National Institute for Health and Care Excellence

Draft for consultation

End of life care for adults: service delivery

[D] Evidence review: Care Coordinator and Lead Healthcare Professional

NICE guideline

Evidence review

April 2019

Draft for consultation

This evidence review was developed by the National Guideline Centre

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1.1 Review question 1: Is a care coordinator clinically and cost-effective to facilitate the continuity and coordination of care for people who are in their last year of life?

1.2 Review question 2: Is a lead health professional clinically and cost-effective to facilitate the continuity and coordination of care for people who are in their last year of life?

1.3 Introduction

End of Life Care Coordinator:

People in the last year of life may require a range of supportive services in the community, hospitals, hospices and care homes. These services may be formal or informal, often including a range of health, social care and charitable services working together with the person and people important to them.

This chapter will focus on the evidence for the role of an End of Life care Coordinator who, in a timely manner, is able to:

- Screen for the unique care and support needs of the individual and those important to them, using person - centred approaches;
- Recognise and respond to diversity, discrimination and disadvantage of an individuals' circumstances, whilst acknowledging that people chose to live and die in different ways;
- Act as an expert navigator to plan and set up an individually tailored network of support systems providing the right care at the right time in the right place;
- Know when to refer on to or seek advice from specialist services;
- Be responsive to changing needs and priorities of care.

The committee acknowledged this role can have many different titles and have agreed to refer to this role as care coordinator in this review.

Lead Healthcare professional:

Continuity and coordination of care have frequently been identified as challenges in the delivery of effective care in the last year of life, especially for those who are receiving hospital and other specialist services. Patients and those important to them report that, with multiple services potentially involved in providing support, they may still be uncertain about who to turn to when different problems arise. This review question sought to explore the impact of identifying a lead healthcare professional to coordinate support in the last year of life, across all NHS sectors and in charitable institutions such as hospices.

1.4 PICO table

For full details see the review protocol in Appendix A.

Table 1: PICO characteristics of review question 1

Population	Adults (aged over 18 years) with progressive life-limiting conditions thought to be entering the last year of life
Interventions	Someone who organises care : Facilitator Key worker Coordinator Case manager
Comparisons	Usual care Each other
Outcomes	CRITICAL - Quality of life (Continuous) - Preferred and actual place of death (Dichotomous) - Preferred and actual place of care (Dichotomous) IMPORTANT - Length of stay (Continuous) - Length of survival (Dichotomous) - 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) - Patient/carer reported outcomes (satisfaction) (Continuous) - Staff satisfaction (Continuous) - Avoidable/inappropriate admissions to ICU (Dichotomous) - Inappropriate resuscitation (Dichotomous)
Study design	Systematic Review RCT Non-randomised comparative study

Table 2: PICO characteristics of review question 2

Population	Adults (aged over 18 years) with progressive life-limiting conditions thought to be entering the last year of life
Intervention	Lead healthcare professional
Comparison	Usual care
Outcomes	CRITICAL - Quality of life (Continuous) - Preferred and actual place of death (Dichotomous) - Preferred and actual place of care (Dichotomous) IMPORTANT - Length of stay (Continuous) - Length of survival (Dichotomous) - 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) - Patient/carer reported outcomes (satisfaction) (Continuous) - Staff satisfaction (Continuous) - Avoidable/inappropriate admissions to ICU (Dichotomous) - Inappropriate resuscitation (Dichotomous)
Study design	Systematic Review RCT Non-randomised comparative study

1.5 Clinical evidence

1.5.1 Included studies

1.5.1.1 Care coordinator

6 studies (reported in 7 papers) were included in the review;[1,2,8,13,41,45,51] these are summarised in the clinical evidence summary below (Table 4). See also the study selection flow chart in Appendix B, forest plots in Appendix D, study evidence tables in Appendix D, GRADE tables in Appendix F and excluded studies list in Appendix H.

1.5.1.2 Lead health professional

A search for trials comparing the effectiveness of lead health professionals versus usual care for people with progressive life-limiting conditions thought to be entering the last year of life was undertaken. No relevant clinical studies comparing a lead health professional with usual care were identified.

1.5.2 Excluded studies

See the excluded studies list in Appendix H.

1.5.3 Summary of clinical studies

Table 3: Summary of clinical studies included in the evidence review for care coordinator

Study	Intervention and comparison	Population	Outcomes	Comments
Addington Hall 1992[1] Raftery 1996[41]	Coordinator: Nurse coordinators. They were based in the community and introduced themselves to patients as nurses providing a link between the hospital, general practitioner and community services. They acted as 'brokers' of services: their role was to assess the need for services from the NHS, local authorities and voluntary sector agencies; to offer advice on how to obtain these services and to contact the agencies themselves if necessary; to ensure that services were provided and were well coordinated; and to monitor the changing needs of the patient and family for services. The coordinators did not provide practical nursing care or advice. Usual care: no access to coordinator	Patient expected to live for one year or less and who were resident within the boundaries of the health authority entered the trial and were allocated to the coordination or control group depending on the general practice with which they were registered. N=554 UK	Preferred and actual place of death (Number of people dying at home, in hospital and hospice); Hospitalisation (admissions); Length of stay (inpatient days); Length of survival; Number of hospital visits (outpatients attendance); Use of community services (home visits; people known to social workers, people known to occupational therapists; people having contact with GP; people having contact with hospice; people having contact with district nurses); Patient/carer reported outcomes (satisfaction)	All recruited patients continued to receive routinely available services, including inpatient and outpatient services in the local acute hospital, general practitioner and community nursing services, Marie curie nurses, services from the local hospice and specialist cancer services from a nearby special health authority. Social services were also available.
Aiken 2006[2]	Case manager: Registered nurse case managers provided 'PhoenixCare' services. PhoenixCare delivered home-based services focused on disease and symptom management, patient and caregiver education on disease	People diagnosed with chronic heart failure (CHF) or chronic obstructive pulmonary disease (COPD) who might live for up to 2 years beyond enrolment, based on expert judgment that drew on available prognostic data. All	Quality of life (at 3 months); Quality of life (at 9 months); Number of accident and emergency visits (ED visits per month)	

Study	Intervention and comparison	Population	Outcomes	Comments
	management and social and psychological support. Registered nurse case managers delivered the primary PhoenixCare services and assumed a leadership role in coordinating PhoenixCare services with the patients' primary care physician, with any case managers provided by the patient's MCO, and with community agencies. A medical director, social worker, and pastoral counsellor provided support to case managers, who coordinated care planning with PhoenixCare members, primary care physicians, health plan case manager, patient/family and community agencies. Usual care: no access to case manager	patients were required to have exhibited recent exacerbation of their conditions as evidenced by treatment in an emergency department, urgent care facility, or hospital within the 3 months prior to enrolment. N=192 USA		
Bakitas 2009[8]	Coordinator: ENABLE (Educate, Nurture, Advise, Before Life Ends). Advance palliative care nurse specialists educated participants about key palliative care principles and crisis prevention via practice problem solving/decision-making skills, symptom management, communication and advance care planning. Coordinated referrals to improve patients' end of life care experience. Designed to facilitate a smooth transition from mostly anti-cancer treatment to mostly	Patients with a new diagnosis of advanced or recurrent life-limiting cancer (prognosis of approx. 1 year). N=322 USA	Quality of life (functional assessment of chronic illness therapy for palliative care); Quality of life (functional assessment of chronic illness therapy for palliative care – patients who died during study); Number of days in hospital; Number of accident and emergency visits; Median length of survival Mortality	

Study	Intervention and comparison	Population	Outcomes	Comments
	palliative care. Intervention included education via manual. The nurse educator contacted the participant weekly for the first four weeks to review each module in the manual. After the completion of the four structured sessions the nurse phoned the participant at least monthly. The nurse educator also triaged medical complaints and offered to arrange care and services as needed, including palliative and hospice care. Monthly contacts continued as long as the participant was alive. In the later stages the nurse communicated with the caregiver. Usual care: Patients were allowed to use all usual oncology, palliative care and other medical centres without restrictions. The cancer centre had a consultative interdisciplinary palliative care team comprised of a physician and nurse practitioners.			
Brumley 2003[13]	Coordinator: Multidisciplinary palliative care program (TCPC), an interdisciplinary home-based program for patients at the end of life. The program offers enhanced pain control, symptom management and psychosocial support to improve quality of life. Care is provided by a core team consisting	Hospice homebound patients with a diagnosis of a life threatening disease, primarily Chronic obstructive pulmonary disease (COPD), Chronic heart failure (CHF), or cancer; two or more emergency department visits or hospital admissions in the past year, and limited life expectancy	Preferred and actual place of death; Use of community services (physicians visits; skilled nursing care visits, total home care visits); Number of hospital visits; Number of visits to accident and emergency	

Study	Intervention and comparison	Population	Outcomes	Comments
	of a physician, nurse and social worker with expertise in pain control, other symptom management and psychosocial intervention. Patients are assigned a palliative care physician who coordinates care from a variety of health care practitioners. Home visits are provided by all team members (including physicians) to provide medical care, support and education as needed by patients and their caregivers. Telephone support and afterhours visits are available 24/7, as needed by the patient. ACP is provided. Usual care: hospice patients who did not receive the program	(not more than approximately one year to live) N=558 USA		
Seow 2008[45]	The Omega Life Program (OLP) - Nurse case managers lead the program and provided an initial and ongoing holistic assessment of physical, psychosocial, and spiritual needs of patient and family. Case managers educate patients and families about various topics, including advance directives, hospice options, insurance and prescription benefits, and symptom management. Patients and families are taught to contact case managers for information and needs rather than emergencies. Patients are followed by the case	Current cancer diagnosis, with a date of enrolment or refusal to the program, and a confirmed date of death while insured under the managed care organisation. N=121 USA	Length of survival (deaths since referral; 8-30 days); Length of survival (deaths since referral; 31-120 days); Length of survival (deaths since referral; >120 days); Hospitalisation (odds of having one or more hospital admissions)	

Study	Intervention and comparison	Population	Outcomes	Comments
	manager from enrolment through to death. The case manager also coordinates care between multiple providers, integrate various providers into the care team, and serve as the main point of contact for the patient and the families to help them navigate the health system. Usual care: Patients referred to the OLP who elected not to enrol. Continued to receive usual care.			
Wang 2015[51]	Nurse case management program (Omega Life Program): in palliative care provided by a Medicaid MCO. Usual care: people who were referred to the OLP at least 30 days prior to death but did not enrol in the program.	People with a Cancer diagnosis; no hospice election, aged between 18 and 65 years at time of Omega Life Program (OLP) referral; being referred to OLP and having died during the study period. N=186 USA	Length of stay (inpatient days; ICU days; hospice days); Hospitalisation (inpatient admission); Number of visits to A&E (treat-and-release ED visit); Use of community services (persons with hospice election); Preferred and actual place of death (persons with death in hospital); Avoidable/inappropriate admissions to ICU (ICU admissions)	

1.5.4 Summary of clinical studies included in the evidence review for lead health professional

No relevant clinical studies were identified.

See Appendix D for full evidence tables.

1.5.5 Quality assessment of clinical studies included in the evidence review on care coordinator

Table 4: Question 1 – Care coordinator versus usual care: data unsuitable for GRADE due to inadequate reporting of outcome measure

Study	Outcome	Intervention results	Intervention group (n)	Comparison results	Comparison group (n)	Risk of bias[a]
Addington-Hall 1992 (Coordinator versus usual care)	Length of survival (mean days between study entry and death)	Mean 211 days	55	Mean 232 days	64	Very high
Aiken 2006 (Case manager versus usual care)	Quality of life (SF-36) 3 months	COPD patients in the intervention group reported greater Vitality than COPD controls				High
	Quality of life (SF-36) 9 months	Control patients declined in both Physical function and General health while intervention patients did not. Superior Physical functioning and General health emerged in the intervention above control participants.				High
Bakitas 2009 (Coordinator versus usual care)	Quality of life (Functional assessment of chronic illness therapy for palliative care) until death - 0 to 184 higher indicates better quality of life	Mean: 4.6 SE: 2 p=0.02	161	-	-	Very high
	Quality of life (Functional assessment of chronic illness therapy for palliative care) patients who died during study - 0 to 184 higher indicates better quality of life	Mean: 8.6 SE: 3.6 p=0.02	161	-	-	Very high
	Hospitalisation (mean days in hospital)	Mean: 6.6 p=0.14	161	Mean: 6.5	161	High
	Hospitalisation (mean number of emergency department visits)	Mean: 0.86	161	Mean:0.63	161	Very high
	Length of survival (median length of survival)	Median (95%CI): 14 (10.6-18.4)	161	Median (95%CI): 8.5 (7.0-11.1)	161	Very high
Seow 2008	Hospitalisation (odds of having	OR 0.138 (95%CI 0.03 - 0.57)				High

Study	Outcome	Intervention results	Intervention group (n)	Comparison results	Comparison group (n)	Risk of bias[a]
(Case manager versus usual care)	one or more hospital admission versus those in comparison group, controlling for time since referral, age, and gender)	p=0.006				

[a] Risk of bias is based on checklist for individual studies, please see evidence tables for further details.

Table 5: Clinical evidence summary: Nurse coordinator compared to usual care in adults thought to be entering their last year of life

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 Coordinator (95% CI)
Satisfaction (carers agreeing with statement 'care was well coordinated') after bereavement	94 (1 study)	⊕⊖⊖⊖ VERY LOW[a,b,c] due to risk of bias, indirectness, imprecision	RR 0.97 (0.7 to 1.33)	628 per 1000	19 fewer per 1000 (from 188 fewer to 207 more)
Satisfaction (carers satisfied with care from district nurses)	118 (1 study)	⊕⊖⊖⊖ VERY LOW[a,b,c] due to risk of bias, indirectness, imprecision	RR 1.35 (0.95 to 1.94)	435 per 1000	152 more per 1000 (from 22 fewer to 409 more)
Satisfaction (carers satisfied with care from GP)	118 (1 study)	⊕⊖⊖⊖ VERY LOW[a,b,c]	RR 1 (0.78 to	677 per 1000	0 fewer per 1000

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 Coordinator (95% CI)
		due to risk of bias, indirectness, imprecision	1.28)		(from 149 fewer to 190 more)
Satisfaction (carers satisfied with care from hospital)	118 (1 study)	⊕⊖⊖⊖ VERY LOW[a,b,c] due to risk of bias, indirectness, imprecision	RR 1.16 (0.92 to 1.48)		
				645 per 1000	103 more per 1000 (from 52 fewer to 310 more)
Satisfaction (patients satisfied with care from district nurses)	203 (1 study)	⊕⊖⊖⊖ VERY LOW[a,b,c] due to risk of bias, indirectness, imprecision	RR 1.5 (1.13 to 1.99)		
				404 per 1000	202 more per 1000 (from 53 more to 400 more)
Satisfaction (patients satisfied with care from GP)	203 (1 study)	⊕⊖⊖⊖ VERY LOW[a,b,c] due to risk of bias, indirectness, imprecision	RR 1.09 (0.89 to 1.32)		
				636 per 1000	57 more per 1000 (from 70 fewer to 204 more)
Satisfaction (patients satisfied with care from hospital)	203 (1 study)	⊕⊖⊖⊖ VERY LOW[a,b,c] due to risk of bias,	RR 1.31 (1 to 1.71)		
				455 per 1000	141 more per 1000 (from 0 more to 323 more)

Outcomes	No of Participants (studies) Follow up	Quality of the evidence (GRADE)	Relative effect (95% CI)	Anticipated absolute effects	
				Risk with Usual care	Risk difference with Coordinator (95% CI)
		indirectness, imprecision			
Preferred and actual place of death (people dying at home)	167 (1 study)	⊕⊖⊖⊖ VERY LOW[a,b,c] due to risk of bias, indirectness, imprecision	RR 1.14 (0.6 to 2.17)	173 per 1000	24 more per 1000 (from 69 fewer to 202 more)
Preferred and actual place of death (people dying elsewhere)	167 (1 study)	⊕⊖⊖⊖ VERY LOW[a,b,c] due to risk of bias, indirectness, imprecision	RR 0.94 (0.14 to 6.53)	25 per 1000	1 fewer per 1000 (from 21 fewer to 137 more)
Preferred and actual place of death (people dying in hospice)	167 (1 study)	⊕⊖⊖⊖ VERY LOW[a,b,c] due to risk of bias, indirectness, imprecision	RR 0.78 (0.36 to 1.72)	148 per 1000	33 fewer per 1000 (from 95 fewer to 107 more)
Preferred and actual place of death (people dying in hospital)	167 (1 study)	⊕⊖⊖⊖ VERY LOW[a,b,c] due to risk of bias, indirectness, imprecision	RR 0.76 (0.52 to 1.11)	444 per 1000	107 fewer per 1000 (from 213 fewer to 49 more)

Outcomes	No of Participants (studies) Follow up	Quality of the evidence (GRADE)	Relative effect (95% CI)	Anticipated absolute effects	
				Risk with Usual care	Risk difference with Coordinator (95% CI)
Use of community services (people known to occupational therapists)	167 (1 study)	⊕⊖⊖⊖ VERY LOW[a,c] due to risk of bias, imprecision	RR 1.09 (0.8 to 1.5)	457 per 1000	41 more per 1000 (from 91 fewer to 228 more)
Use of community services (people known to social workers)	167 (1 study)	⊕⊖⊖⊖ VERY LOW[a,c] due to risk of bias, imprecision	RR 0.89 (0.62 to 1.28)	432 per 1000	48 fewer per 1000 (from 164 fewer to 121 more)
Use of community services (patients having contact with district nurses) 2 weeks before final interview	202 (1 study)	⊕⊖⊖⊖ VERY LOW[a,c] due to risk of bias, imprecision	RR 0.94 (0.66 to 1.33)	394 per 1000	24 fewer per 1000 (from 134 fewer to 130 more)
Use of community services (patients having contact with GP-home visit) 2 weeks before final interview	202 (1 study)	⊕⊖⊖⊖ VERY LOW[a,c] due to risk of bias, imprecision	RR 0.96 (0.58 to 1.6)	232 per 1000	9 fewer per 1000 (from 98 fewer to 139 more)
Use of community services (patients having contact with GP-surgery consultation) 2 weeks before final interview	202 (1 study)	⊕⊖⊖⊖ VERY LOW[a,c] due to risk of bias,	RR 0.69 (0.36 to 1.34)	182 per 1000	56 fewer per 1000 (from 116 fewer to 62 more)

Outcomes	No of Participants (studies) Follow up	Quality of the evidence (GRADE)	Relative effect (95% CI)	Anticipated absolute effects	
				Risk with Usual care	Risk difference with Coordinator (95% CI)
		imprecision			
Use of community services (patients having contact with hospice or MacMillan sister) 2 weeks before final interview	202 (1 study)	⨁⊖⊖⊖ VERY LOW[a,c] due to risk of bias, imprecision	RR 0.61 (0.25 to 1.51)	111 per 1000	43 fewer per 1000 (from 83 fewer to 57 more)
Hospitalisation (admissions)	167 (1 study)	⨁⊖⊖⊖ VERY LOW[a,c] due to risk of bias, imprecision		The mean hospitalisation (admissions) in the control groups was 3.3 admissions	The mean hospitalisation (admissions) in the intervention groups was 0.8 lower (1.76 lower to 0.16 higher)
Length of stay (inpatient days)	167 (1 study)	⨁⊖⊖⊖ VERY LOW[a,c] due to risk of bias, imprecision		The mean length of stay (inpatient days) in the control groups was 40 days	The mean length of stay (inpatient days) in the intervention groups was 15.9 lower (28.32 to 3.48 lower)
Number of hospital visits (outpatient attendance)	167 (1 study)	⨁⊖⊖⊖ VERY LOW[a,c] due to risk of bias, imprecision		The mean number of hospital visits (outpatient attendance) in the control groups was 10.1	The mean number of hospital visits (outpatient attendance) in the intervention groups was 7.9 higher (4.96 to 10.84 higher)
Use of community services (home visits-district nurses, Macmillan nurses, hospital oncology nurses, hospice homecare team)	167 (1 study)	⨁⊖⊖⊖ VERY LOW[a,c] due to risk of		The mean use of community services (home visits-district nurses, Macmillan nurses, hospital oncology nurses, hospice	The mean use of community services (home visits-district nurses, Macmillan nurses, hospital oncology nurses, hospice homecare team) in

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 Coordinator (95% CI)
		bias, imprecision		homecare team) in the control groups was 37.5	the intervention groups was 23 lower (38.4 to 7.6 lower)

[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 or 2 increments because the majority of the evidence had indirect outcomes
[c] Downgraded by 1 increment if the confidence interval crossed one MID or by 2 increments if the confidence interval crossed both MIDs

Table 6: Clinical evidence summary: Home-nurse case manager compared to usual care in adults with diagnosed with CHF or COPD thought to be entering their last two years of life

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 Case manager (95% CI)
Number of visits to Accident and Emergency (Emergency Department visits) 6 months	192 (1 study) 6 months	⨁⨁⊖⊖ LOW[a] due to risk of bias		The mean number of visits to Accident and Emergency(ED visits) 6 months in the control groups was 0.1	The mean number of visits to Accident and Emergency (ED visits) 6 months in the intervention groups was 0.01 higher (0.08 lower to 0.1 higher)

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

Table 7: Clinical evidence summary: Nurse coordinator compared to usual care in adults with life-limiting cancer thought to be entering their last year of life

Outcomes	No of	Quality of the	Relative	Anticipated absolute effects

	Participants (studies) Follow up	evidence (GRADE)	effect (95% CI)	Risk with Usual care	Risk difference with Coordinator (95% CI)
Length of survival (mortality) at 14.6 months	322 (1 study) 14.6 months	⊕⊕⊖⊖ LOW[a,b] due to risk of bias, indirectness	RR 0.94 (0.82 to 1.08)	739 per 1000	44 fewer per 1000 (from 133 fewer to 59 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 or 2 increments because the majority of the evidence had indirect outcomes

Table 8: Clinical evidence summary: Palliative care physician coordinator compared to usual care in adults with progressive life-limiting conditions thought to be entering their last year of life

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 MDT (home-based palliative care program) (95% CI)
People dying at home	298 (1 study)	⊕⊖⊖⊖ VERY LOW[a,b] due to risk of bias, indirectness	RR 1.53 (1.31 to 1.79)	568 per 1000	301 more per 1000 (from 176 more to 449 more)
Number of hospital visits	300 (1 study)	⊕⊖⊖⊖ VERY LOW[b,c] due to risk of bias, imprecision		The mean number of hospital visits in the control groups was 9.352	The mean number of hospital visits in the intervention groups was 6.99 lower (9.46 to 4.52 lower)
Number of visits to accident and emergency (ED visits)	300 (1 study)	⊕⊖⊖⊖ VERY LOW[b,c] due to risk of bias, imprecision		The mean number of visits to accident and emergency (Emergency Department visits) in the control groups was 2.297	The mean number of visits to accident and emergency (Emergency Department visits) in the intervention groups was 1.37 lower (1.78 to 0.95 lower)
Use of community services	300	⊕⊖⊖⊖		The mean use of community	The mean use of community services

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 MDT (home-based palliative care program) (95% CI)
(physicians visits)	(1 study)	VERY LOW[b,c] due to risk of bias, imprecision		services (physicians visits) in the control groups was 11.089	(physicians visits) in the intervention groups was 5.75 lower (8.9 to 2.6 lower)
Use of community services (skilled nursing care visits)	300 (1 study)	⊕⊖⊖⊖ VERY LOW[b,c] due to risk of bias, imprecision		The mean use of community services (skilled nursing care visits) in the control groups was 4.575	The mean use of community services (skilled nursing care visits) in the intervention groups was 3.72 lower (6.2 to 1.24 lower)
Use of community services (total home health visits)	300 (1 study)	⊕⊖⊖⊖ VERY LOW[b,c] due to risk of bias, imprecision		The mean use of community services (total home health visits) in the control groups was 13.247	The mean use of community services (total home health visits) in the intervention groups was 21.8 higher (14.63 to 28.98 higher)

[a] Downgraded by 1 or 2 increments because the majority of the evidence had indirect outcomes
[b] Downgraded by 1 increment if the confidence interval crossed one MID or by 2 increments if the confidence interval crossed both MIDs
[c] 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

Table 9: Clinical evidence summary: Nurse case manager compared to usual care in adults with life-limiting cancer thought to be entering their last year of life

Outcomes	No of Participants (studies) Follow up	Quality of the evidence (GRADE)	Relative effect (95% CI)	Anticipated absolute effects	
				Risk with Usual care (Seow 2008)	Risk difference with Case manager (95% CI)
Length of survival (deaths since referral (120+ days))	89 (1 study) 8-30 days	⊕⊖⊖⊖ VERY LOW[a,c] due to risk of bias, imprecision	RR 0.68 (0.37 to 1.23)		
				450 per 1000	144 fewer per 1000 (from 283 fewer to 104 more)
Length of survival (deaths since referral (31-	89	⊕⊖⊖⊖	RR 0.72		

Outcomes	No of Participants (studies) Follow up	Quality of the evidence (GRADE)	Relative effect (95% CI)	Anticipated absolute effects	
				Risk with Usual care (Seow 2008)	Risk difference with Case manager (95% CI)
120 days))	(1 study) 31-120 days	VERY LOW[a,c] due to risk of bias, imprecision	(0.38 to 1.39)	400 per 1000	112 fewer per 1000 (from 248 fewer to 156 more)
Length of survival (deaths since referral (8-30 days))	89 (1 study) 120+ days	⊕⊖⊖⊖ VERY LOW[a] due to risk of bias, imprecision	RR 2.71 (0.92 to 7.98)		
				150 per 1000	257 more per 1000 (from 12 fewer to 1000 more)
Length of stay	186 (1 study)	⊕⊖⊖⊖ VERY LOW[a] due to risk of bias			The mean length of stay in the intervention groups was 0.1 lower (2.54 lower to 2.34 higher)
ICU days	186 (1 study)	⊕⊖⊖⊖ VERY LOW[a,b] due to risk of bias, indirectness			The mean icu days in the intervention groups was 1 lower (3.69 lower to 1.69 higher)
Hospice days	186 (1 study)	⊕⊖⊖⊖ VERY LOW[a,b,c] due to risk of bias, indirectness, imprecision,			The mean hospice days in the intervention groups was 14.7 higher (1.09 to 28.31 higher)
Inpatient admission	186 (1 study)	⊕⊖⊖⊖ VERY LOW[a,b,c] due to risk of bias, indirectness, imprecision	OR 0.46 (0.23 to 0.92)		
				-	-
Avoidable/inappropriate admissions to ICU	186 (1 study)	⊕⊖⊖⊖ VERY LOW[a,c] due to risk of bias, imprecision	OR 0.47 (0.23 to 0.96)	-	-
Treat-and-release ED visit	186 (1 study)	⊕⊖⊖⊖ VERY LOW[a,b,c] due to risk of bias, indirectness, imprecision	OR 1.41 (0.62 to 3.21)		
				-	-

Outcomes	No of Participants (studies) Follow up	Quality of the evidence (GRADE)	Relative effect (95% CI)	Anticipated absolute effects	
				Risk with Usual care (Seow 2008)	Risk difference with Case manager (95% CI)
Persons with hospice election	186 (1 study)	⨁⊖⊖⊖ VERY LOW[a,b] due to risk of bias, indirectness	OR 0.81 (0.41 to 1.60)	-	-
Persons with death in hospital	186 (1 study)	⨁⊖⊖⊖ VERY LOW[a,b,c] due to risk of bias, indirectness, imprecision	OR 0.47 (0.23 to 0.96)	-	-

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 or 2 increments because the majority of the evidence had indirect outcomes
c Downgraded by 1 increment if the confidence interval crossed one MID or by 2 increments if the confidence interval crossed both MIDs

1.5.6 Quality assessment of clinical studies included in the evidence review on lead health professional

No relevant clinical studies were identified.

See Appendix F for full GRADE tables.

1.6 Economic evidence

1.6.1 Included studies

No relevant health economic studies were identified for either question.

1.6.2 Excluded studies

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

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

1.6.3 Unit costs

Table 10 and Table 11 provide some unit costs of health care professionals who might take of the role of either a care coordinator or lead healthcare professional for someone who is in the last year of life.

Table 10: UK costs of community-based health care staff time

Health Care Professional	Cost – hourly	Hours worked per year	Cost – annual
Nurse (Band 2 to Band 8a)	£22 - £73	1,553 – 1,573	£34,166 - £114,829
General Practitioner	NA	NA	£221,245[(a)] £222,445[(b)]
Scientific and professional staff (Band 2 to 8a)[(c)]	£23 - £74	1,569 – 1,603	£36,087 - £117,660

Source: Curtis (2016)[16]

(a) Annual (excluding travel), including direct care staff costs, without qualification costs

(b) Annual (including travel), including direct care staff costs, without qualification costs

(c) Please see Curtis (2016)[16] for details of the health care professionals included in this category by band. Examples include: Physiotherapists, Occupational therapists, Counsellors, Pharmacists.

Table 11: UK costs of hospital-based health care staff time

Health Care Professional	Cost – hourly	Hours worked per year	Cost – annual
Nurse (Band 2 to Band 9)	£23 - £122	1,573 – 1,611	£36,409 - £191,906
Doctors (FY1 – Consultant)	£24 - £106	1,698 – 2,133	£51,192 - £194,828
Scientific and professional staff (Band 2 to 8d-9)	£24 - £78	1,592 – 1,603	£38,208 - £125,034

Source: PSSRU[16]

1.7 Resource costs

The recommendations made based on this review (see section 1.9) may have a substantial impact on resources.

Additional costs could be incurred for the following reasons: the costs of the implementation of the role of an end of life care coordinator provided by GP services, hospital services and specialist services. The magnitude of the resource impact depends on the scale to which the above is already part of current practice of end of life care. This will depend on local circumstances. Savings could be made through: reduced duplication of activities by

healthcare professionals; reduced number of appointments for people in the last year of life; better coordination of end of life care; hospital admissions and hospital deaths avoided; reduced length of stay of hospital spells for people in the last year of life and through the facilitation of access to end of life care services for people in the last year of life. Further detail can be found in the resource impact tools that support the guideline, which will be available after final publication.

1.8 Evidence statements

1.8.1 Clinical evidence statements

1.8.1.1 Question 1 - Care coordinator

Nurse coordinator compared to usual care in adults thought to be entering their last year of life

There was evidence of clinically important benefit for the intervention group in carers and patients' satisfaction with care from district nurses and hospital team, while there was no clinically important benefit in carers and patients' satisfaction with care from GP, and carers satisfaction with care coordination, (1 study, n=118, very low quality). Clinically important benefit of having a coordinator was observed in the number of people dying in hospital, but no clinically important difference was observed in the number of people dying at home, in hospice or elsewhere (1 study, n=167, very low quality). There was no clinically important difference in the intervention group in terms of use of a range of community services, except for fewer clinically important contacts with hospice or Macmillan sisters, and home-visits from nurses and hospice homecare team (1 study, n=202, very low quality). There was also evidence of clinically important benefit of the intervention in terms of admissions to hospital, length of stay and number of hospital visits (outpatient attendance) (1 study, n=167, very low quality).

Home-nurse case manager compared to usual care in adults with diagnosed with CHF or COPD thought to be entering their last two years of life

For the outcome of number of visits to emergency department, there was no clinically important difference between the two groups (1 study, n=192, low quality).

Nurse coordinator compared to usual care in adults with life-limiting cancer thought to be entering their last year of life

For the outcome of length of survival (mortality), there was no clinically important difference between the two groups (1 study, n=322, low quality).

Palliative care physician coordinator compared to usual care in adults with progressive life-limiting conditions thought to be entering their last year of life

There was evidence of clinically important benefit for the intervention group in the number of people dying at home, number of hospital visits, number of visits to accident and emergency and use of community services (physicians visits, and skilled nursing care visits) (1 study, n=300, very low quality). There was evidence of clinically important benefit favouring the control group in the outcome of use of community services (total number of home health visits) (1 study, n=300, very low quality).

Nurse case manager compared to usual care in adults with life-limiting cancer thought to be entering their last year of life

For the outcome of length of survival, there was clinically important benefit of the intervention in the number of deaths at greater than 31 days from referral, but clinically important benefit favouring the control group in the number of deaths earlier than 31 days from referral (1

study, n=89, very low quality). There was a clinical benefit of nurse case manager compared to usual care for the following outcomes: days in the ICU, days in the hospice, in hospital, treat-and-release ED visit, hospice election, death in hospital and admissions to ICU (n=186, very low quality). There was no clinical difference for length of stay (n=186, very low quality).

1.8.1.2 Question 2 – Lead health professional

No relevant published evidence was identified.

1.8.2 Health economic evidence statements

1.8.2.1 Question 1 - Care coordinator

No relevant economic evaluations were identified.

1.8.2.2 Question 2 – Lead health professional

No relevant economic evaluations were identified.

1.9 Recommendations

D1. Provide end of life care coordination for adults who are approaching the end of their life through:

- community and primary care services for adults being cared for in their usual place of residence, for example, provided by the person's GP or another health and socal care practitioner in the primary or community care team
- hospital services for adults whose treatment is based in secondary or tertiary care.

D2. End of life care coordination based in secondary or tertiary care (for example, provided by health and social care practitioners based in hospices or disease-specific specialists in hospitals) should ensure there is communication with the health and social care practitioners providing community-based care.

D3. Health and social care practitioners providing end of life care coordination should:

- provide information to the person approaching the end of their life, their carers and others important to them, about who the multipractitioner team members are (this should include the lead healthcare professionals in each setting responsible for their care), the roles of the team members and how services are accessed
- ensure that holistic needs assessments are done and the person's needs are discussed and acted on
- ensure that care is coordinated across and between the multipractitioner teams and between care settings
- ensure that regular discussions and reviews of care and advance care plans take place
- share information about the person's care between members of the multipractitioner teams.

1.10 Rationale and impact

1.10.1 Why the committee made the recommendations

Providing end of life care coordination

(Recommendation D1)

The evidence on identifying barriers to accessing services showed that continuity and coordination of care are often identified as being unsatisfactory for adults approaching the end of their life and their carers. The evidence also highlighted a lack of information and poor communication with carers, which could be improved with better coordination of care.

The committee agreed that good coordination of care and effective communication systems are especially important when people have contact with multiple services and organisation.

The committee also agreed that good coordination of care should include systems to review appointments and home visits, both to support efficiency of care and also to avoid overwhelming the person with multiple visits from different services.

(Recommendations D2-D3)

The evidence showed that having someone to organise care was of some benefit, particularly in reducing unscheduled and emergency hospital visits and admissions. However, it was not clear if this should be a specific role or who should do this. Thereforethe committee listed the key principles within end of life care coordination that community, hospital and hospice services could provide in colloboration rather than specifying who should take on this role and where it should be located.

Reviewing current care

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

To encourage more research in this area, research recommendations were also developed (see Chapters B (Early vs Late referral) for the research recommendation on Early review of service provision and referral to additional specialist palliative care services. See also Chapter J (Review of service provision and identification of additional services) for research recommendation on planned regular community-based reviews.

1.10.2 Impact of the recommendations on practice

Providing end of life care coordination

Recommendation D1

The recommendation reflects current good practice available in some services, but there is variation nationally. In areas where good coordination of care is lacking, it should result in more efficient service provision and help to minimise crises and support people to stay in their preferred place of care. Good care coordination should also reduce the use of unnecessary services and avoid duplication of care.

Recommendations D2-D3

The recommendations reflect current good practice available in some services, but there is variation nationally. Where good coordination of care is lacking, the recommendations should result in more efficient service provision and help to minimise crises and support people to receive personalised and planned care in their preferred place. Care coordination by health care professionals is taking place currently in the NHS but the committee are uncertain how

extensively it is practiced. Additional resources may be needed to coordinate care across services and deliver the key roles of end of life care coordination , but it should help to reduce the use of unnecessary services and avoid duplication of care.

Reviewing current needs

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

Additional evidence and the committee's discussions can be found in evidence review J: identifying the need for additional services; timing and frequency of review of services.

1.11 The committee's discussion of the evidence

1.11.1 Interpreting the evidence

1.11.1.1 The outcomes that matter most

The Committee identified quality of life and preferred place of care and death as the critical outcomes to measure the impact of a care coordinator to the provision of palliative care services. These critical outcomes were identified as outcomes that would reflect a direct benefit to the patient as they are about maintaining or improving their quality of life and upholding their choices in the last year of life. The following outcomes were identified as important for decision making and focus on the impact and use of health resources as well as the impact on the patient; length of hospital 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/inappropriate admissions to ICU, inappropriate attempts at cardiopulmonary resuscitation and staff, patient and carer satisfaction .

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

There were some difficulties in interpreting the evidence as it is hard to make a judgement on whether the outcome is a benefit to the person. For example length of hospital stay could be a positive or negative outcome for the patient. Without more details on the person's preferences a conclusion on the benefit can only be assumed.

It should be noted that the use of a coordinator will bring multiple agencies together and the clinical decisions that are made about which treatments will be started or discontinued can have a bearing on the place of care and the professionals with whom they will be in contact with.

The same outcomes applied to lead healthcare professionals.

Care coordinator

For the critical outcomes, three studies reported actual place of death, which was an indirect outcome for actual place of death compared to preferred place of death. One of the studies reported quality of life in a narrative format.

For the important outcomes, two studies reported the outcome length of survival. Two studies reported the use of community services. One study reported hospice days and persons with hospice election. Two studies reported the number of hospital visits. Two studies reported the number of hospital admissions but none reported whether these were unscheduled or avoidable. Two studies reported the number of visits to accident and

emergency. Two studies reported length of stay. One study reported satisfaction of patient or family. One study reported number of admissions to ICU and number of days in ICU but did not report whether it was unscheduled, inappropriate or avoidable admissions. No studies reported inappropriate attempts at cardiopulmonary resuscitation or staff satisfaction.

Lead Health Professional

No relevant clinical studies were identified.

1.11.1.2 The quality of the evidence

Care coordinator

The quality of the evidence ranged from very low to low. This was due to high risk of bias (due to selection bias, performance bias and incomplete outcome reporting) as well as the imprecise nature of the results extracted and analysed in this review. Indirectness in some outcomes (for example: actual and final place of death; hospital admissions) further contributed to the final GRADE rating.

For two of the papers, data were only reported as mean with no standard deviation for length of survival and hospitalisation; another study reported the quality of life outcome in a narrative format. Conclusions on the efficacy based on these outcomes could not be made with any degree of certainty.

A number of the studies did not describe the comparator (usual care).

The Committee noted that the only study conducted in the UK was performed 25 years ago and considered that it was important to note that care for people in the last year of life has considerably changed in the last few years.

Lead health professional

No relevant clinical studies were identified.

1.11.1.3 Benefits and harms

Care coordinator

The Committee commented there was low to very low quality evidence indicating a clinically important benefit of a care coordinator in reducing the use of community services, hospital and ICU admissions and visits, visits to accident and emergency and death in hospital. There were more hospice placements and time spent in hospice in those with a care coordinator. There was mixed evidence in terms of patients and carers' satisfaction and whether there was a benefit or no difference in length of stay in hospital and the ICU.

The Committee was not surprised to see mixed evidence in terms of length of survival, as they felt that for this type of intervention this would be a less significant outcome.

Furthermore, the Committee noted that most of the studies reported it was a nurse that coordinated the services, in contrast another study reported the greatest reduction in service use had a physician in this role. However, the Committee commented that the role of coordinator could also be carried out by other health professionals and observed that these roles are often not profession specific and entail several functions.

Lead health professional

No relevant clinical studies were identified for this review.

Summary

Overall, the Committee agreed there was no conclusive evidence describing how coordination of services should be carried out. However, as there was no significant evidence of harm, and based on their expert knowledge, the Committee agreed that care coordination for people in their last year of life is likely to be valuable. The Committee acknowledged that coordinationof care is important to provide consistent care, particularly in the context of the complexity of care often present in the the last year of life. The Committee agreed on a consensus recommendation that people in the last year of life should have their care co-ordinated . The Committee noted that people providing this care are mostly located in the community and would often be the person's general practitioner, or another member of the community team, as these professionals are ideally placed to have a general overview of the patient's care. However, for people whose care is more dependent on secondary or tertiary care services, for example people who are still receiving active disease-modifying treatment in hospital, the coordination of care could be provided by health professionals based in secondary or tertiary care. The Committee agreed there should be a single point of contact for all people involved in the person's care, providing information on service provision and patient advocacy, coordinating care and management.

1.11.2 Cost effectiveness and resource use

Care coordination

The resource and cost impact of end of life care coordination depends on which member of staff is assigned the role. Different health care professionals cost the NHS different amounts (see the unit costs section of this report). The committee agreed that there is likely to be a resource impact regardless of who carries out the role.

During discussion, the committee considered that having coordination would change the use of resources in terms of a patient's direct medical costs. The committee noted that through coordination, patients could be referred for services that they themselves would not have easy access to. Unfortunately, it would be difficult to assess the effect this would have on costs. In some scenarios it could be cost increasing and in others it could be cost saving, for example if the services decreased the number of avoidable hospital admissions.

No published economic evaluations were identified for this review question. The Addington-Hall (1992) study reported that implementing a nurse co-ordinator led to fewer people dying at hospital or in a hospice and more people dying at home. This should decrease costs as some research suggests there is an estimated potential net saving of £958 per person who dies in the community rather than in hospital. [36] The study also reported that the intervention group used less community services such as district nurse services, GP-home visits, GP-surgery visits, hospice visits or healthcare professional contact time. The mean number of hospital visits was 0.8 lower in the intervention group and the mean length of stay in hospital was 15.9 days lower, although the number of outpatient hospital visits was higher in the intervention group. Although the study did not report costs, the committee felt that the results suggest that costs were likely to have been lower in the intervention group. However, the committee acknowledged the high risk of bias in the results of the study and that as it was published over 20 years ago the services available and their configurations are likely to be very different today.

Brumley (2003) reported more people dying at home and fewer hospital visits in the intervention group which suggests that the intervention lowered costs. As the study did not report costs this is only an assumption.

The coordination of services varies by service models and availability across the country in terms of skill mix, professional background, and existence of a distinct role. In areas where this distinct role does not currently exist (and others may have picked up the function) then

recommending care coordination might have significant resource implications. Care coordination by health care professionals is taking place currently in the NHS and is accepted good practice but the committee are uncertain how extensively it is practiced.

Lead Health Professional

The committee agreed that implementing the use of GPs as lead health professionals would have a resource implication in terms of GP time. However, they noted that it would not be likely to cost a significant amount more than current practice as (according to the committee) the majority of GPs are already carrying out this role. The committee highlighted that having a lead health professional in place could be cost saving to the NHS if were to lead to better methods of information sharing and less duplications of tasks. The committee also noted that the lead health professional might change over the last year of life, depending on the setting that the patient is being care for in.

No economic evidence was identified for this review question and the question was not prioritised for original economic analysis therefore the estimated low cost of implementing the recommendation comes from committee member consensus.

1.11.3 Other factors the committee took into account

The Committee noted that current practice shows a considerable heterogeneity across the UK, and that care coordination of some form is in place in most planned admissions. There are currently different initiatives, particularly local ones in general practices, but these are not currently evaluated.

The Committee were aware of other existing NICE guidance on the role of lead healthcare professionals in NG31 Care of dying adults in the last days of life. The recommendation was based on qualitative evidence on barriers and facilitators to the multi-professional team, dying person and those important to them in being involved in shared decision-making to inform the development of personalised care plans for the last few days of life. The Committee noted that service delivery is more complex over the last year of life, compared to the last days of life, and agreed that someone should be responsible for coordinating that care.

The recommendation focuses on healthcare professionals delivering coordinated care , the committee noted that although this service was usually based in community health services it was possible that this could be undertaken by members of the social care team (for example, social workers) working within a multipractitioner team.

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Appendices

Appendix A: Review protocols

Table 12: Review protocol for is a Care coordinator **c clinically and cost-effective to facilitate the continuity and coordination of care for people who are in their last year of life?**

Question number: 2

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

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

Field names are based on PRISMA-P.]

ID	Field	Content
I	Review question	Is a care facilitator/key worker/coordinator/case manager clinically and cost-effective to facilitate the continuity and coordination of care for people who are in their last year of life?
II	Type of review question	Intervention review. A review of health economic evidence related to the same review question was conducted in parallel with this review. For details see the health economic review protocol for this NICE guideline.
III	Objective of the review	To identify whether facilitator/key worker/coordinator/case manager is clinically and cost-effective to facilitate the continuity and coordination of care for people who are in their last year of life
IV	Eligibility criteria – population / disease / condition / issue / domain	Adults (aged over 18 or over) with progressive life-limiting conditions thought to be entering the last year of life.
V	Eligibility criteria – intervention(s) / exposure(s) / prognostic factor(s)	• Facilitator • Key worker • Coordinator • Case manager
VI	Eligibility criteria – comparator(s) / control or reference (gold) standard	• To each other • Usual care (no facilitator/coordinator/key worker/case manager)
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 stay (Continuous) • Length of survival (Dichotomous) • 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 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	• Children and young people (17 years or younger) in their last year of life • Studies will only be included if they reported one of more of the outcomes listed above • Descriptive (non-comparative) studies will be excluded
X	Proposed sensitivity / subgroup analysis, or meta-regression	Subgroup analyses if there is heterogeneity: • Younger adults (aged 18-25) • Frail elderly • People with dementia • People with hearing loss • People with advanced heart and lung disease • People in prisons • Socioeconomic inequalities (people from lower income brackets) • Homeless people/vulnerably housed • Travellers • People with learning difficulties • People with disabilities • People with mental health problems • Migrant workers • LGBT • People in whom life-prolonging therapies are still an active option
XI	Selection process – duplicate screening / selection / analysis	Quality assurance will be undertaken by a senior research fellow prior to completion. Review strategy/other analysis: • Information on identification tools used as part of a service will be extracted. • Due to the expected complexity of the service models implemented in the studies, studies will be reported separately if necessary. In such case, studies on the populations included in the subgroup list will be highlighted to the Committee and will be considered when making the recommendations
XII	Data management	• Pairwise meta-analyses were performed using Cochrane

	(software)	Review Manager (RevMan5). • GRADEpro was used to assess the quality of evidence for each outcome. • Endnote was used for: ○ Bibliography, citations, sifting and reference management • Evibase was used for ○ Data extraction and quality assessment / critical appraisal
XIII	Information sources – databases and dates	Clinical search databases to be used: Medline, Embase, Cochrane Library, Current Nursing and Allied Health Literature (CINAHL), PsycINFO, Healthcare Management Information Consortium (HMIC), Social Policy and Practice (SSP), Applied Social Sciences Index and Abstracts (ASSIA) Date: All years Health economics search databases to be used: Medline, Embase, NHSEED, HTA Date: Medline, Embase from 2014 NHSEED, HTA – All years Language: Restrict to English only
XIV	Identify if an update	Not applicable.
XV	Author contacts	https://www.nice.org.uk/guidance/indevelopment/gid-cgwave0799
XVI	Highlight if amendment to previous protocol	For details please see section 4.5 of Developing NICE guidelines: the manual.
XVII	Search strategy – for one database	For details please see Appendix B
XVIII	Data collection process – forms / duplicate	A standardised evidence table format will be used, and published as appendix D of the evidence report.
XIX	Data items – define all variables to be collected	For details please see evidence tables in Appendix D (clinical evidence tables) or G (health economic evidence tables).
XX	Methods for assessing bias at outcome / study level	Standard study checklists were used to critically appraise individual studies. For details please see section 6.2 of Developing NICE guidelines: the manual The risk of bias across all available evidence was evaluated for each outcome using an adaptation of the 'Grading of Recommendations Assessment, Development and Evaluation (GRADE) toolbox' developed by the international GRADE working group http://www.gradeworkinggroup.org/ [Please document any deviations/alternative approach when GRADE isn't used or if a modified GRADE approach has been used for non-intervention or non-comparative studies.]
XXI	Criteria for quantitative synthesis	For details please see section 6.4 of Developing NICE guidelines: the manual.
XXII	Methods for quantitative analysis – combining studies and exploring (in)consistency	For details please see the separate Methods report for this guideline.

XXIII	Meta-bias assessment – publication bias, selective reporting bias	For details please see section 6.2 of Developing NICE guidelines: the manual. [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 [add link to history page of the guideline] developed the evidence review. The committee was convened by the National Guideline Centre (NGC) and chaired by [add name of Chair] in line with section 3 of Developing NICE guidelines: the manual. Staff from NGC undertook systematic literature searches, appraised the evidence, conducted meta-analysis and cost-effectiveness analysis where appropriate, and drafted the evidence review in collaboration with the committee. For details please see Developing NICE guidelines: the manual.
XXVII	Sources of funding / support	NGC is funded by NICE and hosted by the Royal College of Physicians.
XXVIII	Name of sponsor	NGC is funded by NICE and hosted by the Royal College of Physicians.
XXIX	Roles of sponsor	NICE funds NGC to develop guidelines for those working in the NHS, public health and social care in England.
XXX	PROSPERO registration number	Not registered [If registered, add PROSPERO registration number]

Table 13: Review protocol for is a lead health professional clinically and cost-effective to facilitate the continuity and coordination of care for people who are in their last year of life?

Question number: 3

Relevant section of Scope:

Field names are based on PRISMA-P.]

ID	Field	Content
I	Review question	Is a lead health professional clinically and cost-effective to facilitate the continuity and coordination of care for people who are in their last year of life?
II	Type of review question	Intervention review. A review of health economic evidence related to the same review question was conducted in parallel with this review. For details see the health economic review protocol for this NICE guideline.
III	Objective of the review	To identify whether a lead health professional is clinically and cost-effective to facilitate the continuity and coordination of care for people who are in their last year of life.
IV	Eligibility criteria – population / disease / condition	Adults (aged over 18 or over) with progressive life-limiting conditions thought to be entering the last year of life.

	/ issue / domain	
V	Eligibility criteria – intervention(s) / exposure(s) / prognostic factor(s)	• Lead health professional • Usual care (no lead health professional)
VI	Eligibility criteria – comparator(s) / control or reference (gold) standard	• To each other • Usual care (no facilitator/coordinator/key worker/case manager)
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 stay (Continuous) • Length of survival (Dichotomous) • 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 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	• Children and young people (17 years or younger) in their last year of life • Studies will only be included if they reported one of more of the outcomes listed above • Descriptive (non-comparative) studies will be excluded
X	Proposed sensitivity / subgroup analysis, or meta-regression	Subgroup analyses if there is heterogeneity: • Younger adults (aged 18-25) • Frail elderly • People with dementia • People with hearing loss • People with advanced heart and lung disease • People in prisons • Socioeconomic inequalities (people from lower income brackets) • Homeless people/vulnerably housed • Travellers • People with learning difficulties • People with disabilities • People with mental health problems • Migrant workers

		• LGBT • People in whom life-prolonging therapies are still an active option
XI	Selection process – duplicate screening / selection / analysis	Quality assurance will be undertaken by a senior research fellow prior to completion. Review strategy/other analysis: • Information on identification tools used as part of a service will be extracted. • Due to the expected complexity of the service models implemented in the studies, studies will be reported separately if necessary. In such case, studies on the populations included in the subgroup list will be highlighted to the Committee and will be considered when making the recommendations
XII	Data management (software)	• Pairwise meta-analyses were performed using Cochrane Review Manager (RevMan5). • GRADEpro was used to assess the quality of evidence for each outcome. • Endnote was used for: o Bibliographies / citations, text mining, and study sifting • Evibase was used for o Data extraction and quality assessment / critical appraisal
XIII	Information sources – databases and dates	Databases: Medline, Embase, The Cochrane Library, CINAHL Date limits for search: all years Language: English only
XIV	Identify if an update	Not applicable.
XV	Author contacts	https://www.nice.org.uk/guidance/indevelopment/gid-cgwave0799
XVI	Highlight if amendment to previous protocol	For details please see section 4.5 of Developing NICE guidelines: the manual.
XVII	Search strategy – for one database	For details please see Appendix B
XVIII	Data collection process – forms / duplicate	A standardised evidence table format will be used, and published as appendix D of the evidence report.
XIX	Data items – define all variables to be collected	For details please see evidence tables in Appendix D (clinical evidence tables) or G (health economic evidence tables).
XX	Methods for assessing bias at outcome / study level	Standard study checklists were used to critically appraise individual studies. For details please see section 6.2 of Developing NICE guidelines: the manual The risk of bias across all available evidence was evaluated for each outcome using an adaptation of the 'Grading of Recommendations Assessment, Development and Evaluation (GRADE) toolbox' developed by the international GRADE working group http://www.gradeworkinggroup.org/ [Please document any deviations/alternative approach when GRADE isn't used or if a modified GRADE approach has been used for non-intervention or non-comparative studies.]
XXI	Criteria for quantitative synthesis	For details please see section 6.4 of Developing NICE guidelines: the manual.
XXII	Methods for quantitative	For details please see the separate Methods report for this guideline.

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

Table 14: Health economic review protocol

Review question	All questions – health economic evidence
Objectives	To identify health economic studies relevant to any of the review questions.
Search criteria	• Populations, interventions and comparators must be as specified in the clinical review protocol above. • Studies must be of a relevant health economic study design (cost–utility analysis, cost-effectiveness analysis, cost–benefit analysis, cost–consequences analysis, comparative cost analysis). • Studies must not be a letter, editorial or commentary, or a review of health economic evaluations. (Recent reviews will be ordered although not reviewed. The bibliographies will be checked for relevant studies, which will then be ordered.) • Unpublished reports will not be considered unless submitted as part of a call for evidence. • Studies must be in English.
Search strategy	A health economic study search will be undertaken using population-specific terms and a health economic study filter – see Appendix G *[in the Full guideline]*
Review strategy	Studies not meeting any of the search criteria above will be excluded. Studies published before 2007, abstract-only studies and studies from non-OECD countries or

the USA will also be excluded.

Each remaining study will be assessed for applicability and methodological limitations using the NICE economic evaluation checklist which can be found in Appendix H of Developing NICE guidelines: the manual (2014).[37]

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 H.

The health economist will be guided by the following hierarchies.

Setting:

- UK NHS (most applicable).
- OECD countries with predominantly public health insurance systems (for example, France, Germany, Sweden).
- OECD countries with predominantly private health insurance systems (for example, Switzerland).
- Studies set in non-OECD countries or in the USA will be excluded before being assessed for applicability and methodological limitations.

Health economic study type:

- Cost–utility analysis (most applicable).
- Other type of full economic evaluation (cost–benefit analysis, cost-effectiveness analysis, cost–consequences analysis).
- Comparative cost analysis.
- Non-comparative cost analyses including cost-of-illness studies will be excluded before being assessed for applicability and methodological limitations.

Year of analysis:

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

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

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

1

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 15: Database date parameters and filters used

Database	Dates searched	Search filter used
Medline (Ovid)	1946 – 04 January 2019	Exclusions
Embase (Ovid)	1974 – 04 January 2019	Exclusions
The Cochrane Library (Wiley)	Cochrane Reviews to Issue 1 of 12, January 2019 CENTRAL to Issue 1 of 12, January 2019 DARE, and NHSEED to Issue 2 of 4 2015 HTA to Issue 4 of 4 2016	None
CINAHL, Current Nursing and Allied Health Literature (EBSCO)	Inception – 04 January 2019	Limiters - English Language; Exclude MEDLINE records; Publication Type: Clinical Trial, Journal Article, Meta Analysis, Randomized Controlled Trial, Systematic Review: Age Groups: All Adult; Language: English
PsycINFO (ProQuest)	Inception – 04 January 2019	Study type
HMIC. Healthcare Management Information Consortium (Ovid)	1979 – 04 January 2019	Exclusions
SPP, Social Policy and Practice	1981 – 04 January 2019	Study types
ASSIA, Applied Social Sciences Index and Abstracts (ProQuest)	1987 – 04 January 2019	None

Medline (Ovid) search terms

1.	Palliative care/
2.	Terminal care/
3.	Hospice care/
4.	palliat*.ti,ab.
5.	Terminally Ill/
6.	((terminal* or long term or longterm) adj2 (care* or caring or ill*)).ti,ab.
7.	((dying or terminal) adj (phase* or stage*)).ti,ab.
8.	life limit*.ti,ab.
9.	Nursing Homes/
10.	((care or nursing) adj2 (home or homes)).ti,ab.
11.	Respite Care/
12.	((respite or day) adj2 (care or caring)).ti,ab.
13.	Hospices/
14.	hospice*.ti,ab.
15.	*Patient care planning/
16.	*"Continuity of Patient Care"/
17.	((advance* or patient*) adj3 (care or caring) adj3 (continu* or plan*)).ti,ab.
18.	*Attitude to Death/
19.	(attitude* adj3 (death* or dying*)).ti,ab.
20.	*Physician-Patient Relations/
21.	*Long-Term Care/
22.	*"Delivery of Health Care"/
23.	(end adj2 life).ti,ab.
24.	EOLC.ti,ab.
25.	((last or final) adj2 (year or month*) adj2 life).ti,ab.
26.	((dying or death) adj2 (patient* or person* or people or care or caring)).ti,ab.
27.	or/1-26
28.	letter/
29.	editorial/
30.	news/
31.	exp historical article/
32.	Anecdotes as Topic/
33.	comment/
34.	case report/
35.	(letter or comment*).ti.
36.	or/28-35

37.	randomized controlled trial/ or random*.ti,ab.
38.	36 not 37
39.	animals/ not humans/
40.	exp Animals, Laboratory/
41.	exp Animal Experimentation/
42.	exp Models, Animal/
43.	exp Rodentia/
44.	(rat or rats or mouse or mice).ti.
45.	or/38-44
46.	27 not 45
47.	limit 46 to English language
48.	(exp child/ or exp pediatrics/ or exp infant/) not (exp adolescent/ or exp adult/ or exp middle age/ or exp aged/)
49.	47 not 48
50.	patient care team/
51.	interdisciplinary communication/
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 round* or panel* or forum* or fora or communicat* or collaborat* or relat*)) or MDT or IDT).ti,ab.
54.	(key adj2 work*).ti,ab.
55.	((healthcare or care) adj2 (lead or leader or leads or facilitat*)).ti,ab.
56.	((healthcare or care) adj1 profession*).ti,ab.
57.	*Case Management/
58.	(case adj2 manage*).ti,ab.
59.	(co-ordinator* or coordinator* or coordinate* or co-ordinate*).ti,ab.
60.	Or/50-59
61.	49 and 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/74-79
69.	49 and 60 and 68
70.	(commission* adj2 (support* or service* or model*)).ti,ab.
71.	((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.
72.	Critical Pathways/

73.	((critical or clinic* or service* or care) adj2 path*).ti,ab.
74.	Patient Care Bundles/
75.	(care adj2 (bundle* or service* or package* or standard*)).ti,ab.
76.	or/70-75
77.	(assess* or criteria* or predict* or recogni* or identif* or refer*).ti,ab.
78.	49 and 76 and 77
79.	gold standard*.ti,ab.
80.	49 and 79
81.	(amber adj2 bundle).ti,ab.
82.	78 or 80 or 81
83.	Social Welfare/ec, ed, es, eh, ma, st, sn, td [Economics, Education, Ethics, Ethnology, Manpower, Standards, Statistics & Numerical Data, Trends]
84.	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]
85.	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]
86.	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]
87.	Telemedicine/ec, es, ma, mt, og, st, sn, td, ut [Economics, Ethics, Manpower, Methods, Organization & Administration, Standards, Statistics & Numerical Data, Trends, Utilization]
88.	exp remote consultation/
89.	*telemedicine/ or *telepathology/ or *teleradiology/ or *telerehabilitation/
90.	(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.
91.	((tele* or remote) adj2 consult*).ti,ab.
92.	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]
93.	(mobile adj2 (health or care) adj2 unit*).ti,ab.
94.	(hospital-based home care or HBHC or hospital-based hospice care or acute hospital care).ti,ab.
95.	(hospital adj3 (domicil* or home)).ti,ab.
96.	home hospitali*ation.ti,ab.
97.	exp Home Care Agencies/
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/83-102
104.	*"Continuity of Patient Care"/
105.	*Aftercare/ or *Patient discharge/ or *Patient handoff/ or *Patient transfer/ or *Transitional care/
106.	Patient Discharge Summaries/

107.	((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.
108.	((care or caring or serv*) adj2 (continu* or change* or transition* or transfer*)).ti,ab.
109.	(discharg* adj2 (facilitat* or rapid* or pathway* or path way* or plan* or program*)).ti,ab.
110.	Or/104-109
111.	exp Advance Care Planning/
112.	(advance* adj2 (plan* or decision* or directive*)).ti,ab.
113.	living will*.ti,ab.
114.	or/111-113
115.	After-Hours Care/
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.	Hospital 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 telemedicine/
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.	hotlines/
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.	Caregivers/
131.	Spouses/
132.	Family/
133.	(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.
134.	Or/130-133
135.	((replacement or break* or holiday* or respite) adj3 (care* or service*)).ti,ab.
136.	((communit* or support* or psychosocial* or psycholog*) adj3 (service* or group* or system*)).ti,ab.
137.	((group* or support* or psychosocial* or psycholog*) adj3 (selfhelp or self help or therap*)).ti,ab.

138.	((psychosocial* or psycholog*) adj2 support*).ti,ab.
139.	Self-Help Groups/
140.	exp social support/
141.	Counseling/
142.	(counseling or counselling*).ti,ab.
143.	(buddy* or buddies).ti,ab.
144.	((health* or medical*) adj2 check*).ti,ab.
145.	((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.
146.	or/125-145
147.	49 and 134 and 146
148.	49 and (103 or 110 or 114 or 129)
149.	61 or 69 or 82 or 147 or 148

1 **Embase (Ovid) search terms**

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

28.	letter.pt. or letter/
29.	note.pt.
30.	editorial.pt.
31.	case report/ or case study/
32.	(letter or comment*).ti.
33.	or/28-32
34.	randomized controlled trial/ or random*.ti,ab.
35.	33 not 34
36.	animal/ not human/
37.	nonhuman/
38.	exp Animal Experiment/
39.	exp Experimental Animal/
40.	animal model/
41.	exp Rodent/
42.	(rat or rats or mouse or mice).ti.
43.	or/35-42
44.	27 not 43
45.	(exp child/ or exp pediatrics/ or exp infant/) not (exp adolescent/ or exp adult/ or exp middle age/ or exp aged/)
46.	44 not 45
47.	limit 46 to English language
48.	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.	Or/50-57
59.	47 and 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.	(palliativ* adj2 (care or caring)).ti,ab.
65.	Or/60-64

66.	47 and 58 and 65
67.	(commission* adj2 (support* or service* or model*)).ti,ab.
68.	((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.
69.	*Clinical Pathway/
70.	((critical or clinic* or service* or care) adj2 path*).ti,ab.
71.	*Care Bundle/
72.	(care adj2 (bundle* or service* or package* or standard*)).ti,ab.
73.	or/67-72
74.	(assess* or criteria* or predict* or recogni* or identif* or refer*).ti,ab.
75.	47 and 73 and 74
76.	gold standard*.ti,ab.
77.	47 and 76
78.	(amber adj2 bundle).ti,ab.
79.	75 or 77 or 78
80.	(advance* adj2 (plan* or decision* or directive*)).ti,ab.
81.	living will*.ti,ab.
82.	80 or 81
83.	*Caregiver/
84.	*Spouse/
85.	*Family/
86.	(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.
87.	Or/83-86
88.	((replacement or break* or holiday* or respite) adj3 (care* or service*)).ti,ab.
89.	((communit* or support* or psychosocial* or psycholog*) adj3 (service* or group* or system*)).ti,ab.
90.	((group* or support* or psychosocial* or psycholog*) adj3 (selfhelp or self help or therap*)).ti,ab.
91.	((psychosocial* or psycholog*) adj2 support*).ti,ab.
92.	*Self-Help/
93.	*Social support/
94.	*Counseling/
95.	(counseling or counselling*).ti,ab.
96.	(buddy* or buddies).ti,ab.
97.	((health* or medical*) adj2 check*).ti,ab.
98.	((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.
99.	or/88-98
100.	47 and 87 and 99

101.	*social welfare/
102.	*community health nursing/ or *community care/
103.	*senior center/
104.	*telemedicine/ or *telehealth/
105.	*teleconsultation/
106.	(telehealth or tele health or virtual hospital* or helpline* or help line* or rapid response team* or mobile health unit*).ti,ab.
107.	*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/
108.	*health care personnel/ or *health auxiliary/ or *nursing home personnel/
109.	(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.
110.	((tele* or remote) adj2 consult*).ti,ab.
111.	(mobile adj2 (health or care) adj2 unit*).ti,ab.
112.	(hospital-based home care or HBHC or hospital-based hospice care or acute hospital care).ti,ab.
113.	(hospital adj3 (domicil* or home)).ti,ab.
114.	home hospitali*ation.ti,ab.
115.	(social adj (welfare or care)).ti,ab.
116.	(nurs* adj4 (home-visit* or home visit* or home-based or home based)).ti,ab.
117.	((district* or communit* or home or visit*) adj nurs*).ti,ab.
118.	(community adj2 (health care or healthcare or nursing or nurse*)).ti,ab.
119.	((hospitali*ation* or admission* or readmission* or admit*) adj3 (reduc* or avoid* or prevent* or inappropiate or increase* or risk*)).ti,ab.
120.	Or/101-119
121.	*patient care/ or *case management/ or *patient care planning/ or *rapid response team/
122.	*aftercare/
123.	*hospital discharge/
124.	*clinical handover/
125.	*transitional care/
126.	*patient care planning/
127.	*medical record/
128.	((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.
129.	((care or caring or serv*) adj2 (continu* or change* or transition* or transfer*)).ti,ab.
130.	(discharg* adj2 (facilitat* or rapid* or pathway* or path way* or plan* or program*)).ti,ab.
131.	Or/121-130
132.	(after hours care or after-hours care).ti,ab.
133.	((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.

134.	rapid response.ti,ab.
135.	rapid response team/
136.	(critical care adj2 outreach).ti,ab.
137.	medical emergency team*.ti,ab.
138.	(hospital* adj2 home*).ti,ab.
139.	hospital at night.ti,ab.
140.	("NHS 111" or "NHS 24" or "NHS Direct").ti,ab.
141.	exp telehealth/
142.	(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.
143.	telephone/
144.	(hotline* or helpline* or help-line* or call cent* or call service*).ti,ab.
145.	((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.
146.	or/132-145
147.	47 and (82 or 120 or 131 or 146)
148.	59 or 66 or 79 or 100 or 147

1 **Cochrane Library (Wiley) search terms**

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

#27.	(or #1-#26)
#28.	MeSH descriptor: [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.	(or #28-#37)
#39.	#27 and #38
#40.	MeSH descriptor: [Interdisciplinary Communication] explode all trees
#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.	(palliativ* near/2 (care or caring)):ti,ab
#46.	(or #40-#45)
#47.	#27 and #38 and #46
#48.	MeSH descriptor: [Advance Care Planning] explode all trees
#49.	(advance* near/2 (plan* or decision* or directive*)):ti,ab
#50.	living will*:ti,ab
#51.	(or #48-#50)
#52.	(commission* near/2 (support* or service* or model*)):ti,ab
#53.	((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
#54.	MeSH descriptor: [Critical Pathways] explode all trees
#55.	((critical or clinic* or service* or care) near/2 path*):ti,ab
#56.	MeSH descriptor: [Patient Care Bundles] explode all trees
#57.	(care near/2 (bundle* or service* or package* or standard*)):ti,ab
#58.	(or #52-#57)
#59.	(assess* or criteria* or predict* or recogni* or identif* or refer*):ti,ab
#60.	#27 and #58 and #59
#61.	gold standard*:ti,ab
#62.	#27 and #61
#63.	(amber near/2 bundle):ti,ab
#64.	#60 or #62 or #63

#65.	MeSH descriptor: [Caregivers] this term only
#66.	MeSH descriptor: [Spouses] this term only
#67.	MeSH descriptor: [Family] this term only
#68.	(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
#69.	(or #65-68)
#70.	((replacement or break* or holiday* or respite) near/3 (care* or service*)):ti,ab
#71.	((communit* or support* or psychosocial* or psycholog*) near/3 (service* or group* or system*)):ti,ab
#72.	((group* or support* or psychosocial* or psycholog*) near/3 (selfhelp or self help or therap*)):ti,ab
#73.	((psychosocial* or psycholog*) near/2 support*):ti,ab
#74.	MeSH descriptor: [Self-Help Groups] this term only
#75.	MeSH descriptor: [Social Support] explode all trees
#76.	MeSH descriptor: [Counseling] this term only
#77.	(counseling or counselling*):ti,ab
#78.	(buddy* or buddies):ti,ab
#79.	(health or medical*) near/3 check*:ti,ab
#80.	(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
#81.	(or #70-#60)
#82.	#27 and #69 and #81
#83.	MeSH descriptor: [Social Welfare] explode all trees
#84.	MeSH descriptor: [Charities] explode all trees
#85.	MeSH descriptor: [Adult Day Care Centers] explode all trees
#86.	MeSH descriptor: [Community Health Nursing] explode all trees
#87.	MeSH descriptor: [Home Care Services] explode all trees
#88.	MeSH descriptor: [Senior Centers] explode all trees
#89.	MeSH descriptor: [Telemedicine] this term only
#90.	MeSH descriptor: [Remote Consultation] explode all trees
#91.	(telehealth or tele health or virtual hospital* or helpline* or help line* or rapid response team*):ti,ab
#92.	MeSH descriptor: [Mobile Health Units] explode all trees
#93.	((community based or community dwelling home or rural) near/3 (care or health care or healthcare)):ti,ab
#94.	(hospital-based home care or HBHC or hospital-based hospice care or acute hospital care):ti,ab
#95.	((hospitali*ation* or admission* or readmission* or admit*) near/3 (reduc* or avoid* or prevent* or inappropiate or increase* or risk*)):ti,ab
#96.	(home based versus hospital based):ti,ab
#97.	(hospital near/3 (domicil* or home)):ti,ab
#98.	(home hospitali*ation):ti,ab

#99.	MeSH descriptor: [Home Care Services, Hospital-Based] explode all trees
#100.	MeSH descriptor: [Home Health Nursing] explode all trees
#101.	MeSH descriptor: [Homemaker Services] explode all trees
#102.	MeSH descriptor: [Home Care Agencies] explode all trees
#103.	MeSH descriptor: [Home Health Aides] explode all trees
#104.	(social care):ti,ab
#105.	MeSH descriptor: [Nurses, Community Health] explode all trees
#106.	(nurs* near/4 (home-visit* or home visit* or home-based or home based)):ti,ab
#107.	((district* or communit* or home or visit*) near nurs*):ti,ab
#108.	(Or #83-#107)
#109.	MeSH descriptor: [Continuity of Patient Care] this term only
#110.	MeSH descriptor: [Aftercare] this term only
#111.	MeSH descriptor: [Patient Discharge] this term only
#112.	MeSH descriptor: [Patient Handoff] this term only
#113.	MeSH descriptor: [Patient Transfer] this term only
#114.	MeSH descriptor: [Transitional Care] this term only
#115.	MeSH descriptor: [Patient Discharge Summaries] this term only
#116.	((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
#117.	((care or caring or serv*) near/2 (continu* or change* or transition* or transfer*)):ti,ab
#118.	(discharg* near/2 (facilitat* or rapid* or pathway* or path way* or plan* or program*)):ti,ab
#119.	(or #109-#118)
#120.	MeSH descriptor: [After-Hours Care] explode all trees
#121.	((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
#122.	rapid next response:ti,ab
#123.	MeSH descriptor: [Hospital Rapid Response Team] explode all trees
#124.	medical next emergency next team*:ti,ab
#125.	(hospital* near/2 home*):ti,ab
#126.	hospital next at next night:ti,ab
#127.	(NHS next (111 or 24 or direct)):ti,ab
#128.	MeSH descriptor: [Telemedicine] this term only
#129.	(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
#130.	MeSH descriptor: [Hotlines] explode all trees
#131.	(hotline* or helpline* or help-line* or call cent* or call service*):ti,ab
#132.	((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
#133.	(or #120-#132)
#134.	#27 and (#51 or #108 or #119 or #133)

#135.	#39 or #47 or #64 or #82 or #134

1 **CINAHL (EBSCO) search terms**

S1.	MH Palliative care
S2.	MH Terminal care
S3.	MH Hospice care
S4.	TI palliat* OR AB palliat*
S5.	MW Terminally ill
S6.	TI (terminal* or long term or longterm) AND TI (care* or caring or ill*)
S7.	AB (terminal* or long term or longterm) AND AB (care* or caring or ill*)
S8.	TI (dying or terminal) AND TI (phase* or stage*)
S9.	AB (dying or terminal) AND AB (phase* or stage*)
S10.	TI life limit* OR AB life limit*
S11.	MH Nursing homes
S12.	TI (care or nursing) AND TI (home or homes)
S13.	AB (care or nursing) AND AB (home or homes)
S14.	MH Respite care
S15.	TI (respite or day) AND TI (care or caring)
S16.	AB (respite or day) AND AB (care or caring)
S17.	MH Hospices
S18.	TI Hospice* OR AB Hospice*
S19.	(MH "Patient Care Plans")
S20.	MH Attitude to Death
S21.	TI attitude* AND TI (death* or dying)
S22.	AB attitude* AND AB (death* or dying)
S23.	MH Physician-Patient Relations
S24.	(MH "Long Term Care")
S25.	(MH "Health Care Delivery")
S26.	TI end AND TI life OR AB end AND AB life
S27.	TI EOLC OR AB EOLC
S28.	TI (last or final) AND TI (year or month) AND TI life
S29.	AB (last or final) AND AB (year or month) AND AB life
S30.	TI (dying or death) AND TI (patient* or person* or people or care or caring)
S31.	AB (dying or death) AND AB (patient* or person* or people or care or caring)
S32.	TI advance* AND TI (plan* or decision* or directive*)
S33.	AB advance* AND AB (plan* or decision* or directive*)
S34.	S1 OR S2 OR S3 OR S4 OR S5 OR S6 OR S7 OR S8 OR S9 OR S10 OR S11 OR S12 OR S13 OR S14 OR S15 OR S16 OR S17 OR S18 OR S19 OR S20 OR S21 OR S22 OR S23 OR S24 OR S25 OR S26 OR S27 OR S28 OR S29 OR S30 OR S31 OR S32 OR S33
S35.	(MH "Multidisciplinary Care Team+")
S36.	MDT OR IDT
S37.	((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*))

S38.	((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*))
S39.	TI (key n2 work*) OR AB (key n2 work*)
S40.	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*)))
S41.	TI (((healthcare or care) n1 profession*)) OR AB (((healthcare or care) n1 profession*))
S42.	MH Case Management
S43.	TI (case n2 manage*) OR AB (case n2 manage*)
S44.	TI ((co-ordinator* or coordinator* or coordinate* or co-ordinate*)*)) OR AB ((co-ordinator* or coordinator* or coordinate* or co-ordinate*))
S45.	S35 OR S36 OR S37 OR S38 OR S39 OR S40 OR S41 OR S42 OR S43 OR S44
S46.	S34 AND S45
S47.	MeSH descriptor: [Interdisciplinary Communication] explode all trees
S48.	MeSH descriptor: [Communication Barriers] explode all trees
S49.	(communicat* or discuss* or speak* or talk* or convers* or contact):ti,ab
S50.	((handover or hand over or share or shared or sharing or transfer*) near/3 information*):ti,ab
S51.	(followup or follow up):ti,ab
S52.	(palliativ* near/2 (care or caring)):ti,ab
S53.	S47 OR S48 OR S49 OR S50 OR S51 OR S52
S54.	S34 AND S45 AND S53
S55.	TI commission* AND TI ((support* or service* or model*))
S56.	AB commission* AND AB ((support* or service* or model*))
S57.	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*)
S58.	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*)
S59.	TI (critical or clinic* or service* or care) AND TI path*
S60.	AB (critical or clinic* or service* or care) AND AB path*
S61.	TI care AND TI (bundle* or service* or package* or standard*)
S62.	AB care AND AB (bundle* or service* or package* or standard*)
S63.	S55 OR S56 OR S57 OR S58 OR S59 OR S60 OR S61 OR S62
S64.	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*)
S65.	S34 AND S63 AND S64
S66.	TI gold standard* OR AB gold standard*
S67.	S34 AND S66
S68.	TI amber AND TI bundle
S69.	AB amber AND AB bundle
S70.	S68 OR S69
S71.	S65 OR S67 OR S70
S72.	TI advance* AND TI (plan* or decision* or directive*)
S73.	AB advance* AND AB (plan* or decision* or directive*)
S74.	S72 OR S73

S75.	(MM "Social Welfare")
S76.	(MH "Charities")
S77.	(MM "Adult Day Center (Saba CCC)") OR (MM "Housing for the Elderly") OR (MM "Older Adult Care (Saba CCC)")
S78.	(MH "Community Health Nursing+") OR (MM "Community Health Centers")
S79.	(MH "Home Health Care+") OR (MM "Home Health Aides") OR (MM "Home Health Care Information Systems") OR (MM "Home Health Aide Service (Saba CCC)")
S80.	(MM "Housing for the Elderly") OR (MM "Rural Health Centers") OR (MM "Community Health Centers")
S81.	(MH "Telemedicine+") OR (MH "Telehealth+")
S82.	(MM "Remote Consultation") OR (MM "Telephone Consultation (Iowa NIC)") OR (MM "Services for Australian Rural and Remote Allied Health")
S83.	telehealth or tele health or virtual hospital* or helpline* or help line* or rapid response team* or senior center*
S84.	(MM "Rural Health Personnel") OR (MM "Mobile Health Units")
S85.	remote consultation
S86.	((community based or community dwelling home or rural) n3 (care or health care or healthcare))
S87.	hospital-based home care or HBHC or hospital-based hospice care or acute hospital care
S88.	((hospitali?ation* or admission* or readmission* or admit*) n3 (reduc* or avoid* or prevent* or inappropiate or increase* or risk*))
S89.	home based versus hospital based
S90.	(hospital n3 (domicil* or home))
S91.	home hospitali?ation
S92.	home care service*
S93.	(MM "Home Health Agencies") OR (MM "Nursing Home Personnel")
S94.	(MM "Homemaker Services") OR (MM "Health Services for the Aged")
S95.	(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")
S96.	social care
S97.	(MM "Hospitals, Community")
S98.	(MM "Home Nursing") OR (MM "Home Nursing, Professional")
S99.	(nurs* n4 (home-visit* or home visit* or home-based or home based))
S100.	((district* or communit* or home or visit*) n nurs*)
S101.	S75 OR S76 OR S77 OR S78 OR S79 OR S80 OR S81 OR S82 OR S83 OR S84 OR S85 OR S86 OR S87 OR S88 OR S89 OR S90 OR S91 OR S92 OR S93 OR S94 OR S95 OR S96 OR S97 OR S98 OR S99 OR S100
S102.	MH Continuity of Patient Care OR MH Aftercare OR MH Patient discharge OR MH Patient handoff OR MH Patient transfer OR MH Transitional care
S103.	(MM "Discharge Planning") OR (MM "Patient Discharge Summaries")
S104.	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*))
S105.	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*))
S106.	AB ((care or caring or serv*)) AND AB ((continu* or change* or transition* or transfer*))

S107.	TI ((care or caring or serv*)) AND TI ((continu* or change* or transition* or transfer*))
S108.	TI discharg* AND TI (facilitat* or rapid* or pathway* or path way* or plan* or program*))
S109.	AB discharg* AND AB (facilitat* or rapid* or pathway* or path way* or plan* or program*))
S110.	S102 OR S103 OR S104 OR S105 OR S106 OR S107 OR S108 OR S109
S111.	out of hours care
S112.	((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*))
S113.	rapid response
S114.	(critical care n2 outreach) OR medical emergency team* OR (hospital* n2 home*) OR hospital at night
S115.	NHS 111 OR NHS 24 OR NHS Direct
S116.	(MH "Telemedicine") OR (MH "Telehealth")
S117.	(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)
S118.	(MH "Telephone Information Services")
S119.	(hotline* or helpline* or help-line* or call cent* or call service*)
S120.	((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*))
S121.	S111 OR S112 OR S113 OR S114 OR S115 OR S116 OR S117 OR S118 OR S119 OR S120
S122.	S34 AND (S74 OR S101 OR S110 OR S121)
S123.	S46 OR S54 OR S71 OR S122

1 **PsycINFO (ProQuest) search terms**

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

1 **HMIC (Ovid) search terms**

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

2 **SPP (Ovid) search terms**

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

21.	limit 20 to (journal or journal article or online resource or online report or report)

ASSIA (ProQuest) search terms

1.	palliat*.ti,ab. ((ti,ab(commission* N/2 (support* or service* or model*)) OR ti,ab((service* or program* or co-ordinat* or coordinat*) N/2 (model* or deliver* or strateg* or support* or access* or method* or system* or policies or policy or availab*))) AND ((SU.EXACT("Care" OR "Clinical nursing" OR "Community homes" OR "Community nursery nursing" OR "Community nursing" OR "Compassionate care" OR "Continuing care" OR "District nursing" OR "Family centred care" OR "Geriatric wards" OR "Group care" OR "Health visiting" OR "Home care" OR "Home from home care" OR "Home health aides" OR "Home helps" OR "Hospices" OR "Hostel wards" OR "Informal care" OR "Integrated care pathways" OR "Intentional care" OR "Intermediate care" OR "Intermediate care centres" OR "Lack of care" OR "Learning disability nursing" OR "Length of stay" OR "Liaison nursing" OR "Long stay wards" OR "Long term care" OR "Long term home care" OR "Long term residential care" OR "Nurse led care" OR "Nursing" OR "Occupational health nursing" OR "Ontological care" OR "Out of home care" OR "Outreach nursing" OR "Palliative care" OR "Paranursing" OR "Pastoral care" OR "Patient care" OR "Primary nursing" OR "Private residential care" OR "Process centred care" OR "Quality of care" OR "Radical health visiting" OR "Residential care" OR "Residential group care" OR "Respite care" OR "Shared care" OR "Social care" "Temporary care" OR "Terminal care" OR "Wards") OR (SU.EXACT("Terminally ill elderly people") OR SU.EXACT("Terminally ill fathers") OR SU.EXACT("Terminally ill elderly men") OR SU.EXACT("Terminally ill elderly women") OR SU.EXACT("Terminally ill young adults") OR SU.EXACT("Terminally ill parents") OR SU.EXACT("Terminally ill women") OR SU.EXACT("Terminally ill widowed sisters") OR SU.EXACT("Terminally ill colleagues") OR SU.EXACT("Terminally ill young girls") OR SU.EXACT("Terminally ill people") OR SU.EXACT("Terminally ill men")) OR SU.EXACT("Advance directives" OR "Do not resuscitate orders" OR "Durable power of attorney for health care" OR "Living wills" OR "Treatment preferences" OR "Treatment needs")) OR (ti,ab((advance* or patient*) N/3 (care or caring) N/3 (continu* or plan*)) or ti,ab(attitude* N/3 (death* or dying*)) or ti,ab(end N/2 life) or ti,ab(EOLC) or ti,ab((last or final) N/2 (year or month*) N/2 life) or ti,ab((dying or death) N/2 (patient* or person* or people or care or caring))))) OR SU.EXACT("End of life decisions")

B.2 Health Economics literature search strategy

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

Table 16: 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

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

1 **Medline (Ovid) search terms**

1.	Palliative care/
2.	Terminal care/
3.	Hospice care/
4.	palliat*.ti,ab.
5.	Terminally Ill/
6.	((terminal* or long term or longterm) adj2 (care* or caring or ill*)).ti,ab.
7.	((dying or terminal) adj (phase* or stage*)).ti,ab.
8.	life limit*.ti,ab.
9.	Nursing Homes/
10.	((care or nursing) adj2 (home or homes)).ti,ab.
11.	Respite Care/
12.	((respite or day) adj2 (care or caring)).ti,ab.
13.	Hospices/
14.	hospice*.ti,ab.
15.	exp Advance Care Planning/
16.	(advance* adj2 (plan* or decision* or directive*)).ti,ab.
17.	living will*.ti,ab.
18.	*Patient care planning/
19.	*"Continuity of Patient Care"/
20.	((advance* or patient*) adj3 (care or caring) adj3 (continu* or plan*)).ti,ab.
21.	*Attitude to Death/
22.	(attitude* adj3 (death* or dying*)).ti,ab.
23.	*Physician-Patient Relations/
24.	*Long-Term Care/
25.	*"Delivery of Health Care"/
26.	(end adj2 life).ti,ab.
27.	EOLC.ti,ab.
28.	((last or final) adj2 (year or month*) adj2 life).ti,ab.
29.	((dying or death) adj2 (patient* or person* or people or care or caring)).ti,ab.
30.	or/1-29
31.	letter/
32.	editorial/
33.	news/
34.	exp historical article/
35.	Anecdotes as Topic/
36.	comment/
37.	case report/

38.	(letter or comment*).ti.
39.	or/31-38
40.	randomized controlled trial/ or random*.ti,ab.
41.	39 not 40
42.	animals/ not humans/
43.	exp Animals, Laboratory/
44.	exp Animal Experimentation/
45.	exp Models, Animal/
46.	exp Rodentia/
47.	(rat or rats or mouse or mice).ti.
48.	or/41-47
49.	30 not 48
50.	limit 49 to English language
51.	(exp child/ or exp pediatrics/ or exp infant/) not (exp adolescent/ or exp adult/ or exp middle age/ or exp aged/)
52.	50 not 51
53.	economics/
54.	value of life/
55.	exp "costs and cost analysis"/
56.	exp Economics, Hospital/
57.	exp Economics, medical/
58.	Economics, nursing/
59.	economics, pharmaceutical/
60.	exp "Fees and Charges"/
61.	exp budgets/
62.	budget*.ti,ab.
63.	cost*.ti.
64.	(economic* or pharmaco?economic*).ti.
65.	(price* or pricing*).ti,ab.
66.	(cost* adj2 (effectiv* or utilit* or benefit* or minimi* or unit* or estimat* or variable*)).ab.
67.	(financ* or fee or fees).ti,ab.
68.	(value adj2 (money or monetary)).ti,ab.
69.	or/53-68
70.	exp models, economic/
71.	*Models, Theoretical/
72.	*Models, Organizational/
73.	markov chains/
74.	monte carlo method/
75.	exp Decision Theory/
76.	(markov* or monte carlo).ti,ab.
77.	econom* model*.ti,ab.
78.	(decision* adj2 (tree* or analy* or model*)).ti,ab.
79.	or/70-78
80.	quality-adjusted life years/
81.	sickness impact profile/

82.	(quality adj2 (wellbeing or well being)).ti,ab.
83.	sickness impact profile.ti,ab.
84.	disability adjusted life.ti,ab.
85.	(qal* or qtime* or qwb* or daly*).ti,ab.
86.	(euroqol* or eq5d* or eq 5*).ti,ab.
87.	(qol* or hql* or hqol* or h qol* or hrqol* or hr qol*).ti,ab.
88.	(health utility* or utility score* or disutilit* or utility value*).ti,ab.
89.	(hui or hui1 or hui2 or hui3).ti,ab.
90.	(health* year* equivalent* or hye or hyes).ti,ab.
91.	discrete choice*.ti,ab.
92.	rosser.ti,ab.
93.	(willingness to pay or time tradeoff or time trade off or tto or standard gamble*).ti,ab.
94.	(sf36* or sf 36* or short form 36* or shortform 36* or shortform36*).ti,ab.
95.	(sf20 or sf 20 or short form 20 or shortform 20 or shortform20).ti,ab.
96.	(sf12* or sf 12* or short form 12* or shortform 12* or shortform12*).ti,ab.
97.	(sf8* or sf 8* or short form 8* or shortform 8* or shortform8*).ti,ab.
98.	(sf6* or sf 6* or short form 6* or shortform 6* or shortform6*).ti,ab.
99.	or/80-98
100.	52 and (69 or 79 or 99)

1 **Embase (Ovid) search terms**

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

23.	*Long term care/
24.	*Health care delivery/
25.	(end adj2 life).ti,ab.
26.	EOLC.ti,ab.
27.	((last or final) adj2 (year or month*) adj2 life).ti,ab.
28.	((dying or death) adj2 (patient* or person* or people or care or caring)).ti,ab.
29.	or/1-28
30.	letter.pt. or letter/
31.	note.pt.
32.	editorial.pt.
33.	case report/ or case study/
34.	(letter or comment*).ti.
35.	or/30-34
36.	randomized controlled trial/ or random*.ti,ab.
37.	35 not 36
38.	animal/ not human/
39.	nonhuman/
40.	exp Animal Experiment/
41.	exp Experimental Animal/
42.	animal model/
43.	exp Rodent/
44.	(rat or rats or mouse or mice).ti.
45.	or/37-44
46.	29 not 45
47.	limit 46 to English language
48.	(exp child/ or exp pediatrics/ or exp infant/) not (exp adolescent/ or exp adult/ or exp middle age/ or exp aged/)
49.	47 not 48
50.	health economics/
51.	exp economic evaluation/
52.	exp health care cost/
53.	exp fee/
54.	budget/
55.	funding/
56.	budget*.ti,ab.
57.	cost*.ti.
58.	(economic* or pharmaco?economic*).ti.
59.	(price* or pricing*).ti,ab.
60.	(cost* adj2 (effectiv* or utilit* or benefit* or minimi* or unit* or estimat* or variable*)).ab.
61.	(financ* or fee or fees).ti,ab.
62.	(value adj2 (money or monetary)).ti,ab.

63.	or/50-62
64.	statistical model/
65.	exp economic aspect/
66.	64 and 65
67.	*theoretical model/
68.	*nonbiological model/
69.	stochastic model/
70.	decision theory/
71.	decision tree/
72.	monte carlo method/
73.	(markov* or monte carlo).ti,ab.
74.	econom* model*.ti,ab.
75.	(decision* adj2 (tree* or analy* or model*)).ti,ab.
76.	or/66-75
77.	quality-adjusted life years/
78.	"quality of life index"/
79.	short form 12/ or short form 20/ or short form 36/ or short form 8/
80.	sickness impact profile/
81.	(quality adj2 (wellbeing or well being)).ti,ab.
82.	sickness impact profile.ti,ab.
83.	disability adjusted life.ti,ab.
84.	(qal* or qtime* or qwb* or daly*).ti,ab.
85.	(euroqol* or eq5d* or eq 5*).ti,ab.
86.	(qol* or hql* or hqol* or h qol* or hrqol* or hr qol*).ti,ab.
87.	(health utility* or utility score* or disutilit* or utility value*).ti,ab.
88.	(hui or hui1 or hui2 or hui3).ti,ab.
89.	(health* year* equivalent* or hye or hyes).ti,ab.
90.	discrete choice*.ti,ab.
91.	rosser.ti,ab.
92.	(willingness to pay or time tradeoff or time trade off or tto or standard gamble*).ti,ab.
93.	(sf36* or sf 36* or short form 36* or shortform 36* or shortform36*).ti,ab.
94.	(sf20 or sf 20 or short form 20 or shortform 20 or shortform20).ti,ab.
95.	(sf12* or sf 12* or short form 12* or shortform 12* or shortform12*).ti,ab.
96.	(sf8* or sf 8* or short form 8* or shortform 8* or shortform8*).ti,ab.
97.	(sf6* or sf 6* or short form 6* or shortform 6* or shortform6*).ti,ab.
98.	or/77-97
99.	49 and (63 or 76 or 98)

1 **NHS EED and HTA (CRD) search terms**

#1.	MeSH DESCRIPTOR Palliative Care IN NHSEED,HTA
#2.	MeSH DESCRIPTOR Terminal Care IN NHSEED,HTA

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

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1 # Appendix C: Clinical evidence selection

Figure 1: Flow chart of clinical study selection for the reviews of MDT, Care coordinator and Lead health professional

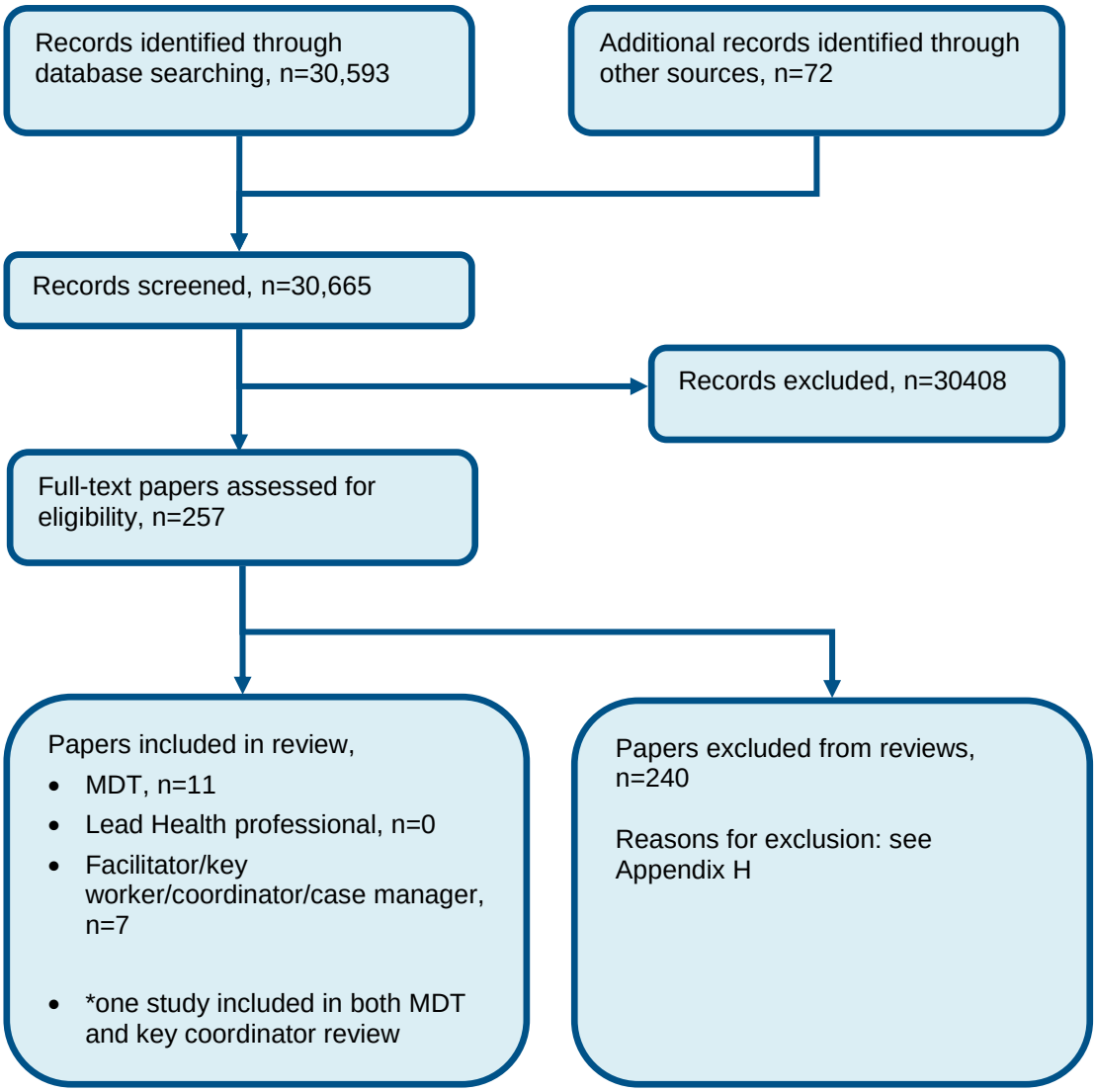
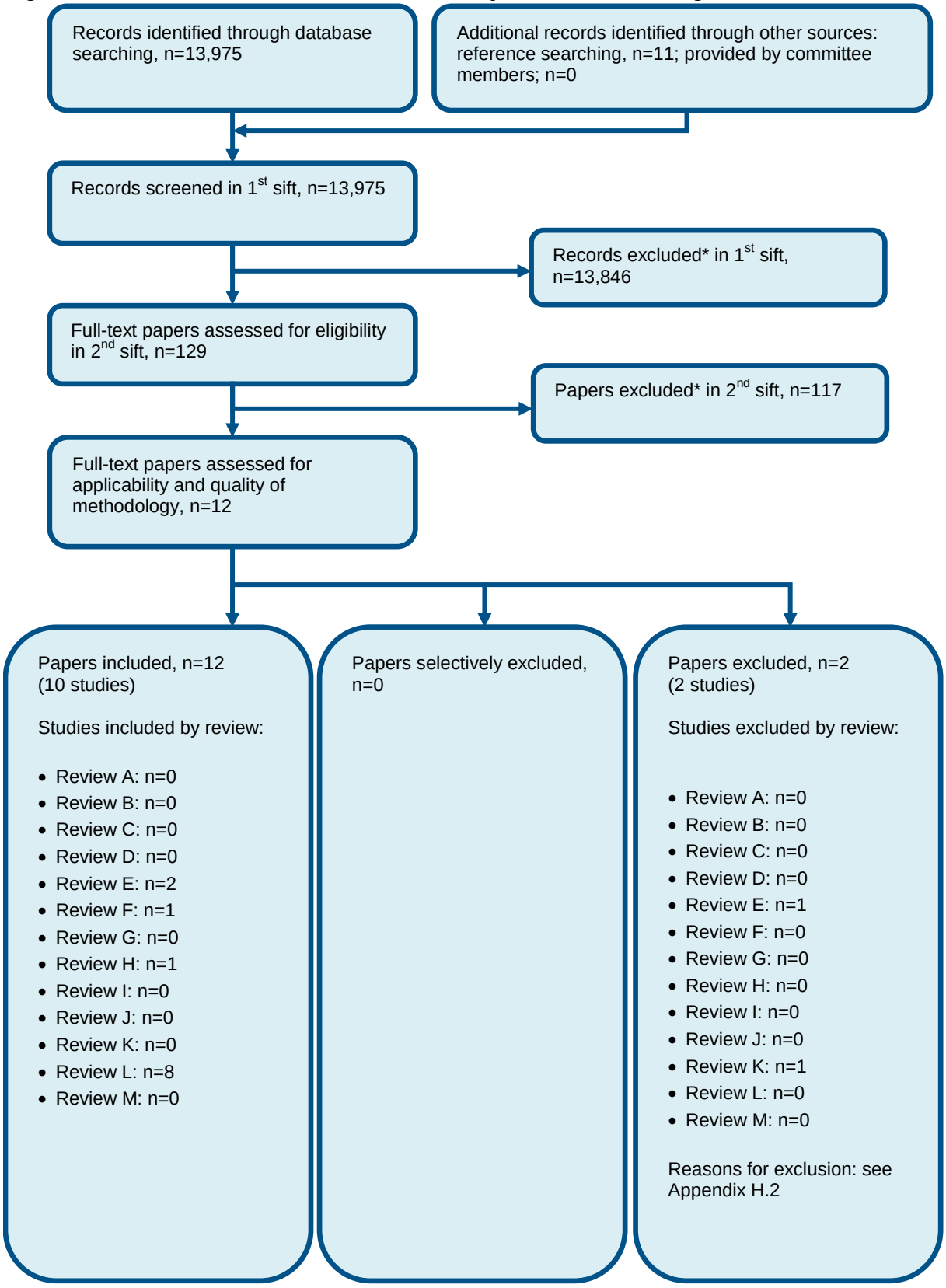


Figure 2: Flow chart of health economic study selection for the guideline



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

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Appendix D: Clinical evidence tables

D.1 Care coordinator

Study (subsidiary papers)	Addington-hall 1992[1] (Raftery 1996[41])
Study type	RCT (Service randomised; Parallel)
Number of studies (number of participants)	2 (n=554)
Countries and setting	Conducted in United Kingdom; Setting: A South London health authority
Line of therapy	Not applicable
Duration of study	Intervention + follow up: 3 years (1987-1990)
Method of assessment of guideline condition	Adequate method of assessment/diagnosis: prognosis assessed by doctor or senior nurse
Stratum	Adults (aged 18 years or over): stratification by number of general practitioners and postal district
Subgroup analysis within study	Stratified then randomised:
Inclusion criteria	Patient expected to live for one year or less and who were resident within the boundaries of the health authority entered the trial and were allocated to the coordination or control group depending on the general practice with which they were registered.
Exclusion criteria	Not stated
Recruitment/selection of patients	Each time any cancer patient was admitted to the single acute hospital (St George Hospital, Tooting) in the district, the research team was notified and was a doctor or senior nurse familiar with the patient's condition assessed the patient as having a prognosis of more or less than one year. Those attending outpatients clinics (oncology, radiotherapy, general surgery or urology) had their prognoses estimated by the doctors they saw.
Age, gender and ethnicity	Age - Other: N for intervention (n=104) and control group (n=99) respectively: age 18-49 n=3, 5; age 50-64 n=16, 19; age 65-74, n=32, 21; age >75, n=53, 54. Gender (M:F): 94/109. Ethnicity: not stated
Further population details	1. Any specific population: Not applicable
Extra comments	N for intervention (n=104) and control group (n=99), respectively: primary cancer breast 16, 14; lung 19, 22; colorectal 20, 19; prostate 15, 9; other 34, 35; died before the end of the study: 66, 77. Initially 89 practices were allocated to the coordination group and 79 to the control group. In Sept 1987 when it became apparent

Study (subsidiary papers)	Addington-hall 1992[1] (Raftery 1996[41])
	that too few patients were entering the coordination group to keep the nurse coordinators fully employed, 13 randomly selected control group practices were transferred to the coordination group.
Indirectness of population	No indirectness
Interventions	(n=318) Intervention 1: Coordinator. Nurse coordinators. They were based in the community and introduced themselves to patients as nurses providing a link between the hospital, general practitioner and community services. They acted as 'brokers' of services: their role was to assess the need for services from the NHS, local authorities and voluntary sector agencies; to offer advice on how to obtain these services and to contact the agencies themselves if necessary; to ensure that services were provided and were well coordinated; and to monitor the changing needs of the patient and family for services. Patients were encouraged to contact the coordinators if they needed help or advice. The coordinators did not provide practical nursing care or advice, liaising with Macmillan or Marie Curie nurses as appropriate. Initially, two experienced district nurses who held the ENB certificate in care of the Dying patient were recruited as coordinators. One coordinator left during the trial and was replaced first by a health visitor and later by another district nurse, neither of whom held the ENB certificate. The coordinators were in post for one year before the evaluation began. . Duration 3 years. Concurrent medication/care: All recruited patients continued to receive routinely available services. The range of services available included inpatient and outpatient services in the local acute hospital, general practitioner and community nursing services, including both district nurses and Macmillan nurses (who specialise in palliative care); Marie curie nurses, services from the local hospice (Trinity hospice) which included inpatient beds and a home care team (four nursing sisters and medical support) and specialist cancer services from a nearby special health authority (Royal Marsden Hospitals in Sutton and Fulham, where patients were sent for radiotherapy). Social services, including social workers, meals on wheels and home helps, were provided by Wandsworth Borough Council. (n=236) Intervention 2: Usual care. No access to coordinator. Duration 3 years. Concurrent medication/care: All recruited patients continued to receive routinely available services. The range of services available included inpatient and outpatient services in the local acute hospital, general practitioner and community nursing services, including both district nurses and Macmillan nurses (who specialise in palliative care); Marie curie nurses, services from the local hospice (Trinity hospice) which included inpatient beds and a home care team (four nursing sisters and medical support) and specialist cancer services from a nearby special health authority (Royal Marsden Hospitals in Sutton and Fulham, where patients were sent for radiotherapy). Social services, including social workers, meals on wheels and home helps, were provided by Wandsworth Borough Council.
Funding	Academic or government funding (Medical research council)
RESULTS (NUMBERS ANALYSED) AND RISK OF BIAS FOR COMPARISON: NURSE COORDINATOR versus USUAL CARE	

Study (subsidiary papers)	Addington-hall 1992[1] (Raftery 1996[41])

Protocol outcome 1: Length of stay
- Actual outcome for Adults (aged 18 yrs or over): Inpatient days at end of follow up; Group 1: mean 24.1 days (SD 30.6); n=86, Group 2: mean 40 days (SD 48.7); n=81
Risk of bias: All domain - Very high, Selection - Very high, Blinding - High, Incomplete outcome data - High, Outcome reporting - Low, Measurement - Low, Crossover - Low; Indirectness of outcome: No indirectness ; Group 1 Number missing: 232, Reason: 147 died/too ill; 32 moved; 35 refused; 18 full service use data not located; Group 2 Number missing: 155, Reason: 98 died/too ill; 8 moved; 31 refused; 18 full service data not located

Protocol outcome 2: Hospitalisation
- Actual outcome for Adults (aged 18 yrs or over): Admissions at end of follow up; Group 1: mean 2.5 days (SD 3.3); n=86, Group 2: mean 3.3 days (SD 3); n=81
Risk of bias: All domain - Very high, Selection - Very high, Blinding - High, Incomplete outcome data - High, Outcome reporting - Low, Measurement - Low, Crossover - Low; Indirectness of outcome: No indirectness ; Group 1 Number missing: 232, Reason: 147 died/too ill; 32 moved; 35 refused; 18 full service use data not located; Group 2 Number missing: 155, Reason: 98 died/too ill; 8 moved; 31 refused; 18 full service data not located

Protocol outcome 3: Number of hospital visits
- Actual outcome for Adults (aged 18 yrs or over): Outpatient attendances at end of follow up; Group 1: mean 18 (SD 9); n=86, Group 2: mean 10.1 (SD 10.3); n=81
Risk of bias: All domain - Very high, Selection - Very high, Blinding - High, Incomplete outcome data - High, Outcome reporting - Low, Measurement - Low, Crossover - Low; Indirectness of outcome: No indirectness ; Group 1 Number missing: 232, Reason: 147 died/too ill; 32 moved; 35 refused; 18 full service use data not located; Group 2 Number missing: 155, Reason: 98 died/too ill; 8 moved; 31 refused; 18 full service data not located

Protocol outcome 4: Use of community services
- Actual outcome for Adults (aged 18 yrs or over): Home visits (district nurses, Macmillan nurses, hospital oncology nurse, hospice homecare team) at end of follow up; Group 1: mean 14.5 (SD 22); n=86, Group 2: mean 37.5 (SD 67.4); n=81
Risk of bias: All domain - Very high, Selection - Very high, Blinding - High, Incomplete outcome data - High, Outcome reporting - Low, Measurement - Low, Crossover - Low; Indirectness of outcome: No indirectness ; Group 1 Number missing: 214, Reason: 147 died/too ill; 32 moved; 35 refused; Group 2 Number missing: 137, Reason: 98 died/too ill; 8 moved; 31 refused
- Actual outcome for Adults (aged 18 yrs or over): People known to social workers (local authority) at end of follow up; Group 1: 33/86, Group 2: 35/81
Risk of bias: All domain - Very high, Selection - Very high, Blinding - High, Incomplete outcome data - High, Outcome reporting - Low, Measurement - Low, Crossover - Low; Indirectness of outcome: No indirectness ; Group 1 Number missing: 232, Reason: 147 died/too ill; 32 moved; 35 refused; 18 full service use data not located; Group 2 Number missing: 155, Reason: 98 died/too ill; 8 moved; 31 refused; 18 full service data not located

Study (subsidiary papers)	Addington-hall 1992[1] (Raftery 1996[41])
- Actual outcome for Adults (aged 18 yrs or over): People known to occupational therapists at end of follow up; Group 1: 43/86, Group 2: 37/81 Risk of bias: All domain - Very high, Selection - Very high, Blinding - High, Incomplete outcome data - High, Outcome reporting - Low, Measurement - Low, Crossover - Low; Indirectness of outcome: No indirectness ; Group 1 Number missing: 232, Reason: 147 died/too ill; 32 moved; 35 refused; 18 full service use data not located; Group 2 Number missing: 155, Reason: 98 died/too ill; 8 moved; 31 refused; 18 full service data not located - Actual outcome for Adults (aged 18 yrs or over): Pts having contact with GP in 2 weeks before interview (home visits) at end of follow up; Group 1: 23/103, Group 2: 23/99 Risk of bias: All domain - Very high, Selection - Very high, Blinding - High, Incomplete outcome data - High, Outcome reporting - Low, Measurement - Low, Crossover - Low; Indirectness of outcome: No indirectness ; Group 1 Number missing: 232, Reason: 147 died/too ill; 32 moved; 35 refused; Group 2 Number missing: 155, Reason: 98 died/too ill; 8 moved; 31 refused - Actual outcome for Adults (aged 18 yrs or over): Pts having contact with GP in 2 weeks before interview (surgery consultation) at end of follow up; Group 1: 13/103, Group 2: 18/99 Risk of bias: All domain - Very high, Selection - Very high, Blinding - High, Incomplete outcome data - High, Outcome reporting - Low, Measurement - Low, Crossover - Low; Indirectness of outcome: No indirectness ; Group 1 Number missing: 232, Reason: 147 died/too ill; 32 moved; 35 refused; Group 2 Number missing: 155, Reason: 98 died/too ill; 8 moved; 31 refused - Actual outcome for Adults (aged 18 yrs or over): Pts having contact with hospice or Macmillan sister in 2 weeks before interview at end of follow up; Group 1: 7/103, Group 2: 11/99 Risk of bias: All domain - Very high, Selection - Very high, Blinding - High, Incomplete outcome data - High, Outcome reporting - Low, Measurement - Low, Crossover - Low; Indirectness of outcome: No indirectness ; Group 1 Number missing: 214, Reason: 147 died/too ill; 32 moved; 35 refused; Group 2 Number missing: 137, Reason: 98 died/too ill; 8 moved; 31 refused - Actual outcome for Adults (aged 18 yrs or over): Pts having contact with district nurses in 2 weeks before interview at end of follow up; Group 1: 38/103, Group 2: 39/99 Risk of bias: All domain - Very high, Selection - Very high, Blinding - High, Incomplete outcome data - High, Outcome reporting - Low, Measurement - Low, Crossover - Low; Indirectness of outcome: No indirectness ; Group 1 Number missing: 214, Reason: 147 died/too ill; 32 moved; 35 refused; Group 2 Number missing: 137, Reason: 98 died/too ill; 8 moved; 31 refused Protocol outcome 5: Preferred and actual place of death - Actual outcome for Adults (aged 18 yrs or over): N of people dying at home at time of death; Group 1: 17/86, Group 2: 14/81 Risk of bias: All domain - Very high, Selection - Very high, Blinding - High, Incomplete outcome data - High, Outcome reporting - Low, Measurement - Low, Crossover - Low; Indirectness of outcome: Serious indirectness, Comments: preferred place of death not reported; Group 1 Number missing: 232, Reason: 147 died/too ill; 32 moved; 35 refused; 18 full service use data not located; Group 2 Number missing: 155, Reason: 98 died/too ill; 8 moved; 31 refused; 18 full service data not located - Actual outcome for Adults (aged 18 yrs or over): N of people dying in hospital at time of death; Group 1: 29/86, Group 2: 36/81	

Study (subsidiary papers)	Addington-hall 1992[1] (Raftery 1996[41])
Risk of bias: All domain - Very high, Selection - Very high, Blinding - High, Incomplete outcome data - High, Outcome reporting - Low, Measurement - Low, Crossover - Low; Indirectness of outcome: Serious indirectness, Comments: preferred place of death not reported; Group 1 Number missing: 232, Reason: 147 died/too ill; 32 moved; 35 refused; 18 full service use data not located; Group 2 Number missing: 155, Reason: 98 died/too ill; 8 moved; 31 refused; 18 full service data not located - Actual outcome for Adults (aged 18 yrs or over): N of people dying in hospice at time of death; Group 1: 10/86, Group 2: 12/81 Risk of bias: All domain - Very high, Selection - Very high, Blinding - High, Incomplete outcome data - High, Outcome reporting - Low, Measurement - Low, Crossover - Low; Indirectness of outcome: Serious indirectness, Comments: preferred place of death not reported; Group 1 Number missing: 232, Reason: 147 died/too ill; 32 moved; 35 refused; 18 full service use data not located; Group 2 Number missing: 155, Reason: 98 died/too ill; 8 moved; 31 refused; 18 full service data not located - Actual outcome for Adults (aged 18 yrs or over): N of people dying elsewhere (not home, hospital, hospice) at time of death; Group 1: 2/86, Group 2: 2/81 Risk of bias: All domain - Very high, Selection - Very high, Blinding - High, Incomplete outcome data - High, Outcome reporting - Low, Measurement - Low, Crossover - Low; Indirectness of outcome: Serious indirectness, Comments: preferred place of death not reported; Group 1 Number missing: 232, Reason: 147 died/too ill; 32 moved; 35 refused; 18 full service use data not located; Group 2 Number missing: 155, Reason: 98 died/too ill; 8 moved; 31 refused; 18 full service data not located Protocol outcome 6: Length of survival - Actual outcome for Adults (aged 18 yrs or over): Mean days between study entry and death at time of death; Mean; Intervention group)n=55), mean 211 days; control group (n=64), mean 232 days; Risk of bias: All domain - Very high, Selection - Very high, Blinding - High, Incomplete outcome data - High, Outcome reporting - Low, Measurement - Low, Crossover - Low; Indirectness of outcome: No indirectness; Group 1 Number missing: 232, Reason: 147 died/too ill; 32 moved; 35 refused; 18 full service use data not located; Group 2 Number missing: 155, Reason: 98 died/too ill; 8 moved; 31 refused; 18 full service data not located Protocol outcome 7: Patient/carer reported outcomes (satisfaction) - Actual outcome for Adults (aged 18 yrs or over): Carers agreeing with the statement 'care was well coordinated' at after bereavement; Group 1: 31/51, Group 2: 27/43 Risk of bias: All domain - Very high, Selection - Very high, Blinding - High, Incomplete outcome data - High, Outcome reporting - Low, Measurement - Low, Crossover - Low; Indirectness of outcome: Serious indirectness, Comments: n of people satisfied, not satisfaction score; Group 1 Number missing: 214, Reason: 147 died/too ill; 32 moved; 35 refused; Group 2 Number missing: 137, Reason: 98 died/too ill; 8 moved; 31 refused - Actual outcome for Adults (aged 18 yrs or over): Patients satisfied with care from hospital at end of follow up; Group 1: 62/104, Group 2: 45/99 Risk of bias: All domain - Very high, Selection - Very high, Blinding - High, Incomplete outcome data - High, Outcome reporting - Low, Measurement - Low, Crossover - Low; Indirectness of outcome: Serious indirectness, Comments: n of people satisfied, not satisfaction score; Group 1 Number missing:	

Study (subsidiary papers)	Addington-hall 1992[1] (Raftery 1996[41])
	214, Reason: 147 died/too ill; 32 moved; 35 refused; Group 2 Number missing: 137, Reason: 98 died/too ill; 8 moved; 31 refused - Actual outcome for Adults (aged 18 yrs or over): Patients satisfied with care from GP at end of follow up; Group 1: 72/104, Group 2: 63/99 Risk of bias: All domain - Very high, Selection - Very high, Blinding - High, Incomplete outcome data - High, Outcome reporting - Low, Measurement - Low, Crossover - Low; Indirectness of outcome: Serious indirectness, Comments: n of people satisfied, not satisfaction score; Group 1 Number missing: 214, Reason: 147 died/too ill; 32 moved; 35 refused; Group 2 Number missing: 137, Reason: 98 died/too ill; 8 moved; 31 refused - Actual outcome for Adults (aged 18 yrs or over): Patients satisfied with care from district nurses at end of follow up; Group 1: 63/104, Group 2: 40/99 Risk of bias: All domain - Very high, Selection - Very high, Blinding - High, Incomplete outcome data - High, Outcome reporting - Low, Measurement - Low, Crossover - Low; Indirectness of outcome: Serious indirectness, Comments: n of people satisfied, not satisfaction score; Group 1 Number missing: 214, Reason: 147 died/too ill; 32 moved; 35 refused; Group 2 Number missing: 137, Reason: 98 died/too ill; 8 moved; 31 refused - Actual outcome for Adults (aged 18 yrs or over): Carers satisfied with care from hospital at end of follow up; Group 1: 42/56, Group 2: 40/62 Risk of bias: All domain - Very high, Selection - Very high, Blinding - High, Incomplete outcome data - High, Outcome reporting - Low, Measurement - Low, Crossover - Low; Indirectness of outcome: Serious indirectness, Comments: n of people satisfied, not satisfaction score; Group 1 Number missing: 214, Reason: 147 died/too ill; 32 moved; 35 refused; Group 2 Number missing: 137, Reason: 98 died/too ill; 8 moved; 31 refused - Actual outcome for Adults (aged 18 yrs or over): Carers satisfied with care from GP at end of follow up; Group 1: 38/56, Group 2: 42/62 Risk of bias: All domain - Very high, Selection - Very high, Blinding - High, Incomplete outcome data - High, Outcome reporting - Low, Measurement - Low, Crossover - Low; Indirectness of outcome: Serious indirectness, Comments: n of people satisfied, not satisfaction score; Group 1 Number missing: 214, Reason: 147 died/too ill; 32 moved; 35 refused; Group 2 Number missing: 137, Reason: 98 died/too ill; 8 moved; 31 refused - Actual outcome for Adults (aged 18 yrs or over): Carers satisfied with care from district nurses at end of follow up; Group 1: 33/56, Group 2: 27/62 Risk of bias: All domain - Very high, Selection - Very high, Blinding - High, Incomplete outcome data - High, Outcome reporting - Low, Measurement - Low, Crossover - Low; Indirectness of outcome: Serious indirectness, Comments: n of people satisfied, not satisfaction score; Group 1 Number missing: 214, Reason: 147 died/too ill; 32 moved; 35 refused; Group 2 Number missing: 137, Reason: 98 died/too ill; 8 moved; 31 refused
Protocol outcomes not reported by the study	Quality of life; Number of unscheduled admissions; Staff satisfaction; Avoidable/inappropriate admissions to ICU; Inappropriate resuscitation; Preferred and actual place of care; Number of visits to accident and emergency

Study	Aiken 2006[2]
Study type	RCT (Patient randomised; Parallel)
Number of studies (number of participants)	1 (n=192)
Countries and setting	Conducted in USA; Setting: Seven MCOs in the Phoenix, Arizona metropolitan area

Study	Aiken 2006[2]
Line of therapy	Not applicable
Duration of study	Intervention + follow up: enrolment 2 years (1999-2001) + follow up 6 months
Method of assessment of guideline condition	Adequate method of assessment/diagnosis
Stratum	Adults (aged 18 years or over):
Subgroup analysis within study	Stratified then randomised: Randomisation was carried out within diagnosis
Inclusion criteria	People residing at home, members of one of the seven MCOs in the Phoenix, Arizona, metropolitan area. Patients diagnosed with chronic heart failure (CHF) or chronic obstructive pulmonary disease (COPD) who might live for up to 2 years beyond enrolment, based on expert judgment that drew on available prognostic data. All participants were required to be 18 years or older. Patients with CHF were required to be diagnosed with either class IIIB heart failure (symptoms with any activity) or class IV heart failure (symptoms at rest). Patients with COPD were required to have oxygen saturations of less than 88% on room air, or baseline pO2 less than 55 on room air, and to be on continuous oxygen. Across the two diseases, all patients were required to exhibit marked limitation of physical functioning, in that any activity resulted in fatigue, palpitation, dyspnea, or angina. All patients were required to have exhibited recent exacerbation of their conditions as evidenced by treatment in an emergency department, urgent care facility, or hospital within the 3 months prior to enrolment. For purposes of data collection by phone interview, patients were required to have a telephone in the home, and to either speak English or to have a translator present in the home.
Exclusion criteria	Not stated
Recruitment/selection of patients	Patients could be referred by community agencies, hospitals, the MCOs, physicians, family/friends, or by self-referral.
Age, gender and ethnicity	Age - Mean (SD): Intervention group 68(14), control group 70(13). Gender (M:F): 69/121. Ethnicity: 80% intervention group and 84% control group were Caucasian
Further population details	1. Any specific population: Not applicable
Extra comments	.
Indirectness of population	Serious indirectness: Life expectancy up to 2 years
Interventions	(n=101) Intervention 1: Case manager. Registered nurse case managers, each with a caseload of 30-35 patients, provided 'PhoenixCare' services. Phoenixcare delivered home-based services focused on disease and symptom management, patient and caregiver education on disease management and social and psychological support. Registered nurse case managers delivered the primary PhoenixCare services and assumed a leadership role in coordinating PhoenixCare services with the patients' primary care physician, with any case managers provided by the patient's MCO, and with community agencies. A medical director, social worker, and pastoral counsellor provided support to case managers, who coordinated care planning

Study	Aiken 2006[2]
	with PhoenixCare members, primary care physicians, health plan case manager (id there were one), patient/family and community agencies. Three distinct care protocols addressed phases of service delivery: 1) admission and initial case management of medically unstable patients; 2) management of stable patients following stabilisation, 3) support of unstable patients experiencing an exacerbation episode. All three protocols provided disease and symptom management, educational services, and support services. . Duration 6 months follow up. Concurrent medication/care: Patients did not relinquish any health care services for which they were otherwise eligible (n=91) Intervention 2: Usual care. Usual care provided by the MCO, including medication and technical treatment. The focus of MCO case management was medical and disease-oriented, including medication and lab monitoring, weight/blood pressure and blood glucose monitoring, and implementation of prior authorization mechanisms. Services were delivered by phone by all seven MCOs and through occasional home visits (in 5 MCOs). Other support services included disease and symptom education, nutrition, and psychological counselling, transportation and coordination of medical service. Each MCO provided its own individual case management to some portion of their clients. . Duration 6 months follow up. Concurrent medication/care: not stated.
Funding	Other (This was a project of the Robert Wood Johnson Foundation. It was also supported in part by the Flinn Foundation, Phoenix, Arizona, and St Luke Health Initiatives, Phoenix, Arizona.)
RESULTS (NUMBERS ANALYSED) AND RISK OF BIAS FOR COMPARISON: CASE MANAGER versus USUAL CARE Protocol outcome 1: Quality of life - Actual outcome for Adults (aged 18 years or over): SF36 at 3 months; Other: COPD patients in the intervention group reported greater Vitality than COPD controls; Risk of bias: Very high, Selection - Very high, Blinding - High, Incomplete outcome data - Low, Outcome reporting - Low, Measurement - Low, Crossover - Low; Indirectness of outcome: No indirectness - Actual outcome for Adults (aged 18 years or over): SF36 at 9 months; Other: Control patients declined in both Physical function and General health while intervention patients did not. Superior Physical functioning and General health emerged in the intervention above control participants; Risk of bias: Very high, Selection - Very high, Blinding - High, Incomplete outcome data - Low, Outcome reporting - Low, Measurement - Low, Crossover - Low; Indirectness of outcome: No indirectness Protocol outcome 2: Number of visits to accident and emergency - Actual outcome for Adults (aged 18 years or over): Emergency department visits per month at 6 months follow up; Group 1: mean 0.11 (SD 0.34); n=101, Group 2: mean 0.1 (SD 0.31); n=91; Risk of bias: Very high, Selection - Very high, Blinding - High, Incomplete outcome data - Low, Outcome reporting - Low, Measurement - Low, Crossover - Low; Indirectness of outcome: No indirectness	
Protocol outcomes not reported by the study	Hospitalisation; Number of hospital visits; Number of unscheduled admissions; Use of community services; Preferred and actual place of death; Length of survival; Staff satisfaction; Avoidable/inappropriate

Study	Aiken 2006[2]
	admissions to ICU; Inappropriate resuscitation; Patient/carer reported outcomes (satisfaction); Preferred and actual place of care; Length of stay

Study (subsidiary papers)	Bakitas 2009[8] (Bakitas 2009[7])
Study type	Randomised controlled trial
Number of studies (number of participants)	1 (n=322)
Countries and setting	Conducted in USA; Setting: 2 sites: Norris Cotton Cancer Centre, VA medical centre
Line of therapy	Not applicable
Duration of study	Intervention + follow up: Recruitment November 2003-May 2007. Patients were followed up every three months until they died
Method of assessment of guideline condition	Adequate method of assessment/diagnosis
Stratum	Adults (aged 18 years or over)
Subgroup analysis within study	Not applicable
Inclusion criteria	Patients with a new diagnosis of advanced or recurrent life-limiting cancer (prognosis of approx. 1 year). Eligible if they were within 8 to 12 weeks of a new diagnosis of GI tract (unresectable stage III or IV), lung (stage IIIB or IV non-small cell or extensive small cell), genitourinary tract (stage IV), or breast (stage IV and visceral crisis, lung or liver metastasis, estrogen receptor -ve, human epidermal growth factor receptor 2 positive) cancer.
Exclusion criteria	Patients with impaired cognition (<17 on a modified Mini-Mental state Examination), an Axis I psychiatric disorder (schizophrenia, bipolar disorder), or active substance use were excluded.
Recruitment/selection of patients	See population
Age, gender and ethnicity	Age - Mean (SD): 65.3 (11). Gender (M:F): Define. Ethnicity: 99% White
Further population details	1. Any specific population: Not applicable
Extra comments	Patients with a new diagnosis of advanced or recurrent life-limiting cancer. Recruited as soon as possible after diagnosis.
Indirectness of population	No indirectness
Interventions	(n=161) Intervention 1: Coordinator. ENABLE (Educate, Nurture, Advise, Before Life Ends). Advance palliative care nurse specialists educated participants about key palliative care principles and crisis prevention via practice problem solving/decision-making skills, symptom management, communication and advance care planning. Coordinated referrals to improve patients' end of life care experience. Referrals and

Study (subsidiary papers)	Bakitas 2009[8] (Bakitas 2009[7])
	services generally increased as illness progressed. The intervention was primarily conducted by telephone in order to be accessible to the rural population. Designed to facilitate a smooth transition from mostly anti-cancer treatment to mostly palliative care. Intervention included education via manual. The nurse educator contacted the participant weekly for the first four weeks to review each module in the manual. After the completion of the four structured sessions the nurse phoned the participant at least monthly. The nurse educator also triaged medical complaints and offered to arrange care and services as needed, including palliative and hospice care. Monthly contacts continued as long as the participant was alive. In the later stages the nurse communicated with the caregiver. Duration Average length of follow up was 12 months. Concurrent medication/care: Concurrent cancer treatment (n=161) Intervention 2: Usual care. Patients were allowed to use all usual oncology, palliative care and other medical centres without restrictions. The cancer centre had a consultative interdisciplinary palliative care team comprised of a physician and nurse practitioners. Oncologists could refer patients for assessments by this team for symptoms and supportive care while receiving anti-cancer treatments. Patients and family members were often followed up through to death and bereavement. From 2003-2005, the team expanded to include additional physicians, nurse practitioners and a dedicated social worker, chaplain, coordinator/volunteers and administrative staff. Towards the end of the study enrolment, automatic PCT consultation at the time of diagnosis became a routine part of the clinical pathways. The VAMC site also had an Advanced Cancer Illness Care Committee which provided consultation to oncology staff. . Duration Average duration was 12 months. Concurrent medication/care: Concurrent cancer treatment
Funding	Academic or government funding (National Cancer Institute)
RESULTS (NUMBERS ANALYSED) AND RISK OF BIAS FOR COMPARISON: ADDITIONAL COMMUNITY SERVICES ON A REGULAR/ROUTINE BASIS (CARE COORDINATION VIA TELEPHONE) versus USUAL CARE Protocol outcome 1: Quality of life - Actual outcome for Adults (aged 18 yrs or over): Functional Assessment of Chronic Illness Therapy for Palliative Care at Until death; Mean; (Mean 4.6, SE 2, p=0.02)); Risk of bias: All domain - High, Selection - Low, Blinding - High, Incomplete outcome data - Low, Outcome reporting - Low, Measurement - Low, Crossover - Low; Indirectness of outcome: No indirectness ; Group 1 Number missing: 32, Reason: death 15 withdrawals 15 (in addition to those who did not complete baseline assessment) (as above); Group 2 Number missing: 56, Reason: death 20 withdrawals 9 - Actual outcome for Adults (aged 18 yrs or over): Functional Assessment of Chronic Illness Therapy for Palliative Care - patient who died during study at Until death; Mean; (Mean 8.6, SE 3.6, p=0.02)); Risk of bias: All domain - High, Selection - Low, Blinding - High, Incomplete outcome data - Low, Outcome reporting - Low, Measurement - Low, Crossover - Low; Indirectness of outcome: No indirectness ; Group 1 Number missing: 32, Reason: death 15 withdrawals 15 (in addition to those who did not complete baseline assessment) (as above); Group 2 Number missing: 56, Reason: death 20 withdrawals 9	

Study (subsidiary papers)	Bakitas 2009[8] (Bakitas 2009[7])
Protocol outcome 2: Length of stay - Actual outcome for Adults (aged 18 yrs or over): Number of days in hospital at Until death; Mean; (Mean: Intervention 6.6 control 6.5; p=0.14)); Risk of bias: All domain - High, Selection - Low, Blinding - High, Incomplete outcome data - Low, Outcome reporting - Low, Measurement - Low, Crossover - Low; Indirectness of outcome: No indirectness ; Group 1 Number missing: 32, Reason: death 15 withdrawals 15 (in addition to those who did not complete baseline assessment) (as above); Group 2 Number missing: 56, Reason: death 20 withdrawals 9 Protocol outcome 3: Number of visits to accident and emergency - Actual outcome for Adults (aged 18 yrs or over): Number of emergency department visits at Until death; Mean; (Intervention 0.86 Control 0.63)); Risk of bias: All domain - High, Selection - Low, Blinding - High, Incomplete outcome data - Low, Outcome reporting - Low, Measurement - Low, Crossover - Low; Indirectness of outcome: No indirectness ; Group 1 Number missing: 32, Reason: death 15 withdrawals 15 (in addition to those who did not complete baseline assessment) (as above); Group 2 Number missing: 56, Reason: death 20 withdrawals 9 Protocol outcome 4: Length of survival - Actual outcome for Adults (aged 18 yrs or over): Length of survival at Until death; Mean; (Median (95%CI): Intervention 14 (10.6-18.4) Control 8.5 (7.0-11.1); p=0.14)); Risk of bias: All domain - High, Selection - Low, Blinding - High, Incomplete outcome data - Low, Outcome reporting - Low, Measurement - Low, Crossover - Low; Indirectness of outcome: No indirectness ; Group 1 Number missing: 32, Reason: death 15 withdrawals 15 (in addition to those who did not complete baseline assessment) (as above); Group 2 Number missing: 56, Reason: death 20 withdrawals 9 - Actual outcome for Adults (aged 18 yrs or over): N of people alive at 14.6 months; Group 1: 112/161, Group 2: 119/161 Risk of bias: All domain - High, Selection - Low, Blinding - High, Incomplete outcome data - Low, Outcome reporting - Low, Measurement - Low, Crossover - Low; Indirectness of outcome: No indirectness ; Group 1 Number missing: 32, Reason: death 15 withdrawals 15 (in addition to those who did not complete baseline assessment) (as above); Group 2 Number missing: 56, Reason: death 20 withdrawals 9	
Protocol outcomes not reported by the study	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; Staff satisfaction; Avoidable/inappropriate admissions to ICU; Inappropriate resuscitation; Patient/carer reported outcomes (satisfaction); Preferred and actual place of care; Length of stay

Study	Brumley 2003[13]
Study type	RCT (Patient randomised; Parallel)
Number of studies (number of participants)	1 (n=297)
Countries and setting	Conducted in USA; Setting: Southern California TriCentral Service Hospice
Line of therapy	Not applicable

Study	Brumley 2003[13]
Duration of study	Intervention + follow up: 2 years (September 2002-March 2004)
Method of assessment of guideline condition	Adequate method of assessment/diagnosis: Physicians are asked to refer any patient to the TCPC Program if the physician 'would not be surprised if this patient died in the next year'
Stratum	Adults (aged 18 years or over):
Subgroup analysis within study	Not applicable:
Inclusion criteria	Kaiser Permanente (KP) hospice homebound patients who had a diagnosis of a life threatening disease, primarily Chronic obstructive pulmonary disease (COPD), Chronic heart failure (CHF), or cancer; two or more emergency department visits or hospital admissions in the past year, and limited life expectancy (not more than approximately one year to live)
Exclusion criteria	Not stated
Recruitment/selection of patients	Referrals originate from many sources, including physicians, discharge planners, home health nurses, and social workers
Age, gender and ethnicity	Age - Other: Not stated. Gender (M:F): Not stated. Ethnicity: 18% Asian/Pacific Islanders, 13% Hawaiian, 4% Latino, 2% other
Further population details	1. Any specific population:
Extra comments	NA.
Indirectness of population	No indirectness
Interventions	(n=210) Intervention 1: Coordinator. The TriCentral Palliative Care (TCPC) program is an interdisciplinary home-based program for patients at the end of life. The program offers enhanced pain control, symptom management and psychosocial support to improve quality of life. By blending palliative care and curative measures, the TCP program provides gradual transition for patients allowing them to retain their primary physician while receiving home visits from the palliative care team and physician. The program uses an interdisciplinary approach that focuses on the patient and family and in which care is provided by a core team consisting of a physician, nurse and social worker with expertise in pain control, other symptom management and psychosocial intervention. Patients are assigned a palliative care physician who coordinates care from a variety of health care practitioners (including the patients' primary care physician), thus preventing service fragmentation. Home visits are provided by all team members (including physicians) to provide medical care, support and education as needed by patients and their caregivers. Ongoing care management to fill gaps in care is provided to ensure that the patients' medical, social and spiritual needs are being met. Telephone support and afterhours visits are available 24/7, as needed by the patient. ACP that empowers patients and their family to make informed decisions and choices of care about EOLC is provided. Duration 1.5 year. Concurrent medication/care: Usual primary care.

Study	Brumley 2003[13]
	(n=348) Intervention 2: Usual care. Kaiser Permanente hospice patients who did not receive the TCPC program. Duration 1.5 year. Concurrent medication/care: Not stated.
Funding	Other (The study was funded by the Kaiser Permanente Garfield Memorial Fund)
RESULTS (NUMBERS ANALYSED) AND RISK OF BIAS FOR COMPARISON: COORDINATOR versus USUAL CARE Protocol outcome 1: Number of hospital visits - Actual outcome for Adults (aged 18 years or over): Hospital visits at end of follow-up; Group 1: mean 2.359 (SD 10.96); n=161, Group 2: mean 9.352 (SD 10.82); n=139; Risk of bias: Very high, Selection - High, Blinding - High, Incomplete outcome data - High, Outcome reporting - Low, Measurement - Low, Crossover - Low; Indirectness of outcome: No indirectness; Group 1 missing: 49, reason: did not die, Group 2 missing: 209, reason: did not die Protocol outcome 2: Number of visits to accident and emergency - Actual outcome for Adults (aged 18 years or over): Emergency department visits at end of follow-up; Group 1: mean 0.93 (SD 2.51); n=161, Group 2: mean 2.297 (SD 0.92); n=139; Risk of bias: Very high, Selection - High, Blinding - High, Incomplete outcome data - High, Outcome reporting - Low, Measurement - Low, Crossover - Low; Indirectness of outcome: No indirectness; Group 1 missing: 49, reason: did not die, Group 2 missing: 209, reason: did not die Protocol outcome 3: Use of community services - Actual outcome for Adults (aged 18 years or over): Physician visits at end of follow-up; Group 1: mean 5.335 (SD 13.97); n=161, Group 2: mean 11.089 (SD 13.81); n=139; Risk of bias: Very high, Selection - High, Blinding - High, Incomplete outcome data - High, Outcome reporting - Low, Measurement - Low, Crossover - Low; Indirectness of outcome: No indirectness; Group 1 missing: 49, reason: did not die, Group 2 missing: 209, reason: did not die - Actual outcome for Adults (aged 18 years or over): Skilled nursing care visits at end of follow-up; Group 1: mean 0.851 (SD 11); n=161, Group 2: mean 4.575 (SD 10.87); n=139; Risk of bias: Very high, Selection - High, Blinding - High, Incomplete outcome data - High, Outcome reporting - Low, Measurement - Low, Crossover - Low; Indirectness of outcome: No indirectness; Group 1 missing: 49, reason: did not die, Group 2 missing: 209, reason: did not die - Actual outcome for Adults (aged 18 years or over): Total home health visits at end of follow-up; Group 1: mean 35.048 (SD 31.83); n=161, Group 2: mean 13.247 (SD 31.44); n=139; Risk of bias: Very high, Selection - High, Blinding - High, Incomplete outcome data - High, Outcome reporting - Low, Measurement - Low, Crossover - Low; Indirectness of outcome: No indirectness; Group 1 missing: 49, reason: did not die, Group 2 missing: 209, reason: did not die Protocol outcome 4: Preferred and actual place of death - Actual outcome for Adults (aged 18 years or over): People dying at home at end of follow-up; Group 1: 138/159, Group 2: 79/139; Risk of bias: Very high, Selection - High, Blinding - High, Incomplete outcome data - High, Outcome reporting - Low, Measurement - Low, Crossover - Low; Indirectness of outcome: Serious indirectness; Group 1 missing: 61, reason: did not die, Group 2 missing: 209, reason: did not die	
Protocol outcomes not reported by the study	Quality of life; Hospitalisation; Number of unscheduled admissions; Length of survival; Staff satisfaction; Avoidable/inappropriate admissions to ICU; Inappropriate resuscitation; Patient/carer reported outcomes

Study	Brumley 2003[13]
	(satisfaction); Preferred and actual place of care; Length of stay

Study	Seow 2008[45]
Study type	Non-randomised comparative study
Number of studies (number of participants)	1 (n=89)
Countries and setting	Conducted in USA; Setting: Managed care organisation in Maryland.
Line of therapy	Mixed line
Duration of study	Other: NA
Method of assessment of guideline condition	Adequate method of assessment/diagnosis
Stratum	Adults (aged 18 years or over)
Subgroup analysis within study	Not applicable
Inclusion criteria	Current cancer diagnosis, over 18 years old, had a date of enrolment or refusal to the program, and had confirmed date of death while insured under the managed care organisation.
Exclusion criteria	Referred to the program for 1 week or less (deemed too short a time period to benefit from case management)
Recruitment/selection of patients	Enrollees of a Maryland-mandated Medicaid insurance program administered by the managed care organisation.
Age, gender and ethnicity	Age - Mean (SD): 52 (10.54). Gender (M:F): 36/53. Ethnicity: not reported
Further population details	1. Any specific population: Not applicable
Indirectness of population	No indirectness
Interventions	(n=69) Intervention 1: Case manager. The Omega Life Program (OLP) - Nurse case managers lead the program and provided an initial and on-going holistic assessment of physical, psychosocial, and spiritual needs of patient and family. Case managers educate patients and families about various topics, including advance directives, hospice options, insurance and prescription benefits and symptom management. Patients and families are taught to contact case managers for information and needs rather than emergencies. Patients are followed by the case manager from enrolment through to death. The case manager also coordinates care between multiple providers, integrate various providers into the care team, and serve as the main point of contact for the patient and the families to help them navigate the health system. Duration >1 week. Concurrent medication/care: NA

Study	Seow 2008[45]
	(n=20) Intervention 2: Usual care. Patients referred to the OLP who elected not to enrol. Continued to receive usual care. Duration <1 week. Concurrent medication/care: NA
Funding	Study funded by industry (ConnectCare3/ The Beacon Group)
RESULTS (NUMBERS ANALYSED) AND RISK OF BIAS FOR COMPARISON: CASE MANAGER versus USUAL CARE Protocol outcome 1: Hospitalisation - Actual outcome for Adults (aged 18 years or over): Odds of having one or more hospital admission at >1 weeks; OR 0.138 (95%CI 0.03 to 0.57) (P 0.006); Risk of bias: High; Indirectness of outcome: No indirectness Protocol outcome 2: Length of survival - Actual outcome for Adults (aged 18 years or over): Deaths since referral (8-30 days) at 8-30 days; Group 1: 28/69, Group 2: 3/20; Risk of bias: High, Blinding - High, Incomplete outcome data - Low, Outcome reporting - Low, Measurement - Low, Crossover - Low; Indirectness of outcome: No indirectness - Actual outcome for Adults (aged 18 years or over): Deaths since referral (31-120 days) at 31-120 days; Group 1: 20/69, Group 2: 8/20; Risk of bias: High, Blinding - High, Incomplete outcome data - Low, Outcome reporting - Low, Measurement - Low, Crossover - Low; Indirectness of outcome: No indirectness - Actual outcome for Adults (aged 18 years or over): Deaths since referral (120+ days) at 120+ days; Group 1: 21/69, Group 2: 9/20; Risk of bias: High, Blinding - High, Incomplete outcome data - Low, Outcome reporting - Low, Measurement - Low, Crossover - Low; Indirectness of outcome: No indirectness	
Protocol outcomes not reported by the study	Quality of life; 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; Staff satisfaction; Avoidable/inappropriate admissions to ICU; Inappropriate resuscitation; Patient/carer reported outcomes (satisfaction); Preferred and actual place of care; Length of stay

Study	Wang 2015[51]
Study type	Non-randomised comparative study
Number of studies (number of participants)	1 (n=186)
Countries and setting	Conducted in USA
Line of therapy	Not applicable
Duration of study	Other: Between January 1, 2004 and August 31, 2011
Method of assessment of guideline condition	Adequate method of assessment/diagnosis: Retrospective assessment of those who had died.

Study	Wang 2015[51]
Stratum	Overall
Subgroup analysis within study	Not applicable
Inclusion criteria	Cancer diagnosis; no hospice election, aged between 18 and 65 years at time of Omega Life Program (OLP) referral; being referred to OLP and having died during the study period; having enrolled in OLP at least 30 days prior to death; and no other health insurance coverage. The comparison group was the same except the patients in the comparison group were referred to OLP at least 30 days prior to death but did not enrol in OLP.
Exclusion criteria	Not reported.
Recruitment/selection of patients	From data sources: health plan membership enrolment data, administrative claims data; care management data.
Age, gender and ethnicity	Age - Mean (SD): 50.4 (10.3) in intervention group and 51.2 (9.8) in comparator group. Gender (M:F): 59/132 in the intervention group and 32/22 in the comparator group.. Ethnicity: African American 55%; Caucasian 42%; Other 3%
Further population details	N/A
Indirectness of population	No indirectness
Interventions	(n=132) Intervention 1: Case manager. Omega Life Program (OLP) was a nurse case management program in palliative care provided by a Medicaid managed-care organisation. The patients and their families/caregivers were provided with tailored services throughout the course of patient care, including needs assessment, symptom management consultation, care coordination, counselling, advance care planning, and caregiver support. Duration Not reported. Concurrent medication/care: Not reported. Indirectness: No indirectness (n=54) Intervention 2: Usual care. Referred to Omega Life Program but did not enrol in it. Duration Not reported. Concurrent medication/care: Not reported. Indirectness: No indirectness
Funding	No funding

RESULTS (NUMBERS ANALYSED) AND RISK OF BIAS FOR COMPARISON: CASE MANAGER versus USUAL CARE

Protocol outcome 1: Length of stay
- Actual outcome: Inpatient days at 30 days; Group 1: mean 10.7 Days (SD 8); n=132, Group 2: mean 10.8 Days (SD 7.6); n=54
Risk of bias: All domain - Very high Selection - Very high, Blinding - Low, Incomplete outcome data - Low, Outcome reporting - Low, Measurement - Low, Crossover - Low, Subgroups - Low; Indirectness of outcome: No indirectness ; Baseline details: There is no statistical significance given but they had to

Study	Wang 2015[51]
adjust for 3 covariates. Key confounders: Gender, age and days between OLP referral and death - Actual outcome: ICU days at 30 days; Group 1: mean 8.7 Days (SD 10); n=132, Group 2: mean 9.7 Days (SD 7.8); n=54 Risk of bias: All domain - Very high, Selection - Very high, Blinding - Low, Incomplete outcome data - Low, Outcome reporting - Low, Measurement - Low, Crossover - Low, Subgroups - Low; Indirectness of outcome: No indirectness ; Baseline details: There is no statistical significance given but they had to adjust for 3 covariates; Key confounders: Gender, age and days between OLP referral and death. - Actual outcome: Hospice days; Group 1: mean 45.8 Days (SD 53.9); n=132, Group 2: mean 31.1 Days (SD 37.6); n=54 Risk of bias: All domain - Very high Selection - Very high, Blinding - Low, Incomplete outcome data - Low, Outcome reporting - Low, Measurement - Low, Crossover - Low, Subgroups - Low; Indirectness of outcome: No indirectness ; Baseline details: There is no statistical significance given but they had to adjust for 3 covariates.; Key confounders: Gender, age and days between OLP referral and death Protocol outcome 2: Hospitalisation - Actual outcome: Inpatient admission at 30 days; Group 1: 75/132, Group 2: 40/54 (adjusted OR 0.47 (0.21, 1.04)) Risk of bias: All domain - Very high, Selection - Very high, Blinding - Low, Incomplete outcome data - Low, Outcome reporting - Low, Measurement - Low, Crossover - Low, Subgroups - Low; Indirectness of outcome: No indirectness ; Baseline details: There is no statistical significance given but they had to adjust for 3 covariates.; Key confounders: Gender, age and days between OLP referral and death Protocol outcome 3: Number of visits to accident and emergency. - Actual outcome: Treat-and-release ED visit at 30 days; Group 1: 29/132, Group 2: 9/54 (adjusted OR 1.41 (0.62, 3.22)) Risk of bias: All domain - Very high, Selection - Very high, Blinding - Low, Incomplete outcome data - Low, Outcome reporting - Low, Measurement - Low, Crossover - Low, Subgroups - Low; Indirectness of outcome: No indirectness; Baseline details: There is no statistical significance given but they had to adjust for 3 covariates; Key confounders: Gender, age and days between OLP referral and death. Protocol outcome 4: Use of community services - Actual outcome: Persons with hospice election at 30 days; Group 1: 87/132, Group 2: 38/54 (adjusted OR 0.81 (0.41, 1.62)) Risk of bias: All domain - Very high -, Selection - Very high, Blinding - Low, Incomplete outcome data - Low, Outcome reporting - Low, Measurement - Low, Crossover - Low, Subgroups - Low; Indirectness of outcome: No indirectness ; Baseline details: There is no statistical significance given but they had to adjust for 3 covariates.; Key confounders: Gender, age and days between OLP referral and death. Protocol outcome 5: Preferred and actual place of death - Actual outcome: Persons with death in hospital at 30 days; Group 1: 31/132, Group 2: 19/54 (adjusted OR 0.47 (0.23, 0.98)) Risk of bias: All domain - Very high, Selection - Very high, Blinding - Low, Incomplete outcome data - Low, Outcome reporting - Low, Measurement - Low, Crossover - Low, Subgroups - Low; Indirectness of outcome: Serious indirectness, Comments: Does not give preference for place of death; Baseline details: There is no statistical significance given but they had to adjust for 3 covariates.; Key confounders: Gender, age and days between OLP referral and death Protocol outcome 6: Avoidable/inappropriate admissions to ICU - Actual outcome: ICU admission at 30 days; Group 1: 17/132, Group 2: 13/54 (adjusted OR 0.47 (0.21, 1.04)) Risk of bias: All domain - Very high -Selection - Very high, Blinding – Low. Incomplete outcome data – Low. Outcome reporting – Low. Measurement –	

Study	Wang 2015[51]
Low. Crossover - Low; Indirectness of outcome: Serious indirectness, Comments: Does not indicate whether the admissions were avoidable or inappropriate. Baseline details: There is no statistical significance given but they had to adjust for 3 covariates; Key confounders: Gender, age and days between OLP referral and death	
Protocol outcomes not reported by the study	Quality of life; Number of unscheduled admissions; Length of survival; Staff satisfaction; Inappropriate resuscitation; Patient/carer reported outcomes (satisfaction); Preferred and actual place of care; Number of hospital visits

D.2 Lead health professional

None.

Appendix E: Forest plots

E.1 Care coordinator

E.1.1 Nurse coordinator versus usual care (Addington-Hall 1992)

Figure 3: Satisfaction (carers agreeing with the statement 'care was well coordinated') after bereavement

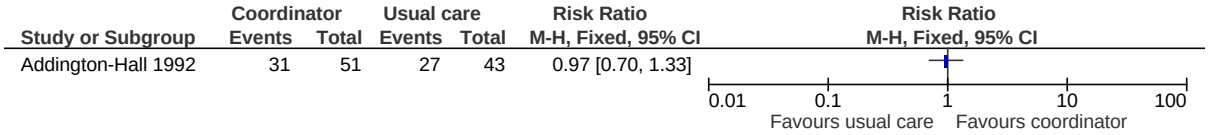


Figure 4: Satisfaction (carers satisfied with care from district nurses)

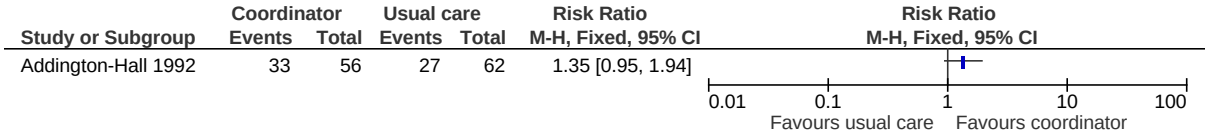


Figure 5: Satisfaction (carers satisfied with care from GPs)

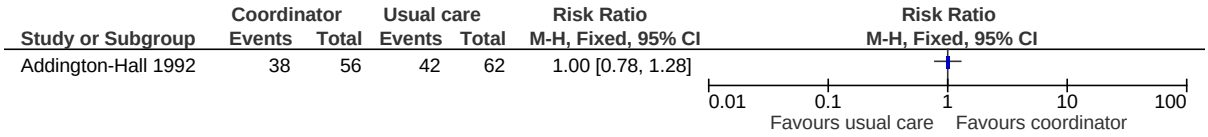


Figure 6: Satisfaction (carers satisfied with care from hospital)

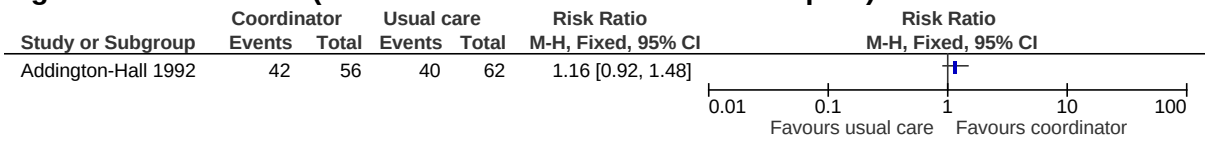


Figure 7: Satisfaction (patients satisfied with care from district nurses)

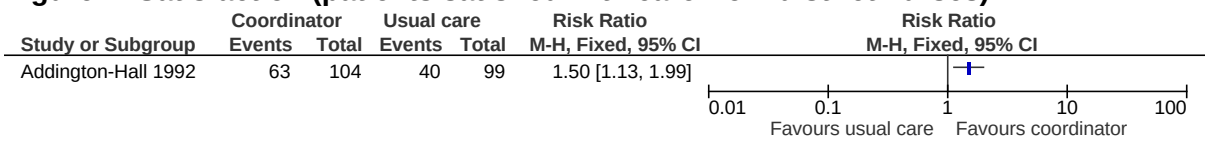


Figure 8: Satisfaction (patients satisfied with care from GPs)

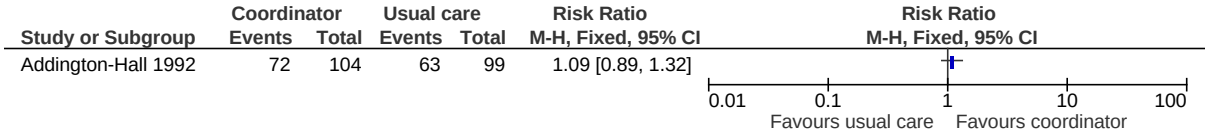


Figure 9: Satisfaction (patients satisfied with care from hospital)

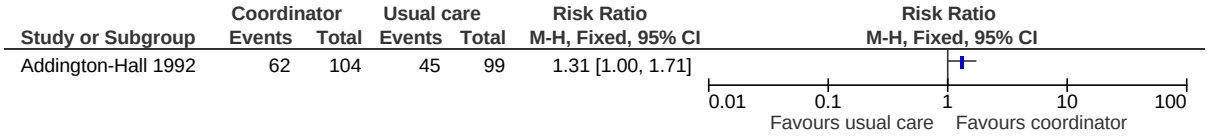


Figure 10: Preferred and actual place of death (people dying at home)

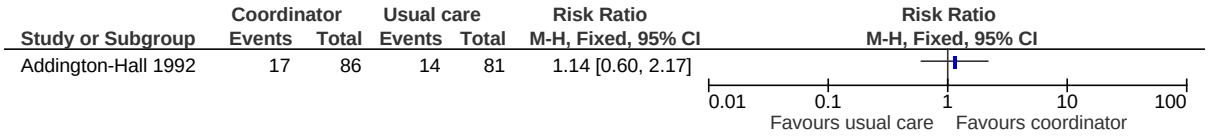


Figure 11: Preferred and actual place of death (people dying in a location other than home, hospice or hospital)

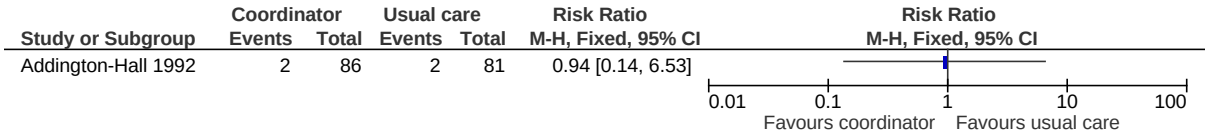


Figure 12: Preferred and actual place of death (people dying in hospice)

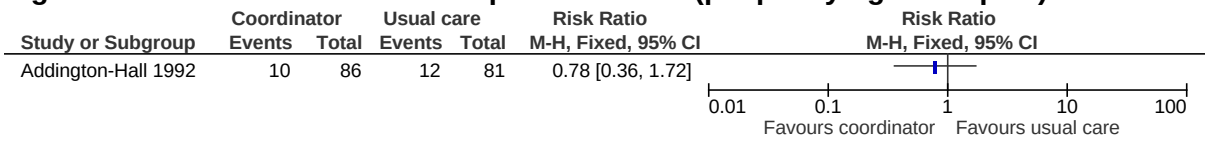
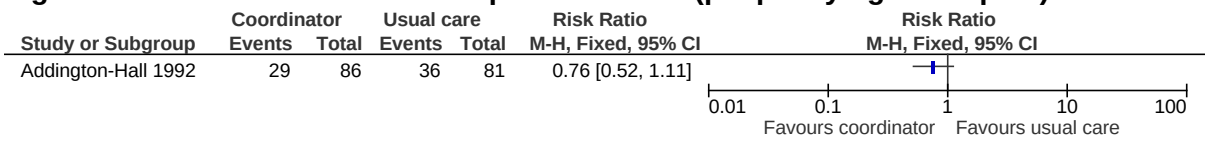


Figure 13: Preferred and actual place of death (people dying in hospital)



1

Figure 14: Use of community services (people known to occupational therapists)

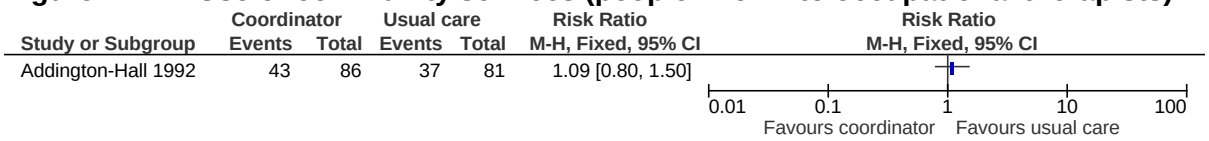


Figure 15: Use of community services (people known to social workers)

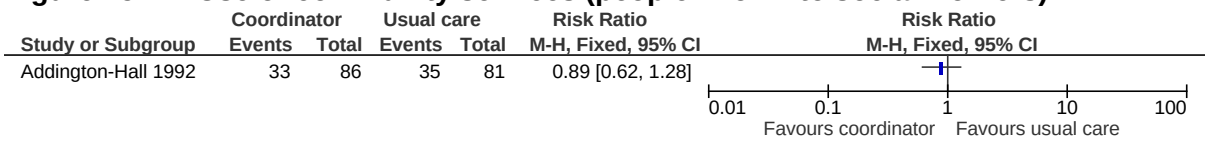
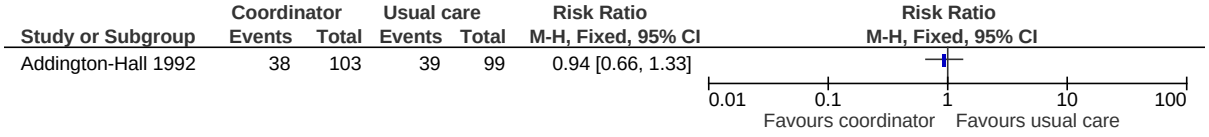


Figure 16: Use of community services (patients having contact with district nurses) 2 weeks before final interview



2

Figure 17: Use of community services (patients having contact with GP-home visits) 2 weeks before final interview

Study or Subgroup	Coordinator Events	Total	Usual care Events	Total	Risk Ratio M-H, Fixed, 95% CI
Addington-Hall 1992	23	103	23	99	0.96 [0.58, 1.60]

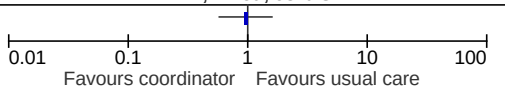


Figure 18: Use of community services (patients having contact with GP-surgery visits) 2 weeks before final interview

Study or Subgroup	Coordinator Events	Total	Usual care Events	Total	Risk Ratio M-H, Fixed, 95% CI
Addington-Hall 1992	13	103	18	99	0.69 [0.36, 1.34]

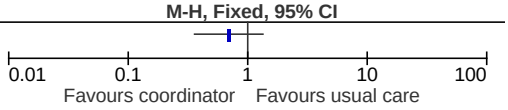


Figure 19: Use of community services (patients having contact with hospice or Macmillan nurses) 2 weeks before final interview

Study or Subgroup	Coordinator Events	Total	Usual care Events	Total	Risk Ratio M-H, Fixed, 95% CI
Addington-Hall 1992	7	103	11	99	0.61 [0.25, 1.51]

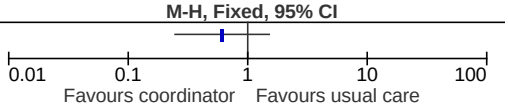


Figure 20: Use of community services (home visits – district nurses, Macmillan nurses, hospital oncology nurses, hospice homecare team)

Study or Subgroup	Coordinator Mean	SD	Total	Usual care Mean	SD	Total	Mean Difference IV, Fixed, 95% CI
Addington-Hall 1992	14.5	22	86	37.5	67.4	81	-23.00 [-38.40, -7.60]

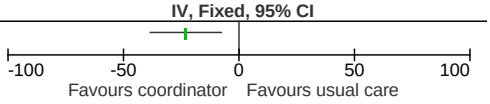


Figure 21: Hospitalisation (n of admissions)

Study or Subgroup	Coordinator Mean	SD	Total	Usual care Mean	SD	Total	Mean Difference IV, Fixed, 95% CI
Addington-Hall 1992	2.5	3.3	86	3.3	3	81	-0.80 [-1.76, 0.16]

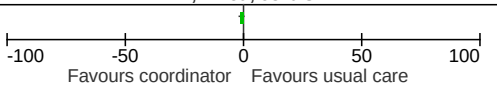


Figure 22: Length of stay (n of inpatient days)

Study or Subgroup	Coordinator Mean	SD	Total	Usual care Mean	SD	Total	Mean Difference IV, Fixed, 95% CI
Addington-Hall 1992	24.1	30.6	86	40	48.7	81	-15.90 [-28.32, -3.48]

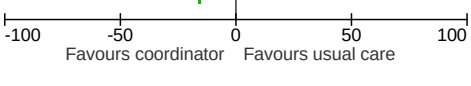
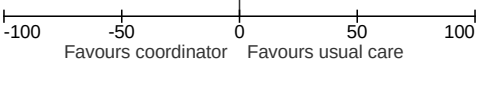


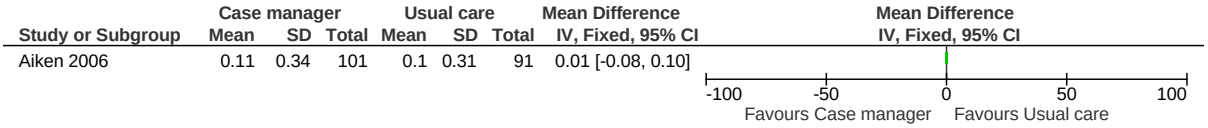
Figure 23: Number of hospital visits (outpatient attendance)

Study or Subgroup	Coordinator Mean	SD	Total	Usual care Mean	SD	Total	Mean Difference IV, Fixed, 95% CI
Addington-Hall 1992	18	9	86	10.1	10.3	81	7.90 [4.96, 10.84]



E.1.2 Nurse case manager versus usual care (Aiken 2006)

Figure 24: Number of visits to Accident and Emergency (Emergency department visits) 6 months



1 E.1.3 Palliative care physician coordinator versus usual care (Brumley 2003)

Figure 25: Preferred and actual place of death (people dying at home)

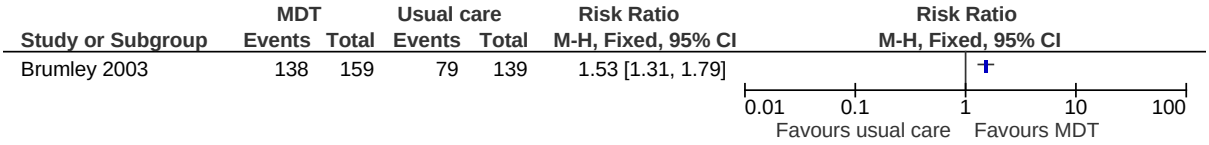


Figure 26: Number of hospital visits

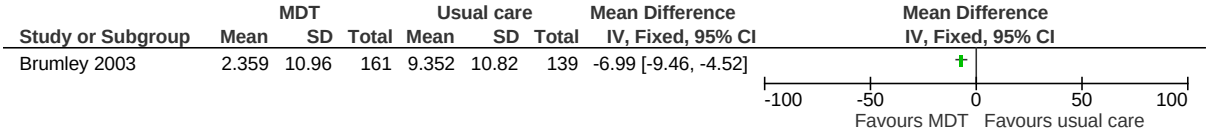


Figure 27: Number of visits to accident and emergency (Emergency department visits)

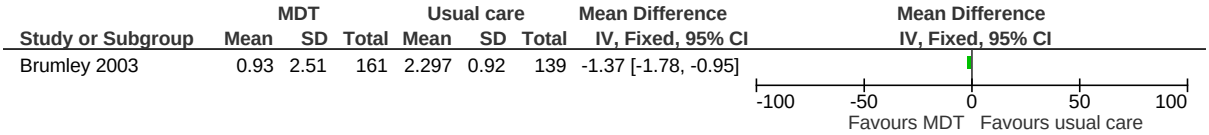


Figure 28: Use of community services (physicians visits)

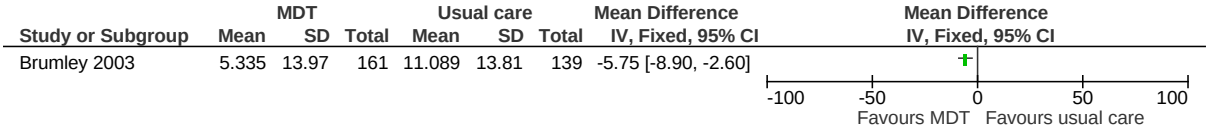


Figure 29: Use of community services (skilled nursing care visits)

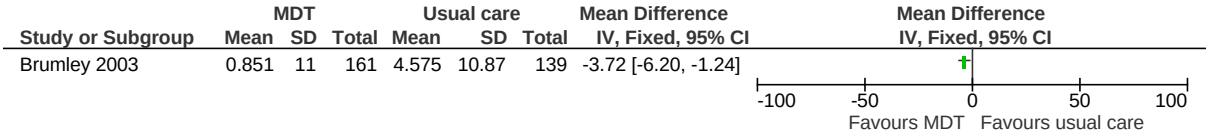
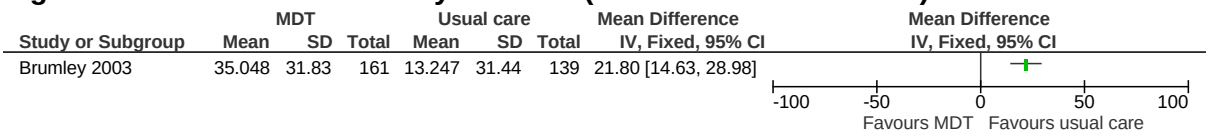


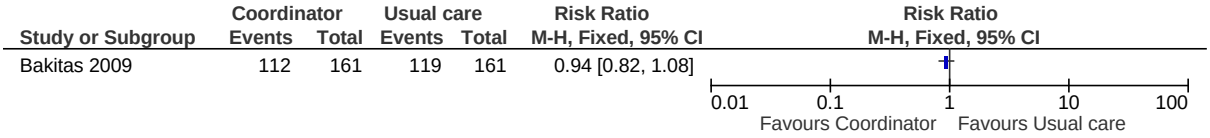
Figure 30: Use of community services (total home health visits)



2

1 E.1.4 Coordinator versus usual care (Bakitas 2009)

Figure 31: Length of survival (mortality) 14.6 months



2 E.1.5 Nurse case manager versus usual care (Seow 2008)

Figure 32: Length of survival (deaths since referral (120+ days))

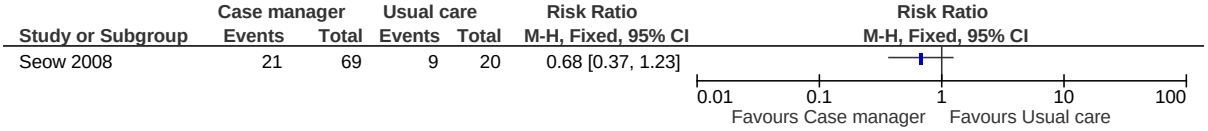


Figure 33: Length of survival (deaths since referral (31-120 days))

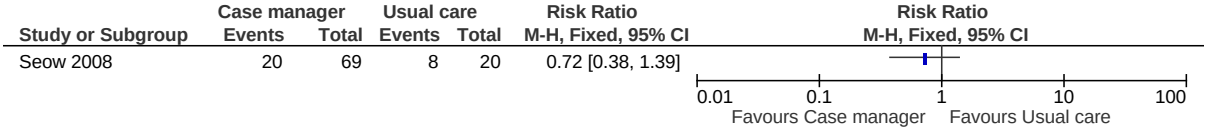
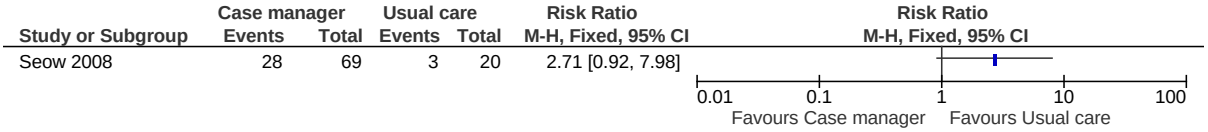


Figure 34: Length of survival (deaths since referral (8-30 days))



3 E.1.6 Nurse case manager versus usual care (Wang 2015)

Figure 35: Length of stay

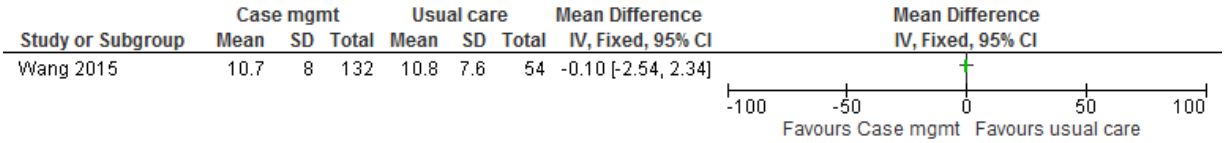


Figure 36: ICU days

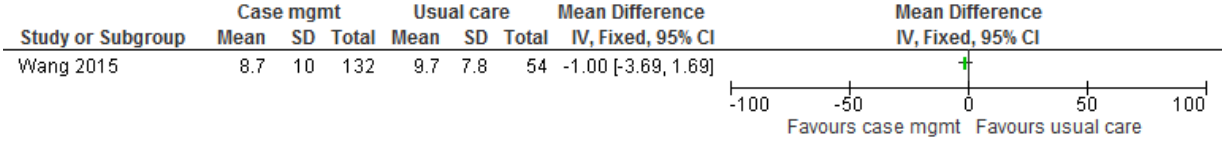
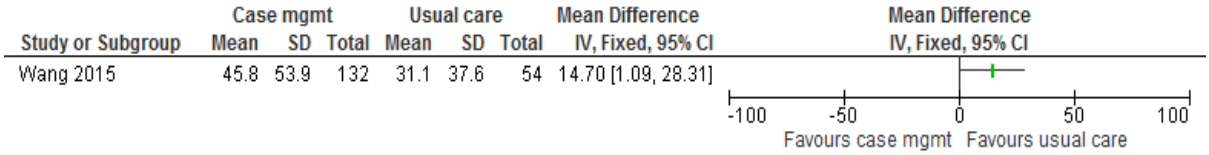


Figure 37: Hospice days



1

Figure 38: Inpatient admission

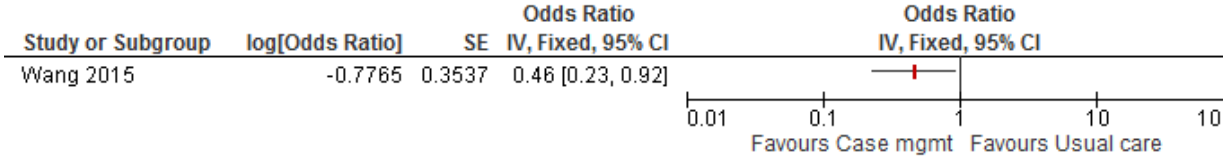


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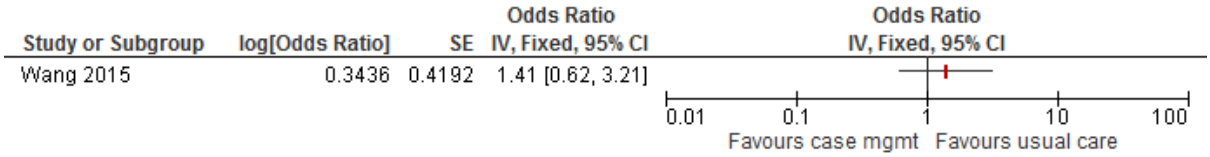
Figure 39: treat-and-release ED visit



3

Figure 40: Persons with hospice election

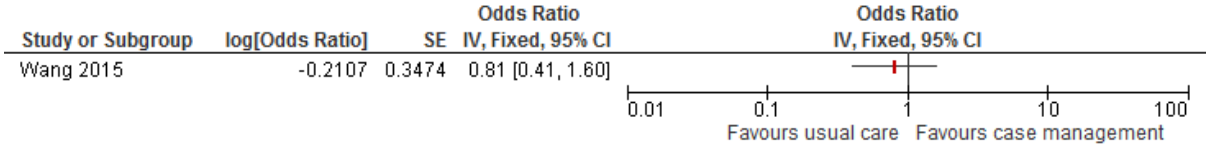


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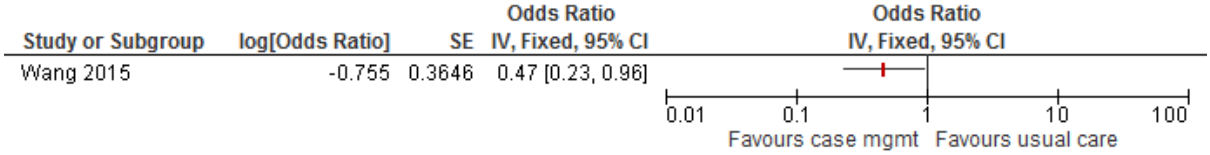
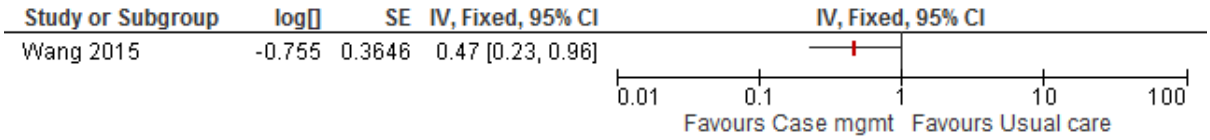
Figure 41: Persons with death in hospital



5

Figu**re 42: Admissions to ICU**



E.2 Lead health professional

None.

Appendix F: GRADE tables

Care coordinator Table 17: Clinical evidence profile: Nurse coordinator compared to usual care in adults thought to be entering their last year of life

Quality assessment							No of patients		Effect		Quality	Importance
No of studies	Design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations	Coordinator	Usual care	Relative (95% CI)	Absolute		
Satisfaction (carers agreeing with statement 'care was well coordinated') after bereavement												
1	randomised trials	very serious[a]	no serious inconsistency	serious[b]	very serious[c]	none	31/51 (60.8%)	27/43 (62.8%)	RR 0.97 (0.7 to 1.33)	19 fewer per 1000 (from 188 fewer to 207 more)	⊕OOO VERY LOW	IMPORTANT
Satisfaction (carers satisfied with care from district nurses)												
1	randomised trials	very serious[a]	no serious inconsistency	serious[b]	serious[c]	none	33/56 (58.9%)	27/62 (43.5%)	RR 1.35 (0.95 to 1.94)	152 more per 1000 (from 22 fewer to 409 more)	⊕OOO VERY LOW	IMPORTANT
Satisfaction (carers satisfied with care from GP)												
1	randomised trials	very serious[a]	no serious inconsistency	serious[b]	serious[c]	none	38/56 (67.9%)	42/62 (67.7%)	RR 1 (0.78 to 1.28)	0 fewer per 1000 (from 149 fewer to 190 more)	⊕OOO VERY LOW	IMPORTANT
Satisfaction (carers satisfied with care from hospital)												
1	randomised trials	very serious[a]	no serious inconsistency	serious[b]	serious[c]	none	42/56 (75%)	40/62 (64.5%)	RR 1.16 (0.92 to 1.48)	103 more per 1000 (from 52 fewer to 310 more)	⊕OOO VERY LOW	IMPORTANT
Satisfaction (patients satisfied with care from district nurses)												
1	randomised trials	very serious[a]	no serious inconsistency	serious[b]	serious[c]	none	63/104 (60.6%)	40/99 (40.4%)	RR 1.5 (1.13 to 1.99)	202 more per 1000 (from 53 more to 400	⊕OOO VERY	IMPORTANT

										more)	LOW	
Satisfaction (patients satisfied with care from GP)												
1	randomised trials	very serious[a]	no serious inconsistency	serious[b]	serious[c]	none	72/104 (69.2%)	63/99 (63.6%)	RR 1.09 (0.89 to 1.32)	57 more per 1000 (from 70 fewer to 204 more)	⊕OOO VERY LOW	IMPORTANT
Satisfaction (patients satisfied with care from hospital)												
1	randomised trials	very serious[a]	no serious inconsistency	serious[b]	serious[c]	none	62/104 (59.6%)	45/99 (45.5%)	RR 1.31 (1 to 1.71)	141 more per 1000 (from 0 more to 323 more)	⊕OOO VERY LOW	IMPORTANT
Preferred and actual place of death (people dying at home)												
1	randomised trials	very serious[a]	no serious inconsistency	serious[b]	very serious[c]	none	17/86 (19.8%)	14/81 (17.3%)	RR 1.14 (0.6 to 2.17)	24 more per 1000 (from 69 fewer to 202 more)	⊕OOO VERY LOW	CRITICAL
Preferred and actual place of death (people dying elsewhere)												
1	randomised trials	very serious[a]	no serious inconsistency	serious[b]	very serious[c]	none	2/86 (2.3%)	2/81 (2.5%)	RR 0.94 (0.14 to 6.53)	1 fewer per 1000 (from 21 fewer to 137 more)	⊕OOO VERY LOW	CRITICAL
Preferred and actual place of death (people dying in hospice)												
1	randomised trials	very serious[a]	no serious inconsistency	serious[b]	very serious[c]	none	10/86 (11.6%)	12/81 (14.8%)	RR 0.78 (0.36 to 1.72)	33 fewer per 1000 (from 95 fewer to 107 more)	⊕OOO VERY LOW	CRITICAL
Preferred and actual place of death (people dying in hospital)												
1	randomised trials	very serious[a]	no serious inconsistency	serious[b]	very serious[c]	none	29/86 (33.7%)	36/81 (44.4%)	RR 0.76 (0.52 to 1.11)	107 fewer per 1000 (from 213 fewer to 49 more)	⊕OOO VERY LOW	CRITICAL
Use of community services (people known to occupational therapists)												
1	randomised trials	very serious[a]	no serious inconsistency	no serious indirectness	serious[c]	none	43/86 (50%)	37/81 (45.7%)	RR 1.09 (0.8 to 1.5)	41 more per 1000 (from 91 fewer to 228 more)	⊕OOO VERY LOW	IMPORTANT

Use of community services (people known to social workers)												
1	randomised trials	very serious[a]	no serious inconsistency	no serious indirectness	very serious[c]	none	33/86 (38.4%)	35/81 (43.2%)	RR 0.89 (0.62 to 1.28)	48 fewer per 1000 (from 164 fewer to 121 more)	⊕OOO VERY LOW	IMPORTANT
Use of community services (Patients having contact with district nurses) 2 weeks before final interview												
1	randomised trials	very serious[a]	no serious inconsistency	no serious indirectness	very serious[c]	none	38/103 (36.9%)	39/99 (39.4%)	RR 0.94 (0.66 to 1.33)	24 fewer per 1000 (from 134 fewer to 130 more)	⊕OOO VERY LOW	IMPORTANT
Use of community services (Patients having contact with GP-home visit) 2 weeks before final interview												
1	randomised trials	very serious[a]	no serious inconsistency	no serious indirectness	very serious[c]	none	23/103 (22.3%)	23/99 (23.2%)	RR 0.96 (0.58 to 1.6)	9 fewer per 1000 (from 98 fewer to 139 more)	⊕OOO VERY LOW	IMPORTANT
Use of community services (Patients having contact with GP-surgery consultation) 2 weeks before final interview												
1	randomised trials	very serious[a]	no serious inconsistency	no serious indirectness	very serious[c]	none	13/103 (12.6%)	18/99 (18.2%)	RR 0.69 (0.36 to 1.34)	56 fewer per 1000 (from 116 fewer to 62 more)	⊕OOO VERY LOW	IMPORTANT
Use of community services (Patients having contact with hospice or MacMillan sister) 2 weeks before final interview												
1	randomised trials	very serious[a]	no serious inconsistency	no serious indirectness	very serious[c]	none	7/103 (6.8%)	11/99 (11.1%)	RR 0.61 (0.25 to 1.51)	43 fewer per 1000 (from 83 fewer to 57 more)	⊕OOO VERY LOW	IMPORTANT
Hospitalisation (admissions) (Better indicated by lower values)												
1	randomised trials	very serious[a]	no serious inconsistency	no serious indirectness	serious[c]	none	86	81	-	MD 0.8 lower (1.76 lower to 0.16 higher)	⊕OOO VERY LOW	IMPORTANT
Length of stay (inpatient days) (Better indicated by lower values)												
1	randomised trials	very serious[a]	no serious inconsistency	no serious indirectness	serious[c]	none	86	81	-	MD 15.9 lower (28.32 to 3.48 lower)	⊕OOO VERY LOW	IMPORTANT
Number of hospital visits (outpatient attendance) (Better indicated by higher values)												

1	randomised trials	very serious[a]	no serious inconsistency	no serious indirectness	serious[c]	none	86	81	-	MD 7.9 higher (4.96 to 10.84 higher)	⊕OOO VERY LOW	IMPORTANT
Use of community services (home visits-district nurses, Macmillan nurses, hospital oncology nurses, hospice homecare team) (Better indicated by lower values)												
1	randomised trials	very serious[a]	no serious inconsistency	no serious indirectness	serious[c]	none	86	81	-	MD 23 lower (38.4 to 7.6 lower)	⊕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 or 2 increments because the majority of the evidence had indirect outcomes
[c] Downgraded by 1 increment if the confidence interval crossed one MID or by 2 increments if the confidence interval crossed both MIDs

Table 18: Home-nurse case manager compared to usual care in adults with diagnosed with CHF or COPD thought to be entering their last two years of life

Quality assessment							No of patients		Effect		Quality	Importance
No of studies	**Design**	**Risk of bias**	**Inconsistency**	**Indirectness**	**Imprecision**	**Other considerations**	**Case manager**	**Usual care**	**Relative (95% CI)**	**Absolute**		
Number of visits to A&E (ED visits) 6 months (follow-up mean 6 months; Better indicated by lower values)												
1	randomised trials	very serious[a]	no serious inconsistency	no serious indirectness	no serious imprecision	none	101	91	-	MD 0.01 higher (0.08 lower to 0.1 higher)	⊕⊕OO LOW	IMPORTANT

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

Table 19: Clinical evidence profile: Nurse coordinator compared to usual care in adults with life-limiting cancer thought to be entering their last year of life

Quality assessment							No of patients		Effect		Quality	Importance
No of studies	Design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations	Coordinator	Usual care (Bakitas 2009)	Relative (95% CI)	Absolute		
Length of survival (mortality) at 14.6 months (follow-up mean 14.6 months)												
1	randomised trials	serious[a]	no serious inconsistency	serious[b]	no serious imprecision	none	112/161 (69.6%)	119/161 (73.9%)	RR 0.94 (0.82 to 1.08)	44 fewer per 1000 (from 133 fewer to 59 more)	⊕⊕OO LOW	CRITICAL

[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 or 2 increments because the majority of the evidence had indirect outcomes

Table 20: Clinical evidence profile: Palliative care physician coordinator compared to usual care in adults with progressive life-limiting conditions thought to be entering their last year of life

Quality assessment							No of patients		Effect		Quality	Importance
No of studies	Design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations	MDT (home-based palliative care program)	Usual care (Brumley 2003)	Relative (95% CI)	Absolute		
People dying at home												
1	randomised trials	very serious[a]	no serious inconsistency	serious[b]	no serious imprecision	none	138/159 (86.8%)	56.8%	RR 1.53 (1.31 to 1.79)	301 more per 1000 (from 176 more to 449 more)	⊕OOO VERY LOW	CRITICAL
Number of hospital visits (Better indicated by lower values)												
1	randomised trials	very serious[a]	no serious inconsistency	no serious indirectness	serious[c]	none	161	139	-	MD 6.99 lower (9.46 to 4.52 lower)	⊕OOO VERY LOW	IMPORTANT
Number of visits to accident and emergency (ED visits) (Better indicated by lower values)												

1	randomised trials	very serious[a]	no serious inconsistency	no serious indirectness	serious[c]	none	161	139	-	MD 1.37 lower (1.78 to 0.95 lower)	⊕OOO VERY LOW	IMPORTANT
Use of community services (physicians visits) (Better indicated by lower values)												
1	randomised trials	very serious[a]	no serious inconsistency	no serious indirectness	serious[c]	none	161	139	-	MD 5.75 lower (8.9 to 2.6 lower)	⊕OOO VERY LOW	IMPORTANT
Use of community services (skilled nursing care visits) (Better indicated by lower values)												
1	randomised trials	very serious[a]	no serious inconsistency	no serious indirectness	serious[c]	none	161	139	-	MD 3.72 lower (6.2 to 1.24 lower)	⊕OOO VERY LOW	IMPORTANT
Use of community services (total home health visits) (Better indicated by lower values)												
1	randomised trials	very serious[a]	no serious inconsistency	no serious indirectness	serious[c]	none	161	139	-	MD 21.8 higher (14.63 to 28.98 higher)	⊕OOO VERY LOW	IMPORTANT

[a] Downgraded by 1 or 2 increments because the majority of the evidence had indirect outcomes
[b] Downgraded by 1 increment if the confidence interval crossed one MID or by 2 increments if the confidence interval crossed both MIDs
[c] 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

Table 21: Clinical evidence profile: Nurse case manager compared to usual care in adults with life-limiting cancer thought to be entering their last year of life

Quality assessment							No of patients		Effect		Quality	Importance
No of studies	**Design**	**Risk of bias**	**Inconsistency**	**Indirectness**	**Imprecision**	**Other considerations**	**Case manager**	**Usual care (Seow 2008)**	**Relative (95% CI)**	**Absolute**		
Length of survival (deaths since referral (120+ days))												
1	observational studies[a]	serious[b]	no serious inconsistency	no serious indirectness	serious[c]	none	21/69 (30.4%)	9/20 (45%)	RR 0.68 (0.37 to 1.23)	144 fewer per 1000 (from 283 fewer to 104 more)	⊕OOO VERY LOW	CRITICAL
Length of survival (deaths since referral (31-120 days))												

1	observational studies[a]	serious[b]	no serious inconsistency	no serious indirectness	very serious[c]	none	20/69 (29%)	8/20 (40%)	RR 0.72 (0.38 to 1.39)	112 fewer per 1000 (from 248 fewer to 156 more)	⊕OOO VERY LOW	CRITICAL
Length of survival (deaths since referral (8-30 days))												
1	observational studies[a]	serious[b]	no serious inconsistency	no serious indirectness	serious[c]	none	28/69 (40.6%)	3/20 (15%)	RR 2.71 (0.92 to 7.98)	257 more per 1000 (from 12 fewer to 1000 more)	⊕OOO VERY LOW	CRITICAL
Length of stay (Better indicated by lower values)												
1	observational studies	very serious[1]	no serious inconsistency	no serious indirectness	no serious imprecision	none	132	54	-	MD 0.1 lower (2.54 lower to 2.34 higher)	⊕OOO VERY LOW	IMPORTANT
ICU days (Better indicated by lower values)												
1	observational studies	very serious[a]	no serious inconsistency	serious[b]	no serious imprecision	none	132	54	-	MD 1 lower (3.69 lower to 1.69 higher)	⊕OOO VERY LOW	IMPORTANT
Hospice days (Better indicated by lower values)												
1	observational studies	very serious[a]	no serious inconsistency	serious[b]	serious[c]	none	132	54	-	MD 14.7 higher (1.09 to 28.31 higher)	⊕OOO VERY LOW	IMPORTANT
Inpatient admission												
1	observational studies	very serious[a]	no serious inconsistency	serious[b]	serious[c]	none	75/132 (56.8%)	40/54 (74.1%)	RR 0.77 (0.62 to 0.95)	170 fewer per 1000 (from 37 fewer to 281 fewer)	⊕OOO VERY LOW	IMPORTANT
Avoidable/inappropriate admissions to ICU												
1	observational studies	very serious[a]	no serious inconsistency	no serious indirectness	serious[c]	none	17/132 (12.9%)	13/54 (24.1%)	RR 0.53 (0.28 to 1.02)	113 fewer per 1000 (from 173 fewer to 5 more)	⊕OOO VERY LOW	IMPORTANT
Treat-and-release ED visit												
1	observational	very	no serious	serious[b]	very serious[c]	none	29/132	9/54	RR 1.32	53 more per 1000	⊕OOO	IMPORTANT

	studies	serious[a]	inconsistency				(22%)	(16.7%)	(0.67 to 2.6)	(from 55 fewer to 267 more)	VERY LOW	
Persons with hospice election												
1	observational studies	very serious[a]	no serious inconsistency	serious[b]	no serious imprecision	none	87/132 (65.9%)	38/54 (70.4%)	RR 0.94 (0.76 to 1.16)	42 fewer per 1000 (from 169 fewer to 113 more)	⊕OOO VERY LOW	IMPORTANT
Persons with death in hospital												
1	observational studies	very serious[a]	no serious inconsistency	serious[b]	serious[c]	none	31/132 (23.5%)	19/54 (35.2%)	RR 0.67 (0.41 to 1.07)	116 fewer per 1000 (from 208 fewer to 25 more)	⊕OOO VERY LOW	IMPORTANT

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

F.1 Lead Health professional

None.

Appendix G: Health economic evidence selection

[Copy health economic flow chart with title to here from the separate master version of the HE Protocol + Flow chart kept on Sharepoint and updated by the HE.

Ensure this is later updated to the final version before submission to NICE.]

Appendix H: Excluded studies

Table 22: Studies included from the clinical review of care coordinator

Study	Exclusion reason
Allen 1999[3]	Not review population
Applebaum 1988[4]	Not review population. Inappropriate study design
Arendts 2014[5]	Not review population. Inappropriate study design (protocol only)
Back 2005[6]	Incorrect interventions
Beklman 2018{Bekelman, 2018 #3537}	Inappropriate intervention and not review population
Boult 2013[9]	Not review population
Bowler 2006[10]	Inappropriate study design. Not review population
Brogaard 2011[11]	Inappropriate study design. Inappropriate comparison
Browne 2001[12]	Not review population
Corbett 2005[14]	Not review population
Cotham 1994[15]	Not review population. Inappropriate study design
Daly 1991[17]	Not review population
Engelhardt 2006[18]	Not review population
Enguidanos 2012[19]	Not review population
Evans 2016[20]	Inappropriate study design
Freijser 2015[21]	Systematic review: literature search not sufficiently rigorous. Systematic review: methods are not adequate/unclear
Grobe 1983[22]	Incorrect interventions
Harrison Dening 2018{Harrison Dening, 2018 #3518}	Inappropriate study design. No comparison
Henderson 2004[23]	Inappropriate study design (narrative review; non-comparative pilot study data)
Howell 2008[24]	Not review population. Inappropriate study design
Huggins 1998[25]	Not review population
Jacobs 2011[26]	Not review population
Johansson 2012[27]	Not review population. Inappropriate study design (narrative review)
Johnson 2015[28]	Not review population
Johnston 2018{Johnston, 2018 #3526}	Inappropriate study design (non-comparative)
Kind 2012[29]	Not review population. Inappropriate study design (non-comparative)
Kinley 2014[30]	Incorrect interventions

Study	Exclusion reason
Kirchberger 2010[31]	Not review population. Inappropriate study design (protocol only)
Kuruvilla 2018{Kuruvilla, 2018 #3545}	Not review population
Lamb 1994[32]	Not review population. Inappropriate study design (qualitative)
Lazarus 2001[33]	Inappropriate study design (narrative review)
Long 1999[34]	Not review population
Macdonald 1994[35]	Inappropriate study design (non-comparative)
O'Donnell 2018{O'Donnell, 2018 #3539}	No outcomes
Pedersen 2010[38]	Not review population. Inappropriate study design (review)
Petrova 2010[39]	Inappropriate study design (non-comparative)
Purdy 2013[40]	Not review population. Systematic review is not relevant to review question or unclear PICO. Systematic review: methods are not adequate/unclear
Salazar 2000[43]	Inappropriate study design. Not review population
Schenker 2015[44]	Inappropriate study design (non-comparative)
Sherman 1991[46]	Not review population
Skillings 2009[47]	Not review population
Van de Mortel 2017[50]	Inappropriate comparison
Wideman 2012[52]	Not review population. Inappropriate study design
Wootton 2009[53]	Not review population
Wulff 2013[54]	Not review population
Yang 2018{Yang, 2018 #3542}	Not review population

Table 23: Studies excluded from the clinical review of lead health professional

Study	Exclusion reason
Corbett 2005[14]	Not review population
Johansson 2012[27]	Not review population. Inappropriate study design (narrative review)
Long 1999[34]	Not review population
Riegel 2002[42]	Not review population
Schenker 2015[44]	Inappropriate study design (non-comparative)
Seow 2008[45]	Incorrect interventions
Spettell 2009[48]	Inappropriate study design (report)
Tam-Tham 2013[49]	Systematic review is not relevant to review question or unclear PICO

H.1 Excluded health economic studies

There were no excluded health economic studies for this review.