	IMPORTANT

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

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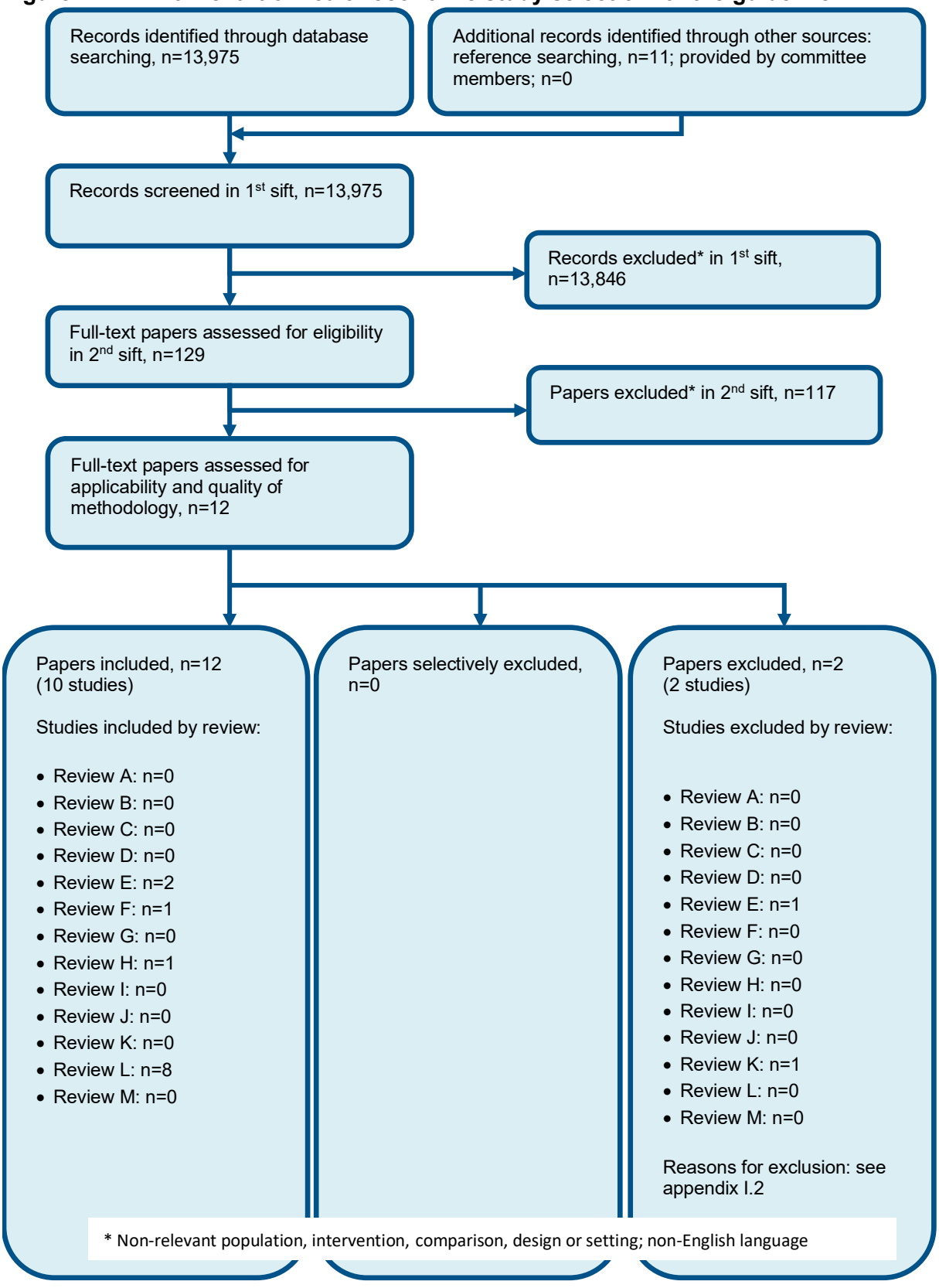
Appendix G: Health economic evidence selection

Figure 11: Flow chart of health economic study selection for the guideline



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Appendix H: Research Recommendation

RR2 What are the advantages of using electronic registers and information sharing databases and which ones perform best for the care of people in the last year of life?

Why this is important

The guideline committee made several recommendations about the need to record when people are identified as entering the last year of life, as well as need to share this and subsequent information during the course of the illness, with other members of the professional teams involved in the care. The committee was aware that in the past, the majority of this information recording and sharing has been done using paper-based systems, relayed between teams and settings using telephone, fax and emails. However, fully electronic databases and information sharing systems using internet protocols are becoming more established in the NHS and also in hospice services. The committee looked for research evidence about which systems performed better and were more reliable for sharing confidential information, but it was unable to find it. Studies conducted in other countries using electronic systems were thought not applicable to the NHS.

It is therefore recommended that research should be done on the systems that are currently available in the UK. The purpose of this research would be to inform healthcare planners and service providers on the most efficient, reliable, secure and confidential, and cost-effective systems to be used for sharing information about the last year of life across a range of settings.

PICO question	**What are the advantages of using electronic registers and information sharing databases and which ones perform best for the care of people in the last year of life?** Population: Adults in the last year of life, with a balance of cancer and non-cancer medical conditions. Intervention(s): Use of an electronic register and database for recording that a person is entering the last year of life; their holistic needs and advance care plans; updating needs and plans at key transition points; sharing information between teams in different care settings; use of the database for key information about carers and other people important to the dying person. The system should be able to disseminate information by internet using safe protocols and ideally on a full range of data capture and display platforms. Comparison: Use of conventional information recording and sharing systems, namely paper-based case-notes, fax, email

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	and telephone messages. Standalone electronic systems, eg embedded in one hospital trust or one hospice, or only used in GP practices, but which are not shared across care settings would also be a comparator with a truly shared electronic, internet-enabled register and database. Outcome(s): The number of people recorded as being in the last year of life; the number of holistic needs assessments and advance care plans carried out ; documentation that correct and up to date information on carers and other people important to the dying person has been recorded and shared; the time to produce discharge reports and letters;the time to communicate reports and letters between settings of care at discharge or on transfer of care; ; no loss of confidential information.
Importance to patients or the population	The committee made several recommendations about the critical value of recording and sharing information about the prognosis of the patient, holistic needs assessments and care plans, and being able to update these assessments and plans. In addition, it is crucial to good end of life care to be able to share this information in real time between different healthcare professionals and social care practitioners, eg on different shifts or out of hours. When patients are being discharged from hospital to their usual place or residence, or between different care settings, it is again important to have such information flowing in anticipation of the move and soon afterwards to capture clinical and healthcare need changes. Ambulance services taking people home or between settings should also be able to access this information. Crucially, all relevant health and social care information needs to be available at times of crisis out of hours. It is important to know if current electronic systems can achieve these requirements, or if next generation systems are required.
Relevance to NICE guidance	There are many recommendations in the guideline about the need to record and share information electronically about the person's condition, holistic needs and care plans, [*give recs*] but the committee was unable to recommend any particular electronic system.
Relevance to the NHS	As electronic databases and clinical information systems are being increasingly used in the NHS, there has been a range of implementations that can be used for the care of people in the last year of life (EPACCS, CANISC etc). Different parts of the NHS use widely different IT systems which can impede data-sharing. It would be great value to care of dying people if the research could show that one system had advantages over others.
National priorities	With the recent withdrawal of the National Council for Palliative Care's annual national Minimum Data-Set collection, there is no current method of generating country and region-level data on end of life care. The use of efficient

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	and confidential electronic systems could be of great value to healthcare planners, as well as service level providers of care.
Current evidence base	The committee was unable to find research evidence for the superiority of any particular electronic system for registering when a person is entering the last year of life and recording their holistic needs and care plans.
Equality	
Study design	This research should be able to compare the performance of a complete electronic package for recording and sharing data promptly, safely and confidentially between healthcare professionals and social care practitioners, and between different teams and care settings. Because of the risks that could arise from running a fully electronic and internet system alongside a conventional paper, telephone and email-based system, it is envisaged that a pre- and post-installation design would be used; or a parallel cohort or cluster randomisation where one locality would use a new electronic system and be compared with another matched locality using the conventional system.
Feasibility	Because of the known difficulties of implementing IT changes in the NHS, there would need to be carefully designed strategies for testing feasibility, security and confidentiality.
Other comments	
Importance	High: the research is essential to inform future updates of key recommendations in the guideline. It will also be of value for healthcare planners and service providers to be guided on the most efficient, effective and cost-effective electronic systems to use in end of life care.

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Appendix I: Excluded studies

I.1 Excluded clinical studies

Table 11: Studies excluded from the clinical review

Study	Exclusion reason
Akhlaq 2016[1]	Not review population
Algilani 2017[2]	Not review population
Ali 2013[3]	inappropriate population
Allsop 2016[4]	Inappropriate study design
Arora 2017[5]	Inappropriate study design
Asprey 2013[6]	inappropriate study design
Astrom 2007[7]	inappropriate population
Basta 2016[8]	inappropriate population
Beyea 2013[9]	inappropriate intervention
Bokhour 2006[10]	inappropriate study design
Boockvar 2010[11]	inappropriate population
Brinkman-Stoppelenburg 2014[12]	Systematic review is not relevant to review question or unclear PICO
Capurro 2014[13]	Systematic review is not relevant to review question or unclear PICO (unclear - references checked)
Carlsson 2012[14]	inappropriate study design
Chan 2016[15]	Not relevant intervention
Chang 2010[16]	Inappropriate intervention
Cherry 2003[17]	Inappropriate population
Cobler 2017[18]	Not review population
Dahm 2008[20]	Inappropriate study design
De Bock 2011[21]	Inappropriate study design
Demiris 2008[23]	Inappropriate study design
Demiris 2009[22]	Inappropriate study design
Dickinson 2014[24]	Inappropriate population
Dorman 2010[25]	Inappropriate study design
Doyle 2008[26]	Inappropriate population
Drury 1996[27]	Inappropriate study design
Dubbert 2017[28]	Not review population
Duplan 2016[29]	Inappropriate study design
Feltes 1994[30]	Inappropriate study design
Gagnon 2009[31]	Inappropriate population
Georgiou 2013[32]	Inappropriate study design
Griffiths 2014[33]	Inappropriate intervention
Grossman 2014[34]	Inappropriate study design
Gulmans 2007[35]	Inappropriate population
Gum 2015[36]	Inappropriate population
Gurwitz 2014[37]	Inappropriate population

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Study	Exclusion reason
Hall 2012[38]	Inappropriate study design
Hansebo 1999[39]	Inappropriate population
Happell 2014[40]	Inappropriate population
Hedlund 2013[41]	Inappropriate intervention
Hendricks-Ferguson 2017[42]	Not review population
Houben 2014[45]	Systematic review is not relevant to review question or unclear PICO
Houben 2014[46]	Inappropriate study design
Houben 2014[44]	Inappropriate intervention; protocol only
Kallen 2012[47]	No relevant outcome
Kiely 2013[48]	Not review population
King 2005[49]	Inappropriate study design
Knott 2011[50]	Inappropriate comparison
Komura 2013[51]	Inappropriate study design
Lau 2013[53]	Inappropriate study design
Lilja 2000[54]	Not review population
Lindberg 2013[55]	Inappropriate population
Lindner 2007[56]	Not review population
Lux 2016[57]	Not in English language
Mahmood-Yousuf 2008[58]	Inappropriate study design
Martin 2017[59]	Inappropriate study design
Mason 2015[60]	Inappropriate comparison
McBride 2014[61]	Inappropriate population
McGough 1999[62]	Inappropriate study design
McSwiggan 2017[63]	Inappropriate study design
Millington-Sanders 2013[64]	Inappropriate study design
Mohan 2007[65]	Inappropriate population
Mola 2009[66]	Not in English language
Moore 2016[67]	Inappropriate study design
Moran 1994[68]	Inappropriate study design
Morikawa 2016[69]	Inappropriate study design
Mueller 2015[70]	Inappropriate study design
Nagpal 2012[71]	Inappropriate study design
Ng 2017[73]	Inappropriate study design
O'Connor 2009[74]	Inappropriate study design
Olsen 2013[75]	Inappropriate study design
Omilion-Hodges 2017[76]	Inappropriate study design
Pautex 2008[77]	Inappropriate intervention
Petrova 2016[78]	Inappropriate study design
Press 2015[79]	Inappropriate population
Price 2016[80]	Inappropriate study design
Pringle 2014[81]	No relevant outcome
Puntillo 2006[82]	Inappropriate study design
Regnard 2000[83]	Inappropriate study design
Reilly 2013[84]	Inappropriate study design
Resnick 2010[85]	Inappropriate study design

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Study	Exclusion reason
Roth 2017[86]	Inappropriate intervention
Sadavarte 2016[87]	Inappropriate study design
Schweitzer 2009[89]	Inappropriate study design
Schweitzer 2009[90]	Inappropriate study design
Schweitzer 2016[88]	Not review population
Shelby-James 2007[91]	No relevant outcome
Siemsen 2012[92]	Inappropriate population
Sinha 2017[93]	No relevant outcome
Smith 2012[94]	Not ordered - could not be found
Soares 2012[95]	Inappropriate population
Stiefel 2017[96]	Inappropriate study design
Stinson 2015[97]	Inappropriate study design
Tamang 2005[98]	Inappropriate study design
Tanabe 2015[99]	Inappropriate study design
Taubert 2010[100]	Inappropriate study design
Tobacman 2004[101]	Inappropriate population
Urquhart 2009[102]	Systematic review is not relevant to review question or unclear PICO
van Gurp 2013[103]	Inappropriate study design
Vickridge 1998[104]	Inappropriate study design
Villarreal 2011[105]	Inappropriate intervention
Wagner 2010[106]	Inappropriate population
Walsh 2004[107]	Inappropriate study design
Wittenberg-Lyles 2005[108]	Inappropriate study design
Yuan 2018{Yuan, 2018 #3541}	No outcomes

I.2 Excluded economic studies

There were no excluded economic studies for this review.

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