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End of life care for adults: service delivery

[C] Evidence review: Barriers to accessing end of life care services

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Evidence review

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1.1 Review question: What are the barriers and facilitators for the initial access to, and planning of end of life care services?

1.2 Introduction

The NHS England Mandate (2013-15) sets an ambition for the NHS to deliver a 'globally recognised' standard of end of life care. This is supported by an assessment of global end of life care performance in which our end of life care was rated the best in the world.[581] However, people are still experiencing barriers to accessing good quality end of life care, or in some cases not accessing end of life care at all.

In 2017 Hospice UK (e-hospice 3rd July Hospice UK analysis 'One in four UK families who need end of life care miss out on crucial support')[350] estimated that one in four people, approximately 118,000, who require end of life care and their families are not able to access the expert care they need at the end of life, including hospice care or other support that they need. This is particularly true for people with conditions other than cancer and their analysis also showed that people from economically and socially deprived areas, BAME communities and LGBT people can experience barriers to accessing end of life care services.

Barriers that prevent people in their last year of life accessing End of Life care can vary but poor communication and coordination of services is an ever-present theme. One of the biggest barriers is for professionals to recognise when someone has entered the last year of life and having the skills to discuss this with openness and sensitivity. This can be compounded by institutional culture, limited resource, restrictive internal policies and lack of training and education all contributing to people experiencing barriers to care during this period. Macmillan Cancer Support (Time to Choose – making choices at end of life 2013)[483] also found similar barriers.

Lack of information about the out-of-hours services, a reticence of some health care professionals to have 'difficult conversations' with patients and carers and poor inter-professional communication can all have an impact on care.

It is said that nearly three quarters of people with cancer would prefer to die at home and yet less than a third are able to do so. (Macmillan – A Time to Choose, 2013).[483]. While it is true that some will change their mind as their symptoms change, none-the-less there is a large gap between what people want and what they experience.

In addition to the general barriers, there are other others specific to different communities and groups, for instance a 2014 Marie Curie and Alzheimer's Society[17] report highlights that 'dementia is often not recognised as a terminal diagnosis, which can lead to poor access to care, inconsistent quality of care d'..

The ability of all health and care professionals to recognise when someone is entering the last year of life and the ability to be able to discuss end of life openly, honestly and sensitively are essential gateways to appropriate end of life care. This chapter reviews the themes found in qualitative work about the barriers to accessing end of life care.

1.3 PICO table

For full details see the review protocol in Appendix A.

Table 1: PICO characteristics of review question

Objective	To determine how services can be improved and what works well to support: • the initial access to end of life care services for people in their last year of life • carers/patient's involvement in planning their last year of life services
Population and setting	Adults (aged over 18 or over) with progressive life-limiting conditions thought to be entering the last year of life. Carers of (or those important to) adults (aged over 18 or over) with progressive life-limiting conditions thought to be entering the last year of life. Includes young carers (<18 years)
Context	Initial access Any type of barriers and facilitators to the initial access of people in their last year of life to end of life care services. For example: • Communication around end of life issues such as for example, awareness of availability of end of life care services • Timing or setting of involvement in initial planning decision making (for example, ACP) • Facilitators (for example: coordinators, leaflets and information) Planning, choices, discharge What works well (and what doesn't) when facilitating discharge • Service features/elements that patients/carers considered as important for effective discharge process. How and when to best incorporate patient's choice in the last year of life care pathway • Process for effective advance care planning • What process should be in place for allowing patients to change their minds/choices throughout their last year of life (after the initial advance care planning).
Review strategy	Synthesis of qualitative research. Results presented in table format. Quality of the evidence will be assessed by a GRADE CerQual approach for each review finding.

1.3.1 Included studies

Thirty four qualitative studies were included in the review; [48, 51, 67, 92, 157, 168, 183, 196, 223, 233, 234, 273, 306, 348, 371, 397, 430, 475, 481, 484, 502, 511, 554, 580, 582, 643, 649, 701, 736, 752, 771, 831, 832, 848] these are summarised in Table 2 below. Key findings from these studies are summarised in section 1.2.2 below. See also the study evidence tables in Appendix D, and excluded studies lists in Appendix F.

Table 2: Summary of studies included in the review

Study	Design	Population	Research aim	Comments
Bajwah 2013[48]	Semi-structured face-to-face interview with thematic qualitative analysis.	Patients with a diagnosis of end-stage non-specific interstitial pneumonia, IPF and idiopathic interstitial pneumonia and their carers. N=12 UK	To explore understanding of the disease, preferences regarding end-of-life planning, and views on communication and coordination of care in patients with Progressive Idiopathic Fibrotic Interstitial Lung Disease (PIF-ILD).	
Bamford 2018 [51]	Semi structured face to face and one focus group interviews with thematic qualitative analysis.	People with dementia. N=11 Bereaved and current carers N=18 UK	To explore the factors that facilitate good End of Life Care for people with advanced dementia from the perspective of stakeholders including family carers and people with dementia.	
Benzar 2011[67]	Semi-structured face-to-face or telephone interviews with thematic qualitative analysis	Patients (and their carers) who received palliative care consultations at Oregon Health and Science University. N=19 USA.	To identify the range of health care experiences of family caregivers and patients who received palliative care consultations after they left hospital, and to understand how palliative care teams might best prepare patients and caregivers for the post-hospital experience	
Briggs 2010[92]	Semi-structured face-to-face interviews with thematic qualitative analysis	Borough-registered patients (n=30) and carers (n=20) aged 16 year and over. Patients were being treated at various hospitals or hospices or were receiving treatment in their homes. N=50 UK	Originated from a consultation in Borough on understanding the experiences and expectations of patients diagnosed with life-limiting diseases during the last year of life.	

Study	Design	Population	Research aim	Comments
Coombs 2017[157]	Field observations and longitudinal semi-structured interviews with thematic qualitative analysis.	Patients with advanced and progressive illness, with high risk of dying in the next 12 months, and their Carers. N=40 New Zealand	To describe decision-making processes that influence transitions in care when approaching the end of life.	Patients were followed up at 3 to 4 months, when 11 patients were available.
Csikai 2010[168]	Semi-structured face-to-face interviews with thematic qualitative analysis	Bereaved hospice caregivers of patients over age 60, who had received home hospice service, who had died at home within 3-6 months of the survey being mailed out for the first phase of the study. N=10 USA	To explore, in-depth, bereaved hospice caregivers' experiences regarding communication with various health care professionals about patients' serious illness and end-of-life care options.	Second phase of a larger study of bereaved hospice caregivers' perceptions of communication about end-of-life care and the transition to hospice care.
Davison 2006[183]	Structured focus group (nominal group technique); face-to-face in-depth interview with thematic qualitative analysis.	Patients with end-stage renal disease purposively selected on the basis of their willingness to discuss the issues. N=24 Canada	To determine the perspectives of patients with ESRD of the salient elements of ACP discussions.	
den Herder-van der Eerden 2017[196]	Longitudinal qualitative study design using interviews with a two-step qualitative content approach	Patients with advanced disease (62% cancer, 24% COPD, 13% heart failure), whose doctors answered 'No' to the surprise question. N=152 Belgium, Germany, Hungary, the Netherlands, and the United Kingdom	To examine how relational, informational and management continuity of care are experienced by patients with advanced diseases and their family caregivers receiving care from several integrated palliative care initiatives in 5 European countries.	Patients were followed up at 3 months, 54% were available for follow-up.
El-Jawahri 2017[223]	Semi-structured interviews with the framework approach qualitative analysis.	Patients with metastatic cancer, with a prognosis under 12 months, and their caregivers. N=16 patients	To assess perceptions about hospice.	

Study	Design	Population	Research aim	Comments
		N=7 Caregivers USA		
Epiphaniou 2014[233]	Semi-structured face-to-face interviews with thematic qualitative analysis	Patients with lung cancer or chronic obstructive pulmonary disease (COPD), assumed to be in the last year of life, recruited from three hospital outpatient clinics situated in one hospital. N=18 UK	To explore patients' experience of care coordination in order to inform current debates on how best to coordinate care and deliver services in end-of-life for patients with lung cancer and those with chronic obstructive pulmonary disease (COPD)	Serial interviews at 3 time points.
Epstein 2015[234]	Open-ended question asked in a face-to-face post-intervention interview with thematic qualitative analysis of the answers	Patients with advanced liver, biliary or pancreas cancers and no prior advance directives at a Cancer Institute. The majority received chemotherapy and all were being followed at least monthly by their outpatient medical oncologist. N=54 USA	To aid in better understanding of, and provide potential solutions to, barriers to communication about end-of-life care	Part of participants' responses to an open-ended question in a randomised trial of an educational video or narrative about CPR
Gerlich 2012[273]	Semi-structured face-to-face interviews with thematic qualitative analysis	Participants of age 70 and above and with heart failure in an advance stage, and if the physicians' answer to the 'surprise question' was 'No'. N=12 Germany	To explore the needs of older patients with advanced heart failure, and their experiences with health care delivery in Germany.	
Hanratty 2012[306]	Semi-structured face-to-face interviews with thematic qualitative analysis	People older than 75 years who had moved between at least two care settings in the previous three months who were aware that they had been diagnosed	To explore older adults' experiences as they move between places of care at the end of life	Part of a larger project on transitions in health care settings at the end of life for people with stroke, heart failure and lung cancer

Study	Design	Population	Research aim	Comments
		with heart failure, lung cancer, or stroke and were thought to be in their last year of life. N=30 UK		
Horne 2012[348]	Semi-structured face-to-face interviews with thematic qualitative analysis	People with advanced lung cancer and their family members who had completed 'active' treatment in one multi-cultural city and one post-industrial town in northern England. N=25 patients; N=19 family members. UK	To explore the views and experiences of people affected by lung cancer about discussing preferences and wishes for end of life care and treatment	
Jack 2016[371]	Semi-structured face-to-face interview with thematic qualitative analysis.	Participants in receipt of Hospice at Home service and deemed to have a life expectancy measured in weeks rather than days. Sixteen patients and 25 caregivers were interviewed. N=41 UK	To explore patients' and family caregivers' experiences and perceptions of Hospice at Home care.	
Johnston 2016[397]	Semi-structured face-to-face interview with thematic qualitative analysis.	Patient and family member/carer and key health professionals involved in their care included. Patients were: considered to be in the last year of their life due to chronic respiratory disease or heart failure. N=6 (patients) UK	To explore patients, and their partners, views and experiences of the EOLC-LTC service.	

Study	Design	Population	Research aim	Comments
Klindtworth 2015[430]	Semi-structured face-to-face interview with thematic qualitative analysis.	Old and very old patients (70 years or over) with severe HF (NYHA III-IV). N=36 Germany	To understand how old and very old patients with advanced HF perceive their disease and to identify their medical, psychosocial and information needs, focusing on the last phase of life.	
Low 2005[475]	Focus groups with thematic qualitative analysis	Patients, informal carers and volunteers from four purposively selected palliative care day units. N=18 patients; N=12 carers; N=22 day unit volunteers. UK.	To explore the experiences of people involved in UK palliative care day services and identify the important outcomes of this service	
MacArtney 2015[481]	Semi-structured face-to-face interview with thematic qualitative analysis	Inpatients at a short stay inpatient specialist palliative care unit, part of a sub-acute care hospital with an attached specialist community palliative care service. Inpatients were within the last few weeks (or in some cases months) of life. N=44 Australia.	To explore experiences shaped by resilience and acceptance to show how they both facilitate as well as restrict possibilities for people at the end of life.	
Macpherson 2013[484]	Semi-structured interviews with thematic qualitative analysis	Patients with severe COPD (as defined by the Gold Standards Framework). N=10 UK	To explore the views of people with COPD about advance care planning.	
McVeigh 2018 ,[511]	Semi-structured interviews (face or face or telephone) with thematic qualitative analysis	Bereaved carers N=17	To explore the view of bereaved carers about specialist and generalist palliative care	

Study	Design	Population	Research aim	Comments
		Northern Ireland and Republic of Ireland.	provision for people with non-malignant respiratory disease.	
Mason 2013[502]	Semi-structured face-to-face interview with thematic qualitative analysis	Patients and their carers using established UK clinical guidelines for the identification of people anticipated to be in their last year of life. N=54 UK	To report the experiences and perceptions of people with advanced multi-morbidity to inform improvements in palliative and end-of-life care.	
Metzger 2013[554]	Semi-structured face-to-face interview with thematic qualitative analysis	Participants with a primary diagnosis of HF, who were referred to the inpatient palliative care consultation service for goals of care discussions. N=40 USA	To describe patients with HF and their family members' experiences with, and perceptions of, inpatient PC consultations.	
Murray 2002[582]	Face-to-face in-depth interview; structured focus group (nominal group technique); with thematic qualitative analysis.	Outpatients with newly diagnosed advanced inoperable lung cancer or with cardiac failure (New York Heart Association grade IV). N=40 UK	To compare the illness trajectories, needs, and service use of patients with cancer and those with advanced non-malignant disease.	
Murray 2016[580]	Semi-structured face-to-face interview with thematic qualitative analysis.	Former caregivers of deceased patients with motor neuron disease who had been referred to a multiprofessional MND service coordinated by a hospital specialising in palliative care and rehabilitation. N=18 Australia	To investigate caregiver perspectives on the acceptability and impact of advance care planning, documented in a letter format, for patients with motor neuron disease and their caregivers.	

Study	Design	Population	Research aim	Comments
Phipps 2003[643]	Semi-structured interview with thematic qualitative analysis.	African-American and white patients with stage III-B or IV colon cancer and their designated family caregivers. N=68 USA.	To investigate differences in attitudes, preferences, and behaviours regarding end of life in terminally ill patients and their designated family caregivers.	
Piamjariyakul 2014[649]	Semi-structured face-to-face interview with thematic qualitative analysis.	Patients with severe chronic cardiovascular illness (i.e. three-vessel coronary artery disease, end stage HF, malignant hypertension, and repeated bouts of atrial fibrillation); many of who also had renal failure and diabetes mellitus. N=30 USA	To explore end-of-life preferences and determine the presence of signed end-of-life advanced directives.	
Romo 2017[701]	Semi-structured face-to-face interview with thematic qualitative analysis.	Community-dwelling adults aged 67 to 98 with a life expectancy of less than 1 year. N=20 USA	To explore how older adults in the community with a limited life expectancy make healthcare decisions and the processes used when they are not in an acute crisis.	
Selman 2017[736]	Semi-structured face-to-face interview with thematic qualitative analysis.	Older people with an advanced disease receiving specialist palliative care who had been hospitalised, and their Carers.N=26UK/USA	To explore challenges to and facilitators of empowerment among older people with advanced disease in hospital, and the impact of palliative care.	
Simpson 2011[752]	Semi-structured face-to-face interview with thematic qualitative analysis.	Eight families (eight patients with a primary diagnosis of COPD in an advanced stage and seven informal caregivers). N=15 Canada	To observe what is required for meaningful, acceptable ACP in the context of advance care planning.	

Study	Design	Population	Research aim	Comments
Spruyt 1999[771]	Semi-structured face-to-face interviews with thematic qualitative analysis	Bereaved family carers of patients referred to an east London community palliative care team. N=18 UK	To describe the palliative care experience of Bangladeshi patients and carers in the Tower Hamlets area in the east of London.	
Walczak 2013[831]	Semi-structured face-to-face interviews with thematic qualitative analysis	English-speaking adult patients with advanced, incurable cancer assessed by their oncologist as having life expectancy of less than 12 months. N=34 USA/Australia	To explore patients' perspectives across two cultures (Australia and USA) regarding communication about prognosis and end-of-life care issues and to consider the ways in which these discussions can be optimised.	
Walczak 2015[832]	Audio-recording of community support programme (CSP) sessions, with thematic analysis.	Patients with in-curable heterogeneous cancer diagnosis and oncologist-assessed 2-12 month life expectancy and their carers. N=42 Australia	To explore responses to a nurse-led CSP, incorporating a question prompt list (booklet of questions patients/caregivers can ask clinicians), promoting life expectancy and EOL-care discussions.	
Whitehead 2012[848]	Narrative face-to-face interviews with thematic qualitative analysis	Patients with motor neurone disease (n=24) and current (n=18) and bereaved (n=10) carers. N=24 patients; N=18 current carers and N=10 bereaved carers UK	To gain a greater understanding of the experiences of living with MND in the final stages of the disease.	

1.3.2 Qualitative evidence synthesis

Table 3: Review findings

Main findings	Statement of finding
Information about prognosis	More information, clearly delivered is required about prognosis, disease progression and planning for the future.
Timing of information	Information about the disease trajectory and dying process should be given earlier, perhaps after diagnosis. Information about EOL hospice care should be earlier as well. Some believed ACP should be started early. Participants hoped health care providers would have adequate training to inform patients at the right time.
Awareness of services	Patients and carers need more awareness of the services available for end-of-life care and how to get support. Preparation for the palliative care consultation would be useful.
Understanding of end-of-life care services	The patients' understanding of the concepts within end-of-life care such as palliative and hospice care was variable. Expectations of services could be confused.
Readiness for discussion	Both the patient and doctor need to be ready for the end-of-life discussion. Patients require acceptance and adjustment and doctors need to be confident in discussion of these issues and that the patient desires the information.
Communication skills	Patient and HCPs communication skills are important in creating conditions for discussion of prognosis and EOL issues. Doctors should be skilled in being sensitive to individual needs and able to raise difficult issues directly, but control of the discussion should be given to the patient.
Options and involvement in decision-making	Patients should have options provided to them and be part of the decision-making process.
EOLC service	Palliative care teams were perceived to spend more time with patients, have individualised care, someone listen to them and be specialised in their care. There was a perceived increase in access to other services via palliative care teams and nurses.
Co-ordination of EOLC	Patients can find the system difficult to navigate. Keyworkers were useful to co-ordinate end-of-life services and to gain access to services. Patients found it easier to have all professionals in one place.
Discharge planning: practical arrangements	Patients required discharge planning of practical arrangements, such as how to access services, medication contingency and instructions.
Appointments	Patients require more control over appointments. Access to appointments outside the home should be considered and appointments inside the home should not be too disruptive to daily life.
Planning ahead	Patients vary in their readiness to plan ahead.
ACP: knowledge	Knowledge of ACP and the perceived benefits of ACP can help patients decide on completion of an ACP.

Main findings	Statement of finding
ACP: written or discussed	Some patients choose to write ACP documentation, whereas others may not, due to a variety of reasons. The process can help discussion of their concerns.

1.3.2.1 Narrative summary of review findings

Barriers and facilitators to access to end of life care

Review finding 1: information about prognosis

There was a lack of information about prognosis, disease progression and how to plan for the future.[48,273,484,67,51,511] Delivery of prognoses varied, some terminal prognoses and future care needs were provided very generally, sometimes clearly,[168] but were often vague, overoptimistic and lacked information on what to expect.[67] Physicians were sometimes reluctant to give complete disclosure of prognosis.[168]

Review finding 2: timing of information

Providing information at an earlier stage about EOL hospice care was highlighted [168] Patients felt information about disease trajectory and the dying process should be given much earlier, even right after diagnosis.[168,223,511] This included information on medical treatments as well as the services to assist with care at the end of life.[168] Some suggested waiting for initial shock of diagnosis to be processed and adjust to the treatment plan, or delaying in-depth information until the patient’s health worsens. Or some thought not until something imminent occurs or there are no other options, with a few specifying that early information would interfere with hope and quality of life.[223] Some participants would actively avoid thoughts of declining health and end-of-life decisions and wanted to live in the present.[701],[51] Participants hoped health care providers would have adequate training to inform patients at the right time what to expect and not to wait until the last minute.[183] One study found that participants thought ACP should be started early.[234]

Review finding 3: Awareness of services

Four studies found that awareness of service provision was sometimes lacking.[48,92,223,554,511] A number of people felt they had little support from services. Limited GP involvement and lack of continuity of care were frequently cited difficulties. Accessing supportive care was described as being extremely difficult for some people, and it was provided at a very late stage in the disease trajectory.[848] The majority of participants in a study of people with heart failure[554] were unprepared for the palliative care referral and consultation , had little or no previous understanding of the term palliative care and were unaware of the that a referral had been made. Those who were not expecting it reacted with suspicion, caution and/or scepticism. Those whom the consultation was expected welcomed it [554]. In one study[223] many people did not utilise hospice because they do not understand enough about it, were not thinking deeply enough about it, or did not learn about it until the last minute. They primarily wanted to know about hospice logistics, including the range of services, locations of care, members of the hospice team, and frequency/length of home hospice visits. Almost all respondents identified interest in reviewing information about hospice in brochure, video or internet format, for a gentle introduction, a broad picture or an in-depth look in to what hospice is actually like.

Review finding 4: Understanding end-of-life care services

Knowledge and understanding of an End-of-life long-term-care service was variable.[396] There were many overlapping and competing expectations with moving from life-prolonging to life-enhancing care. Palliative care held negative connotations, was perceived to be against life-prolonging, and to some equalled dying.[481] Many were unfamiliar with Palliative Care when first mentioned by their doctor and so it produced feelings of anxiety and fear about what it meant for their life expectancy.[481] Patient and caregiver understanding of hospice in the transition process varied, with many mentioning a lack of adequate understanding of hospice philosophy and services.[168] Terminology and service organisation could be a barrier. People with heart failure considered palliative care was synonymous with hospice care. Hospice care was understood as not allowing aggressive management of their Heart Failure symptoms so not controlling them the same as before. They Palliative Care therefore would have no place in their current plan of care, but might be appropriate late if current treatment plan failed or disease became ‘really fatal.’ Those who did not define Palliative Care as hospice, welcomed Palliative Care involvement, even if hospice was not an option for them.[554]

Review finding 5: Readiness for discussion

Participants felt that both the doctor and patient needed to be ready for the discussion. For the patient this means the desire to know the facts overrides any fear or ambivalence about discussing these issues. A key precursor to readiness for patients was adjustment and acceptance, acknowledging their impending death while still maintaining realistic hope and a good quality of life.[831] There are a variety of factors which can aid or impede acceptance and adjustment including continuing treatment to appease family, older people may accept it easier as had long and full life, sufficient time to adjust to disease, faith and exposure to symptoms (their own and others) and evidence of disease, such as scans[831] and seeing other’s experiences of death. Lack of familiarity with with palliative care when it was first mentioned by doctor resulted in feelings of anxiety and fear about what it meant for their life expectancy. Phasing in of palliative care often unsettled experiences of the care and treatment the participant was receiving, making them question their expectations of the future. [481] For the doctor this means feeling comfortable, confident and able to discuss these issues, and clear that the patient desires this information. Readiness was felt to be necessary for discussions to achieve the best possible outcomes with the least discomfort.[831] Appropriate timing and personal coping style helped influence readiness to discuss EOL issues.[832] Some felt it was too early to consider EOL issues in their present circumstances;[832] some found there was no point in beating around the bush. The patients coped with illness by being realistic rather than avoiding what to come.[832] Focusing on positive information rather than negative future outcomes helped coping.

Review finding 6: communication skills

Patient and HCPs’ communication skills were an important factor in creating the conditions for discussion of prognosis and EOL issues and discussion. Important communication skills for doctors included maintaining a calm and open manner, treating patients as individuals, being sensitive to their individual needs[831] and the perception of compassion.[168] Patients needed to feel comfort, trust and respect in their doctor.[168, 348] This did not always occur due to wrong predictions about time left, lack of explanations about what treatments available, wrong information or advice about treatments[348] and when decisions were made without the patients.[484] Continuity in this relationship was important and the Doctor should honestly discuss the situation, acknowledge and explain uncertainty, relate stories of other patients to foster hope[832] and make a recommendation for a plan of care.[168] Although control of the discussion should be actively given to the patient, the doctor should also take the initiative to raise complex or difficult topics such as prognosis and end-of-life issues[831] as participants can find it difficult even if they want to.[484] Continuity fostered trust between the patients and the HCPs. It meant they did not have to repeat their medical histories, nor build new relationships and trust with the HCPs.[196] Lack of trust diminished participant’s sense of control and placed social and emotional burdens on participants. In contrast, strong trust provided a sense of control.[701] Direct communication involved making clear statements about priorities and goals to guide delegates; allowing participants to maintain a sense of control.[701]

One study found that most participants thought nurses were skilled communicators, who could engage patients and caregivers in often difficult discussions about death and dying.[371] In a study of Bangladeshi patients in East London between 1986 and 1993, Spruyt 1999[771] found few people were fluent in spoken English, and fewer literate in English which led to a reliance on family members to translate, with the resulting poor communication in a majority of cases

Review finding 7: options and involvement in decision-making

Many participants mentioned their wish to have options, they felt they needed more information and the option to discuss the issues if they wished,[48,484,736,848] and be included in treatment option discussions, even if they felt they should accept the professionals' recommendations.[484, 582] One study found a quarter of participants had not been presented with different options for future treatment or care [348] and in another study[582] most patients and carers did not feel involved in decision-making or empowered to work in partnership with professionals. Carers reported that some patients were involved in the decision-making process but caregivers often controlled the flow, withheld information and shielded patients from decisions.[168] A brochure and advanced directive template helped patients learn more about their end-of-life care options[752] and the palliative care team were found to take a broader approach, discussing all available options of palliative care and what to expect with their situation, which made them more equipped to make decisions than previously.[554] Patients expressed preference to stay at home, often even with increasing risks at home, rather than being admitted to hospital. All patients stated they had made the decision about their admission into hospital, and this was the view shared by the carers. In this they weighed the benefit of being at home with the risk. They used practical resources, mainly equipment and carer support and anticipating future needs to manage increasing risks. As their condition advanced/deteriorated, different pieces of equipment were sourced to manage the associated risks, enabling them to remain at home. Carers played a vital role in them staying at home.[157] Carers reported a lack of clarity in understanding their role and their involvement in decision making[511].

Review finding 8: EOLC service

One study[475] found people were more comfortable in discussing certain issues with Palliative Care staff than their GP, who they perceived as too busy and not specialised in their care. Patients trusted the palliative care professionals, who they felt were reliable and dependable[396], "listening" to them, "more compassionate", "spending more time" and having a holistic focus.[554] They felt care was individualised as they had one nurse allocated, whereas other services had several individuals and treatment/management approaches. They could form a close relationship[396,475] and discuss ACPs and revisit when appropriate to the individual. Some needed several opportunities to talk about their wishes and makes plans. The decision-making was made together with the nurse and family and plans were perceived as being made jointly, rather than imposed.[396] The patients had confidence that they would manage any problems that arose quickly and effectively.[475] Nearly all reported a positive experience due to the Palliative Care team, feeling informed, supported and reassured. Palliative Care teams advocated for them, liaised with GPs and consultants, expedited prescriptions, facilitated complicated discharges and more flexible hospital appointments, coordinated care, arranged and conducted family meetings and overcame obstacles to them reaching their goals.[396,554] One family member describes them as navigating them through available services and getting a plan in place.[554] There was a smoother transfer from treatment-driven to comfort care. They had an understanding of their prognosis which directed treatment goals, even though this understanding was not the same as the clinicians' understanding of prognosis. Input from other health professionals, such as physiotherapists and occupational therapists were welcomed by some patients, often the main reason for going to PCDS, as they could improve their physical functioning and mobility[475]. Palliative Care staff monitored them regularly and would pre-empt any problems that might arise. The ability to access these professionals provided security and peace of mind that any problems arising could be dealt with.

Review finding 9: Co-ordination of EOLC

Studies found participants did not know who to call with questions.[67] They had difficulty navigating the healthcare system and found a lack of communication between health professionals, and a lack of care co-ordination and continuity among the numerous services providers which lead to perceptions of inconsistent and impersonal care.[48, 67, 196,306,502,51] One study[233] discovered that having a keyworker to coordinate care for patients with lung cancer was useful as a main point of contact who shared the diagnosis with, and referred them to, hospital clinicians. The key worker liaised between professionals which hastened treatment procedures and services. They co-ordinated services outside the hospital, enabling access to hospital, community and social services and felt supported and followed-up regularly. Whereas patients diagnosed with COPD who did not have access to a dedicated key worker reported access to services only during acute exacerbations when they would be admitted as inpatients, which was followed by a discharge back to the community. Lengthy periods between these meant scarce monitoring and follow-up after discharge apart from a small number who had consistent check-ups from their GP or hospital every 6, 9 and12 months. Generally follow-up from professionals in the community or from the hospital was vague. Those with COPD who had lung cancer reported access to different services following the involvement of the key worker: access to financial services, psychological support from community palliative care. One study found that accessing all the relevant palliative care professionals in one place through PCDS was invaluable.[475] One study found a wish for HCPs to look at them with a holistic lens, to support their multi-dimensional needs. They felt the benefit of their HCPs meeting, which produced connected and coherent care.[196]

Review finding 10: discharge planning: practical arrangements

One study[306] found that patients were sent out of the hospital without adequate time to prepare themselves, insufficient community support in place, and little knowledge of how to access the services they required. One account implied a lack of participation in the discharge planning process, with no medication, or instructions. A couple of participants had medication errors and another’s medications which were not similar to those at home.[306] Teaching about medicine use for symptoms was sparse and not written down. Dosing instructions on the bottle were inadequate and caregivers had no contingency plans.[67] Also there were changes to medicines and inconsistencies in instructions.[67] Medication changes, usually when in hospital, led to doubts of their purpose and efficacy.[502] Patients and families noted a lack of power and choice at discharge. Continuous, flexible care provided patients with choice and facilitated communication. Strategies such as staff rostering and having a key contact person appeared to reduce fragmentation of care.[736]

Review finding 11: appointments

Patients and carers reported being unable to make timely GP appointments, experienced delays in obtaining prescriptions. Attending hospital or practice appointments could be a struggle, and unnecessary hospital admissions, particularly at weekends, were seen as distressing for, and by, patients. Patients and carers were reluctant to ask for help. Community services did not necessarily visit at a convenient time[396]. Having a pre-booked visit from the nurse, often on a weekly basis, meant that the onus was not always on the patient to ask for the nurse to call, and encouraged patients to feel empowered to request more contact if they felt it necessary.[396] Participants appreciated having some control over when the nurse visited compared with other community nurse services.[396] Attending clinics was physically demanding and often failed to address complex, ongoing problems.[502] There was a sense of imposed processes on patients without recognising the individual’s needs or wishes, from administrative procedures to provision of aids and appliances. One participant felt social service visits intruded too much on day-to-day routine. Furthermore reliance on family members for transport was common which meant a lot of time spent waiting, taking time off work caused annoyance and guilt.[306]

Review finding 12: planning ahead

One study[348] found that planning for one's own dying and death was not something that people with lung cancer reported having discussed, except in relation to the practical arrangements following death. They preferred to focus on living in the present by 'carrying on as normal' whilst they still felt reasonably well, seeking to postpone facing death until the time came. They also sought to delay awareness of their forthcoming death for as long as possible, preferring not to know when they would die. Family members also felt that when patients appeared well they did not discuss preferences for the future. There was little evidence of integrated care planning or any open discussions about the future between patients, family carers and health professionals. Talking about planning ahead or deteriorating was viewed negatively by some people who had not experiences of doing so.[502] In one study no patients reported formulation of end-of-life plans, or considered end-of-life preferences. All realised the importance of such conversations but did not know how to initiate such conversations with their loved ones. None had palliative care involvement.[48] Patients drew on their experiences of the healthcare system, their beliefs about illness and accounts from friends, family and the media to try to make sense of their health problems and treatments. Often it was understood as 'old but not ill'. Beliefs about just being old meant they focused on the present rather than planning ahead and sought help if very ill or unable to cope.[502] Carers were often unaware of the patients' risk of dying, it could be unexpected. None understood the benefits of planning ahead to optimise quality of life and death. Deteriorating health due to multiple illnesses was interpreted as 'getting old' so palliative care, which was largely associated with managing imminent death, had no role to play.[502] Despite being keen for more involvement in current decisions about their care, participants were very wary about making advance decisions about future treatment. They would not know their future preferences and did not see why making decisions in advance would be helpful.[484] Anticipating future needs and making appropriate changes helped patients cope and remain at home. This often involved patients emotionally preparing themselves for change. If the deterioration was too sudden, they were unable to adjust quickly.[157]

Review finding 13: ACP: knowledge

Information giving was seen by participants to be a critical element of the ACP process as it promoted self-reliance, alleviated fear and uncertainties and helped prepare them for the future, including death, and gave them the knowledge to make decisions that were compatible with their values and beliefs.[183] Even with apprehension in discussing topics such as death and dying, if deemed imperative, ACP was thought important to discuss in order to make the best plan practically, realise goals and fulfil relationship duties.[234] ACP was thought to be important when they had a clear idea about how the process would benefit them, and was much less likely to engage in it if no benefit was perceived.[183]

Review finding 14: ACP: written or discussed

Caregivers reported a lack of written advance directives, but revealed knowledge of patients' wishes for care at the end of life as a way that allowed patient participation in decisions to be made.[168] Documentation of patients wishes (ACP) was easier for patients and caregivers who accepted encroaching death. Some caregivers felt documenting wishes enabled patients to 'let go.' They felt that LFC would have/gave patients' autonomy, feelings of control and courage to say what wanted. Some patients did feel some security from its completion as know wishes would be respected and stop confusion of treatment preferences.[580, 645] Caregivers felt that the letter did, or would help them feel prepared and know what to do, also to negotiate with other family members.[580] Staff could be better informed and better outcomes for all. Some felt it assisted by opening family communication. It clarified decisions for some patients and weighted up QoL versus length of life. Some carers felt it facilitated decision-making through input from expert and sensitive staff,[580] 50% in one study[649] had signed standard advance directives as requested on entry of care home, the other 50% had no written directive or living will. Reason for not having ACP was they never thought of end of life plan, too sick now to think of anything. Hispanic participants feared risk of deportation from completing form.[649] Study dialogue increased awareness of patient illness-related social deprivation, fear and end of life care preferences, subjects they had been unable to discuss before. Families talked of a patients' silence, a stance embraced prior to the study sessions. Some patients felt isolated by anxiety and took opportunity of study to talk of concerns especially loneliness and fear.[752] Patients felt that the initiative to make a living will or proxy directive came from outside themselves, and had to be brought up by others. Some felt it was not needed until the end and could cause emotional distress to them or family to discuss it. It was assumed family would know the preferences without formal documentation.[645] Some patients were willing to make arrangements for after their death, funerals were planned and will in place and ensure family taken care of. Arrangements for the time before death were less definitely defined. They had a range of strongly divergent ways to express their wishes: from written statements of intent (living wills and enduring powers of attorney) to oral delegation of decision-making power to family members or primary representatives. Some made contradictory statements regarding the intention and implementation of advance directives. Some rejected a living will completely as saw no need for the document or mistrust possible actions by physicians, and were confident family would handle things without any written directions.[430]

1.3.3 Excluded studies

See the excluded studies list in Appendix F.

1.3.4 Qualitative evidence summary

Table 4: Summary of evidence

Study design and sample size			Quality assessment		
Number of studies contributing to the finding	**Design**	**Finding**	**Criteria**	**Rating**	**Overall assessment of confidence**
Information about prognosis					
7	Semi-structured interviews	More information, clearly delivered is required about prognosis, disease progression and planning for the future.	Limitations	Minor concerns about methodological limitations	MODERATE
			Coherence	Very minor concerns about coherence[a]	
			Relevance	No concerns about relevance	
			Adequacy	No concerns about adequacy	

[a] All the studies supported the main finding but there where small differences in the level of information that people received and wanted and in the clarity of the information given

Table 5: Summary of evidence

Study design and sample size			**Quality assessment**		
Number of studies contributing to the finding	**Design**	**Finding**	**Criteria**	**Rating**	**Overall assessment of confidence**
Timing of information					
7	Semi-structured interviews and focus groups	Information about the disease trajectory and dying process should be given earlier, perhaps after diagnosis. Information about EOL hospice care should be earlier as well. Some believed ACP should be started early. Participants hoped health care providers would have adequate training to inform patients at the right time.	Limitations	Minor concerns about methodological limitations	LOW
			Coherence	Minor concerns about coherence[a]	
			Relevance	No concerns about relevance	
			Adequacy	No concerns about adequacy	

[a] The majority of the data supported information being given earlier although some data supported delaying information about poor prognosis believing it may take away people's hope and impact on their quality of life.

Table 6: Summary of evidence

Study design and sample size			Quality assessment		
Number of studies contributing to the finding	**Design**	**Finding**	**Criteria**	**Rating**	**Overall assessment of confidence**
Awareness of services					
6	Semi-structured interviews and observations	Patients and carers need more awareness of the services available for end-of-life care and how to get support. Preparation for the palliative care consultation would be useful.	Limitations	Minor concerns about methodological limitations	MODERATE
			Coherence	No concerns about coherence	
			Relevance	No concerns about relevance	
			Adequacy	No concerns about adequacy	

Table 7: Summary of evidence

Study design and sample size			Quality assessment		
Number of studies contributing to the finding	**Design**	**Finding**	**Criteria**	**Rating**	**Overall assessment of confidence**
Understanding end-of-life care services					
4	Semi-structured interviews	The patients' understanding of the concepts within end-of-life care such as palliative and hospice care was variable. Expectations of services could be confused.	Limitations	Minor concerns about methodological limitations	MODERATE

Study design and sample size		Finding	Quality assessment		
Number of studies contributing to the finding	**Design**		**Criteria**	**Rating**	**Overall assessment of confidence**
			Coherence	No concerns about coherence	
			Relevance	No concerns about relevance	
			Adequacy	No concerns about adequacy	

Table 8: Summary of evidence

Study design and sample size		Finding	Quality assessment		
Number of studies contributing to the finding	**Design**		**Criteria**	**Rating**	**Overall assessment of confidence**
Readiness for discussion					
3	Semi-structured interviews	Both the patient and the doctor need to be ready for the end-of-life discussion. Patients require acceptance and adjustment and doctors need to be confident in discussion of these issues and that the patient desires the information.	Limitations	Minor concerns about methodological limitations	MODERATE
			Coherence	No concerns about coherence	
			Relevance	No concerns about relevance	
			Adequacy	No concerns about adequacy	

Table 9: Summary of evidence

Study design and sample size		Finding	Quality assessment		
Number of studies contributing to the finding	Design		Criteria	Rating	Overall assessment of confidence
Communication skills					
8	Semi-structured interviews	Patient and HCPs communication skills are important in creating conditions for discussion of prognosis and EOL issues and discussion. Doctors should be skilled in being sensitive to individual needs and able to raise difficult issues directly, but control of the discussion should be given to the patient.	Limitations	Minor concerns about methodological limitations	MODERATE
			Coherence	No concerns about coherence	
			Relevance	No concerns about relevance	
			Adequacy	No concerns about adequacy	

Table 10: Summary of evidence

Study design and sample size		Finding	Quality assessment		
Number of studies contributing to the finding	Design		Criteria	Rating	Overall assessment of confidence
Options and involvement in decision-making					
11	Semi-structured interviews and focus groups	Patients should have options provided to them and be part of the decision-making process.	Limitations	Minor concerns about methodological limitations	MODERATE
			Coherence	No concerns about coherence	

Study design and sample size			Quality assessment		
Number of studies contributing to the finding	Design	Finding	Criteria	Rating	Overall assessment of confidence
			Relevance	No concerns about relevance	
			Adequacy	No concerns about adequacy	

Table 11: Summary of evidence

Study design and sample size			Quality assessment		
Number of studies contributing to the finding	Design	Finding	Criteria	Rating	Overall assessment of confidence
EOLC service					
3	Semi-structured interviews and focus groups	Palliative care teams were perceived to spend more time with patients, have individualised care, someone listen to them and be specialised in their care. There was a perceived increase in access to other services via palliative care teams and nurses.	Limitations	Minor concerns about methodological limitations	MODERATE
			Coherence	No concerns about coherence	
			Relevance	Minor concerns about relevance	
			Adequacy	No concerns about adequacy	

Table 12: Summary of evidence

Study design and sample size			Quality assessment		
Number of studies contributing to the finding	Design	Finding	Criteria	Rating	Overall assessment of confidence
Co-ordination of EOLC					
7	Semi-structured and focus groups	Patients can find the system difficult to navigate. Keyworkers were useful to co-ordinate end-of-life services and to gain access to services. Patients found it easier to have all professionals in one place.	Limitations	Minor concerns about methodological limitations	MODERATE
			Coherence	No concerns about coherence	
			Relevance	No concerns about relevance	
			Adequacy	No concerns about adequacy	

Table 13: Summary of evidence

Study design and sample size			Quality assessment		
Number of studies contributing to the finding	Design	Finding	Criteria	Rating	Overall assessment of confidence
Discharge planning: practical arrangements					
4	Semi-structured interviews and observations	Patients required discharge planning of practical arrangements, such as how to access services, medication contingency and instructions.	Limitations	Minor concerns about methodological limitations	MODERATE
			Coherence	No concerns about coherence	

Study design and sample size			Quality assessment		
Number of studies contributing to the finding	**Design**	**Finding**	**Criteria**	**Rating**	**Overall assessment of confidence**
			Relevance	No concerns about relevance	
			Adequacy	No concerns about adequacy	

Table 14: Summary of evidence

Study design and sample size			Quality assessment		
Number of studies contributing to the finding	**Design**	**Finding**	**Criteria**	**Rating**	**Overall assessment of confidence**
Appointments					
3	Semi-structured interviews	Patients require more control over appointments. Access to appointments outside the home should be considered and appointments inside the home should not be too disruptive to daily life.	Limitations	Minor concerns about methodological limitations	MODERATE
			Coherence	No concerns about coherence	
			Relevance	Minor concerns about relevance	
			Adequacy	No concerns about adequacy	

Table 15: Summary of evidence

Study design and sample size			Quality assessment		
Number of studies contributing to the finding	**Design**	**Finding**	**Criteria**	**Rating**	**Overall assessment of confidence**
Planning ahead					
5	Semi-structured interviews	Patients vary in their readiness to plan ahead.	Limitations	Minor concerns about methodological limitations	MODERATE
			Coherence	No concerns about coherence	
			Relevance	No concerns about relevance	
			Adequacy	No concerns about adequacy	

Table 16: Summary of evidence

Study design and sample size			Quality assessment		
Number of studies contributing to the finding	**Design**	**Finding**	**Criteria**	**Rating**	**Overall assessment of confidence**
ACP: knowledge					
2	Semi-structured interviews and focus groups	Knowledge of ACP and the perceived benefits of ACP can help patient decide on completion of an ACP.	Limitations	Minor concerns about methodological limitations	LOW
			Coherence	No concerns about coherence	

Study design and sample size			Quality assessment		
Number of studies contributing to the finding	**Design**	**Finding**	**Criteria**	**Rating**	**Overall assessment of confidence**
			Relevance	No concerns about relevance	
			Adequacy	Concerns about adequacy[a]	

[a] Only two small studies contributed to this finding.

Table 17: Summary of evidence

Study design and sample size			Quality assessment		
Number of studies contributing to the finding	**Design**	**Finding**	**Criteria**	**Rating**	**Overall assessment of confidence**
ACP: written or discussed					
6	Semi-structured interviews	Some patients choose to write ACP documentation, whereas others may not, due to a variety of reasons. The process of ACP can help discussion of their concerns.	Limitations	Minor concerns about methodological limitations	MODERATE
			Coherence	No concerns about coherence	
			Relevance	No concerns about relevance	
			Adequacy	No concerns about adequacy	

1.4 Economic evidence

1.4.1 Included studies

The committee agreed that health economic studies would not be relevant to this review question, and so health economic evidence relating to this question was not sought.

1.5 Resource costs

This evidence review was used to underpin recommendations throughout the guideline. No recommendations were developed specifically based on this evidence, but it was used to supplement the evidence in reviews for other topics and to develop recommendations included in evidence reviews A,D,F,G,H,I,K and M. For information on resource impact please see the resource impact sections in the evidence reviews A,D,F,G,H,I,K and M.

1.6 Evidence statements

1.6.1 Qualitative evidence statements

- See section 1.3.2.1

1.6.2 Health economic evidence statements

- No relevant economic evaluations were identified.

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1.7 Interpreting the evidence

1.7.1.1 The outcomes that matter most

Findings identified in the evidence synthesis

The barriers and facilitators to the initial access of end-of-life care mainly related to acquiring adequate information: about their end-of-life and the available services; and communication at the palliative care consultation, including involvement in decision-making. More, clearly delivered, information about prognosis, disease progression and planning for the future was required. The Committee wished to reflect this in the recommendation to elicit the preferences of the patient for information provision and being involved in decision making (recommendation 1.3.2). Further sub-recommendations included: revisiting the patients' choices, as the Committee agreed in their experience patients' circumstances will change and with this their requirements; the carer involvement review found that transitions of care required improved communication and therefore attention is needed to ensure changes in prognosis are noted.

The timing of information about disease trajectory, the dying and hospice process and ACP was preferred earlier. However they also felt that both the patient and the doctor need to be ready and able to have the end-of-life discussion. Patients require acceptance and adjustment while doctors and other healthcare professionals involved in their care need to be confident in discussing these issues and to be able to judge whether the patient is ready for this information. They should be skilled in being sensitive to patients' needs and be able to raise difficult issues directly, yet ultimate control of the conversation should be given to the patient. Patients should be provided with options and be part of the decision-making process.

There was a lack of awareness of end-of-life services available and how to gain support. Their understanding of the concepts of end-of-life care such as palliative and hospice care was variable which could lead to wrong expectations of services. Patients were very satisfied with the palliative care teams, and found they had more time for them, listened and provided specialist care and access to other services. The system can be difficult to navigate so a keyworker was found to be useful to co-ordinate and gain access to services. The Committee therefore included an End of Life Care Co-ordinator or lead health care professional be involved to ensure information is provided.

There were practical arrangements required as part of the discharge planning process, such as how to access services, medication contingency and instructions. Appointments were found to be too disruptive and not under the patients' control. The Committee agreed strongly about streamlining appointments as multiple appointments, which can often involve a lot of travelling, may stop the patient attending. Streamlining was thought to be better achieved by having the lead health professional oversee appointments.

Patients varied in their readiness to plan ahead. Gaining knowledge of ACPs and their benefits helped patients decide on completing of them. Some preferred to have it in writing, whereas others preferred verbal plans. The process alone helped discussion of their concerns. Therefore making sure the patient has the correct information to make choices on ACP will help the patient decide what they want to do and when to do it.

The Committee agreed that by setting up appropriate systems to: ensure that there was adequate individualised information provision about their end-of-life and subsequent access to services and to maintain an improved appointment service, this would reflect in improvements in the provision of end-of-life care (recommendations 1.8.1 and 1.8.2).

1.7.1.2 The quality of the evidence

Thirty-four studies were included in the review, using structured interviews and focus groups to elicit patients' and carers' views, which was then thematically analysed. The evidence was graded low to moderate quality, the studies overall were well-conducted and analysed. It was downgraded where there were minor methodological limitations, lack of coherence and/or lack of adequacy, with too few studies reporting the finding. Due to mainly moderate quality and the findings agreeing with their experience of barriers to accessing, planning and discharge in end-of-life care the Committee had confidence in their recommendations.

1.7.1.3 Cost effectiveness and resource use

No relevant economic evaluations were identified. The committee considered that while some of these recommendations have potential cost implications, for example establishing new systems and processes to improve coordination of care and establish people's preferences, or training staff to be skilled at discussing people's needs and preferences and conducting holistic needs assessments, these are fundamental aspects of good patient care. Well-coordinated care also has the potential to reduce repetition of different healthcare professional gathering or providing the same information and reducing the number of appointments people are required to attend. These improvements in efficiency could lead to cost savings.

References

Appendices

Appendix A: Review protocols

Table 18: Review protocol for what are the barriers and facilitators for the initial access to and planning of end of life care services?

Question number: 15

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

ID	Field	Content
I	Review question	What are the barriers and facilitators for the initial access to, and planning of end of life care services?
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 determine how services can be improved and what works well to support: • the initial access to end of life care services for people in their last year of life • carers/patient's involvement in planning their last year of life services
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. Carers of (or those important to) adults (aged over 18 or over) with progressive life-limiting conditions thought to be entering the last year of life. • Includes young carers (<18 years)
V	Eligibility criteria – intervention(s) / exposure(s) / prognostic factor(s)	**Initial access** • Any type of barriers and facilitators to the initial access of people in their last year of life to end of life care services. For example: • Communication around end of life issues such as for example, awareness of availability of end of life care services • Timing or setting of involvement in initial planning decision making (for example, ACP) • Facilitators (for example: coordinators, leaflets, information) **Planning, choices, discharge** • What works well (and what doesn't) when facilitating **discharge** • Service features/elements that patients/carers considered as important for effective discharge process. • How and when to best incorporate patient's choice in the last year of life care pathway • Process for effective advance care planning

		• What process should be in place for allowing patients to **change** their minds/choices throughout their last year of life (after the initial advance care planning).
VI	Eligibility criteria – comparator(s) / control or reference (gold) standard	Not applicable.
VII	Outcomes and prioritisation	Not applicable.
VIII	Eligibility criteria – study design	Qualitative studies (for example: interviews, focus groups, observations) **Data synthesis** • Synthesis of qualitative research: Thematic analysis - information synthesised into main review findings. Results presented in a detailed narrative with accompanying diagrams and in table format with summary statements of main review findings.
IX	Other inclusion exclusion criteria	Themes around clinical care; barriers and facilitators to repeated access to end of life services (once the patient has already accessed end of life services)
X	Proposed sensitivity / subgroup analysis, or meta-regression	Not applicable
XI	Selection process – duplicate screening / selection / analysis	Not applicable
XII	Data management (software)	**Appraisal of methodological quality** The methodological quality of each study will be assessed using NGC modified NICE checklists and the quality of the body of evidence as a whole will be assessed by a GRADE CerQual approach for each review finding. Endnote for bibliography, citations, sifting and reference management
XIII	Information sources – databases and dates	Clinical search databases to be used: Medline, Embase, Cochrane Library, Current Nursing and Allied Health Literature (CINAHL), PsycINFO, Healthcare Management Information Consortium (HMIC), Social Policy and Practice (SSP), Applied Social Sciences Index and Abstracts (ASSIA) Date: All years 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 E (health economic evidence tables).
XX	Methods for assessing bias at outcome / study level	Standard study checklists were used to critically appraise individual studies. For details please see section 6.2 of Developing NICE guidelines: the manual The risk of bias across all available evidence was evaluated for each outcome using an adaptation of the 'Grading of Recommendations Assessment, Development and Evaluation (GRADE) toolbox' developed by the international GRADE working group http://www.gradeworkinggroup.org/ [Please document any deviations/alternative approach when GRADE isn't used or if a modified GRADE approach has been used for non-intervention or non-comparative studies.]
XXI	Criteria for quantitative synthesis	For details please see section 6.4 of Developing NICE guidelines: the manual.
XXII	Methods for quantitative analysis – combining studies and exploring (in)consistency	For details please see the separate Methods report for this guideline.
XXIII	Meta-bias assessment – publication bias, selective reporting bias	For details please see section 6.2 of Developing NICE guidelines: the manual. [Consider exploring publication bias for review questions where it may be more common, such as pharmacological questions and certain disease areas. Describe any steps taken to mitigate against publication bias, such as examining trial registries.]
XXIV	Confidence in cumulative evidence	For details please see sections 6.4 and 9.1 of Developing NICE guidelines: the manual.
XXV	Rationale / context – what is known	For details please see the introduction to the evidence review.
XXVI	Describe contributions of authors and guarantor	A multidisciplinary committee [https://www.nice.org.uk/guidance/indevelopment/gid-cgwave0799] developed the evidence review. The committee was convened by the National Guideline Centre (NGC) and chaired by Mark Thomas in line with section 3 of Developing NICE guidelines: the manual. Staff from NGC undertook systematic literature searches, appraised the evidence, conducted meta-analysis and cost-effectiveness analysis where appropriate, and drafted the evidence review in collaboration with the committee. For details please see Developing NICE guidelines: the manual.
XXVII	Sources of funding / support	NGC is funded by NICE and hosted by the Royal College of Physicians.
XXVIII	Name of sponsor	NGC is funded by NICE and hosted by the Royal College of Physicians.
XXIX	Roles of sponsor	NICE funds NGC to develop guidelines for those working in the NHS, public health and social care in England.
XXX	PROSPERO registration number	Not registered

Table 19: 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 A.
Review strategy	Studies not meeting any of the search criteria above will be excluded. Studies published before 2007, abstract-only studies and studies from non-OECD countries or the USA will also be excluded. Each remaining study will be assessed for applicability and methodological limitations using the NICE economic evaluation checklist which can be found in Appendix H of Developing NICE guidelines: the manual (2014).[590] **Inclusion and exclusion criteria** • If a study is rated as both 'Directly applicable' and with 'Minor limitations' then it will be included in the guideline. A health economic evidence table will be completed and it will be included in the health economic evidence profile. • If a study is rated as either 'Not applicable' or with 'Very serious limitations' then it will usually be excluded from the guideline. If it is excluded then a health economic evidence table will not be completed and it will not be included in the health economic evidence profile. • If a study is rated as 'Partially applicable', with 'Potentially serious limitations' or both then there is discretion over whether it should be included. **Where there is discretion** The health economist will make a decision based on the relative applicability and quality of the available evidence for that question, in discussion with the guideline committee if required. The ultimate aim is to include health economic studies that are helpful for decision-making in the context of the guideline and the current NHS setting. If several studies are considered of sufficiently high applicability and methodological quality that they could all be included, then the health economist, in discussion with the committee if required, may decide to include only the most applicable studies and to selectively exclude the remaining studies. All studies excluded on the basis of applicability or methodological limitations will be listed with explanation as excluded health economic studies in Appendix M. The health economist will be guided by the following hierarchies. *Setting:* • UK NHS (most applicable). • OECD countries with predominantly public health insurance systems (for example, France, Germany, Sweden).

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

Appendix B: Literature search strategies

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

For more detailed information, please see the Methodology Review.

B.1 Clinical search literature search strategy

Searches for patient views were run in Medline (OVID), Embase (OVID), CINAHL, Current Nursing and Allied Health Literature (EBSCO) and PsycINFO (ProQuest). Search filters were applied to the search where appropriate.

Table 20: 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

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

Medline (Ovid) search terms

1.	Palliative care/
2.	Terminal care/
3.	Hospice care/
4.	palliat*.ti,ab.
5.	Terminally Ill/
6.	((terminal* or long term or longterm) adj2 (care* or caring or ill*)).ti,ab.
7.	((dying or terminal) adj (phase* or stage*)).ti,ab.
8.	life limit*.ti,ab.
9.	Nursing Homes/
10.	((care or nursing) adj2 (home or homes)).ti,ab.
11.	Respite Care/
12.	((respite or day) adj2 (care or caring)).ti,ab.
13.	Hospices/
14.	hospice*.ti,ab.
15.	*Patient care planning/
16.	*"Continuity of Patient Care"/
17.	((advance* or patient*) adj3 (care or caring) adj3 (continu* or plan*)).ti,ab.

18.	*Attitude to Death/
19.	(attitude* adj3 (death* or dying*)).ti,ab.
20.	*Physician-Patient Relations/
21.	*Long-Term Care/
22.	*"Delivery of Health Care"/
23.	(end adj2 life).ti,ab.
24.	EOLC.ti,ab.
25.	((last or final) adj2 (year or month*) adj2 life).ti,ab.
26.	((dying or death) adj2 (patient* or person* or people or care or caring)).ti,ab.
27.	or/1-26
28.	letter/
29.	editorial/
30.	news/
31.	exp historical article/
32.	Anecdotes as Topic/
33.	comment/
34.	case report/
35.	(letter or comment*).ti.
36.	or/28-35
37.	randomized controlled trial/ or random*.ti,ab.
38.	36 not 37
39.	animals/ not humans/
40.	exp Animals, Laboratory/
41.	exp Animal Experimentation/
42.	exp Models, Animal/
43.	exp Rodentia/
44.	(rat or rats or mouse or mice).ti.
45.	or/38-44
46.	27 not 45
47.	limit 46 to English language
48.	(exp child/ or exp pediatrics/ or exp infant/) not (exp adolescent/ or exp adult/ or exp middle age/ or exp aged/)
49.	47 not 48
50.	(commission* adj2 (support* or service* or model*)).ti,ab.
51.	((service* or program* or co-ordinat* or co ordinat* or coordinat*) adj2 (model* or deliver* or strateg* or support* or access* or method* or system* or policies or policy or availab*)).ti,ab.
52.	Critical Pathways/
53.	((critical or clinic* or service* or care) adj2 path*).ti,ab.
54.	Patient Care Bundles/
55.	(care adj2 (bundle* or service* or package* or standard*)).ti,ab.
56.	or/50-55
57.	(assess* or criteria* or predict* or recogni* or identif* or refer*).ti,ab.
58.	49 and 56 and 57
59.	gold standard*.ti,ab.
60.	49 and 59

61.	(amber adj2 bundle).ti,ab.
62.	58 or 60 or 61
63.	patient care team/
64.	interdisciplinary communication/
65.	(((interdisciplin* or inter-disciplin* or interprofession* or inter-profession* or multidisciplin* or multi-disciplin* or multi-profession* or multiprofession* or transprofession* or trans-profession*) adj2 (team* or staff* or meeting* or manag* or appointment* or system* or program* or practic* or advic* or advis* or caring or intervention* or ward* or round* or panel* or forum* or fora or communicat* or collaborat* or relat*)) or MDT or IDT).ti,ab.
66.	(((integrat* or network*) adj2 (team* or staff* or meeting* or manag* or appointment* or system* or program* or practic* or advic* or advis* or caring or intervention* or ward* or round* or panel* or forum* or fora or communicat* or collaborat* or relat*)) or MDT or IDT).ti,ab.
67.	(key adj2 work*).ti,ab.
68.	((healthcare or care) adj2 (lead or leader or leads or facilitat*)).ti,ab.
69.	((healthcare or care) adj1 profession*).ti,ab.
70.	*Case Management/
71.	(case adj2 manage*).ti,ab.
72.	(co-ordinator* or coordinator* or coordinate* or co-ordinate*).ti,ab.
73.	Or/63-72
74.	"referral and consultation"/
75.	(referral* or referred or referring or refer or refers or consult*).ti,ab.
76.	(recommend* or direct*).ti,ab.
77.	or/74-76
78.	Social Welfare/ec, ed, es, eh, ma, st, sn, td [Economics, Education, Ethics, Ethnology, Manpower, Standards, Statistics & Numerical Data, Trends]
79.	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]
80.	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]
81.	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]
82.	Telemedicine/ec, es, ma, mt, og, st, sn, td, ut [Economics, Ethics, Manpower, Methods, Organization & Administration, Standards, Statistics & Numerical Data, Trends, Utilization]
83.	exp remote consultation/
84.	*telemedicine/ or *telepathology/ or *teleradiology/ or *telerehabilitation/
85.	(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.
86.	((tele* or remote) adj2 consult*).ti,ab.
87.	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]
88.	(mobile adj2 (health or care) adj2 unit*).ti,ab.
89.	(hospital-based home care or HBHC or hospital-based hospice care or acute hospital care).ti,ab.

90.	(hospital adj3 (domicil* or home)).ti,ab.
91.	home hospitali*ation.ti,ab.
92.	exp Home Care Agencies/
93.	(social adj (welfare or care)).ti,ab.
94.	(nurs* adj4 (home-visit* or home visit* or home-based or home based)).ti,ab.
95.	((district* or communit* or home or visit*) adj nurs*).ti,ab.
96.	(community adj2 (health care or healthcare or nursing or nurse*)).ti,ab.
97.	((hospitali*ation* or admission* or readmission* or admit*) adj3 (reduc* or avoid* or prevent* or inappropiate or increase* or risk*)).ti,ab.
98.	or/78-97
99.	Caregivers/
100.	Spouses/
101.	Family/
102.	(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.
103.	Or/99-102
104.	((replacement or break* or holiday* or respite) adj3 (care* or service*)).ti,ab.
105.	((communit* or support* or psychosocial* or psycholog*) adj3 (service* or group* or system*)).ti,ab.
106.	((group* or support* or psychosocial* or psycholog*) adj3 (selfhelp or self help or therap*)).ti,ab.
107.	((psychosocial* or psycholog*) adj2 support*).ti,ab.
108.	Self-Help Groups/
109.	exp social support/
110.	Counseling/
111.	(counseling or counselling*).ti,ab.
112.	(buddy* or buddies).ti,ab.
113.	((health* or medical*) adj2 check*).ti,ab.
114.	((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.
115.	or/104-114
116.	49 and 103 and 115
117.	49 and (73 or 77 or 98)
118.	62 or 116 or 117

Embase (Ovid) search terms

1.	*Palliative therapy/
2.	*Terminal care/
3.	*Hospice care/
4.	palliat*.ti,ab.
5.	*Terminally ill patient/

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

49.	((service* or program* or co-ordinat* or co ordinat* or coordinat*) adj2 (model* or deliver* or strateg* or support* or access* or method* or system* or policies or policy or availab*)).ti,ab.
50.	*Clinical Pathway/
51.	((critical or clinic* or service* or care) adj2 path*).ti,ab.
52.	*Care Bundle/
53.	(care adj2 (bundle* or service* or package* or standard*)).ti,ab.
54.	or/48-53
55.	(assess* or criteria* or predict* or recogni* or identif* or refer*).ti,ab.
56.	47 and 54 and 55
57.	gold standard*.ti,ab.
58.	47 and 57
59.	(amber adj2 bundle).ti,ab.
60.	56 or 58 or 59
61.	interdisciplinary communication/
62.	patient care team*.ti,ab.
63.	(((interdisciplin* or inter-disciplin* or interprofession* or inter-profession* or multidisciplin* or multi-disciplin* or multi-profession* or multiprofession* or transprofession* or trans-profession*) adj2 (team* or staff* or meeting* or manag* or appointment* or system* or program* or practic* or advic* or advis* or caring or intervention* or ward* or round* or panel* or forum* or fora or communicat* or collaborat* or relat*)) or MDT or IDT).ti,ab.
64.	(((integrat* or network*) adj2 (team* or staff* or meeting* or manag* or appointment* or system* or program* or practic* or advic* or advis* or caring or intervention* or ward* or round* or panel* or forum* or fora or communicat* or collaborat* or relat*)) or MDT or IDT).ti,ab.
65.	(key adj2 work*).ti,ab.
66.	((healthcare or care) adj2 (lead or leader or leads or facilitat*)).ti,ab.
67.	((healthcare or care) adj1 profession*).ti,ab.
68.	*Case Management/
69.	(case adj2 manage*).ti,ab.
70.	(co-ordinator* or coordinator* or coordinate* or co-ordinate*).ti,ab.
71.	Or/61-70
72.	exp patient referral/
73.	(referral* or referred or referring or refer or refers or consult*).ti,ab.
74.	(recommend* or direct*).ti,ab.
75.	or/72-74
76.	*social welfare/
77.	*community health nursing/ or *community care/
78.	*senior center/
79.	*telemedicine/ or *telehealth/
80.	*teleconsultation/
81.	(telehealth or tele health or virtual hospital* or helpline* or help line* or rapid response team* or mobile health unit*).ti,ab.
82.	*home care/ or *home health agency/ or *home monitoring/ or *home oxygen therapy/ or *home physiotherapy/ or *home rehabilitation/ or *home respiratory care/ or *respite care/ or *visiting nursing service/
83.	*health care personnel/ or *health auxiliary/ or *nursing home personnel/

84.	(telemedicine or tele medicine or telehealth or tele health or virtual hospital* or helpline* or help line* or rapid response team* or telepathology or teleradiology or telerehabilitatio).ti,ab.
85.	((tele* or remote) adj2 consult*).ti,ab.
86.	(mobile adj2 (health or care) adj2 unit*).ti,ab.
87.	(hospital-based home care or HBHC or hospital-based hospice care or acute hospital care).ti,ab.
88.	(hospital adj3 (domicil* or home)).ti,ab.
89.	home hospitali*ation.ti,ab.
90.	(social adj (welfare or care)).ti,ab.
91.	(nurs* adj4 (home-visit* or home visit* or home-based or home based)).ti,ab.
92.	((district* or communit* or home or visit*) adj nurs*).ti,ab.
93.	(community adj2 (health care or healthcare or nursing or nurse*)).ti,ab.
94.	((hospitali*ation* or admission* or readmission* or admit*) adj3 (reduc* or avoid* or prevent* or inappropiate or increase* or risk*)).ti,ab.
95.	or/76-94
96.	*Caregiver/
97.	*Spouse/
98.	*Family/
99.	(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.
100.	Or/96-99
101.	((replacement or break* or holiday* or respite) adj3 (care* or service*)).ti,ab.
102.	((communit* or support* or psychosocial* or psycholog*) adj3 (service* or group* or system*)).ti,ab.
103.	((group* or support* or psychosocial* or psycholog*) adj3 (selfhelp or self help or therap*)).ti,ab.
104.	((psychosocial* or psycholog*) adj2 support*).ti,ab.
105.	*Self-Help/
106.	*Social support/
107.	*Counseling/
108.	(counseling or counselling*).ti,ab.
109.	(buddy* or buddies).ti,ab.
110.	((health* or medical*) adj2 check*).ti,ab.
111.	((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.
112.	or/101-111
113.	47 and 100 and 112
114.	47 and (71 or 75 or 95)
115.	60 or 113 or 114

Cochrane Library (Wiley) search terms

#1.	MeSH descriptor: [Palliative Care] this term only
#2.	MeSH descriptor: [Terminal Care] this term only
#3.	MeSH descriptor: [Hospice Care] this term only
#4.	palliat*:ti,ab
#5.	MeSH descriptor: [Terminally Ill] this term only
#6.	((terminal* or long term or longterm) near/2 (care* or caring or ill*)):ti,ab
#7.	((dying or terminal) near (phase* or stage*)):ti,ab
#8.	life limit*:ti,ab
#9.	MeSH descriptor: [Nursing Homes] explode all trees
#10.	((care or nursing) near/2 (home or homes)):ti,ab
#11.	MeSH descriptor: [Respite Care] this term only
#12.	((respite or day) near/2 (care or caring)):ti,ab
#13.	MeSH descriptor: [Hospices] this term only
#14.	hospice*:ti,ab
#15.	MeSH descriptor: [Patient Care Planning] this term only
#16.	MeSH descriptor: [Continuity of Patient Care] this term only
#17.	((advance* or patient*) near/3 (care or caring) near/3 (continu* or plan*)):ti,ab
#18.	MeSH descriptor: [Attitude to Death] explode all trees
#19.	(attitude* near/3 (death* or dying*)):ti,ab
#20.	MeSH descriptor: [Physician-Patient Relations] this term only
#21.	MeSH descriptor: [Long-Term Care] this term only
#22.	MeSH descriptor: [Delivery of Health Care] this term only
#23.	(end near/2 life):ti,ab
#24.	EOLC:ti,ab
#25.	((last or final) near/2 (year or month*) near/2 life):ti,ab
#26.	((dying or death) near/2 (patient* or person* or people or care or caring)):ti,ab
#27.	(or #1-#26)
#28.	(commission* near/2 (support* or service* or model*)):ti,ab
#29.	((service* or program* or co-ordinat* or co ordinat* or coordinat*) near/2 (model* or deliver* or strateg* or support* or access* or method* or system* or policies or policy or availab*)):ti,ab
#30.	MeSH descriptor: [Critical Pathways] explode all trees
#31.	((critical or clinic* or service* or care) near/2 path*):ti,ab
#32.	MeSH descriptor: [Patient Care Bundles] explode all trees
#33.	(care near/2 (bundle* or service* or package* or standard*)):ti,ab
#34.	(or #28-#33)
#35.	(assess* or criteria* or predict* or recogni* or identif* or refer*):ti,ab
#36.	#27 and #34 and #35
#37.	gold standard*:ti,ab
#38.	#27 and #37
#39.	(amber near/2 bundle):ti,ab
#40.	#36 or #38 or #39
#41.	MeSH descriptor: [Patient Care Team] explode all trees
#42.	MeSH descriptor: [Interdisciplinary Communication] explode all trees
#43.	(((interdisciplin* or inter-disciplin* or interprofession* or inter-profession* or multidisciplin* or multi-disciplin* or multi-profession* or multiprofession* or

	transprofession* or trans-profession*) near/2 (team* or staff* or meeting* or manag* or appointment* or system* or program* or practic* or advic* or advis* or caring or intervention* or ward* or round* or panel* or forum* or fora or communicat* or collaborat* or relat*)) or MDT or IDT):ti,ab
#44.	((integrat* or network*) near/2 (team* or staff* or meeting* or manag* or appointment* or system* or program* or practic* or advic* or advis* or caring or intervention* or ward* or round* or panel* or forum* or fora or communicat* or collaborat* or relat*)):ti,ab
#45.	(key near/2 work*):ti,ab
#46.	((healthcare or care) near/2 (lead or leader or leads or facilitat*)):ti,ab
#47.	((healthcare or care) near/1 profession*):ti,ab
#48.	MeSH descriptor: [Case Management] this term only
#49.	(case near/2 manage*):ti,ab
#50.	(co-ordinator* or coordinator* or coordinate* or co-ordinate*):ti,ab
#51.	(or #41-#50)
#52.	MeSH descriptor: [Referral and Consultation] explode all trees
#53.	(referral* or referred or referring or refer or refers or consult*):ti,ab
#54.	(recommend* or direct*):ti,ab
#55.	(or #52-#54)
#56.	MeSH descriptor: [Social Welfare] explode all trees
#57.	MeSH descriptor: [Charities] explode all trees
#58.	MeSH descriptor: [Adult Day Care Centers] explode all trees
#59.	MeSH descriptor: [Community Health Nursing] explode all trees
#60.	MeSH descriptor: [Home Care Services] explode all trees
#61.	MeSH descriptor: [Senior Centers] explode all trees
#62.	MeSH descriptor: [Telemedicine] this term only
#63.	MeSH descriptor: [Remote Consultation] explode all trees
#64.	(telehealth or tele health or virtual hospital* or helpline* or help line* or rapid response team*):ti,ab
#65.	MeSH descriptor: [Mobile Health Units] explode all trees
#66.	((community based or community dwelling home or rural) near/3 (care or health care or healthcare)):ti,ab
#67.	(hospital-based home care or HBHC or hospital-based hospice care or acute hospital care):ti,ab
#68.	((hospitali*ation* or admission* or readmission* or admit*) near/3 (reduc* or avoid* or prevent* or inappropiate or increase* or risk*)):ti,ab
#69.	(home based versus hospital based):ti,ab
#70.	(hospital near/3 (domicil* or home)):ti,ab
#71.	(home hospitali*ation):ti,ab
#72.	MeSH descriptor: [Home Care Services, Hospital-Based] explode all trees
#73.	MeSH descriptor: [Home Health Nursing] explode all trees
#74.	MeSH descriptor: [Homemaker Services] explode all trees
#75.	MeSH descriptor: [Home Care Agencies] explode all trees
#76.	MeSH descriptor: [Home Health Aides] explode all trees
#77.	(social care):ti,ab
#78.	MeSH descriptor: [Nurses, Community Health] explode all trees
#79.	(nurs* near/4 (home-visit* or home visit* or home-based or home based)):ti,ab
#80.	((district* or communit* or home or visit*) near nurs*):ti,ab
#81.	(or #56-#80)

#82.	MeSH descriptor: [Caregivers] this term only
#83.	MeSH descriptor: [Spouses] this term only
#84.	MeSH descriptor: [Family] this term only
#85.	(spouse* or wife or wives or husband* or carer* or caregiver* or care giver* or significant other* or friend* or partner* or family or families or individual* or sibling* or brother* or sister* or relative or relatives or mothers* or daughters* or father* or son or sons or uncle* or aunt* or grand mother* or grandmother* or grandfather* or grand father* or aunt* or uncle* or cousin* or niece* or nephew*):ti,ab
#86.	(or #82-#85)
#87.	((replacement or break* or holiday* or respite) near/3 (care* or service*)):ti,ab
#88.	((communit* or support* or psychosocial* or psycholog*) near/3 (service* or group* or system*)):ti,ab
#89.	((group* or support* or psychosocial* or psycholog*) near/3 (selfhelp or self help or therap*)):ti,ab
#90.	((psychosocial* or psycholog*) near/2 support*):ti,ab
#91.	MeSH descriptor: [Self-Help Groups] this term only
#92.	MeSH descriptor: [Social Support] explode all trees
#93.	MeSH descriptor: [Counseling] this term only
#94.	(counseling or counselling*):ti,ab
#95.	(buddy* or buddies):ti,ab
#96.	(health or medical*) near/3 check*:ti,ab
#97.	(spouse* or wife or wives or husband* or carer* or caregiver* or care giver* or significant other* or friend* or partner* or family or families or individual* or sibling* or brother* or sister* or relative or relatives or mothers* or daughters* or father* or son or sons or uncle* or aunt* or grand mother* or grandmother* or grandfather* or grand father* or aunt* or uncle* or cousin* or niece* or nephew*) near/3 (education or educate or educating or information or literature or leaflet* or booklet* or pamphlet* or website* or knowledge):ti,ab
#98.	(or #87-#97)
#99.	#27 and #86 and #98
#100.	#27 and (#51 or #55 or #81)
#101.	#40 or #99 or #100

CINAHL (EBSCO) search terms

S1.	MH Palliative care
S2.	MH Terminal care
S3.	MH Hospice care
S4.	TI palliat* OR AB palliat*
S5.	MW Terminally ill
S6.	TI (terminal* or long term or longterm) AND TI (care* or caring or ill*)
S7.	AB (terminal* or long term or longterm) AND AB (care* or caring or ill*)
S8.	TI (dying or terminal) AND TI (phase* or stage*)
S9.	AB (dying or terminal) AND AB (phase* or stage*)
S10.	TI life limit* OR AB life limit*
S11.	MH Nursing homes
S12.	TI (care or nursing) AND TI (home or homes)
S13.	AB (care or nursing) AND AB (home or homes)
S14.	MH Respite care
S15.	TI (respite or day) AND TI (care or caring)

S16.	AB (respite or day) AND AB (care or caring)
S17.	MH Hospices
S18.	TI Hospice* OR AB Hospice*
S19.	(MH "Patient Care Plans")
S20.	MH Attitude to Death
S21.	TI attitude* AND TI (death* or dying)
S22.	AB attitude* AND AB (death* or dying)
S23.	MH Physician-Patient Relations
S24.	(MH "Long Term Care")
S25.	(MH "Health Care Delivery")
S26.	TI end AND TI life OR AB end AND AB life
S27.	TI EOLC OR AB EOLC
S28.	TI (last or final) AND TI (year or month) AND TI life
S29.	AB (last or final) AND AB (year or month) AND AB life
S30.	TI (dying or death) AND TI (patient* or person* or people or care or caring)
S31.	AB (dying or death) AND AB (patient* or person* or people or care or caring)
S32.	TI advance* AND TI (plan* or decision* or directive*)
S33.	AB advance* AND AB (plan* or decision* or directive*)
S34.	S1 OR S2 OR S3 OR S4 OR S5 OR S6 OR S7 OR S8 OR S9 OR S10 OR S11 OR S12 OR S13 OR S14 OR S15 OR S16 OR S17 OR S18 OR S19 OR S20 OR S21 OR S22 OR S23 OR S24 OR S25 OR S26 OR S27 OR S28 OR S29 OR S30 OR S31 OR S32 OR S33
S35.	TI commission* AND TI ((support* or service* or model*))
S36.	AB commission* AND AB ((support* or service* or model*))
S37.	TI (service* or program* or co-ordinat* or co ordinat* or coordinat*) AND TI (model* or deliver* or strateg* or support* or access* or method* or system* or policies or policy or availab*)
S38.	AB (service* or program* or co-ordinat* or co ordinat* or coordinat*) AND AB (model* or deliver* or strateg* or support* or access* or method* or system* or policies or policy or availab*)
S39.	TI (critical or clinic* or service* or care) AND TI path*
S40.	AB (critical or clinic* or service* or care) AND AB path*
S41.	TI care AND TI (bundle* or service* or package* or standard*)
S42.	AB care AND AB (bundle* or service* or package* or standard*)
S43.	S35 OR S36 OR S37 OR S38 OR S39 OR S40 OR S41 OR S42
S44.	TI (assess* or criteria* or predict* or recogni* or identif* or refer*) OR AB (assess* or criteria* or predict* or recogni* or identif* or refer*)
S45.	S34 AND S43 AND S44
S46.	TI gold standard* OR AB gold standard*
S47.	S34 AND S46
S48.	TI amber AND TI bundle
S49.	AB amber AND AB bundle
S50.	S48 OR S49
S51.	S45 OR S47 OR S50
S52.	(MH "Multidisciplinary Care Team+")
S53.	MDT OR IDT
S54.	((interdisciplin* or inter-disciplin* or interprofession* or inter-profession* or multidisciplin* or multi-disciplin* or multi-profession* or multiprofession* or

	transprofession* or trans-profession*) n2 (team* or staff* or meeting* or manag* or appointment* or system* or program* or practic* or advic* or advis* or caring or intervention* or ward* or round* or panel* or forum* or fora or communicat* or collaborat* or relat*))
S55.	((integrat* or network*) n2 (team* or staff* or meeting* or manag* or appointment* or system* or program* or practic* or advic* or advis* or caring or intervention* or ward* or round* or panel* or forum* or fora or communicat* or collaborat* or relat*))
S56.	TI (key n2 work*) OR AB (key n2 work*)
S57.	TI (((healthcare or care) n2 (lead or leader or leads or facilitat*))) OR AB (((healthcare or care) n2 (lead or leader or leads or facilitat*)))
S58.	TI (((healthcare or care) n1 profession*)) OR AB (((healthcare or care) n1 profession*))
S59.	MH Case Management
S60.	TI (case n2 manage*) OR AB (case n2 manage*)
S61.	TI ((co-ordinator* or coordinator* or coordinate* or co-ordinate*)*)) OR AB ((co-ordinator* or coordinator* or coordinate* or co-ordinate*))
S62.	S52 OR S53 OR S54 OR S55 OR S56 OR S57 OR S58 OR S59 OR S60 OR S61
S63.	(MH "Referral and Consultation+")
S64.	TI (referral* or referred or referring or refer or refers or consult*) OR AB (referral* or referred or referring or refer or refers or consult*)
S65.	TI (recommend* or direct*) OR AB (recommend* or direct*)
S66.	S63 OR S64 OR S65
S67.	(MM "Social Welfare")
S68.	(MH "Charities")
S69.	(MM "Adult Day Center (Saba CCC)") OR (MM "Housing for the Elderly") OR (MM "Older Adult Care (Saba CCC)")
S70.	(MH "Community Health Nursing+") OR (MM "Community Health Centers")
S71.	(MH "Home Health Care+") OR (MM "Home Health Aides") OR (MM "Home Health Care Information Systems") OR (MM "Home Health Aide Service (Saba CCC)")
S72.	(MM "Housing for the Elderly") OR (MM "Rural Health Centers") OR (MM "Community Health Centers")
S73.	(MH "Telemedicine+") OR (MH "Telehealth+")
S74.	(MM "Remote Consultation") OR (MM "Telephone Consultation (Iowa NIC)") OR (MM "Services for Australian Rural and Remote Allied Health")
S75.	telehealth or tele health or virtual hospital* or helpline* or help line* or rapid response team* or senior center*
S76.	(MM "Rural Health Personnel") OR (MM "Mobile Health Units")
S77.	remote consultation
S78.	((community based or community dwelling home or rural) n3 (care or health care or healthcare))
S79.	hospital-based home care or HBHC or hospital-based hospice care or acute hospital care
S80.	((hospitali?ation* or admission* or readmission* or admit*) n3 (reduc* or avoid* or prevent* or inappropiate or increase* or risk*))
S81.	home based versus hospital based
S82.	(hospital n3 (domicil* or home))
S83.	home hospitali?ation
S84.	home care service*
S85.	(MM "Home Health Agencies") OR (MM "Nursing Home Personnel")
S86.	(MM "Homemaker Services") OR (MM "Health Services for the Aged")

S87.	(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")
S88.	social care
S89.	(MM "Hospitals, Community")
S90.	(MM "Home Nursing") OR (MM "Home Nursing, Professional")
S91.	(nurs* n4 (home-visit* or home visit* or home-based or home based))
S92.	((district* or communit* or home or visit*) n1 nurs*)
S93.	S67 OR S68 OR S69 OR S70 OR S71 OR S72 OR S73 OR S74 OR S75 OR S76 OR S77 OR S78 OR S79 OR S80 OR S81 OR S82 OR S83 OR S84 OR S85 OR S86 OR S87 OR S88 OR S89 OR S90 OR S91 OR S92
S94.	S34 AND (S62 OR S66 OR S93)
S95.	S51 OR S94

PsycINFO (ProQuest) search terms

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

HMIC (Ovid) search terms

1.	exp End of life care/
2.	(terminal* adj ill*).ti,ab.
3.	((dying or terminal) adj (phase* or stage*)).ti,ab.
4.	life limit*.ti,ab.
5.	(end adj2 life).ti,ab.
6.	EOLC.ti,ab.
7.	((last or final) adj2 (year or month*) adj2 life).ti,ab.
8.	((dying or death) adj2 (patient* or person* or people or care or caring)).ti,ab.
9.	or/2-8
10.	(exp child/ or exp Paediatrics/ or exp infant/) not (exp adolescent/ or exp adult/ or exp middle age/ or exp older people/)
11.	9 not 10
12.	limit 11 to English

13.	limit 12 to (audiovis or book or chapter dh helmis or circular or microfiche dh helmis or multimedias or website)
14.	limit 12 to (audiocass or books or cdrom or chapter or dept pubs or diskettes or folio pamp or "map" or marc or microfiche or multimedia or pamphlet or parly or press or press rel or thesis or trustdoc or video or videos or website)
15.	13 or 14
16.	12 not 15
17.	euthanasia/
18.	euthanasia.ti,ab.
19.	17 or 18
20.	16 not 19

SPP (Ovid) search terms

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

ASSIA (ProQuest) search terms

1.	palliat*.ti,ab. ((ti,ab(commission* N/2 (support* or service* or model*)) OR ti,ab((service* or program* or co-ordinat* or coordinat*) N/2 (model* or deliver* or strateg* or support* or access* or method* or system* or policies or policy or availab*))) AND ((SU.EXACT("Care" OR "Clinical nursing" OR "Community homes" OR "Community nursery nursing" OR "Community nursing" OR "Compassionate care" OR "Continuing care" OR "District nursing" OR "Family centred care" OR "Geriatric wards" OR "Group care" OR "Health visiting" OR "Home care" OR "Home from home care" OR "Home health aides" OR "Home helps" OR "Hospices" OR "Hostel wards" OR "Informal care" OR "Integrated care pathways" OR "Intentional care" OR "Intermediate care" OR "Intermediate care centres" OR "Lack of care" OR "Learning disability nursing" OR "Length of stay" OR "Liaison nursing" OR "Long stay wards" OR "Long term care" OR "Long term home care" OR "Long term residential care" OR "Nurse led care" OR "Nursing" OR "Occupational health nursing" OR "Ontological care" OR "Out of home care" OR "Outreach nursing" OR "Palliative care" OR "Paranursing" OR "Pastoral care" OR "Patient care" OR "Primary nursing" OR "Private residential care"

	OR "Process centred care" OR "Quality of care" OR "Radical health visiting" OR "Residential care" OR "Residential group care" OR "Respite care" OR "Shared care" OR "Social care" "Temporary care" OR "Terminal care" OR "Wards") OR (SU.EXACT("Terminally ill elderly people") OR SU.EXACT("Terminally ill fathers") OR SU.EXACT("Terminally ill elderly men") OR SU.EXACT("Terminally ill elderly women") OR SU.EXACT("Terminally ill young adults") OR SU.EXACT("Terminally ill parents") OR SU.EXACT("Terminally ill women") OR SU.EXACT("Terminally ill widowed sisters") OR SU.EXACT("Terminally ill colleagues") OR SU.EXACT("Terminally ill young girls") OR SU.EXACT("Terminally ill people") OR SU.EXACT("Terminally ill men")) OR SU.EXACT("Advance directives" OR "Do not resuscitate orders" OR "Durable power of attorney for health care" OR "Living wills" OR "Treatment preferences" OR "Treatment needs")) OR (ti,ab((advance* or patient*) N/3 (care or caring) N/3 (continu* or plan*)) or ti,ab(attitude* N/3 (death* or dying*)) or ti,ab(end N/2 life) or ti,ab(EOLC) or ti,ab((last or final) N/2 (year or month*) N/2 life) or ti,ab((dying or death) N/2 (patient* or person* or people or care or caring))))) OR SU.EXACT("End of life decisions")

B.2 Health Economics literature search strategy

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

Table 21: Database date parameters and filters used

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

Medline (Ovid) search terms

1.	Palliative care/
2.	Terminal care/
3.	Hospice care/
4.	palliat*.ti,ab.
5.	Terminally Ill/
6.	((terminal* or long term or longterm) adj2 (care* or caring or ill*)).ti,ab.
7.	((dying or terminal) adj (phase* or stage*)).ti,ab.

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

52.	50 not 51
53.	economics/
54.	value of life/
55.	exp "costs and cost analysis"/
56.	exp Economics, Hospital/
57.	exp Economics, medical/
58.	Economics, nursing/
59.	economics, pharmaceutical/
60.	exp "Fees and Charges"/
61.	exp budgets/
62.	budget*.ti,ab.
63.	cost*.ti.
64.	(economic* or pharmaco?economic*).ti.
65.	(price* or pricing*).ti,ab.
66.	(cost* adj2 (effectiv* or utilit* or benefit* or minimi* or unit* or estimat* or variable*)).ab.
67.	(financ* or fee or fees).ti,ab.
68.	(value adj2 (money or monetary)).ti,ab.
69.	or/53-68
70.	exp models, economic/
71.	*Models, Theoretical/
72.	*Models, Organizational/
73.	markov chains/
74.	monte carlo method/
75.	exp Decision Theory/
76.	(markov* or monte carlo).ti,ab.
77.	econom* model*.ti,ab.
78.	(decision* adj2 (tree* or analy* or model*)).ti,ab.
79.	or/70-78
80.	quality-adjusted life years/
81.	sickness impact profile/
82.	(quality adj2 (wellbeing or well being)).ti,ab.
83.	sickness impact profile.ti,ab.
84.	disability adjusted life.ti,ab.
85.	(qal* or qtime* or qwb* or daly*).ti,ab.
86.	(euroqol* or eq5d* or eq 5*).ti,ab.
87.	(qol* or hql* or hqol* or h qol* or hrqol* or hr qol*).ti,ab.
88.	(health utility* or utility score* or disutilit* or utility value*).ti,ab.
89.	(hui or hui1 or hui2 or hui3).ti,ab.
90.	(health* year* equivalent* or hye or hyes).ti,ab.
91.	discrete choice*.ti,ab.
92.	rosser.ti,ab.
93.	(willingness to pay or time tradeoff or time trade off or tto or standard gamble*).ti,ab.
94.	(sf36* or sf 36* or short form 36* or shortform 36* or shortform36*).ti,ab.
95.	(sf20 or sf 20 or short form 20 or shortform 20 or shortform20).ti,ab.
96.	(sf12* or sf 12* or short form 12* or shortform 12* or shortform12*).ti,ab.

97.	(sf8* or sf 8* or short form 8* or shortform 8* or shortform8*).ti,ab.
98.	(sf6* or sf 6* or short form 6* or shortform 6* or shortform6*).ti,ab.
99.	or/80-98
100.	52 and (69 or 79 or 99)

Embase (Ovid) search terms

1.	*Palliative therapy/
2.	*Terminal care/
3.	*Hospice care/
4.	palliat*.ti,ab.
5.	*Terminally ill patient/
6.	((terminal* or long term or longterm) adj2 (care* or caring or ill*)).ti,ab.
7.	((dying or terminal) adj (phase* or stage*)).ti,ab.
8.	life limit*.ti,ab.
9.	*Nursing home/
10.	((care or nursing) adj2 (home or homes)).ti,ab.
11.	*Respite Care/
12.	((respite or day) adj2 (care or caring)).ti,ab.
13.	*Hospice/
14.	hospice*.ti,ab.
15.	*Patient care planning/
16.	(advance* adj2 (plan* or decision* or directive*)).ti,ab.
17.	living will*.ti,ab.
18.	*Patient care/
19.	((advance* or patient*) adj3 (care or caring) adj3 (continu* or plan*)).ti,ab.
20.	*Attitude to Death/
21.	(attitude* adj3 (death* or dying*)).ti,ab.
22.	*Doctor patient relation/
23.	*Long term care/
24.	*Health care delivery/
25.	(end adj2 life).ti,ab.
26.	EOLC.ti,ab.
27.	((last or final) adj2 (year or month*) adj2 life).ti,ab.
28.	((dying or death) adj2 (patient* or person* or people or care or caring)).ti,ab.
29.	or/1-28
30.	letter.pt. or letter/
31.	note.pt.
32.	editorial.pt.
33.	case report/ or case study/
34.	(letter or comment*).ti.
35.	or/30-34

36.	randomized controlled trial/ or random*.ti,ab.
37.	35 not 36
38.	animal/ not human/
39.	nonhuman/
40.	exp Animal Experiment/
41.	exp Experimental Animal/
42.	animal model/
43.	exp Rodent/
44.	(rat or rats or mouse or mice).ti.
45.	or/37-44
46.	29 not 45
47.	limit 46 to English language
48.	(exp child/ or exp pediatrics/ or exp infant/) not (exp adolescent/ or exp adult/ or exp middle age/ or exp aged/)
49.	47 not 48
50.	health economics/
51.	exp economic evaluation/
52.	exp health care cost/
53.	exp fee/
54.	budget/
55.	funding/
56.	budget*.ti,ab.
57.	cost*.ti.
58.	(economic* or pharmaco?economic*).ti.
59.	(price* or pricing*).ti,ab.
60.	(cost* adj2 (effectiv* or utilit* or benefit* or minimi* or unit* or estimat* or variable*)).ab.
61.	(financ* or fee or fees).ti,ab.
62.	(value adj2 (money or monetary)).ti,ab.
63.	or/50-62
64.	statistical model/
65.	exp economic aspect/
66.	64 and 65
67.	*theoretical model/
68.	*nonbiological model/
69.	stochastic model/
70.	decision theory/
71.	decision tree/
72.	monte carlo method/
73.	(markov* or monte carlo).ti,ab.
74.	econom* model*.ti,ab.
75.	(decision* adj2 (tree* or analy* or model*)).ti,ab.

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

NHS EED and HTA (CRD) search terms

#1.	MeSH DESCRIPTOR Palliative Care IN NHSEED,HTA
#2.	MeSH DESCRIPTOR Terminal Care IN NHSEED,HTA
#3.	MeSH DESCRIPTOR Hospice Care IN NHSEED,HTA
#4.	(palliat*) IN NHSEED, HTA
#5.	MeSH DESCRIPTOR Terminally Ill IN NHSEED,HTA
#6.	(((terminal* or long term or longterm) adj2 (care* or caring or ill*))) IN NHSEED, HTA
#7.	(((dying or terminal) adj (phase* or stage*))) IN NHSEED, HTA
#8.	(life limit*) IN NHSEED, HTA
#9.	MeSH DESCRIPTOR Nursing Homes IN NHSEED,HTA
#10.	(((care or nursing) adj2 (home or homes))) IN NHSEED, HTA
#11.	MeSH DESCRIPTOR Respite Care IN NHSEED,HTA
#12.	(((respite or day) adj2 (care or caring))) IN NHSEED, HTA
#13.	MeSH DESCRIPTOR Hospices IN NHSEED,HTA
#14.	(hospice*) IN NHSEED, HTA
#15.	MeSH DESCRIPTOR Advance Care Planning EXPLODE ALL TREES IN NHSEED,HTA
#16.	((advance* adj2 (plan* or decision* or directive*))) IN NHSEED, HTA

#17.	(living will*) IN NHSEED, HTA
#18.	MeSH DESCRIPTOR Patient Care Planning IN NHSEED,HTA
#19.	MeSH DESCRIPTOR Continuity of Patient Care IN NHSEED,HTA
#20.	(((advance* or patient*) adj3 (care or caring) adj3 (continu* or plan*))) IN NHSEED, HTA
#21.	MeSH DESCRIPTOR Attitude to Death IN NHSEED,HTA
#22.	((attitude* adj3 (death* or dying*))) IN NHSEED, HTA
#23.	MeSH DESCRIPTOR Physician-Patient Relations IN NHSEED,HTA
#24.	MeSH DESCRIPTOR Long-Term Care IN NHSEED,HTA
#25.	MeSH DESCRIPTOR Delivery of Health Care IN NHSEED,HTA
#26.	((end adj2 life)) IN NHSEED, HTA
#27.	(EOLC) IN NHSEED, HTA
#28.	(((last or final) adj2 (year or month*) adj2 life)) IN NHSEED, HTA
#29.	(((dying or death) adj2 (patient* or person* or people or care or caring))) IN NHSEED, HTA
#30.	#1 OR #2 OR #3 OR #4 OR #5 OR #6 OR #7 OR #8 OR #9 OR #10 OR #11 OR #12 OR #13 OR #14 OR #15 OR #16 OR #17 OR #18 OR #19 OR #20 OR #21 OR #22 OR #23 OR #24 OR #25 OR #26 OR #27 OR #28 OR #29
#31.	(#30) IN NHSEED
#32.	(#30) IN HTA

Appendix C: Clinical evidence selection

Figure 1: Flow chart of qualitative study selection for the review of what are the barriers and facilitators the initial access to, and planning of end of life care services?

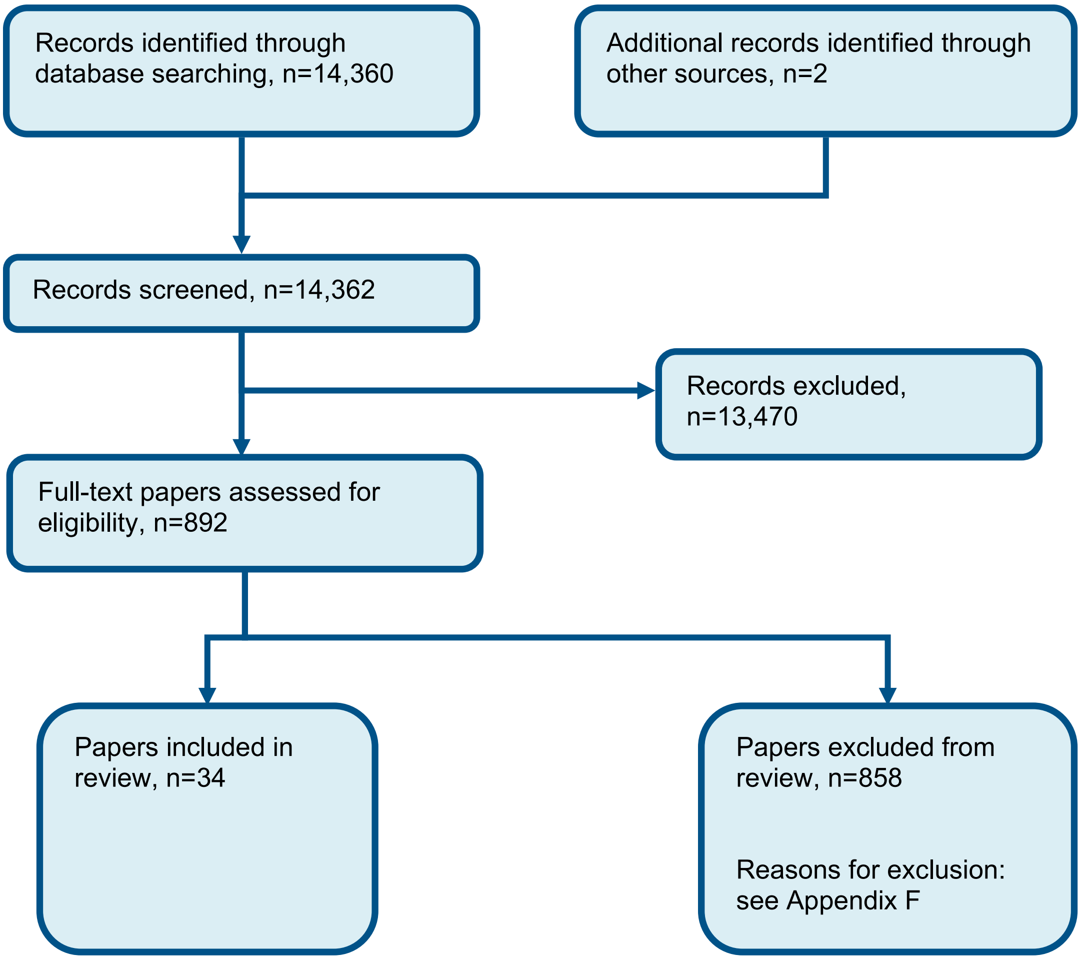
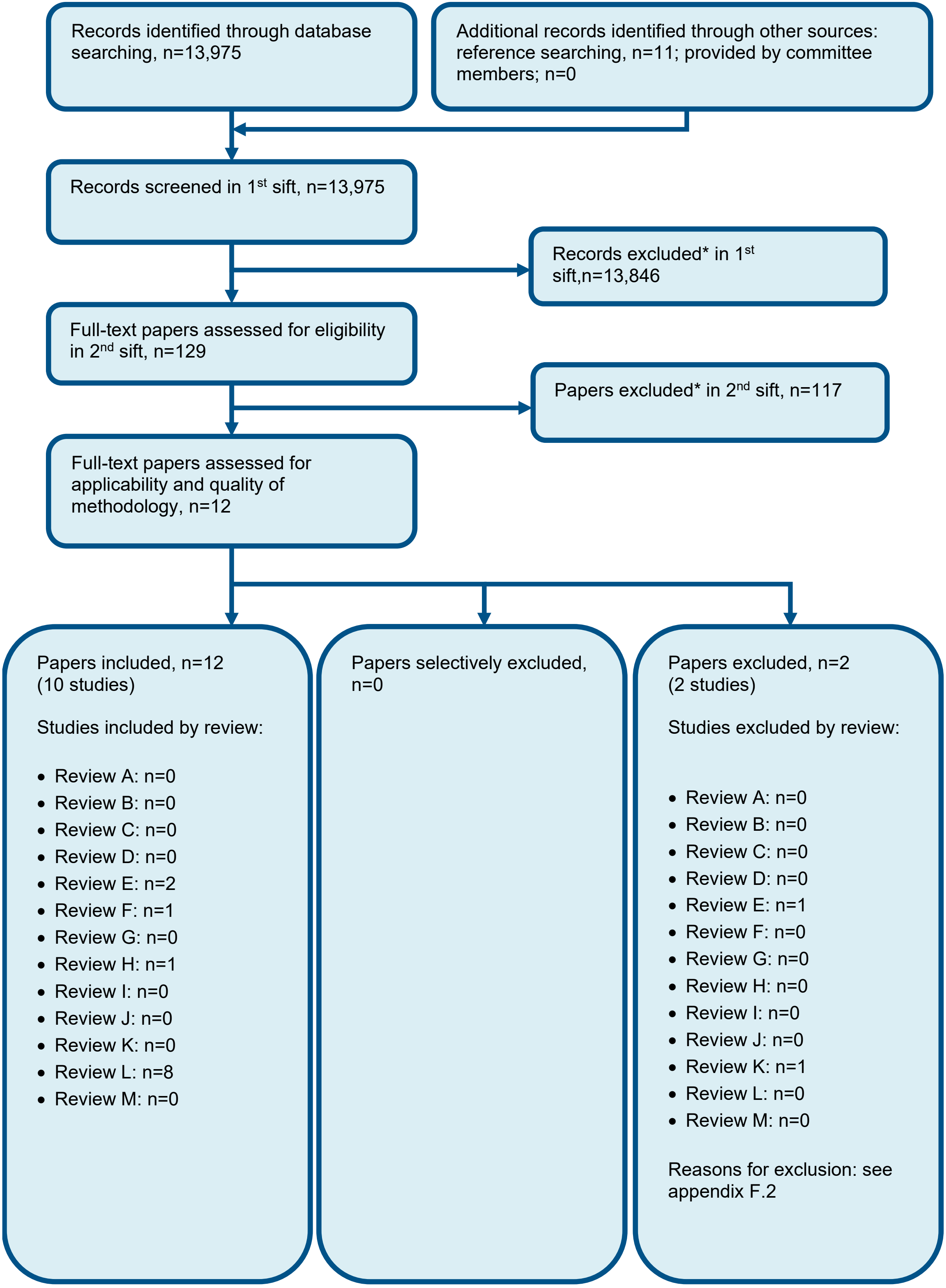


Figure 2: Flow chart of health economic study selection for the guideline



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

Appendix D: Qualitative evidence tables

Study	Bamford 2018[51]
Aim	To explore the factors that facilitate good End of Life Care for people with advanced dementia from the perspective of stakeholders including family carers and people with dementia.
Population	People with dementia who had joined a Case Register for those willing to participate in research studies and those registered with Join Dementia Research. N=11 Bereaved and current carers N=18
Setting	Newcastle University. October 2013 to January 2016.
Study design	Qualitative interview study
Methods and analysis	Face-to-face interviews following a Q-Sort activity. One focus group with the carers The interviews and focus groups focused on accounts of End of Life Care in dementia and the perceived barriers and facilitators to the delivery of care. Topic guides where used to structure the discussions while allowing for the emergence of new ideas from participants. All interviews were audio-recorded, and transcribed in full and anonymised for analysis. This was part of a project that took a social constructivist perspective and explored multiple perspectives of people delivering and receiving care. The interviews and focus groups were thematically analysed and key issues where identified. Emergent themes were discussed in data workshops with the themes being modified when the final version of the codes were agreed.
Findings	**Timing of planning discussions:** Barriers identified to planning ahead included a preference to focus on living in the present; a lack of awareness that dementia is a terminal condition, assumptions that family members and healthcare professional would know their wishes and be able to make decisions on their behalf if necessary ,confidence in the quality of the current and future provision and difficulties in engaging in discussions about end of life care when they felt fit and healthy. Carers reported they were uncertain about the preferences of the person with dementia and could find the decision- making burdensome.

Study	Bamford 2018[51]
	Coordination and continuity of care: This requires close coordination between different agencies and co-ordination within services. Issues with poor communication were identified.
Limitations and applicability of evidence	Small sample size. Little information on potential bias of researcher. Applicable.

Study	Bajwah 2013[48]
Aim	To explore understanding of the disease, preferences regarding end-of-life planning, and views on communication and coordination of care in patients with Progressive Idiopathic Fibrotic Interstitial Lung Disease (PIF-ILD).
Population	Patients with a diagnosis of non-specific interstitial pneumonia, IPF and idiopathic interstitial pneumonia, as classified by the American Thoracic Society/European Respiratory Society criteria with a percentage-predicted transfer factor <40%, and an ability to understand and speak English fluently. Carers and health professionals involved in the care of these patients were also identified. Eight patient participants (four from RBH and four from KCH), and four carers (from RBH).
Setting	UK. Royal Brompton (RBH) and Kings College Hospital (KCH) NHS Foundation Trusts between December 2010 and March 2011.
Study design	Qualitative interview study
Methods and analysis	Face-to-face semi-structured interviews. The interviews were informal in style, and loosely followed a topic guide that was initially guided by review of the literature. This topic guide was piloted prior to use. Interviews began with a general discussion about what patients understood by their disease and its prognosis, and then progressed to explore end-of-life preferences and communication-related issues. Prompts were used to elicit further information. All interviews were audio-recorded, transferred verbatim onto a secure transcription database, and then imported into NVIVO 9software to facilitate analysis using the constant comparative method. Each transcript was subject to line-by-line axial coding by SB. Codes were scrutinised for internal consistency through an iterative process. Codes and subcodes were tabulated during the charting process to allow abstraction and synthesis of themes. The complete coding frame and sample comparison were reviewed by SB, JK and IJH to confirm the analysis and interpretation. To maximise analytical rigour, a selection of the interviews was reviewed by a second researcher (JK), and consensus achieved. Excerpts from the interview transcripts are presented below, to illustrate themes. All participants' names have been changed to preserve anonymity.
Findings	**End-of-life information needs:** All participants shared a common sentiment about the lack of information to help plan for the future. Central to this was a wish to understand exactly how they would deteriorate at the end of life. "I haven't sort of um haven't really

Study	Bajwah 2013[48]
	discussed how it will develop with anybody, but you know that may be my own fault if I don't talk about it um to somebody, and you don't know them I've got nothing to worry about (laughs)". Patients wanted to have the option of gathering further information, and being able to discuss issues, if they wished, which they did not feel was currently the case.
	End-of-life planning, decision making and care: No patients, and no patients cared for by the carers, reported they had formulated end-of-life plans, or considered end-of-life preferences, such as preferred place of care or preferred place of death. A number of carers were aware of broad preferences, but in-depth conversations had not occurred. All patients, and all carers, realised the importance of such conversations, but did not know how to initiate conversations with their loved ones. No patients, or carers, reported palliative care involvement stating that they were not aware of any such services.
	Coordination of care: Patients and carers reported being very satisfied with the specialist respiratory care received. However, communication between health professionals and coordination of care was flagged as a problem by all participants. "I think they try to liaise between each other but it so often falls apart … there is really a short coming amongst um getting information from one aspect of the medical profession to the other."
Limitations and applicability of evidence	Small sample size. Little information on potential bias of researcher. Applicable.

Study	Benzar 2011 [67]
Aim	To identify the range of health care experiences of family caregivers and patients who received palliative care consultations after they left the hospital, and to understand how palliative care teams might best prepare patients and caregivers for the post-hospital experience.
Population	Patients who received palliative care consults at Oregon Health and Science University (OHSU) and who were: 1) discharged alive between two weeks and three months before identification of patient for interview; 2) discharged to either home without hospice, home with hospice, nursing home, or inpatient hospice and English-speaking. Purposely recruited to include subjects who were non-white, did not carry a diagnosis of cancer, and were discharged to nursing homes. N=19 patients and/or their caregivers. Patient characteristics: Age (mean (SD)): 66 years (16); male: 8; female: 11; ethnic minorities: 4; Alive for interview: 4; Patient location of care after hospital discharge: inpatient hospice: 4; home hospice: 6; home, no hospice: 7; nursing home: 2; Survival after hospital discharge: 5 days or under: 5; 6-12 days: 5; 13030 days: 5; 31-90 days: 0; over 90 days: 4.

Study	**Benzar 2011** [67]
	Caregiver characteristics: Age (mean (SD)): 50 years (13); male: 5; female: 14; ethnic minorities: 5; caregiver relationship to patient: daughter/stepdaughter: 8; wife: 2; son/stepson: 2; friend; other 5.
Setting	OHSU consults from September 1, 2006-August 31st 2007.
Study design	Retrospective qualitative study.
Methods and analysis	Semi-structured in-depth interviews for 1-2 hours. Interviews were analysed by 2 independent coders using NVivo v.8. They started with broad questions that allowed subjects to determine, in the context of semi-structured interviews, what was important about their experience with palliative care and the discharge process. The interviews were then analysed using qualitative description. A researcher coded all 19 interview transcripts line by line, identifying 84 discrete codes. These codes were then organised into 15 codes within 6 major themes, the interview transcripts were re-coded by the original researcher and independently by a second researcher. Inter-coder reliability was calculated as letter-by-letter agreement using NVivo. Of the 6 themes, 3 were concerns that could be addressed by a palliative care team before hospital discharge. They chose to focus further analysis on these. The other three themes were related to experiences after hospital discharge that were outside of the scope of an inpatient palliative care team and therefore outside the scope of their study.
Findings	**Prognosis:** lacking information about prognosis and disease progression was a recurrent theme. In the hospital, prognoses were sometimes vague or overoptimistic and lacked information about what caregivers should expect. In one consult the main documented goal was to discuss goals of care and prognosis, and the patient's chart confirmed that these had been discussed however the caregiver thought attempts to discuss prognosis were dancing around the topic, and that they had to really tell the person. Another participant felt he had to read into what the doctors were saying about his father's death. He was concerned that not everyone would have been able to draw the conclusion that his father was about to die. Another participant was surprised when her mother, who originally went home with hospice for cancer, died unexpectedly while later from a dialysis shunt infection, which she felt she had not been told to watch out for.
	Symptom management: families often lacked the education that they needed to recognise and manage symptoms. In some cases, teaching about medicine use for symptoms was sparse and not written down. If dosing instructions on the prescription bottle were inadequate, caregivers had no contingency plans. Inconsistencies were found in instructions and One participant said "the prescribed her [her mother] with over £1000 in medicines….the discharge paper was blank…they didn't give her what she needed. They changed what was working to other medicines. It seemed like we had never spoken to those people at all", the authors verified that the discharge medication summary was blank, and the dosing instructions provided by the pharmacy did not correspond with the doses the patient had been taking in hospital. Another caregiver of someone on home hospice for end-stage liver disease was not prepared to adjust medication doses when needed. Although symptom control was a major emphasis of this patient's palliative care consultation in the hospital, after hospital discharge, the caregiver was confused over the pain medication as it left the patient sleeping all day.
	Whom to call with questions: another area of concern was who to contact with questions and concerns. Some quotes also reflect difficulty with simply navigating the healthcare system. Both of the patients mentioned had only one documented encounter with palliative care during their stay. The daughter of an 85-year-old female who went home without hospice after a GI bleed had difficulty learning about options for home care. She said "several times we didn't know what was out there to help us…She wanted to come home and we wanted to provide care for her at home…But we didn't know what other type of care there was…We finally got some of

Study	Benzar 2011 [67]
	that information but…We had to struggle to search it out, and answers weren't readily available." One participant was grateful to find a receptionist at the doctor's office to help her through the process. "The medical system, if you are not part of it, is a pretty foreign thing…if you find a person that will work with you, whether it be a doctor, a nurse…the scheduler…They are there to help guide you through the system. But finding them and really cultivating that relationship makes a huge difference." **Hospice:** only one of the preceding quotations came from a patient cared for by a hospice program. Their data included multiple examples in which patients and families with hospice mentioned that hospice nurses answered all their questions, helped them adjust medications, and contacted the physicians for them. However only 53% of patients in this study were discharged to home or inpatient hospice. Additionally, even patients discharged with hospice experienced gaps in the discharge planning process before they left the hospital. **Palliative care teams:** another key finding was that, at the time of their interviews (up to three months after hospital discharge), several patients and their families did not remember their interactions with the palliative care team, despite being shown pictures of team members to help jog their memories. In other cases, interviewees remembered the palliative care team members but could not distinguish interactions with them from interactions with other types of care teams.
Limitations and applicability of evidence	Unclear on data saturation. Applicable.

Study	Briggs 2010[92]
Aim	Originated from a consultation in Borough on understanding the experiences and expectations of patients diagnosed with life-limiting diseases during the last year of life.
Population	Borough-registered patients (n=30) and carers (n=20) aged 16 year and over. Patients were being treated at various hospitals or hospices or were receiving treatment in their homes. N=50; males: 18; women: 32; Aged: 40 to 90 years old; Ethnicity: white: 35, black African: 5, Asian: 4, Irish: 2, mixed race: 2. Non-cancerous conditions (COPD, heart failure, Parkinson's disease, dementia, strokes, heart disease and HIV): 32, cancerous conditions 19.
Setting	End of life care services within Borough's PCT, England.
Study design	Qualitative interview study.
Methods and analysis	Open-ended qualitative interviews and observations. The interviews examined the patient's carer's knowledge of service, experiences of each service with which they had contact, the efficiency of those services and suggestions for improvements. Observations were also made of patient/carer/professional interactions in some patients' home settings.

Study	**Briggs 2010**[92]
	Interviews lasted between 30 minutes and 1.5 hours and were transcribed verbatim for inductive analysis, so data were categorised thematically, with the key areas of investigation providing the overall framework for coding.
Findings	**Context:** patients' and carers' views on Borough EOL care services: participants appreciated GPs for their ability to respond to emergencies and prioritise EOL patients, as well as advocate for patients in the absence of effective communication from other agencies and departments.
	Developing tense emotions in the course of care: diagnosis of a terminal condition and the subsequent period was a highly sensitive time. Large family and friend support networks helped where they could and often advocated on their behalf, but not all patients were blessed with this. In these instances, some patients tended not to be aware of services provision or were tired of reporting their social and practical circumstances because the persistence involved in 'speaking up', 'filling in forms', and 'making phone calls' made for heavy demands on these patients. This was why they tended to either 'get on as best they could' or gave up after a few phone calls or if no one 'followed up on them'.
Limitations and applicability of evidence	Little information on potential bias of researcher. No examples of interview guide. No details of the decision to stop data collection and more details required about coding and themes. Applicable

Study	**Coombs 2017**[157]
Aim	To describe decision-making processes that influence transitions in care when approaching the end of life.
Population	Patients with advanced and progressive illness, with high risk of dying in the next 12 months, and their carers. N=40
Setting	Residential care home, a medical assessment unit and a general medical unit in New Zealand.
Study design	Qualitative interview study.
Methods and analysis	Field observations and longitudinal semi-structured interviews with thematic qualitative analysis.
Findings	How patients managed risk in decision making about transitions in care: Patients expressed preference to stay at home, often even with increasing risks at home, rather than being admitted to hospital. All patients stated they had made the decision about their admission into hospital, and this was the view shared by the carers. In this they weighed the benefit of being at home with the risk. They used practical resources, mainly equipment and carer support and anticipating future needs to manage increasing risks. Equipment (e.g bed pans, commode, walking aids, wheelchairs, personal alarms) which helped them to undertake the activities of daily living. As their condition advanced/deteriorated, different pieces of equipment were sourced to manage the associated risks, enabling them to remain at home.

Study	Coombs 2017[157]
	Carers played a vital role in them staying at home. Anticipating future needs and making appropriate changes helped patients cope and remain at home. This often involved patients emotionally preparing themselves for change. If the deterioration was too sudden, they were unable to adjust quickly.
Limitations and applicability of evidence	Little information on potential bias of researcher. Applicable, but there were HCPs as well as patients and carers included within the study so only one theme (out of two) could be included.

Study	Csikai 2010 [168]
Aim	To explore the communication process between patients' caregivers and health care professionals, including social worker about serious illness and end of life.
Population	Bereaved hospice caregivers of patients over 60 receiving home hospice services. N=10; Age range: 45-88 years; care recipients' ages range: 67-99 years. The relationships to the care recipients were: husbands, wives, daughters, daughter-in-law, and sister. Primary diagnoses: various cancers, heart and lung diseases. Hospice stay range: 1 week – 2 years.
Setting	1 large and 2 small urban setting Hospices in USA.
Study design	Qualitative (phenomenological) study.
Methods and analysis	Semi-structured in-depth interviews conducted within 3-6 months from the time of the patient's death. Interviews lasted 1 1/2 – 2 hours. A semi-structured interview guide was used that contained broad and open-ended questions. The primary domains examined were communication with health care professionals about end-of-life care options and decisions/transitions to hospice. All data were transcribed with the aid of a professional transcriptionist. The data were then compiled and rigorously analysed by reading and re-reading transcripts several times and creating codes and noting the emerging themes. Atlas-ti was used for data management. Using content, context and comparative approaches, the researchers organised the participants' statements into categories/codes to identify underlying patterns and themes. All data were coded by considering the responses of all participants and by dividing them into categories that covered various responses. Codes and categories were compared, contrasted and sorted until no new categories and codes emerged.
Findings	**Involvement of health care professionals:** most of the participants talked about the central role of the physician in the discussion of the patients' serious illnesses and decision making about end-of-life care options. They reported that the physicians were the primary givers of information about diagnosis/prognosis and recommendations regarding treatment/care plans. The next most mentioned

Study	Csikai 2010 [168]
	professional involved in decision making about care were social workers. They discussed the typical roles as liaison between families and health care professionals and as brokers who facilitated needed referrals for care. One participant said 'I guess they told the social worker and then the social worker passed it on, you know, through all the red tape that they have to go through to set it up." The participants that did remember involvement of a social worker in their situation generally did not have much to offer about their actions and one-half of participants did not mention social workers at all. Other health care professionals such as nurses and hospice personnel were also involved at times in the discussion and transition to hospice care. Nurses however seemed to be tangentially involved mentioned simply as people who were in the room by 6 participants. Two participants mentioned that hospice personnel provided some information about hospice services prior to enrolment.
	Relationship with Physician: the nature and quality of patients' relationships with their primary physicians were important in the communication process. Some reported that the physicians were seen as "god-like" entities. Also the participants spoke of the respect and trust they and the patients had in their physicians and its importance. It seems that with such trust and respect would come the expectation of truthfulness. Patients and caregivers expected that the physician would honestly discuss the situation and make a recommendation for plan of care and in some cases they did not have this.
	Involvement of patients in decisions: patients were reported by some caregivers to be involved in the decision-making process. One participant revealed that he wanted, as well as needed, his wife's (patient) participation. Even though the news was not anticipated to be good, some participants believed it was important that the patients were involved in conversations about their illness and future care plans. Caregivers sometimes also controlled the flow, withheld information and shielded patients from decision making because of the seriousness of the condition, or because of advanced age. A secondary theme regarding patient involvement in decisions was revealed in discussion about advance care planning. These caregivers' generally discussed a lack of written advance directives, but revealed knowledge of patients' wishes for care at the end of life as a way that allowed patient participation in decisions that were made.
	Content of discussion: the content of the discussions about serious illness and end-of-life care options was varied, but typically included disclosure of terminal prognosis and future care needs at least in a general way. In some cases, the diagnosis/prognosis was clearly given. In other cases, there was reluctance on the part of physicians to give complete disclosure of prognosis to the patients and caregivers. In one situation, after information was shared about the prognosis, a couple of options for end-of-life care, including hospice, were outlined, but not adequately descried.
	Understanding of hospice: Patient and caregiver understanding of hospice in the transition process varied. Some mentioned a lack of adequate understanding of hospice philosophy and services. The sentiment was similar to other studies' findings that patients and families only found out about the most beneficial aspect s of hospice after enrolment (Casarett et al 2004; Casarett et al 2003). Other caregivers had previous experience with hospice indirectly through family or friends or previous utilisation of hospice themselves with another family member, so they had a better idea of what to expect.
	Suggestions for improvement: one area for improvement in communication about end-of-life hospice care could be improved was that more information was needed sooner in the discussion/decision-making process. Some of the participants believed that information about the trajectory of the disease and the dying process should be given much earlier, even as soon as right after diagnosis. The information should include what to expect in terms of medical treatments as well as what services are available to assist

Study	**Csikai 2010 [168]**
	with care for the end stage of the disease. The perception of compassion by health professionals is another aspect that can facilitate communication. The caregivers in this study strongly suggested that professionals work together to provide information needed to make end-of-life care decisions.
Limitations and applicability of evidence	Small sample size. Note: study was the second phase of a larger study of bereaved hospice caregivers' perceptions of communication about end-of-life care and the transition to hospice care. The first phase was an exploratory cross-sectional mail survey. Little information on potential bias of researcher. Rigour of data collection unclear as more details needed on how recorded and transcribed. No details of data saturation. Applicable.

Study	**Davison 2006[183]**
Aim	To determine the perspectives of patients with ESRD of the salient elements of ACP discussions.
Population	24 patients with end stage renal disease from the Northern Alberta Renal Program. Participants were purposively selected on the basis of their willingness to discuss the issues and were stratified by age, gender, and dialysis modality. Fourteen patients were recruited from the Renal Insufficiency Clinic and were clinically expected to require dialysis within the next 12 mo.
Setting	Canada. Northern Alberta Renal Program at the University of Alberta between August 2004 and June 2005.
Study design	Qualitative interview study
Methods and analysis	Nominal group technique; face-to-face interviews. Two exploratory focus groups with eight (pre-dialysis and dialysis) patients. The issues raised during focus groups in conjunction with a critical review of the literature formed the basis for the study interviews. Personal audio-recorded interviews, typically lasting 60 to 90 min, subsequently were conducted in 24 study participants. All interviews were transcribed and validated against the recorded material by the interviewer. Data collection and analysis were continual and dialectic; constant comparative and iterative analyses were used. This analysis consisted of identifying and coding sections of transcribed text into thematic categories. Associations between the derived themes were sought by synthesizing, theorizing, and re-contextualizing to create a framework to understand patients' perceptions of the salient elements of facilitated ACP.
Findings	Patient's Perceived Benefit of ACP: Patients clearly identified ACP as an important part of medical care when they had a clear idea of how the process would benefit them. They were much less likely to engage actively in a process from which no benefit was perceived. "Talking about [ACP] lets you know what's going to happen. I need to know what the symptoms are and he wouldn't tell me … because I'm really worried about nausea, vomiting, and not being able to breath. Someone should be talking to you about what's coming."

Study	Davison 2006[183]
	Information Giving: Patients experienced fear and uncertainty about their future. Information giving was seen by these participants as a critical element of the ACP process in that it promoted self-reliance; alleviated fear and uncertainties; helped prepare them for the future, including death; and gave them the knowledge to make decisions that were compatible with their values and beliefs.
	Role of Physicians in Facilitated ACP: Participants clearly believed that physicians were responsible for initiating and guiding facilitated ACP, mainly because physicians were seen as the primary source of information that is central to this process. “I would hope that health care providers are sufficiently trained to inform the patients at the right time what to expect and not wait until the very last minute.”
Limitations and applicability of evidence	Subgroup from a parent study, little information on population details or role of researcher. No details of data saturation. Applicable.

Study	den Herder-van der Eerden 2017[196]
Aim	To examine how relational, informational and management continuity of care are experienced by patients with advanced diseases and their family caregivers receiving care from several integrated palliative care initiatives in 5 European countries.
Population	Patients with advanced disease (62% cancer, 24% COPD, 13% heart failure), whose doctors answered ‘No’ to the surprise question. N=152
Setting	Belgium, Germany, Hungary, the Netherlands, and the United Kingdom.
Study design	Longitudinal qualitative study design
Methods and analysis	Interviews with a two-step qualitative content approach
Findings	**Relational continuity:** this was a prominent theme in all countries. There were positive and negative experiences related to having or not having close relationships with a small number of health care professionals (e.g hospital specialists, general practitioners (GPs), nurses, physiotherapists or hospice care professionals) and seeing them on a regular basis. The HCPs paid attention to them and talked about their personal lives, not just their illness. Being known to HCs provided trust and their needs and wishes could be taken into account to tailor their care. It also meant they could monitor the patients’ illness progress. However lack of relational continuity was often experienced and they had to build new relationships, repeat their histories and did not know what to expect from HCPs. Experiences of relational continuity with GPs varied widely across countries. Those with longstanding relationships with GPs valued this. GPS often had an important role in coordinating care, prescribing medication and making referrals. However many respondent experienced a lack of involvement of GPs. Often they took a backseat when patients were (still) treated by hospital specialist, or specialised palliative care teams, consequently not receiving the support they needed or expected from their GPs.

Study	den Herder-van der Eerden 2017[196]
	Informational continuity: they found it important for HCPs to be well informed, which stopped them repeating their histories and provided trust that the HCP had the right information to make correct treatment decisions. In all countries informational continuity seemed to be weak. This was revealed in situations where many different HCPs were involved, within the hospital, between the hospital specialists and GPs, between hospitals and acute (out-of-hour) situations. It was apparent they were often badly informed about the patient's history, did not have access to other health care professionals' patient records or did not have regular contact. This resulted in repeating medical histories several times, receiving contradictory information, worrying about the quality of care and become agent of information transfer between HCPs, while they did not want to have this responsibility. In all countries there were some respondents who had examples of closely working HCPs in teams or networks, who were well informed of their histories and personal circumstances. They found that these HCPS were often involved in collaborative integrated palliative care initiatives.
	Management continuity: they wanted to be seen as a person with multidimensional needs rather than a medical subject. This required that health care professionals viewed respondents with a holistic lens and provided multiprofessional care in order to support their multidimensional needs. Where this was absent HCPs worked in a fragmented fashion and only dealt with their own medical speciality. This was found mainly among individual hospital specialist and between hospital specialists and GPS. This meant problems were inadequately addressed, remained unaddressed or were discovered too late. Respondents saw a large difference when multiprofessional care was provided. They often did not know how exactly HCPs worked together or were not interested in this as long as they received multiprofessional care. Those that knew their HCPs came together in meetings, felt that their care was connected and coherent.
Limitations and applicability of evidence	No details on data saturation. Applicable.

Study	El-Jawahri 2017[223]
Aim	To assess perceptions about hospice.
Population	Patients with metastatic cancer, with a prognosis under 12 months, and their caregivers. N=16 patients; N=7 Caregivers (of the 16 patients)
Setting	Massachusetts General Hospital Cancer Centre, USA
Study design	Qualitative interview study.
Methods and analysis	Semi-structured interviews with the framework approach qualitative analysis.
Findings	Overarching ideas: there were variable gaps in understanding about hospice, widely perceiving a psychological transition to accepting certain imminent death.

Study	El-Jawahri 2017[223]
	Knowledge of hospice: they defined it as those facing the very EOL e.g last days. Most common perceived role was to provide symptom relief, with emphasis on making comfortable. Some perceived provision of psychosocial or spiritual support for patient and their families and patient medical care. Some inaccurately thought that it assisted with activities of daily living or practical issues. A few found it most relevant to those who lack family support.
	Attitudes about hospice: these reflected (positive and negative); concerns about suffering, loss of dignity, and death, as well as their perceived understanding of hospice services.
	Concerns about suffering, loss of dignity, and death: Those with positive attitudes viewed hospice as a key support in the face of feared outcomes. A safe place for patients with gaps in family support; a relief for family to know their loved ones are being cared for; a comfort for help to reduce suffering and maintain dignity. Those with negative attitudes focused on hospice as a key harbinger of feared outcomes.
	Perceived understanding of hospice services: those with positive attitudes reflected on good prior hospice experience; one with negative reflected on poor prior experience.
	Perceived barriers to hospice utilisation: the perceived barriers were related to knowledge and attitudes, and they highlighted three influencing factors: psychological barriers to projecting a need for hospice, perception of EOL care as a personal or family domain, and a lack of understanding about hospice.
	Psychological barriers to projecting a need for hospice: these barriers were common and referenced uncertainty, emotional cost of losing hope, and avoidance of feared outcomes. One caregiver noted that family members might avoid contacting hospice so they don't put fear into the patient.
	Perception of EOL care as a personal or family domain: several thought that patients may prefer to care for themselves or that family may provide support without the need for hospice. Some voiced specific concerns about hospice staff interfering on patient and family privacy.
	Lack of understanding about hospice: several noted that many may not utilise hospice because they do not understand enough about it or are not thinking deeply enough about it, or don't learn about it until the last minute.
	Preferences of learning about hospice: given perceived barriers to hospice utilisation, they largely showed interest in gaining clarity and/or reassurance about hospice. Almost all identified one aspect they wanted to learn more about.
	Areas of interest: they primarily wanted to know about hospice logistics, including the range of services, locations of care, members of the hospice team, and frequency/length of home hospice visits.
	Preferred methods of learning: responses reflected that hospice was a sensitive and somewhat mysterious topic to broach. Almost all respondents identified interest in reviewing information about hospice in brochure, video or internet format, for a gentle introduction, a broad picture or an in-depth look in to what hospice is actually like. They also expressed interest in discussing hospice with current providers whom they trusted, often as a follow-up to reviewing information. Some wished to learn from current hospice patients or staff or with other interested families, to gain reassurance, a real life view of hospice, or information that one might not have thought to request.

Study	El-Jawahri 2017[223]
	Preferred timing of learning: Perceived optimal timing of learning about hospice reflected attention to what would be the most effective and/or the least detrimental to patients. Most suggested learning early after their diagnosis. Some of these suggested waiting for time to process initial shock of diagnosis and adjust to the treatment plan, or delaying in-depth information until the patient's health worsens. Or some thought not until something imminent occurs or there are no other options, with a few specifying that early information would interfere with hope and quality of life.
Limitations and applicability of evidence	Little information on potential bias of researcher. No examples of interview guide. Applicable.

Study	Epiphaniou 2014 [233]
Aim	To explore patients' experience of care coordination in order to inform current debates on how best to coordinate care and deliver services in end-of-life patients with lung cancer and those with chronic obstructive pulmonary disease (COPD).
Population	Patients with advanced progressive conditions assumed to be in the last year of life. N=18 patients; 6 carers participated in some or all of the serial interviews. Age range: 46-90; males: 12; females: 6. Patients with lung cancer: 11; COPD: 7; Service usage: number of consultations between October 2011 and September 2012: GP at practice: 102; GP at home: 19; GP on phone: 103; district nurse: 3; palliative care nurse: 39; lung nurse: 6.
Setting	Three hospital outpatient clinics of the Respiratory Department at a London teaching hospital between October 2011 and September 2012.
Study design	Qualitative longitudinal study.
Methods and analysis	Patients were interviewed by a psychologist with extensive experience and training in conducting and analysing qualitative interviews. Interviews were audio-recorded and completed at home at three different time points using a semi-structured interview schedule. The topic guide for the first and subsequent interviews focused on 1) the condition (diagnosis, prognosis, current problems, support, and support needs); 2) experiences when interacting with the NHS (professionals' coordination, experiences when visiting the clinics, being discharged from the clinics, experiences following the visit and referrals if they were well coordinated); 3) perceptions of future care (i.e. the plans for the future); and 4) perceptions of current and future care (what coordination meant for them, how it can improve, perception on whether they felt their care was coordinated, care expectations). Interviews were transcribed verbatim and imported into NVIVO 9, where thematic analysis procedures were implemented. The psychologist read and re-read the transcripts and searched for meanings and patterns with regard to patients' experiences in care coordination. Notes and ideas which would be used in subsequent stages were coded. Initial codes from the data, with interview extracts as examples, were then recorded to be used later on. Codes were then organised and annotated into themes which at the end would adequately capture the contours of the coded data. As a final stage, the psychologist re-read the entire dataset and also

Study	**Epiphaniou 2014** [233]
	discussed the themes to reach a consensus with two researchers and following final agreement, the coding frame was applied to the entire dataset.
Findings	**Timeline:** was the main theme emerging from the analysis indicating participants' experiences across their illness trajectory, i.e. from diagnosis to the time of the interview. Across their illness trajectory, patients discussed their experiences with regard to the role of a key worker, a specialist nurse or a community palliative care nurse. The specialist nurse coordinated their care between and within hospitals and community services while the CPCN coordinated care in the community. Along with the role, monitoring and follow-up was a second emerging sub-theme. In order to aid transparency, the results are reported separately for lung cancer and COPD patients.
	Experiences of lung cancer patients: **- Role of key worker: coordination between and within hospital settings:** for some the key worker shared the diagnosis and referred them to hospital clinicians. The key worker was also the main point of contact and also liaised with other professionals to hasten treatment procedures for prompt treatment services. **- Role of key worker:** coordination with the services outside the hospitals: furthermore the key worker coordinated care with community services such as social services, the GP, or referred patients to community palliative care services. For some patients and carers the key worker requested financial support on their behalf. They also contacted the GP for emergencies. Seven patients who required palliative care were referred by the key worker to community palliative care services. **- Role of key worker: to provide support:** the majority of patients with lung cancer and their carers appreciated the key worker being caring and supportive. However, one carer commented on the key worker not responding to calls and thus not being supportive. **- Role of CPCN: coordination of care in the community:** when referred to community palliative care services, CPCNs acted as the patients' main coordinator within the community. The CPCN also prepared for the future and provided support. Consequently the involvement of a coordinator across their illness trajectory enabled access to hospital, community and social services. Patients and carers felt supported and appreciated the professional's role. **- Monitoring and follow-up:** patients with lung cancer reported regular follow-ups.
	Experiences of patients diagnosed with COPD: unlike lung cancer patients, COPD patients did not usually have access to a dedicated key worker for their illness. Patients reported access to services during acute exacerbations, which were followed by a discharge back to the community. Lengthy periods between these meant scarce monitoring and follow-up after discharge. However, a small number of patients (n=4) reported consistent check-ups from their GP or hospital every 6,9,12 months. Acute exacerbations: after an acute exacerbation some COPD patients are admitted as inpatients. Monitoring and follow up: contrary to their expectations, some patients reported vague follow-up from professionals in the community or from the hospital. However, some reported check-ups at the hospital or GP. Only one patient with COPD reported follow-up from community services following discharge from hospital. Most patients persevered to manage their illness on their own. Patients with COPD who had lung cancer (n=3) reported access to different services following the involvement of the key worker: access to financial services; psychological support and support form community palliative care.

Study	**Epiphaniou 2014** [233]
Limitations and applicability of evidence	Little information on potential bias of researcher. No details on data saturation. Applicable.

Study	**Epstein 2015** [234]
Aim	To aid in better understanding of, and provide potential solutions to, barriers to communication about end-of-life care.
Population	Patients with advanced liver, biliary or pancreas cancers and no prior advance directives. The majority was receiving chemotherapy and all were being followed at least monthly by their outpatient medical oncologist. N=26 (12 participants from the video arm and 14 participants from the video arm) who articulated questions, comments, or both. The total number in the RCT N=54. Approximately half of all 54 participants outlived the 6-moth pre-planned follow-up duration of the study period.
Setting	Memorial Sloan Kettering Cancer Centre, USA.
Study design	Qualitative interview study.
Methods and analysis	Qualitative thematic content analysis of participants' responses to a RCT of an educational video or narrative about CPR in patients with advanced gastrointestinal cancers. Articulated questions and/or comments were analysed by two reviewers into themes from each participant. After jointly reviewing individual thematic coding results the reviewers' reached consensus on seven distinct themes.
Findings	**Advance care planning should be started early:** comments included 'we have to discuss it', 'we have not discussed it' and 'it's better to deal with these things when you're reasonably healthy.'
	Information about the process of cardiopulmonary resuscitation (CPR) affirmed existing personal beliefs/knowledge/values
	Participants were apprehensive about ACP but wanted to discuss it: they were often apprehensive to discuss inherently difficult topics, but expressed the concomitant desire, nonetheless, to plan for the future through such discussions. This 'paradox' of ACP illustrated itself in different ways. Sometimes it arose within the family unit itself, or a patient expressed both components of the paradox (e.g that ACP is difficult yet important), it came through in analysis either directly or more subtly.
	Gaps in medical knowledge emerged: critical to education and ultimate decisions about medical treatment, gaps in knowledge emerged.
	CPR information was helpful or acceptable: while less common than the 'paradox'' theme, impressions also arose regarding the palatability of the educational material on CPR, including the notion that such information was helpful.
	Physicians should be involved in ACP: some responses spoke directly to this theme. Other responses more indirectly referenced the role of the physician, or at least the healthcare team. This theme relates to a slightly different paradox that others described: a minority of admitted cancer patients have discussed advance directives with their oncologist (or want to with their oncologist) although half would want their oncologist to be the doctor (as opposed to a previously unknown, admitting physician) with whom they discuss

Study	**Epstein 2015** [234]
	such issues should these conversations be deemed as ‘necessary’ to have. Therefore, despite an understandable degree of apprehension to discuss topics as difficult as death and dying, if presented as imperative, advance care planning is generally recognised by the patient, and sometimes the family caregiver, as important to discuss with the oncologist in order to best plan practically, realise life goals, and fulfil relationship duties.
	Medical questions arose: not only did gaps in knowledge emerge, but so did medical questions about CPR and other treatments illustrating the utility of these educational media to act as a vehicle through which modifications can be made to medical treatment decisions, and shed light on common and often complex aspects about end-of-life care.
Limitations and applicability of evidence	Little information on potential bias of researcher. Applicable

Study	**Gerlich 2012**[273]
Aim	To explore the needs of older patients with advanced heart failure, and their experiences with health care delivery in Germany.
Population	The main inclusion criteria were participants of age 70 and above and with heart failure in an advance stage according to the New York Heart Association Functional Classification. Furthermore, to identify patients with poor prognosis, the recruiting senior physicians in the geriatric hospitals used the ‘surprise question’ (‘Would I be surprised if my patient were to die in the next 12 months?’). In the present study, patients were included if the physicians’ answer to the ‘surprise question’ was ‘No’.
Setting	Germany; two geriatric hospitals in Hannover and Heidelberg.
Study design	Qualitative interview study.
Methods and analysis	All interviews were carried out at the place of recruitment by the same interviewer (KK) who was externally supervised. The patient interviews were digitally recorded and verbally transcribed. All 25 transcripts of the baseline interviews were scrutinised for the initial incorporation into the data material. The transcripts were analysed by a qualitative descriptive approach. All meaningful text units were identified and open-coded separately by two researchers. The codes were then grouped into several relevant subcategories which were subsequently summarized into three main categories. No new categories emerged after the analysis of the 12th interview and consequently at this point we stopped the baseline analysis. The analytic process and the emerging categories were continuously discussed in the study group until a consensus was reached. The analysis was supported by the software program MAXQDA® for the analysis and organization of the material.
Findings	**Information needs:** Patients reported that they had been informed about their illness, but the patients’ understanding of their heart disease seemed rather unspecific. One patient explained only that ‘something was wrong with his heart’
	Prognosis: It seemed that the prognosis of heart failure was rarely discussed between patients and carers. Heart failure was not recognized as a potentially life-limiting disease, and issues of death and dying were not directly mentioned by any of the patients interviewed.

Study	Gerlich 2012[273]
Limitations and applicability of evidence	Small sample size. Unclear if themes reached saturation. Applicable

Study	Hanratty 2012 [306]
Aim	To explore older adults' experiences as they move between places of care at the end of life
Population	People older than 75 years who had moved between at least two care settings in the previous three months who were aware that they had been diagnosed with heart failure, lung cancer, or stroke and were thought to be in their last year of life. N=30; age range 69-93 years; more than half were living in disadvantaged areas of northwest England. The interviewees had collectively moved 67 times between care settings in the three months before being interviewed.
Setting	Northern England in 2009-2010.
Study design	Qualitative study with semi-structured face-to-face interviews
Methods and analysis	Part of a larger project on transitions in health care settings at the end of life for people with stroke, heart failure and lung cancer. All interviews were conducted by one researcher. They were recorded and transcribed verbatim. The interview topic guide covered the participants' social context and relevant life history, their understanding of their illness, the nature of any transitions they had experienced, and how they understood and interpreted their experiences of transitions. There was a comprehensive list of prompts under each topic to ensure consistency. The participants were asked to talk about their experiences, good and bad, of health and social care as they moved between care settings in the last six months. They sought perceptions of the quality of care in each setting in addition to the experience of moving between places and the care received immediately after a transfer. Data analysis used the principles of Framework, a modified form of thematic analysis. The transcripts were read and reread by two researchers, then line-by-lie coding for initial categories which were then grouped into themes.
Findings	**Prioritisation of institutional processes:** many of the interviews conveyed a sense that the care system was imposing processes on patients with limited recognition of or flexibility to the individuals' needs or wishes. The problems ranged from administrative procedures, such as outpatient appointments, to the provision of aids and appliances. In some situations, the imposition of rules intruded directly into life at home. One interviewee descried how they had to ask for fewer social service carers to visit, as they, too, intruded on her day-to-day routine. The authors state that adherence to procedure is important for patient safety and the efficient running of a large organisation, but it also may leave staff unable to respond flexibly to an individual's needs or wishes. These issues emerged in discussion of the organisation of visits to the hospital after hospital discharge. Reliance on working family members for transport was common, and time spent waiting and time taken off work was a source of annoyance and guilt.

Study	Hanratty 2012[306]
	Support across settings: some of the accounts suggested that the older adults felt that they were sent out of hospital without adequate time to prepare themselves, insufficient community support in place, and little knowledge of how to access the services they required. One account implied a lack of participation in the discharge planning process. 'They kept telling me I was going home and I was alright, I was going home. My legs hadn't been seen to, the infections hadn't gone, the swelling hadn't gone down, but they were quite willing to send me home, and then they decided to keep me in, and that happened to me four times in hospital and in the end, it came that…they sent me home I had no medication ot come home with, just I had just got my old insulin but they gave me no instructions, no knowledge, nothing and the sister was on the phone when I left, and she never bothered she just waved like that when I went out (Female, aged 80 years, lung cancer). Another participant was able to advocate successfully for his own care but noted an apparent failure in communication between hospital and community. Many of the problems appeared to be minor, but the consequences for the elderly and unwell could be considerable.
	Being heard: a good understanding of the purpose of any move into or out of an institution, and the associated practical arrangements, may help to minimise any distress associated with the transition. There were many examples of communication between health professionals and patients that was effective and well received by patients. The feeling that, at times, no one was listening to patients or families emerged as a theme from patients with all three conditions. This was particularly apparent when they had just moved into or out of hospital.
	Dignity: clear examples of mistakes associated with transitions were rare in the study. Possible errors with medications were described by only two of the participants when they were leaving the hospital. A third interviewee was concerned that medication dispensed from a hospital pharmacy may not have been for her, as they were dissimilar to medications that she had at home. But as older adults were placed into new and unfamiliar situations, they described care that may have lacked dignity. Loss of false
Limitations and applicability of evidence	Little information on potential bias of researcher. No details on data saturation. Applicable

Study	Horne 2012[348]
Aim	To explore the views and experiences of people affected by lung cancer about discussing preferences and wishes for end of life care and treatment.
Population	People with lung cancer and their family members who spoke English and had completed 'active' treatment were invited by their lung cancer nurse specialist to take part in the study. Together with an invitation letter, an information sheet outlined the topic and the types of questions they would be asked. Forty-two patients and twenty-seven family members were invited. A purposive sample of 25 patients of white British origin

Study	Horne 2012[348]
	(18 men and 7 women) aged between 47 and 85, and 19 family members were recruited. Fourteen family members were related to patient participants and five family members were related to two patients who declined to take part. Twenty-one patient participants had died within 30 months of the study starting.
Setting	UK. Participants were recruited via a specialist cancer centre in a city and a local cancer centre in a town in the north of England, UK. The settings were chosen because it was thought they would allow sufficient recruitment within the identified data collection period. Both settings employed lung cancer nurse specialists.
Study design	Qualitative interview study with semi-structured face-to-face interviews
Methods and analysis	After participants gave consent to participate they were invited by the principal researcher to be interviewed. Most chose to be interviewed in their home either alone or jointly with a family member. Family members of invited patient participants were invited to attend one of two group interviews. A semi-structured interview guide was developed with the support of the research advisory group which included doctors, nurses and a bereaved carer. Questions within the interview guide were developed to explore participants' views about discussing and planning for their future. Process consent was used periodically to check peoples' willingness to continue the interview. Data were collected between December 2006 and May 2008 and interviews lasted an average of 31 min. Interviews continued until no new categories emerged. All interviews were audio-taped with the patient and family members' consent and transcribed verbatim. Each transcript was given a unique code and pseudonyms were used to preserve anonymity. Field notes were written immediately following each interview and focus group. Transcripts were manually coded by the principal researcher and checked by the co-authors for consistency. The analysis was conducted using a constructivist grounded theory approach which meant that analysis began following the first interview using a constant comparative method, a continuous and iterative process throughout data collection. Conceptual categories were developed by taking data apart line by line into small units of meaning and then building it back together to develop the theoretical interpretation. Later interviews were used to theoretically sample emerging categories by refining the interview questions used to test out the emerging categories. Emerging categories were shared with the advisory group to check for 'fit' and further refine the interview guide to test emerging categories. Data were compared and contrasted across interviews looking for similarities and differences to draw out meanings and relationships. Negative examples and silences were considered in the process of analysis. Theoretical memos and conceptual diagrams were used to aid construction of the theoretical interpretation by considering relationships between categories. Data from family members and joint interview data were analysed separately. Following the development of substantive categories these findings were used to triangulate the emerging theoretical interpretation. Credibility and rigour were enhanced by checking with the research advisory group if the theoretical interpretation of the findings 'fitted' with their clinical practice and were understandable to them. A framework for evaluating qualitative research provided quality indicators to help the researchers establish the veracity of the study, its conduct and findings.
Findings	**Facing death when it comes:** Planning for one's own dying and death was not something that people with lung cancer reported having discussed, except in relation to the practical arrangements that would be necessary following their death. People instead preferred to focus on living in the present by 'carrying on as normal' whilst they still felt reasonably well, and seeking to postpone facing

Study	Horne 2012[348]
	death until the time came. They also sought to delay awareness of their forthcoming death for as long as possible, preferring not to know when they would die. ‘‘And I just think if I get to be poorly, I know myself if I’m poorly and I’m going to think to myself yeah things need to be, I’ll do it then. But at the present time I feel okay and I’m not going to be discussing what’s going to happen if I die or God knows I don’t want to go down that road, not yet anyway’’. Eighteen of the 25 patients talked about not feeling ill; they therefore took a stance of disbelief towards their diagnosis or death being imminent. They did not see the need to discuss the future. Some participants reported that whilst they felt well, they would continue to let their families think they were still well. Likewise family members reported that when patients appeared well, this impeded any discussion of preferences for the future.
	Clinical discussions about the future: Eight people talked about the doctor knowing what was best for them, trusting in the doctors’ knowledge of cancer with implicit acceptance of treatment or advice. Others reported that they did not trust their doctor or had no ‘faith in’ them, which they related to wrong predictions about the time left to live, lack of explanations about what treatments were available and wrong information or advice about treatments. Explanations when given were offered in steps and focussed on medical issues. Eleven people reported that their doctors had not presented different options for future treatment or care. Thirteen patients reported that health professionals did not have ‘deep discussions’ or initiate discussions about the future which they related to lack of clinic time, a focus on their condition or their own desire not to discuss the future.
	Previous experience: Seventeen people with lung cancer reported experiences of other peoples’ cancer or deaths. Fourteen talked about their experience of others dying and seven of these 14 related this to cancer. One person spoke about their experiences of someone with cancer who had not died. For some these experiences influenced them to make a will or make decisions. Some people talked about not wanting to be a burden on their family having witnessed the effect on family of someone’s death. Still others talked about foregoing treatment and linked this to the unfortunate experiences of others.
Limitations and applicability of evidence	Little information on potential bias of researcher. No details on data saturation. Applicable.

Study	Jack 2016[371]
Aim	To explore patients' and family caregivers' experiences and perceptions of Hospice at Home care.
Population	Participants were in receipt of Hospice at Home service on at least three occasions and were deemed to have a life expectancy measured in weeks rather than days. Sixteen patients and 25 caregivers were interviewed (n = 41). The majority of patients had a cancer diagnosis and were, in the main, older people with 88% (14) aged over 71 years; additionally, 37% (6) lived alone (factors recognized as challenges in providing a home death).
Setting	UK. Service located in North West England covering two counties. The Hospice at Home service was developed to support people to remain at home and to die at home.
Study design	Qualitative interview study

Study	Jack 2016[371]
Methods and analysis	Face-to-face semi-structured interviews. A topic guide was developed from the previous elements of the evaluation of the service. A conversational style was adopted with semi-structured digitally recorded interviews to enable relevant issues to be covered, but which provided flexibility for pursuing appropriate elements of inquiry raised by the participants. Interviews mostly took place in the participant's home (one was undertaken at the hospice when the patient was attending day therapy and one family caregiver requested a telephone interview). Individual or joint interviews were offered to patients and family caregivers and only two had individual interviews. Some patients had more than one family caregiver participate, for example, where several family members shared the care. Data were collected from October 2014 - July 2015.
Findings	**Communication:** There was a clear consensus among participants that the Nurses were skilled communicators able to engage patients and caregivers in often difficult discussions about death and dying. “They [Nurses] approach you and talk about cancer… a lot of people hide their emotions, they can't cope with it. All of the staff have approached it … in the manner that I would have liked to have been approached … Because of the nature of their work, you have the confidence in speaking to them, speaking about what's going to happen to you, where you're going and what's the by-product, the future, without any of the silliness”
	Caring for caregivers: Caregivers find it difficult to hand over the patient's care to others, putting the needs of the patient above their own. Additionally, knowing that someone had their best interests in mind was reassuring to caregivers who felt that their needs and their health were clearly regarded as important.
Limitations and applicability of evidence	Little information on potential bias of researcher. No details on data saturation. No examples of interview guide. Applicable.

Study	Johnston 2016[397]
Aim	To explore patients, and their partners, views and experiences of the EOLC-LTC service.
Population	Patient and family member/carer and key health professionals involved in their care included. Patients were: considered to be in the last year of their life due to chronic respiratory disease or heart failure; having the mental capacity to give informed consent; physically able to complete a 30 minute interview; established on the services caseload for at least 3 months; having palliative care needs (past/present and on-going). The second group consisted of approximately six key stakeholders. N=6 patients; age range 59-83; males: 4, females: 2.
Setting	End-of-life care Long term conditions service (EOLC-LTC), East Midlands from February 2014-February 2016.
Study design	Qualitative study.

Study	Johnston 2016[397]
Methods and analysis	Interview data from both groups of participants were combined and analysed thematically. All interviews were conducted, transcribed verbatim and checked by the interviewer. Data were entered onto NVivo and coded by the researcher, who revised initial coding following constant comparison of the scripts. Initial themes and subthemes were identified then reviewed, revised and agreed.
Findings	**Accessing routine care:** patients and carers reported being unable to make timely GP appointments (particularly their 'own' GP), and experiencing delays in obtaining prescriptions. Attending hospital or practice appointments could be a struggle, and unnecessary hospital admissions, particularly at weekends, were seen as distressing for, and by , patients. Patients and carers were reluctant to ask for help. Community services did not necessarily visit at a convenient time.
	Knowledge and understanding of the EOLC-TC service: knowledge and understanding of the service was variable. Although patients and their carers gave very positive feedback about their care, few reported knowing about the service in any depth, and generally referred to the name of their own nurse, or to the service, by the short four-letter acronym of the organisation funded to the service.
	Qualities of the Service: Particular elements of the manner in which the service was delivered, were highly valued by patients and clinicians alike. Patients expressed their confidence in the service and liked having the same individual nurse allocated to them, who they could get to know well. Although occasionally the nurses had to cover for each other, for example: annual leave, patients were accepting of this as the team were seen to work closely together and share the same approach to treatment. With other services several different individuals might visit the patient, and treatment approaches and management might be contradictory, which was a concern of carers as well as patients. Patients valued the reliability and dependability of the EOLC nurses, were confident that they would visit as requested/arranged and do what they had promised. The EOLC-LTC nurses were perceived as able to expedite prescriptions, facilitate more flexible hospital appointments and liaise with GPs and consultants on the patients' behalf. Having a regular pre-booked visit from the nurse, often on a weekly basis, meant that the onus was not always on the patient to ask for the nurse to call, and encouraged patients to feel empowered to request more contact if they feel it necessary. Patients and carers also appreciated having some control over when the nurse visited compared with other community nurse services. Patients described how they saw the EOLC-LTC nurses as delivering a comprehensive service that could and would help with anything and everything.
	Building a close/therapeutic relationship: Spending time with the patient: the frequency and consistency of the EOLC-LTC nurse visits helped a close relationship to develop between the nurse, the patient, their family and other support networks. The ability of clinicians to 'have time' and to share this with their patients was valued. It was common for patients and carers to describe how they felt able to talk about anything with their EOLC-LTC nurse. This communication was facilitated by the closeness of the relationship and knowledge of the individual and their family. This included discussions about advance care planning, which could be revisited, as appropriate to the individual. Some patients needed several opportunities to talk about their wishes and make plans.

Study	Johnston 2016[397]
	The process of decision-making in condition management was referred to by patients as being one made together with the EOLC-LTC nurse and their family; plans were perceived as being made jointly, rather than being imposed.
Limitations and applicability of evidence	Little information on potential bias of researcher. No examples of interview guide. Very small sample size. No details of strengths and limitations of study. Applicable.

Study	Klindtworth 2015[430]
Aim	To understand how old and very old patients with advanced HF perceive their disease and to identify their medical, psychosocial and information needs, focusing on the last phase of life.
Population	Old and very old patients (70 years or over) with severe HF (NYHA III-IV). N=25; males: 11; females: 14; age (mean): 85 years; living situation: home: 18 (72%), assisted living/nursing care home: 7 (28%).
Setting	3-monthly intervals over a period of up to 18 months.
Study design	Qualitative longitudinal interview study.
Methods and analysis	In-depth interviews. Interviews were all conducted with the first author and comprehensive field notes were taken during the interview to gather data on non-verbal reactions and the course of the interview in order to facilitate contextualisation of the data. An interview postscript was written shortly after the interviews to record the context, atmosphere and the interviewer's subjective impressions for each interview. The interview guide covered the patients' experiences with heart failure, their main concerns at present (physical, psychological, social or spiritual), views on their care and treatment, and information about their condition and treatment. The interview guide used for the sequential interviews included the same key topics as the one employed in the first interview, whilst focusing predominantly on perceived changes in the patient's illness trajectory and life, and deepening individual issues identified in previous interviews. Interviews were audio-recorded and transcribed verbatim. All transcripts were checked with the audio file and thoroughly anonymised. The iterative analysis started after the first interviews. Researchers' field notes and interview postscripts were sued to enhance the interpretation. The qualitative analysis was performed using an inductive approach according to the principles of Grounded Theory. Starting with a careful look at the transcripts they openly coded relevant passages in the interviews with respect to the research questions using the qualitative data analysis software MAXQDA 10. First coding steps were conducted by two researchers and subsequently synthesised. The field notes, interview postscripts and interview memos were used to enhance the joint interpretation. During the process codes were subsumed alongside main categories into sub-categories. Additionally they conducted in-depth analysis of relevant passages to identify latent structures of meanings. -analysed using qualitative methods in relation to Grounded theory. Frequent team meetings (with experts in public health, nursing care, sociology, general medicine and palliative care) intensified reflection on the data.
Findings	**Dealing with the end of life:**

Study	**Klindtworth 2015[430]**
	Value and worthlessness in old age: Although most patients expressed a strong preference to die at home, specialist palliative care and facilities (for example: hospices) were not discussed as an option to realise dying at home. At the same time, some of the interviewees did not reject hospitalisation if pain became unbearable.
	Preparation for death: given the limited lifetime remaining, the respondents thought it particularly relevant that arrangements be made before they passed away. In all cases, the patients' funeral was already planned and a will in place regarding their personal finances. Many patients said it was important to know that their family was provided for. However, arrangements for the time before death, i.e. the process of dying and concomitant medical concerns were often less definitely defined. While all interviewees did not want life-prolonging treatments, they had a range of strongly divergent ways to express their wishes: from written statements of intent (living wills and enduring powers of attorney) to oral delegation of decision-making power to family members or primary representatives. What is more, some made contradictory statements regarding the intention and implementation of advance directives. Some patients, however, reject the living will completely because they see no need for this document or mistrust possible actions by physicians; thus, they are confident that their family will handle things without any written directions. Renewed inquiry during the sequential interview sessions suggested that this attitude did not change over time.
	Delivery of health care: **Perceptions regarding care:** Appropriateness of (medical) care: the interviewed patients' assessment of the quality of medical and nursing care varied depending on whether they thought the treatment was appropriate, necessary and met their needs. If decisions about medical treatment, prescriptions and home visits made by the professionals do not meet a patients' expectations, they may be perceived as inadequate or 'wrong', particularly with treatment of pain.
	Continuity of care: transition situations, i.e. from hospital to home, often reveal gaps in the provision of care. Although all patients interviewed preferred to be cared for at home, joint discussions between doctor and patient regarding medical and therapeutic treatment options in ambulatory settings did not take place. One patient perceived recurrent visits to a day unit (in addition to visits by nursing and medical assistants) as stressful.
Limitations and applicability of evidence	No details on data saturation. Applicable.

Study	**Low 2005 [475]**
Aim	To explore the experiences of people involved in UK palliative care day services and identify the important outcomes of this service.
Population	Patients, informal carers and volunteers from four palliative care day units in the UK. All PCDS patients could participate if they were first time users of the service who had been attending for less than four months; needed to speak English and able to give consent.

Study	Low 2005 [475]
	Carers were those providing the majority of emotional and physical support and not employed by a statutory body. Volunteers were all involved in the provision of PCDS, whether in a supportive role, or delivery of therapies or as volunteer drivers. N=18 patients; N=12 carers; N=22 day unit volunteers; N=11 PCDS managers. Median age: 60 years. Predominantly white British (16/18). Focus groups ranged from three to six participants.
Setting	Four purposively selected (to reflect the wide range of PCDS service delivery in the UK) palliative day units in the UK (Solihull, North Glasgow, East Surrey and Bradford).
Study design	Qualitative study with focus groups.
Methods and analysis	Focus group was conducted with each of these groups and a separate focus group with the 11 PCDS managers. Each focus group was facilitated by the research nurse and the Senior Research Fellow. The focus groups aimed to cover the following: perceptions of the benefits of PCDS and challenges facing PCDS; perceptions of the impact of PCDS on their quality of life; perceptions of the challenges in delivering PCDS. The focus groups were audiotaped and transcribed verbatim for thematic analysis. Themes were generated individual and the discussed by both reviewers.
Findings	Benefits of PCDS on service users: - Access to palliative care health professionals: patients indicated that the ease of accessing all the relevant palliative care professionals in one place through PCDS was invaluable. In particular, most patients highlighted that they felt more comfortable in discussing certain issues with these staff rather than their GP who they perceived as being too busy and not specialists in cancer care. Patients trusted these palliative care professionals and had confidence that they would manage any problems that arose quickly and effectively. They also highlighted that the PCDS staff were monitoring them regularly and would pre-empt any problems that might arise. In turn, the ability to access these professionals provided patients with the security and peace of mind that any health problems that arose could be dealt with. Input from other health professionals such as physiotherapists and occupational therapists were welcome by some patients and often their main reason for coming to PCDS. They saw treatment from these professionals as the opportunity to improve their physical functioning and mobility.
Limitations and applicability of evidence	Little information on potential bias of researcher. No details on data saturation. More details required on development of themes. Applicable.

Study	MacArtney 2015[481]
Aim	To explore experiences shaped by resilience and acceptance to show how they both facilitate as well as restrict possibilities for people at the end of life.
Population	Characteristics: n=40; male: 46%, female: 54%; mean age (range): 68 (30 to 91) years; those known to have died post-interview the median days' survival was 23 (range 1 to 112) days.

Study	**MacArtney 2015[481]**
	Purposive sample of inpatients on specialist care unit in a hospital who were in last few weeks (or in some cases months of life); cognitively able to undertake an interview (a score of >23 on the Mini Mental State Examination); not in significant pain and capable of providing consent. Most had high palliative care needs requiring an inpatient stay.
Setting	Specialist palliative care unit, part of a sub-acute care hospital that also had an attached specialist community palliative care unit. Australia.
Study design	Qualitative interview study
Methods and analysis	In-depth semi-structured interviews with thematic qualitative analysis. The interviews south to cover, when appropriate, four key areas of the patient's experiences of inpatient specialist palliative care, including reflections on their illness and time before admission; how they came to be an palliative care inpatient; what location they preferred to be cared for in and where they had considered dying; and their personal and existential reflections on illness and dying. A dialogical interviewing approach was used to probe for detail and ask questions as the interview progressed. Interview techniques appropriate to the palliative care setting were used. Thematic qualitative analysis was used. Participants were treated as providing 'socially competent' understandings of their experiences. From this the accounts were then explored to draw out the underlying structures, practices and discourses that shaped participant's understandings. After each interview was completed and transcribed each interview was read systematically to identify themes, patterns and issues. These would then be developed or challenged through reading of other interviews and in discussion with colleagues. As the analysis developed, the authors would go back over transcripts and notes to compile similar, atypical, conflicting and contrasting examples.
Findings	'Palliative care equals dying': expectations of palliative care. There were a number of overlapping and competing expectations with the movement from life-prolonging to life-enhancing care. Palliative care held negative connotations for many patients in the study, one patient expressing that they were scared of palliative care as to them it equalled dying. As well as the negative connotations and expectations of what palliative care might mean, the impact of palliative care on carers was talked about as leading to resistance and pressure to not engage palliative care. With carers perhaps not understanding the meaning of palliative care. As well as questions about what palliative care is, approaching palliative care can involve relational dynamics including managing the emotional expectations of others, such as carers, family and healthcare professionals. Several participants explained how a 'dysfunctional' relational dynamic with their doctors affected their gradual shift in focus away from curative or life-prolonging options. The expectation that the palliative care of a patient is against the oncologist's 'business' reflects a tension between life-prolongin and life-enhancing strategies of care that was perceived to exist by some participants. It is possible that the resulting confusion and perceived exclusivity of these two pathways mirrors a difficult dynamic in the field whereby palliative care practices have increasingly been mainstreamed, at the same time as efforts have been made to demark a professional specialisation of palliative care. The resulting 'crisis of definitions' means that what is meant by palliative care and how it is delivered is therefore relationally dependent. One patient found palliative care became more associated with finding easier ways to die and less about quality of life issues. Another 'rebelled against this [palliative care], because he couldn't understand its meaning or purpose. For those with no experience of

Study	**MacArtney 2015[481]**
	palliative care the sudden transition to it tended to invoke fears long associated with palliative care, such as ideas of 'giving-up' and discursive framing of palliative care as a way for clinicians to (quasi-legally) help their dying patient have a quicker death. As a consequence, many described how the complexity they faced allowed them to re-engage their treatment under a discourse of resilience, while also being resistant to any move towards palliative care as an end of life strategy. This resulted in many participants initially perceiving palliative care to be sitting outside of the curative-hope framework, and, to a certain extent, found it to also be a challenge to that framework. Nonetheless, as we explore in the following section, for a number of participants, experiencing palliative care raised questions about their life-prolonging treatment pathway.
	'Being around a little longer': extending resilience with palliative care. The majority of participants were unfamiliar with palliative care when it was first topicalised by their doctor and thus their introduction to it was talked about as producing feelings of anxiety and fear about what it meant for their life expectancy. Other studies found that in part to help mitigate such reactions the preferred clinical strategy is to 'phase in' the patient's introduction to palliative care while continuing to receive technically life-prolonging treatment (Gardiner 2011; Meyers 2004; O'Leary 2009). For several participants in this study this phasing in of palliative care often helped to problematize experiences of the care and treatment the participant was receiving. The use of palliative care is experienced here as making life more comfortable, as the participant seeks to prolong life for as long as possible. Yet the relational dynamic of 'wanting to be around for a bit longer' is qualitatively focused on being around for family. The phasing in of palliative care not only brought into questions participants' expectations of the future, but it also helped to question the fears and anxieties of SPC. Some participants made the distinction that the aim of their current admission to specialist palliative care was to find a better form of pain management, rather than as part of an end of life process. The transition to palliative care was initially understood as finding ways to remain resilient within a life-prolonging framework, with palliative care providing the necessary pain and symptom relief to continue with life-prolonging options.
	'After a while you just can't keep going': toxic resilience: The move to palliative care can disrupt previous notions, expectations and experiences of care and treatment. What was of particular interest was how resilience within a potentially curative or life-prolonging focus became viewed as a problematic, even toxic, dynamic and counter-productive to maintaining or enhancing the participant's quality of life as they approached the end of life.
	'I just accepted it': knowing and feeling the right time to stop: faced with the implications of remaining resilient (or at times toxic resilience), several (but not all) participants engaged another (potentially) normative ethic in negotiating the transition to palliative care – that of acceptance.
Limitations and applicability of evidence	Little information on potential bias of researcher. Small sample size. No details of data saturation. Not a lot of details of transferability to other settings and limitations not discussed. Applicable

Study	**MacPherson 2013[484]**
Aim	To explore the views of people with severe COPD about advance care planning.
Population	Patients with severe COPD as defined by the Gold Standards Framework - have a diagnosis of COPD and one or more of: Disease assessed to be severe for example: (FEV1 <30% predicted – with caveats about quality of testing); recurrent hospital admission (>3 admissions in 12 months for COPD exacerbations); fulfils long-term oxygen therapy criteria; MRC grade 4/5 – shortness of breath after 100 metres on the level or confined to house through breathlessness; signs and symptoms of right heart failure, combination of other factors, for example: anorexia, previous ITU/NIV/resistant organism, depression; >6 weeks of systemic steroids for COPD in the preceding 12 months. N=10
Setting	UK. The participants were interviewed in their own homes.
Study design	Qualitative interview study
Methods and analysis	A Breathe-Easy group (support group of patients with lung conditions, supported by the British Lung Foundation) was consulted before the study to inform the initial topic guide. The participants were interviewed in their own homes, with a relative present if they preferred, using a semi-structured approach with a broad topic guide that evolved during the study. Each interview was digitally audio recorded, with field notes added immediately afterwards. All interviews were completed on one visit between September 2010 and February 2011. The digital recordings of each interview were transcribed verbatim with the field notes added alongside. Each transcript was read and sections representing opinions, experiences or emotions were coded, and a rough coding tree formed. These codes were then examined and the coding framework adjusted. Two transcripts were also coded by another author (CW) to minimise bias and ensure all themes were identified and explored. The coding framework was iteratively developed from the data with both descriptive codes and analytical codes used. The software package Transana17 was used to assist with transcription and data management. A grounded theory approach was used to generate theories from the data collected, based entirely on the themes and subthemes identified.
Findings	Information provision: Most participants reported having had little discussion with healthcare professionals about COPD itself, causing anger in some participants, particularly about a perceived lack of communication around the time of diagnosis. “Nobody’s ever talked to me about anything really, seriously. I did...I said to you I didn’t even know I had COPD. That’s how much the doctors have talked to me.” Some had a fatalistic attitude to life in many participants, describing feeling that they would die whatever happened and there was little that they or anyone could do to affect what happened up to that point.
	Discussions about the future: Two participants reported having had some discussion about the future with healthcare professionals. The first had consisted of a district nurse mentioning that he [the participant] was very unwell, and had he thought about the future, which he took to mean had he planned his funeral. He had become very upset by this, and had complained about that nurse. All other participants described consultations with health professionals being very focused on the present, usually on their current problem. Their future or preferences for treatments were never discussed, and some participants were unable to imagine discussing these issues within the consultations they had. Most participants wanted more information about how their disease would progress, and more discussion about the future. They found it difficult to raise these discussions themselves, despite wanting to.

Study	MacPherson 2013[484]
	Decision making: Participants were keen to be involved in decisions about their treatment and to discuss treatment options. When treatments were decided without any discussion with the patient, this damaged their relationship and trust with their healthcare provider. A few patients preferred their doctors to generally make decisions, and they would be happy to go along with their advice, believing it to be the patient's responsibility to raise any concerns they had about the proposed treatment.
	Planning for the future: Despite being keen for more involvement in current decisions about their care, participants were wary about making advance decisions about future treatment. Similar to the concerns of the participant due to complete an advanced care planning document, participants had concerns about knowing their future treatment preferences and did not see why making decisions in advance would be helpful. Participants recognised that their symptoms varied significantly, and all had adapted to this by making routine decisions on a day-to-day basis. They generally had a reasonable idea of their preferences, but not enough to make a binding decision that would then be applicable in the future.
Limitations and applicability of evidence	Small sample size. More detail required about coding and theme development. Applicable.

Study	McVeigh 2018,[511]
Aim	To explore the specialist and generalist palliative care provision for people with non-malignant respiratory disease.
Population	Bereaved carers
Setting	Rural and urban Northern and Republic of Ireland between 2012 and 2013.
Study design	Qualitative interview study
Methods and analysis	Convenience sample of 17 bereaved carers Face-to-face or telephone semi-structured interviews. Interviews ranged from 22-8 minutes with an average of 50 minutes. All interviews were digitally-recorded, transferred verbatim. Data were analysed adopting a thematic analysis framework. NVivo was used to manage the data and support the categorisation and of the data. Stage 1: assignment of descriptive themes to sections of the data to describe their meaning. Stage 2:descriptive themes were used to generate interpretative themes and highlight emerging patterns. Stage 3. Identification of overarching themes. .
Findings	**Lack of preparedness for death.** Barriers identified included the unpredictable nature of non-malignant respiratory disease and lack of knowledge about prognosis.

Study	McVeigh 2018,[511]
	Availability of services. Barriers identified included lack of availability to services (Republic of Ireland not Northern Ireland) and late introduction of the services.
	Role Ambiguity:lack of clarity around the role of the caregiver and the input into conversations and decision making about care.
Limitations and applicability of evidence	Small sample size. Little information on potential bias of researcher. Applicable.

Study	Mason 2013[502]
Aim	To report the experiences and perceptions of people with advanced multi-morbidity to inform improvements in palliative and end-of-life care.
Population	Patients and their carers using established UK clinical guidelines for the identification of people anticipated to be in their last year of life. 42 interviews with patients alone, two with carers alone and 43 as joint interviews. Participants completed one (8), two (10) or three (19) interviews. Within 9 months 11 (30%) had died. N=37 patient and N=17 carers. Age (range): 76 (55-92); males: 23, females: 14; multiple conditions: heart, respiratory, liver and renal failure, lung cancer, neurological conditions and mild dementia.
Setting	An acute admissions unit in a Scottish regional hospital; a large English general practice and a London respiratory outpatient clinic.
Study design	Qualitative study.
Methods and analysis	Semi-structured serial interviews with patients and case-linked family carers at 8-12 weekly intervals, using a multi-perspective approach. Patients were interviewed in their own homes and invited to talk about their understanding of their health conditions and their experiences of receiving care from different care providers and settings. Each patient was followed for 5-9 months. The interviews were audio-recorded, transcribed and imported into NVivo software for analysis. Data from each setting was analysed separately. A constructivist approach was taken and thematic analysis chosen because of its utility in comparing data from divergent sources. Cross-case analysis was then conducted to produce an integrated understanding of themes across settings and in different contexts. Interpretive analysis of the subgroup with multi-morbidity explored themes pertaining to experiences and understanding of living with deteriorating health due to multiple conditions.
Findings	Experiences of care: multiple services: as might be expected, the patient and carer experiences reflected a continuing struggle to cope with multiple care systems, services and staff. At the same time, they tried to maintain a semblance of normality amidst growing feelings of dependency. Participants gave accounts of complicated, confusing and sometimes unresponsive services. Lack of care

Study	Mason 2013[502]
	coordination and continuity among the numerous service providers led to perceptions of inconsistent and impersonal care. No diagnostic label and little explanatory language to describe their health problems made requesting appointments or a GP visit difficult. Attending clinics was physically demanding and these often failed to address complex, on-going problems Many patients took more than 10 different medicines daily. Frequent medication changes, usually associated with hospital admissions, led to doubts about their purpose and efficacy. Carers had to deal with the increasing physical and emotional demands of caring, oversee multiple medications, and do all this with little indication of how long it might last. Patients without a family carer struggled to manage everything by themselves.
	Understanding of deteriorating health due to multiple conditions: patients and carers drew on their experiences of the healthcare system, their beliefs about illness and accounts from friends, family and the media to try to make sense of their health problems and treatments. The most common interpretation was that the various conditions suffered by the patient were inevitable effects of aging. This understanding of deteriorating health as 'old but not ill' was used to rationalise perceived failings of the healthcare system. Some suggested that their care was poorer because they were 'older,' leading to complaints about inequity. Beliefs about just being old meant that these people generally focused on living as well as possible in the present. They avoided planning ahead and only sought help if they were very ill or unable to cope. Not depending on services was seen as a way to preserve autonomy, and being a carer was a responsibility to be accepted and not questioned. There was little evidence of integrated care planning or any open discussions about the future between patients, family carers and health professionals. Talking about planning ahead or deteriorating was viewed negatively by some people who had no experiences of doing so. Patients and carers were often unaware of the patient's risk of dying. When a crisis or death did occur, it often felt unexpected, even if the GP had hinted that it could happen at any time. None of the participants showed any understanding of the potential benefits of planning ahead to optimise quality of life and death. Deteriorating health due to multiple illnesses was interpreted as 'getting old' so palliative care, which was largely associated with managing imminent death, had no role to play.
Limitations and applicability of evidence	Little information on potential bias of researcher. No details about interview guide. No details of data saturation. More details needed on development of themes and opposing viewpoints. Applicable.

Study	Metzger 2013[554]
Aim	To describe patients with HF and their family members' experiences with, and perceptions of, inpatient PC consultations.
Population	Participants were English-speaking adults with a primary diagnosis of HF, who were referred to the inpatient palliative care consultation service for goals of care discussions. Family members were required to be English-speaking adults, and identified by the patient participant as being involved in either the planning or delivery of his/her care. N=40; N=24 patients with late-stage HF and/or N=16 designated family members. Age mean (range): 70 years (26-93 years); male: 62.5%, female: 37.5%); Race: Caucasian: 83%, African American: 17%. PC performance score (scale 0-100): median: 50-60, range

Study	Metzger 2013[554]
	20-70. All of the patient participants fit the criteria for NYHA Stage III or IV HF or ACC/AHA HF Class C or D. Most had multiple comorbidities and had been hospitalised more than once in the previous years.
Setting	Participants over a 9 month period from the inpatient palliative care consultation service of a 750 bed tertiary academic medical centre in upstate New York. The medical centre features inpatient and outpatient HF services, and is a designated hea3rt transplant centre.
Study design	Qualitative descriptive research design.
Methods and analysis	In-depth semi-structured interviews conducted by a single researcher using interview guides. Interviews were digitally recorded, transcribed verbatim by and entered into ATLAS-ti, along with field notes from interviews. Qualitative content analysis used to identify themes and patterns in the data. Interview transcripts were first read to get a sense of the whole, and then coded line-by-line, using a start list of codes inductively developed from the data. As the analysis proceeded patterns and relationships, both within and across cases, were sought. Themes were then derived from this analysis.
Findings	Participants had little previous knowledge of PC and formed impressions based on their interactions with the team: 1a) The surprise consult: the majority of participants were unprepared for the PC consult. They reported having no or little previous understanding of the term palliative care, and being unaware of the existence of the PC consultation service and/or that a referral had been made. Those participants, for whom the PC consult was unanticipated, generally reacted initially with suspicion, caution, and/or scepticism. For example, one participant reported that she initially suspected that her cardiologist had enlisted the PC team to convince her to consent to the placement of an LVAD, an intervention she had previously declined. Those participants, for whom the PC consult was expected, generally welcomed it. 1b) Forming impressions: after meeting with the PC team nearly all of the participants offered definitions of PC, with many, but not all equating PC with hospice or end-of-life care. They reported that their definitions were based on information from the referring team and/or their interactions, over time, with the PC team. 1c) “they come from a different world”: when asked to compare the PC team to other hospital-based teams, participants generally emphasised the differences between them. They attributed these differences primarily to the unique style and focus of the PC team. They described clinicians from the PC services as “listening”, being “more compassionate”, “sending more time”, and having a holistic focus. 1d) Outcomes of PC: “they made it better”. Nearly all reported that working with the PC team had a positive impact on their hospital experience, feeling informed, supported and reassured. Participants’ perceptions of their relationships with the referring team providers influenced whether they viewed the overall outcome of the PC team’s involvement as additive or corrective.
	Participants described the overall role of PC as one of support 2b) working the system: the majority of participants reported that the PC team was involved in activities such as: advocating for them with other agencies or providers, facilitating complicated discharges, coordinating care, arranging and conducting family meetings, and overcoming obstacles in order to assist them in reaching their goals. One family member talks about them navigating them through the available services and getting a plan in place, which is the biggest hurdle, one patient felt they are the people that can get things done for you, with every person being custom.

Study	Metzger 2013[554]
	2c) Providing information: the majority of participants reported that the PC team conveyed information during their hospital stay. Providing information did not make the PC team unique, however, as most clinicians offer information. Rather, differences in the nature and scope of the information distinguished the PC service from other services. PC clinicians took a broader approach, discussing all available options, including the option of PC, and what to expect (prognostic information) with respect to the individual patient's situation. One family member reported during the second interview, that before meeting with the PC team, she and her family felt ill-equipped to make decisions related to her mother's care, as they were unaware of available options. Other participants also commented on the benefits of having options. 2d) Transitioning to comfort care: Several participants reported that the PC team was instrumental in facilitating a "smooth" or "easy" transfer from aggressive, disease treatment-driven care to comfort care.
	Participants had a sense of prognosis which directed treatment goals: all of the participants reported having an understanding of patient prognosis. However, in only half of the cases were the participants' understanding of patient prognosis in agreement with their understanding of the clinician's prognosis. Where there was agreement participants discussed changes over time in their patient care goals based on a shared or agreed understanding of prognosis. With one exception, they all redirected to a comfort care approach. In the discordant cases, none of the participants demonstrated changes in goals over time, and all pursued a plan of care that reflected their own understanding of prognosis, which was always more optimistic than that of the clinicians.
	The conflation of PC and hospice was a barrier to PC in HF care: Although participants were not asked about hospice in HF care many announced that hospice would not work for them. When asked about the reasons that hospice was not an option for them the participants discussed their understanding of the "rules" of hospice. They explained that these rules were "deal-breakers" for HF patients primarily because they hindered aggressive management of their HF symptoms. For example not controlling symptoms the same as before. Many felt PC is synonymous with hospice care. In those cases the majority of participants predicted that PC would have no place in their current plan of care. Several suggested however, that PC might play a role "down the road" if the current treatment plan failed and/or their disease became "really fatal". For those show did not define PC as hospice or strictly end-of-life care, continued PC involvement was welcomed, even if participants predicted hospice would not be an option.
Limitations and applicability of evidence	Little information on potential bias of researcher. No details of transferability to other settings and limitations of the study. Applicable.

Study	Murray 2002[582]
Aim	To compare the illness trajectories, needs, and service use of patients with cancer and those with advanced non-malignant disease.
Population	Outpatients with newly diagnosed advanced inoperable lung cancer or with cardiac failure (New York Heart Association grade IV). 59 patients consented in outline to participate. The average age of the 20 patients with lung cancer was 65 years, 15 lived with their spouse, 12 had non-small cell lung cancer, 17 were offered and 16 received chemotherapy or radiotherapy, and five were alive at the

Study	Murray 2002[582]
	end of the study. The average age of the 20 patients with cardiac failure was 74 years, the commonest cause was ischaemic heart disease, 11 lived with a carer, and seven were alive at the end of the study.
Setting	UK. Interviews conducted in patients' home.
Study design	Qualitative interview study
Methods and analysis	Nominal group technique; face-to-face interviews. In depth interviews at three monthly intervals for up to a year with patients and their main informal carer in the patient's home. Patients were asked to talk about the main issues they were facing and their views about the care and support they were receiving. At 8-12 weeks after any bereavement we interviewed carers, if appropriate, the general practitioner, and other key professionals. A focus group for each diagnostic group allowed key health and social care professionals, a chaplain, patients, informal carers, and voluntary sector representatives to discuss the issues raised by the interviews and consider alternative service options. Interviews and focus groups were tape recorded and transcribed (with field notes). Analysis was ongoing throughout the fieldwork to allow emergent themes to be fed back into the data collection. These themes and the research questions formed the basis of the coding strategy. The qualitative computer package QSR NVivo and the techniques of narrative analysis were used. A second researcher (AW) read all the transcripts and assisted with coding. Regular review and discussion of the evolving themes by the multiprofessional steering group and data from the focus groups contributed to data synthesis and interpretation.
Findings	Information and understanding of illness and prognosis: Many appreciated honesty, although a few patients, carers, and professionals colluded to avoid issues related to dying. Treatment options were discussed but most patients thought they should accept the professionals' recommendations. "As I say, these people are the experts and, you've got to, if you don't abide by what they tell you, its your fault then". Most patients and carers did not feel involved in decision making or empowered to work in partnership with professionals. "I wouldn't say that I take much part in the decision making really. It just happens. They decide and that's that"
	Service provision: There was some misunderstanding among patients, carers, and professionals about the roles of different professionals and agencies, which resulted in failure to access help.
Limitations and applicability of evidence	Little information on population details. Little information on potential bias of researcher. No examples of the interview guide. More details on analysis and how themes developed required. Applicable.

Study	Murray 2016[580]
Aim	To investigate caregiver perspectives on the acceptability and impact of advance care planning, documented in a letter format, for patients with motor neuron disease and their caregivers.

Study	Murray 2016[580]
Population	Former caregivers of deceased patients with motor neuron disease who had been referred to a multiprofessional MND service coordinated by a hospital specialising in palliative care and rehabilitation. 10 patients had created a disease-specific advanced directive, 'Letter of Future Care', and 8 had not. Those who had not entered the service just before the LFC was introduced or who for administrative reasons had not been offered the LFC. N=18
Setting	Multidisciplinary MND service
Study design	Qualitative cross-sectional study.
Methods and analysis	Semi-structured individual interviews conducted by a nurse with expertise in qualitative research methods, who was independent of the care team. The interviewer guided discussion concerning the quality of end-of-life decision-making experienced, whether the LFC was or would be helpful, limitations of the letter and how the letter or ACP process could be improved. Sample letters were shown to participants during interviews to facilitate recall of the LFC or enable hypothetical discussions to occur for those not familiar with the LFC. Interviews were audio-taped and transcribed verbatim. A narrative approach was used to synthesise data, capturing the essence of individual and collective 'stories'. 8 transcripts were read and manually coded by 2 researchers, through a unified coding scheme. Any discrepancies in thematic coding were discussed between researchers, until consensus was reached. A single researcher coded remaining transcripts, in consultation with another researcher.
Findings	Readiness for death: Acceptance: documentation of patients' wishes (ACP) was easier for patients and caregivers who accepted encroaching death. For example, one patient, who had witnessed her sister die from MND, was eager to make her wishes known. In some cases, acceptance appeared to precede LFC completions. Another participant surmised that it could be difficult for some patients if they are not facing reality that they will die. Some patients wished to maintain hope for as long as possible. Several participants thought that if initiated too soon, completing the LFC might be too confronting, emotional, conflictual and would diminish hope. Facilitating acceptance: some caregivers felt that documenting wishes enabled patients to 'let go'. Despite several participants' accounts of the LFC's facilitative role, opening family communication, allowing patients to 'let go', confronting the inevitable and disallowing avoidance, others felt that the letter was unimportant or unnecessary. Some patients had already accepted death and knew their wishes.
	Empowerment: Patient autonomy and security: many caregivers felt that the LFC gave, or would have given, patients' autonomy, feelings of control and courage to say what they wanted. One patient without a LFC, received a percutaneous endoscopic gastrostomy (PEG) tube although it may have been contrary to her wishes. The patients' sister described the staff as pursing this option insistently and believed that her sister agreed only to 'keep the peace'; she though a LFC may have helped her sister refuse the unwanted PEG tube. LFC completion engendered feelings of security in some patients, who were comforted by the knowledge their wishes would be respected. Caregiver preparation, negotiation and diminished regret: some caregivers thought the letter did, or would, help them feel prepared and know what to do.

Study	Murray 2016[580]
	Caregivers also described how the LFC helped them negotiate with the rest of the family. Many participants indicated that documented wishes did, or would, reduce decisional burden and help caregivers avoid regret. Informing staff: the LFC was deemed important for informing staff of patients' wishes. If staff were well informed, better outcomes were anticipated for everyone.
	Connections: Family discussion and agreement: several participants found the LFC assisted by opening family communication. The LFC generated meaningful discussion and facilitated agreement in several families Connection with others: in some cases, the LFC encouraged connections beyond the immediate family. Some caregivers felt strengthened by connections the letters seemed to cultivate.
	Clarifying decisions and choices: QoL and technology: preparing the LFC clarified for some patients and families the importance of weighing up QoL versus length of life. Some caregivers spoke of intrusiveness of medical technology and how it compromised patient comfort.
	Decisional roles: with regard to end-of—life decision-making and the preparation of the LFC, decisional roles were sometimes connected with previous roles assumed by the couple. Some caregivers advised that the LFC facilitated decision-making through input from expert and sensitive staff.
Limitations and applicability of evidence	No examples of interview guide. More details required on development of themes. Applicable.

Study	Phipps 2003[643]
Aim	To investigate differences in attitudes, preference, and behaviours regarding end of life in terminally ill patients and their designated family caregivers.
Population	African-American and white patients with stage III-B or IV colon cancer and their designated family caregivers. N=68
Setting	USA. Patients identified from: the Albert Einstein Cancer Centre office schedule, from the tumour registry, from the Cancer Centre Hospice program, and from Oncologists and other physicians.
Study design	Qualitative interview study
Methods and analysis	Qualitative analysis of responses to open-ended questions was undertaken to elucidate the reasons why people did or did not engage in actions related to advance care planning. As part of the interview, patients were asked whether they had discussed their preferences regarding the use of life-sustaining interventions with others. Open-ended follow up questions were then asked on the basis of their responses.

Study	Phipps 2003[643]
	Transcripts of the audiotaped interviews were processed for coding and analysis using Atlas-ti, a software package for computer-assisted qualitative data analysis. Reliability of codes was established using Kappa to measure inter-rater reliability. Systematic coding of all transcripts enabled the research team to categorise reasons that patients and caregivers cited in response to their answers to discrete questions such as “Do you have a living will?” and “can you tell me why you have one (or why not)?” Reasons cited in this report are the coding categories and are not study participants actual words, except where noted.
Findings	Reasons for living will/proxy directives: To exercise control over the future and to avoid confusion about treatment preferences. Other less commonly cited reasons were past or personal experience (with a terminal illness) and to protect or shield loved ones (from having to make difficult treatment decisions.
	Reasons for not having a living will or proxy directives: “no one has brought it up to me” or “it hasn’t come up”, indicating patients saw the initiative as coming from outside of themselves (external locus of control). Other reasons cited included the belief that formal documentation was not needed until they were near the end, concerns about emotional distress for either patient or family in discussing the topic of the patients illness and treatment preferences; and assumption that the patients family would know his/her treatment preferences without the need for formal documentation.
Limitations and applicability of evidence	Little information on potential bias of researcher. More details required about theme development. Themes not refined. Applicable.

Study	Piamjariyakul 2014[649]
Aim	To explore end-of-life preferences and determine the presence of signed end-of-life advanced directives.
Population	Patients with severe chronic cardiovascular illness (i.e. three-vessel coronary artery disease, end stage HF, malignant hypertension, and repeated bouts of atrial fibrillation); many of who also had renal failure and diabetes mellitus. N=30, mean aged decade=70 years.
Setting	USA. Interviews took place in participants’ homes.
Study design	Qualitative interview study
Methods and analysis	Semi-structured face-to-face interview with thematic qualitative analysis. The study took place in the patients’ home using open-ended questions. Patients were first asked about their decisions to have nursing care for their severe chronic cardiovascular illness at home. At the close of discussion, the interviewer was trained to state: “Now we would like to talk with you about some sensitive issues in a person’s last days”. Patients were then asked a) “Do you have a signed off

Study	Piamjariyakul 2014[649]
	end-of-life advance directive or a living will?"; b) "How did you obtain the end of life advance directive or living will information?" and c) "With whom did you discuss the end-of-life car and the types of care you would like to receive during the last days and minutes of your life?". Each interview lasted 30-45 minutes. Content analysis was used to summarise patients' responses into themes. Interviews were reviewed separately by two experienced nurse researchers (who did not provide clinical care to participants) who identified responses into single content units. These two nurses independently categorised the interview data units by topics according to terms found within the patients words and phrases. Then the two nurses compared their content units and the terms identified across all patients interview data. The nurses' discussion of their coding led to agreement about categorising these responses into five themes.
Findings	Presence of signed off advance directive or a living will: 50% of patients had signed standard advance directives as requested on entry of care home, remaining 50% had no written directive or living will. Patients expressed reasons for not completing an advance directing: "I never thought about this [end of life plan]", "I'm too sick now, I can't think about anything". It was also noted that Hispanic participants feared a risk of deportation if any form were completed or document signed.
Limitations and applicability of evidence	Little information on potential bias of researcher. No details of transcribing. Lack of data to support themes and themes could be more refined. Not a lot of details of transferability to other settings and limitations not discussed Applicable.

Study	Romo 2017[701]
Aim	To explore how older adults in the community with a limited life expectancy make healthcare decisions and the processes used when they are not in an acute crisis.
Population	Community-dwelling adults aged 67 to 98 with a life expectancy of less than 1 year.
Setting	USA: Medical programs and geriatrics clinics at the University of California, San Francisco, and the San Francisco Veterans Affairs Medical Center.
Study design	Qualitative cross-sectional study.
Methods and analysis	Interviews were audio recorded and professionally transcribed verbatim. The interview guide was developed to elicit the participants experience with decision making and explore the underlying process. Analysis was done through the iterative process of constant comparative analysis. Open coding was undertaken to label distinct concepts in the data, and focused and axial coding were used to relate concepts across the data and group them into meaningful categories. To assess the face validity of the emerging themes, interim findings were presented to independent professionals with expertise in aging, medicine, nursing, social work, and sociology. Data analysis continued until the data revealed no new themes or concepts that furthered the analysis or understanding of the phenomenon.

Study	Romo 2017[701]
Findings	Burden of decision making: Participants acknowledged that they were delegating decisions to others while also noting that they did not discuss their preferences with others. Participants relied on family because they believed family would make appropriate choices and alleviate burden of deciding.
	Avoidance: Some participants would actively avoid thoughts of declining health and end-of-life decisions.
	Trust: Lack of trust diminished participant's sense of control and placed social and emotional burdens on participants. In contrast, strong trust provided a sense of control and served as a resource for participants during acute illness.
	Communication: Direct communication involved making clear statements about priorities and goals to guide delegates; allowing participants to maintain a sense of control.
	Demands: Healthcare decisions created ambiguity that needed to be resolved. Health status increased complexity of decisions, particularly during acute episodes when providers were unknown to them.
Limitations and applicability of evidence	Applicable.

Study	Selman 2017[736]
Aim	To explore challenges to and facilitators of empowerment among older people with advanced disease in hospital, and the impact of palliative care.
Population	Older people (aged >65) with an advanced disease receiving specialist palliative care, who had been hospitalised for >24 hours and their carers.
Setting	UK/USA: Six urban hospitals (three in England, two in Ireland, and one in USA)
Study design	Qualitative cross-sectional study.
Methods and analysis	Interviews were face-to-face, audio recorded and professionally transcribed verbatim. Patients and caregivers were interviewed separately. Interview transcripts and field data were imported into NVivo v10.0. Direct thematic analysis was used. Analysis occurred over four stages: (1) analysis by site with line by line coding; (2) narrative summaries were produced for each data set and tabulated alongside themes; (3) integration of site-level findings where country level findings were compared and synthesised; (4) A cross-site narrative summary to draw out main findings.
Findings	Communication/information: Clinicians inadequate communication skills and deprioritisation of relational care hinder patients self-management, At all sites a lack of information from staff and poor communication with staff, particularly regarding end of life issues, prevented patients from taking a more active role in managing their disease and treatment, making decisions and planning for the future.

Study	Selman 2017[736]
	Environment: Busy routinised inpatient care restricted patients' choice and control. Patients and families noted a lack of power and choice at discharge. Continuous, flexible care provided patients with choice and facilitated communication. Strategies such as staff rostering and having a key contact person appeared to reduce fragmentation of care.
	Holistic care: Patient centred, holistic approach empowered patients by putting their perspectives, wishes and needs in relation to decision-making and information provision at the heart of care.
Limitations and applicability of evidence	Unclear if saturation was reached. Applicable.

Study	Simpson 2011[752]
Aim	To observe what is required for meaningful, acceptable ACP in the context of advance care planning.
Population	Eight families (eight patients with a primary diagnosis of COPD in an advanced stage according to CTS severity criteria and seven informal caregivers (person most involved with his/her supportive care)) were recruited by a physician or registered respiratory therapist.
Setting	Canada. Sessions took place in the patients house.
Study design	Qualitative interview study
Methods and analysis	Semi-structured face-to-face interview with thematic qualitative analysis. The study employed interpretive description, a qualitative research methodology developed by nursing professionals seeking the understand gaps in and improve clinical practice. Sessions were loosely structured according to a conversation guide. Each family was provided with a copy of the local health districts brochure entitled 'Patient and Family Education Document, March 2007: Let's Talk About Advance Directives', which also provided an advance directive template. The study included two visits with each family concluding with a request for participant feedback on experience as a way to assess acceptability and meaningfulness of the process for participants. Study sessions were digitally recorded, transcribed verbatim, and resulting data entered into Atlas.ti 5.6, a qualitative software program to aid analysis. While data analysis was not complete, it entails processes of identification and coding of concepts, patterns, and related themes, grouping of themes into thematic networks, interpretation of relationships between and among themes, and consideration of the implications of these findings with respect to the study question as relevant to the particular clinical context of ACP in advanced COPD.

Study	Simpson 2011[752]
Findings	Knowledge: The brochure and advance directive template facilitated family and patient learning more about end-of-life care options. Some families had already thought about end of life care, but were grateful to hear about and clarify the patients' end-of-life care preferences and reasons behind them.
	Countering silence around the subject: Study dialogue enabled increased awareness of patient illness-related social deprivation, fear, and end-of-life care preferences, subjects they had been unable to discuss before. "He doesn't like to talk to me about stuff because he thinks he is stressing me out". Families spoke about a patients' silence, a stance embraced prior to the study sessions. One patients purposefully avoided thinking or talking about death or dying because she was terrified about dying.
	Talking with an interested clinician: Some patients felt isolated by anxiety, and took the opportunity of the study to talk about their concerns, especially loneliness and fear.
Limitations and applicability of evidence	No details of data saturation. Methods for identifying or extrapolating themes required more details. Not a lot of details of transferability to other settings and limitations not discussed. Applicable.

Study	Spruyt 1999[771]
Aim	To describe the palliative care experience of Bangladeshi patients and carers in the Tower Hamlets area in the east of London.
Population	The bereaved carers of Bangladeshi patients under the community team between 1986 and 1993. N=18
Setting	UK. Tower Hamlets.
Study design	Qualitative interview study
Methods and analysis	Face-to-face semi-structured interviews. Patients were identified by review of all admissions to the team between 1986 and 1993. Case notes were reviewed for demographic data, evidence of communication difficulties, intensity of input of care and any special areas of concern. An introductory letter written in Bengali and English was sent to all carers traced. The interviews were conducted in Sylheti, using a semi-structured questionnaire designed for the study. Interviews were manually recorded at the time of the interview. The interviewer met frequently with the researcher for discussion of each interview, at which time additional information was appended.
Findings	Communication/language: Few patients were fluent in spoken English and fewer were literate in English. The one female patient and one female carer who were literate in English were both less than 30 years old. There was reliance on family members, and particularly on children, to interpret for health professionals. Poor communication as a problem in 16 cases. "Although I was the main carer, I was kept in the dark and not involved in any decision-making until my husband died". Two of the three carers who had a professional interpreter felt that it had been helpful.

Study	Spruyt 1999[771]
Limitations and applicability of evidence	Little information on role of researcher, data collection and analysis. Applicable.

Study	Walczak 2013[831]
Aim	To explore patients' perspectives across two cultures (Australia and USA) regarding communication about prognosis and end-of-life care issues and to consider the ways in which these discussions can be optimised.
Population	English-speaking adult patients with advanced, incurable cancer assessed by their oncologist as having life expectancy of less than 12 months. N=15 Australian and N=19 US patients. Australian demographics: age (mean (range)): 67.6 (54-86); male: 12(80%), female: 3 (20%). US demographics: age (mean (range)): 58 (34-75); male: 6 (31.6%), female 13 (68.4%).
Setting	Oncology treatment centres in Australia(2) and USA (1).
Study design	Qualitative study
Methods and analysis	N=15 Australian and N=11 US patients completed individual semi-structured interviews. A further N=8 US patients participated in a focus group. Participants were offered the option of participating in a focus group or completing an individual interview. Research assistants trained in qualitative methods conducted the individual semi-structured interviews and one US focus group. Sampling was discontinued when information redundancy was reached, and no additional information was forthcoming after three consecutive interviews. Interviews and focus groups were recorded and transcribed verbatim, and interpreted using thematic text analysis with an inductive, data-driven approach. Interview and focus group questions were designed by an expert advisory group comprising oncologists, palliative care physicians, psychologists, nurses, and a health services researcher. Participants were asked about their experiences of communicating about prognosis and end-of-life care issues, barriers and facilitators of such discussions and their views about how these discussions could be optimised. The research team reviewed and interpreted the data using NVvivo 7. The researchers read all the transcripts and four researchers independently developed codes to represent the meanings of the text. They met regularly to compared codes and achieve consensus about a code names and definitions. Recurrent themes were established along with illustrative examples. Comparison was made between coded Australian and US transcripts and identified recurrent themes to discern points of commonality and divergence between the two groups.
Findings	Readiness for discussions about prognosis and end-of-life issues: prior to a discussion of prognosis and end-of-life issues, participants felt that both the doctor and patient needed to be ready for the discussion. For the patient, this means that the desire to know the facts overrides any fear or ambivalence about discussing these issues. For the doctor, this means feeling comfortable, confident and able to

Study	**Walczak 2013[831]**
	discuss these issues, and clear that the patient desires this information. Readiness was felt to be necessary for discussions to achieve the best possible outcomes with the least discomfort.
	Adjustment and acceptance: a key precursor to patients achieving a sense of readiness to discuss prognosis and end-of-life issues was adjustment and acceptance. This involved being able to acknowledge their impending death while still maintaining realistic hope and a good quality-of-life. It also involved being able to accept the uncertainty inherent in their life expectancy, symptoms and general disease trajectory. -Some patients described continuing aggressive treatment to satisfy the wishes of family despite wanting to focus on comfort care. It subsequently appeared that patients and families were constantly influencing each other as they waxed and waned in acceptance and readiness. If the family accepted the status of the patient's illness and supported the patient's choices it was easier for the patient to accept their illness and make appropriate choices. Age also emerged as a promoting factor. Older patients surmised that adjusting to a life limiting illness would be more challenging for younger patients and that because they themselves had a long and full life, they could better accept the prospect of dying. -Having sufficient time to adjust to the disease enabled acceptance and readiness. Patients who had recently been diagnosed or who had only recently been told that their cancer was incurable seemed more ambivalent about discussing prognosis and end-of-life issues. None expressly stated that they were unwilling to ever discuss prognosis and end-of-life care issues, but some wanted to delay these discussions. - Having religious or spiritual faith also seemed to promote adjustment and acceptance, as did life experience that exposed the patient to death or fostered a pragmatic approach to situations beyond their control. -Exposure to the symptoms and physical evidence of their disease was also seen to promote adjustment and acceptance. While feeling well, the concept of death and dying seemed unreal and unbelievable to both patients and families. Seeing scans of the cancer growing in their bodies also promoted acceptance of the reality of their situation. Past experience of cancer or life threatening illness also promoted adjustment and acceptance as it gave the patient a point of reference against which to judge and normalise their current experiences. Past experiences could be patients' own or those of individuals close to them. Salient experiences such as a friend or relatives' poor quality of death due to inappropriate medical interventions acted to motivate the patient to accept their situation and discuss end-of-life care. -Mental space was also necessary for patient to engage in end-of-life discussions. Those struggling with depression or uncontrolled pain or symptoms found it difficult to focus on anything but their physical or mental suffering. A positive mood, control of pain and symptoms and an absence of unfinished business allowed patients the mental space necessary to adjust to and accept the realities of their condition.
	Skills, understandings and relationship elements: patients and health professional communication skills emerged as an important factor in creating the conditions for discussion of prognosis and end-of-life issues and in the discussions themselves. Patients felt that they needed to be open and assertive and communicate their needs, persist if the information or outcomes they desired were not forthcoming and cooperate with their doctor to facilitate discussions and goal setting. Patients' sense of self-efficacy and comfort in asking questions and communicating with their doctor also appeared to be helpful. Patients also identified important doctor skills in this context. These included maintaining a calm and open manner in all contact with the patient, treating the patient as an individual and

Study	Walczak 2013[831]
	being sensitive to their individual needs. Participants also indicate that control of discussion should be actively given to the patient, but that the doctor should also take the initiative to raise complex or difficult topics such as prognosis and end-of-life issues. In discussing these issues and responding to patients' questions, participants felt that doctors should be honest, acknowledge and explain uncertainty where it exists, and relate the stories of other patients to foster hope and illustrate uncertainty. -Also contributing to adjustment and acceptance was a good doctor/patient relationship that was characterised by patients as a feeling of comfort and trust in their doctor. It was also noted that continuity in this relationship was important. The doctor skills highlighted above were seen to contribute to this relationship. -A clear and explicit agreement and permission from both parties to discuss these complex and difficult topics was highlighted as an important step towards readiness to discuss end-of-life issues. Patients recognised that not only was it important for the doctor to invite discussion of prognosis and end-of-life issues, but also that the patient needed to give their doctor permission to raise these issues aswell.
	Outcome themes: a proximal outcome of these discussions was for patients to achieve some sense of control over their situation. This equated to getting the necessary facts about the illness and developing a consensus plan for future care with all involved parties including the patient, doctor and the patient's significant others. Patients felt there was considerable comfort in knowing that their wishes would be respected. A secondary outcomes of these discussions was a sense of being able to move on. Having discussed these issues and achieved some sense of control, participants valued maintaining a sense of normality in their everyday lives and a restoration or affirmation of their identity as a whole person rather than merely as a dying patient. This in turn enabled them to 'let go' of unrealistic expectations for future outcomes and embrace the idea of enjoying a good quality-of-life for however much time might remain to them.
	Participant group differences: the themes identified appeared to apply equally to Australian and US patients with both groups presenting similar perspectives on optimising discussions of prognosis and end-of-life issues. Differences did, however, emerge in the attitudes Australian and US patients displayed towards these discussion. US patients displayed a more sceptical attitude than Australian patients towards discussions of these issues, often questioning the accuracy or worth of such information and suggesting that their doctors would avoid discussing negative issues. Where Australian patients mostly spoke of their relationship with their doctor in a personal and positive way, US patients spoke about their doctor in a more detached and neutral way, perhaps indicating differences in the doctor/patient relationship between the two cultures.
Limitations and applicability of evidence	No details of the potential bias of researcher. No details of data saturation or opposing views in the data. Applicable.

Study	Walczak 2015[832]
Aim	To explore responses to a nurse-led CSP, incorporating a question prompt list (booklet of questions patients/caregivers can ask clinicians), promoting life expectancy and EOL-care discussions.

Study	Walczak 2015[832]
Population	English-speaking adult oncology patients with advanced, incurable heterogeneous cancer diagnoses and an oncologist-assessed 2-12 month life expectancy (n=31) and their English-speaking adult primary informal caregivers gave informed consent for participation (n=11). Consecutive patients and caregivers were identified by oncologists at six treatment centres in Sydney, Australia, were informed that the study was evaluating strategies to help with the difficult discussions and decisions they may face in the future and were recruited by research assistants.
Setting	Australia. Consecutive patients and caregivers were identified by oncologists at six treatment centres in Sydney.
Study design	Qualitative interview study
Methods and analysis	Audio-recording of community support programme (CSP) sessions, with thematic analysis. The communication support program (CSP) was informed by the self-determination theory of health-related behaviour change, and aimed to increase 'autonomous motivation' to discuss prognosis/EOL-care preferences and 'competence' to undertake such discussions. Two nurses were trained to deliver the intervention, consisting of 1) a face-to-face meeting and 2) a follow-up phone call. Patients (and their participating caregiver) attended a 60-90 minute face-to-face meeting at their treatment centre approximately 1 week before a follow-up oncology consultation. Nurses established rapport and introduced a previously developed and piloted QPL for patients with advanced, incurable cancer and their caregivers. It included questions regarding prognosis, treatment options/decisions, palliative care, lifestyle, patient/family support, ACP and caregiver-specific issues. The QPL was explored in depth, focussing on prognosis/EOL-care content, and participants were encouraged to choose questions for their next consultation. This analysis examined responses to the QPL and life expectancy and ACP content during the face-to-face meeting. The research team reviewed and interpreted the data using thematic text analysis with an inductive, data-driven approach, managed with NVivo. Transcripts were explored with respect to patient/caregiver responses to: 1) the QPL in general, 2) prompting to discuss life expectancy and 3) prompting to discuss ACP. Ten transcripts were initially analysed by two researchers (AW and IH) to form a preliminary code tree, which was applied to 6 further transcripts to refine codes and establish agreement. Remaining transcripts were individually coded. Through iterative reading, recurrent themes and illustrative examples were established. Successive rounds of discussion and resolution of code names/definitions and themes and review of coding procedures by investigators not directly involved in developing the coding framework ensured methodological rigor.
Findings	Readiness to discuss EOL-issues: appeared influenced by 1) appropriate timing and 2) personal coping style. Some participants stated they coped with illness by being realistic and not avoiding what was to come. Such participants were more likely to be ready for discussions and respond positively to the QPL. Others maintained that whilst discussing EOL issues may be worthwhile in principle, it was too early to consider them in their present circumstances.
	Realism and non-avoidance: "when it came down to that point and he said, "Do you really want to know and how much do you want to know?" He said, "Is there a point that you want me to hold back? Do you want the soft or the hard version? …it's always going to be hard but how do you want it?"… "I want every bit of information you can give me and as detailed as possible." I mean there's no point pussy footing around."

Study	Walczak 2015[832]
	Avoiding negative outcomes: Some indicated that they coped by consciously choosing to live day-by-day and focus on positive information rather than considering negative future outcomes. “I don’t think I’m going to die that quick… I’m not thinking I’m going to live a hundred years, I’m thinking I still have time really… You have to die one day, nobody can live forever [but] I feel better if I’m not thinking about it”
Limitations and applicability of evidence	Little information on population details. No details of potential bias of researcher. No examples of interview guide. Themes could be more refined and data presented per person rather than combined. Applicable.

Study	Whitehead 2012[848]
Aim	To gain a greater understanding of the experiences of living with MND in the final stages of the disease.
Population	A sample of 24 people with MND and 18 current and 10 bereaved family carers were recruited through a MND Care and Research Centre in Northwest England.
Setting	UK. In the community.
Study design	Qualitative interview study
Methods and analysis	Audio-recording of community support programme (CSP) sessions, with thematic analysis. A qualitative, phenomenological approach was deemed the most appropriate method. Interviews ranged from 45 minutes to two hours. A list of subjects was developed in the event that participants required a prompt. To incorporate the narratives of patients with severe speech difficulties, interviews were also conducted by email. The option to complete a personal diary (handwritten, computer typed, tape recorded or series of face-to-face interviews) was offered to patients and current carers so that their experiences of services could be documented for a period of up to one year to provide insight into how these experiences may have altered over time. Thematic analysis was considered the most suitable approach for organizing the data as a result of its highly sensitive and flexible nature. Transcription of the data was carried out and identifying information was removed. QSR Nvivo 8, a computerized data analysis tool, was used to assist the analytic process. Transcripts were read through a number of times; initial codes were identified, reviewed and revised. From these codes, overarching themes were then constructed that were considered to capture the ‘richness of the phenomenon.’ To increase rigour, the initial three transcripts were analysed first, discussed by three members of the research team and a coding frame was created that was then used to aid the formulation of themes in the remaining interviews and diary extracts. In order to ensure that the themes provided an authentic account of the individuals’ narratives, verification was obtained from some of the participants; due to the terminal and debilitating nature of the disease it was not possible to do this for all involved in the study.

Study	Whitehead 2012[848]
Findings	Information: Some participants felt there was a need for additional information to help them make decisions regarding end-of-life care. “And I would like to know how it will be managed and what my choices are”. One participant who was on non-invasive ventilation felt she was not being given enough information regarding her options. She did not feel that she was being included in decisions and this was having a detrimental effect on her self-worth “I asked about a possible trache and ventilator for the future. He said a definite ‘NO’, he wouldn’t advise it and neither would the other consultant there. The main reason was expense of care package. But what about what I want!!!! That didn’t seem to matter. He said to make a longer appointment next time to discuss it further, but that is not for another 6 months. Maybe he hopes by then I won’t be well enough to discuss it. I feel useless and as if my life isn’t even worth talking about”.
	Services at EOLC: A number of people felt that they had to cope with very little support from services. Limited general practitioner (GP) involvement and lack of continuity of care were frequently cited difficulties. Accessing supportive care was described as being extremely difficult, and for some people, it was provided at a very late stage in the disease trajectory “And right at the very end of his life, I mean this letter is dated at end of July, well he died beginning of August, they decided that he might qualify for care which would be free. They had to take it to a hearing, the district nurse had to go to a hearing, and they did a tremendous amount of work between them to get it set up. . . anyway he got it but he didn’t live long enough to get anything from it, really it should have been brought out six months before, probably more care at an earlier stage and for longer than that,. . . the continuing care came in too late”
Limitations and applicability of evidence	No details on potential bias of researcher. No details of data saturation. Transferability of findings to other settings not discussed. Applicable.

Appendix E: Health economic evidence selection

None.

Appendix F: Excluded studies

F.1 Excluded clinical studies

Table 22: Studies excluded from the qualitative review

Reference	Reason for exclusion
Aasmul 2018 [1]	No relevant outcome
Abba 2013[2]	Not relevant population
Abel 2011[3]	Inappropriate study design
Abrahamson 2016[4]	Not relevant to PICO
Adam 2000[5]	No relevant outcomes
Adam 2015[6]	Not relevant population
Addington-Hall 2005[7]	Inappropriate study design
Agnew 2008[8]	No relevant outcome
Ahluwalia 2012[9]	Not relevant population
Ahmed 2004[10]	Inappropriate study design
Ahmedzai 2004[11]	Not review population
Ahrens 2003[12]	Inappropriate study design
Albizu-Rivera 2016[13]	Inappropriate study design
Allen 2004[14]	Inappropriate study design
Allen 2011[15]	Inappropriate study design
Almuzaini 1998[16]	Inappropriate study design
Amador 2016[18]	Inappropriate study design
Amati 2014[19]	Not relevant population
Ammari 2015[20]	Inappropriate study design
Ampe 2014[21]	Inappropriate study design
Ampe 2016[22]	Inappropriate study design
Anderson 2008[23]	No relevant outcomes
Andreassen 2015[24]	Not relevant to PICO
Andrews 2011[25]	No relevant outcome
Ang 1999[27]	Inappropriate study design
Ang 2016[26]	Not relevant population
Ankuda 2017[28]	No relevant outcome
Anonymous 2015[54]	Inappropriate study design
Aoki 2017[29]	Inappropriate study design
Aoun 2005[32]	Inappropriate study design
Aoun 2015[30]	No relevant outcome
Aoun 2015[31]	No relevant outcomes

Arendts 2015[33]	Not review population
Arias Rojas 2015[34]	Inappropriate study design
Asgeirsdottir 2013[35]	No relevant outcome
Ashley 2016[36]	Inappropriate study design
Ashworth 2000[37]	Not relevant population
Asprey 2013[38]	Not relevant population
Auret 2015[39]	Inappropriate study design
Avis 1999[40]	Not relevant population
Azami-Aghdash 2015[41]	Not relevant population
Back 2005[42]	Inappropriate study design
Back 2009[43]	No relevant outcome
Bailey 2007[45]	Inappropriate study design
Bailey 2016[44]	No relevant outcomes
Bainbridge 2015[47]	Inappropriate study design
Bainbridge 2017[46]	No relevant outcome
Bakitas 2017[49]	No relevant outcomes
Balboni 2014[50]	Inappropriate study design
Barbera 2010[52]	Inappropriate study design
Barnes 2011[53]	Not relevant population
Bass 1984[55]	Inappropriate study design
Baughman 2015[56]	Inappropriate study design
Beattie 1998[57]	Not review population
Beaver 1999[58]	No relevant outcomes
Beccaro 2007[60]	Inappropriate study design
Beccaro 2010[59]	Inappropriate study design
Beck 2015[61]	Inappropriate study design
Becker 2010[62]	Not relevant population
Beernaert 2014[63]	Not relevant population
Beernaert 2015[64]	Not review population
Bekelman 2011[65]	Not relevant population
Belisomo 2017[66]	Inappropriate study design
Bergman-Evans 2008[68]	Inappropriate study design
Bernal 2007[69]	Inappropriate study design
Bertain 2015[70]	Inappropriate study design
Betz 2013[71]	Inappropriate study design
Black 2005[72]	Inappropriate study design
Black 2006[73]	Inappropriate study design
Blackwell 2017[74]	Not review population
Bodner 2015[75]	Not relevant population
Boersma 2017[76]	Not review population
Bone 2016[77]	Not review population
Boot 2014[78]	No relevant outcome
Boucher 2010[79]	No relevant outcome
Boyd 2010[80]	Not relevant population
Brackley 2009[81]	Inappropriate study design
Bradley 1997[83]	Inappropriate study design

Bradley 2010[82]	Not relevant population
Bradley 2011[84]	No relevant outcomes
Bray 2013[85]	Not relevant population
Brazil 2003[88]	Inappropriate study design
Brazil 2005[89]	Inappropriate study design
Brazil 2005[87]	Inappropriate study design
Brazil 2010[86]	No relevant outcomes
Brenner 1997[90]	Inappropriate study design
Bridge 2002[91]	No relevant outcome
Brinkman-Stoppelenburg 2014[93]	Inappropriate study design
Bristowe 2015[95]	Not relevant population
Bristowe 2015[94]	No relevant outcomes
Brooke 2014[96]	Inappropriate study design
Brooks 2016[97]	not relevant population
Broom 2012[98]	Not relevant population
Browne 2014[99]	Not relevant population
Buecken 2012[100]	Inappropriate study design
Burchardi 2005[101]	Not relevant population
Bussmann 2015[102]	No relevant outcomes
Byrne 2008[104]	Inappropriate study design
Byrne 2013[103]	Inappropriate study design
Cagle 2016[105]	Inappropriate study design
Callahan 2012[106]	Not review population
Cameron 2009[107]	Not relevant population
Candrian 2017[108]	Mixed population
Cantor 2003[109]	Inappropriate study design
Carabez 2016[110]	Not relevant population
Carduff 2014[111]	No relevant outcomes
Carey 2016[112]	Not review population
Carlsson 2007[113]	Inappropriate study design
Caron 2005[114]	No relevant outcomes
Carr 2011[115]	Inappropriate study design
Carr 2012[116]	Inappropriate study design
Carrero Planes 2016[117]	Not English Language
Cartwright 2007[119]	Inappropriate study design
Cartwright 2014[118]	Inappropriate study design
Casarett 2003[123]	Inappropriate study design
Casarett 2004[120]	Inappropriate study design
Casarett 2008[122]	Inappropriate study design
Casarett 2008[121]	Inappropriate study design
Cervantes 2017[124]	Not review population
Chambaere 2015[125]	Inappropriate study design
Chan 2000[126]	Inappropriate study design
Chandran 2016[127]	No relevant outcomes
Chang 1992[129]	Inappropriate study design
Chang 2012[128]	Not relevant population

Cherin 2000[130]	Inappropriate study design
Chiao 2015[131]	not relevant population
Chini 2010[132]	inappropriate study design
Chirgwin 2010[133]	Inappropriate study design
Chong 2015[135]	Not relevant population
Chong 2015[134]	Inappropriate study design
Ciemins 2015[136]	no relevant outcomes
Claessen 2013[137]	Inappropriate study design
Clark 2015[138]	not relevant population
Claxton-Oldfield 2014[139]	Not review population
Clayton 2005[141]	Inappropriate comparison
Clayton 2005[140]	no relevant population
Clements 2009[142]	Inappropriate study design
Cohen 2010[145]	not relevant population
Cohen 2012[144]	Inappropriate study design
Cohen-Mansfield 2003[143]	inappropriate study design
Collier 2015[147]	No relevant outcome
Collier 2016[146]	Inappropriate study design
Collins 1994[148]	inappropriate study design
Collins 1998[150]	Not relevant population
Collins 2004[149]	inappropriate study design
Collins 2011[152]	Inappropriate study design
Collins 2016[151]	Inappropriate study design
Colman 2013[153]	Inappropriate study design
Connell 2010[154]	No relevant outcome
Conner 2015[155]	No relevant outcomes
Coombs 2015[156]	Not relevant population
Cornally 2016[158]	Not review population
Cornetta 2015[159]	Inappropriate study design
Correa-Casado 2017[160]	Not English language
Cortis 2007[161]	No relevant outcomes
Cramm 2015[162]	Not relevant to PICO
Crawford 2010[163]	Not review population
Crofford 1980[164]	Unable to locate
Crooks 2009[165]	Not review population
Cruz-Oliver 2017[166]	Not relevant to PICO
Csikai 2006[167]	Inappropriate study design
Csikos 2010[169]	Not review population
Cui 2014[170]	Inappropriate study design
Currow 2008[171]	Inappropriate study design
Curtis 2000[172]	Inappropriate study design
Curtis 2004[173]	Inappropriate study design
Curtis 2005[174]	No relevant outcomes
da Silva 2012[175]	Not English language
Dahm 2008[176]	Inappropriate study design
Dalgaard 2010[177]	Not review population

Dalisay-Gallardo 2012[178]	Unable to locate
Danis 2014[179]	No relevant outcomes
Daveson 2014[180]	No relevant outcomes
Davies 2004[181]	Not relevant population
Davies 2014[182]	Not relevant population
Davison 2016[184]	Inappropriate study design
De Gendt 2013[185]	Inappropriate study design
De Graaff 2003[186]	No relevant outcome
de Graaff 2010[187]	No relevant outcome
de Graaff 2012[188]	Not relevant population
de Veer 2008[189]	Inappropriate study design
De Vleminck 2013[190]	Inappropriate study design
De Vleminck 2014[191]	Not relevant population
Deeg 2004[192]	No relevant outcome
Demiglio 2013[193]	Not relevant population
Demiris 2008[194]	Not relevant population
den Herder 2017[196]	No relevant outcome
den Herder 2018 [195]	No relevant outcome
Dening 2012[197]	No relevant outcome
Dening 2013[198]	No relevant outcomes
Denvir 2014[199]	Not relevant population
Desai 2016[200]	Not review population
Dev 2012[202]	No relevant outcomes
Dev 2013[201]	Inappropriate study design
Dickinson 2013[203]	Not relevant population
Dillon 2016[204]	Not review population
Dionne-Odom 2015[205]	Inappropriate study design
Diwan 2004[206]	Not relevant population
Docherty 2008[207]	No relevant outcomes
Donnelly 2010[208]	No relevant outcomes
Douglas 2002[209]	Inappropriate study design
Dow 2010[210]	Inappropriate study design
Drach 2004[806]	Inappropriate study design
Dube 2017[211]	Not review population
Duffy 2006[212]	Inappropriate study design
Duggleby 2017[213]	Not relevant outcomes
Dulko 2013[214]	Inappropriate study design
Dumanovsky 2015[215]	Inappropriate study design
Dunn 1996[216]	Not relevant population
Dyche 2003[217]	Not review population
Early 2000[218]	Inappropriate study design
Easterbrook 2005[219]	Not review population
Edwards 2012[220]	No relevant outcomes
Ehrlich 2012[221]	Not review population
Ekberg 2014[222]	Not relevant population
Elkington 2004[224]	No relevant outcome

Ellis 2015[225]	No relevant outcomes
Ellison 2002[226]	Inappropriate study design
Elpern 1993[227]	Inappropriate study design
Emanuel 1999[228]	Inappropriate study design
Emanuel 2000[229]	Inappropriate study design
Emlet 1993[230]	Inappropriate study design
Endacott 2016[231]	Not review population
Enguidanos 2017[232]	Inappropriate study design
Erel 2017[235]	Not review PICO
Erlen 2005[236]	Inappropriate study design
Esteves 2015[237]	No relevant outcome
Evans 2006[238]	No relevant outcomes
Ewing 2009[241]	Not relevant population
Ewing 2016[239]	Inappropriate study design
Ewing 2016[240]	Not review population
Exley 2005[243]	No relevant outcome
Exley 2005[242]	No relevant outcome
Fairbrother 2014[244]	No relevant outcomes
Fakhoury 1996[245]	Inappropriate study design
Farber 2003[246]	No relevant outcomes
Faull 2014[247]	No relevant outcome
Feeg 2005[248]	Inappropriate study design
Fetherstonhaugh 2017[249]	Not review population
Field 1998[250]	No relevant outcome
Finkelstein 2015[251]	Inappropriate study design
Fishman 2009[252]	Inappropriate study design
Fitzsimons 2007[253]	No relevant outcome
Flock 2011[254]	Inappropriate study design
Flynn 2009[255]	Not review population
Foebel 2012[256]	Inappropriate study design
Formiga 2004[257]	Inappropriate study design
Fosse 2014[258]	Not enough study details
Foti 2005[259]	Inappropriate study design
Frey 2013[260]	Not relevant population
Frey 2014[261]	Not relevant population
Freytag 2017[262]	Not review population
Fridriksdottir 2006[263]	Inappropriate study design
Fried 2009[264]	Not relevant population
Froggatt 2006[265]	Inappropriate study design
Frost 2011[266]	Inappropriate study design
Funk 2009[267]	no relevant outcomes
Gardiner 2013[268]	Not relevant population
Garland 1984[269]	Inappropriate study design
Garner 2013[270]	Not relevant population
Garrouste-Orgeas 2010[271]	inappropriate study design
Gaudio 2012[272]	no relevant outcome

Giesbrecht 2010[275]	Not relevant population
Giesbrecht 2016[274]	inappropriate study design
Gilissen 2017[276]	Not relevant to PICO
Gill 2010[277]	inappropriate study design
Glaudemans 2015[278]	Inappropriate study design
Glogowska 2016[279]	Not relevant population
Godkin 2002[280]	Not peer reviewed
Goff 2015[281]	Not relevant population
Gomes 2010[282]	Inappropriate study design
Goodwin 2002[283]	inappropriate study design
Gordon 1996[284]	Inappropriate study design
Gordon 2013[285]	Inappropriate study design
Górska 2013[286]	Not relevant population
Gott 2007[287]	Not relevant population
Gott 2009[289]	Inappropriate study design
Gott 2011[290]	Not relevant population
Gott 2013[288]	not relevant population
Gotze 2014[291]	Inappropriate study design
Graham 2009[292]	Not relevant population
Grande 2006[293]	Inappropriate study design
Green 2016[294]	Not review population
Groh 2013[295]	Inappropriate study design
Gross 2006[296]	Inappropriate study design
Grudzen 2013[297]	Not relevant population
Guerriere 2013[298]	Inappropriate study design
Guo 2010[299]	No relevant outcomes
Hahn-Goldberg 2015[300]	Inappropriate study design
Hales 2014[301]	Inappropriate study design
Hall 2014[302]	Inappropriate study design
Hallenbeck 2007[303]	Inappropriate study design
Hannon 2012[304]	Inappropriate study design
Hanrahan 1995[305]	Inappropriate study design
Hanratty 2014[307]	No relevant outcomes
Hansen 2015[308]	No relevant outcomes
Happ 2002[309]	Inappropriate study design
Hardiman 2003[310]	Not review population
Harding 2002[313]	No relevant outcomes
Harding 2012[312]	No relevant outcomes
Harding 2012[311]	Not review population
Harrop 2016[314]	Not relevant to PICO
Hatcher 2014[315]	Not relevant population
Hauser 2004[316]	Inappropriate study design
Hebert 2009[317]	Inappropriate study design
Heffner 2011[318]	Inappropriate study design
Hendrix 2013[319]	Inappropriate study design
Henson 2016[320]	Not relevant outcomes

Hewison 2015[321]	Not relevant population
Heyland 2006[323]	Inappropriate study design
Heyland 2009[322]	Inappropriate study design
Heyman 2006[325]	Inappropriate study design
Heyman 2008[324]	Not relevant population
Higgins 2013[326]	Inappropriate study design
Higginson 1990[327]	Inappropriate study design
Hiltunen 1995[328]	Inappropriate study design
Hinderer 2010[329]	Not peer reviewed
Hinkle 2015[330]	Inappropriate study design
Hirakawa 2009[332]	Inappropriate study design
Hirakawa 2017[331]	Not review population
Ho 2016[333]	Not review population
Hobson 2011[334]	Inappropriate study design
Hochgraeber 2015[335]	Not review population
Hodgkinson 2007[336]	Inappropriate study design
Hofmann 1997[337]	Inappropriate study design
Hogden 2013[338]	Not relevant population
Holdsworth 2015[339]	No relevant outcome
Holland 2014[340]	Inappropriate study design
Holley 2003[341]	Inappropriate study design
Holm 2015[342]	Not relevant to PICO
Holm 2015[343]	Not relevant outcomes
Holmes 2010[344]	Inappropriate study design
Hong 2010[345]	Not relevant population
Honselman 2008[346]	Not peer reviewed
Hopkinson 2001[347]	Not review population
Horsfall 2013[349]	No relevant outcomes
Houben 2014[352]	Inappropriate study design
Houben 2014[351]	Inappropriate study design
Houben 2015[353]	Inappropriate study design
Howe 2007[354]	Inappropriate study design
Hsiu Chen 2017[355]	Unable to locate
Huang 2012[356]	Inappropriate study design
Huang 2016[357]	Not review population
Hudson 2006[359]	No relevant outcomes
Hudson 2017[358]	Not review population
Hughes 1992[360]	Inappropriate study design
Hutchison 2017[361]	Not review population
Hyde 2011[362]	No relevant outcomes
Hynes 2012[363]	no relevant outcomes
Iliffe 2013[364]	Inappropriate study design
Imhof 2016[365]	Not review population
Ingleton 2003[367]	Inappropriate study design
Ingleton 2009[368]	No relevant outcome
Ingleton 2011[366]	Not relevant population

Inoue 2015[369]	Inappropriate study design
Jack 2013[370]	Not relevant population
Jackson 2010[372]	Not relevant population
Jackson 2012[374]	No relevant outcome
Jackson 2016[373]	Not relevant population
Janda 2006[375]	Not relevant population
Janssen 2011[378]	Inappropriate study design
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Jansson 2017[379]	Inappropriate study design
Jarrett 1999[381]	No relevant outcome
Jarrett 1999[380]	No relevant outcome
Jelinek 2014[382]	Not relevant population
Jeong 2010[383]	Not relevant population
Jeong 2011[384]	Not relevant population
Jeyasingam 2008[385]	Inappropriate study design
Jezewski 1998[387]	not relevant population
Jezewski 2005[386]	Inappropriate study design
JinShil 2013[388]	Inappropriate study design
Jo 2007[389]	no relevant outcomes
Joad 2011[390]	no relevant outcomes
Joanna Briggs 2012[391]	Inappropriate study design
Jóhannesdóttir 2018 [392]	Not review population
Johnson 1999[394]	No relevant outcome
Johnson 1999[395]	Inappropriate study design
Johnson 2011[393]	Not relevant population
Jones 1993[399]	No relevant outcome
Jones 2011[398]	Inappropriate study design
Judge 2011[400]	Inappropriate study design
Kaamba 2015[402]	Inappropriate study design
Kaasalainen 2011[403]	Not relevant population
Kallianis 2017[404]	Not review population
Ka-Ming Ho 2016[401]	Not review population
Kang'ethe 2011[405]	No relevant outcomes
Kaspers 2013[406]	Inappropriate study design
Kataoka-Yahiro 2011[407]	Not review population
Kavalieratos 2014[408]	Not relevant population
Kayser 2014[409]	Not relevant population
Ke 2015[411]	Not relevant population
Ke 2016[410]	Not relevant population
Keegan 2001[412]	No relevant outcome
Keeley 2004[413]	No relevant outcomes
Kehl 2009[414]	No relevant outcomes
Keim-Malpass 2015[415]	Not review population
Kellogg 1992[416]	Inappropriate study design
Kettl 2007[417]	Inappropriate study design

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Kim 2016[418]	Inappropriate study design
Kimbell 2015[420]	No relevant outcomes
King 2004[421]	No relevant outcomes
King 2005[422]	Not relevant population
Kingsbury 2005[423]	Inappropriate study design
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Kirk 2010[426]	Not relevant population
Kizawa 2015[428]	Not relevant population
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Krakauer 2002[437]	Inappropriate study design
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Kryworuchko 2012[440]	No relevant outcomes
Kulkarni 2016[441]	Not relevant population
Kutner 2009[442]	no relevant outcomes
Kwak 2014[443]	Not relevant population
Kwak 2014[444]	Inappropriate study design
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Lambert South 2017[446]	No relevant outcomes
Lamont 2000[447]	Inappropriate study design
Lau 2010[448]	Not relevant population
Leadbeater 2014[449]	Not relevant population
Lee 2009[451]	Not relevant population
Lee 2014[450]	No relevant outcomes
Lee 2017[452]	Inappropriate study design
Leichtentritt 1999[453]	Not relevant population
Leow 2016[454]	Not relevant to PICO
Leung 2015[455]	Inappropriate study design
Lewis 2015[457]	No relevant outcomes
Lewis 2016[456]	Inappropriate study design
Leydon 2013[458]	No relevant outcome
Lhussier 2007[459]	Not relevant population
Liden 2010[460]	No relevant outcome
Lim 2016[461]	Inappropriate study design
Lin 2009[462]	Inappropriate study design
Lin 2017[463]	Not review PICO
Linderholm 2010[464]	No relevant outcomes

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Lohfeld 2000[467]	Not relevant population
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Lopez 2017[470]	Not review population
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Lord 2016[472]	Inappropriate study design
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Lund 2015[478]	Inappropriate study design
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MacDonald 2011[482]	No relevant outcomes
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Mangan 2003[489]	No relevant outcomes
Manheim 2016[490]	Not relevant outcomes
Manna 2015[491]	Inappropriate study design
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Marchand 2006[494]	Not relevant population
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Martin 1999[498]	Not review population
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Maschi 2014[501]	Inappropriate study design
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Mattes 2015[505]	Inappropriate study design
Mattiussi 2012[506]	Not English language
May 2014[509]	Inappropriate study design
May 2014[508]	Inappropriate study design
May 2016[507]	Not review population
Mc Veigh 2014[510]	Inappropriate study design
McCabe 1995[512]	Inappropriate study design
McCarthy 2003[513]	Inappropriate study design
McCarthy 2016[514]	No relevant outcomes
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McDonald 2016[516]	Inappropriate study design

McGilton 2017[517]	Not relevant population
McGinnis 1986[518]	Inappropriate study design
McGrath 2004[519]	No relevant outcomes
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McGrath 2013[520]	Not relevant population
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McKenzie 2017[525]	Not review population
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McMahan 2013[530]	Not review population
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McSwiggan 2017[540]	Not relevant population
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McWilliam 1993[542]	Not relevant population
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Mehta 2009[544]	No relevant outcomes
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Mehta 2017[546]	Not relevant to PICO
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Meier 2011[547]	Inappropriate study design
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Melcher 2015[550]	Not relevant to PICO
Mellor 2008[551]	Not relevant population
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Mercadante 2017[552]	Inappropriate study design
Mezey 2002[555]	Inappropriate study design
Miceli 2003[556]	Inappropriate study design
Michael 2014[557]	No relevant outcome
Michael 2017[558]	Not relevant population
Milberg 2004[562]	No relevant outcome
Milberg 2005[560]	No relevant outcome
Milberg 2011[561]	No relevant outcomes
Milberg 2014[559]	Inappropriate study design
Milberg 2016[563]	not relevant population

Miller 1998[565]	Inappropriate study design
Miller 2005[564]	Inappropriate study design
Mitchell 2015[566]	Not relevant population
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Moir 2015[569]	Inappropriate study design
Möllerberg 2017[570]	Not relevant outcomes
Moore 2013[571]	No relevant outcomes
Moore 2017[572]	Not relevant to PICO
Moorman 2013[573]	Inappropriate study design
Morin 2007[574]	No relevant outcome
Morita 2004[575]	Inappropriate study design
Mousing 2017[576]	Not review population
Mousing 2018 [577]	Not review population
Muders 2015[578]	Not relevant outcomes
Munck 2008[579]	No relevant outcomes
Murray 2003[583]	No relevant outcomes
Murungu 2015[584]	Inappropriate study design
Musa 2015[585]	Inappropriate study design
Namasivayam 2014[586]	Not relevant population
Nanda 2010[587]	Inappropriate study design
Nash 2015[588]	Not relevant population
Natan 2010[589]	Inappropriate study design
Newton 2002[591]	Inappropriate study design
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Nishie 2014[596]	Inappropriate study design
Noble 2008[597]	Not review population
Noelker 1995[598]	Inappropriate study design
Noh 2014[599]	Not review population
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Noh 2016[600]	Inappropriate study design
Norinder 2017[602]	Unable to locate
Norris 2007[603]	Inappropriate study design
O'Brien 2010[604]	Not relevant population
O'Dea 2000[605]	Inappropriate study design
Offerman 2014[609]	Inappropriate study design
O'Hare 2016[606]	Not relevant population
Okamoto 2016[610]	Not relevant population
Ólafsdóttir 2018[611]	Not relevant to PICO
O'Leary 2008[607]	Inappropriate study design
Oliver 2005[612]	Not relevant population
Oliver 2009[613]	No relevant outcomes
Oosterveld-Vlug 2017[614]	No relevant outcomes

Osse 2006[615]	Inappropriate study design
Ostlund 2012[616]	Inappropriate study design
O'Sullivan 2016[608]	Not review population
Paal 2017[617]	No relevant outcomes
Pandini 2016[618]	Inappropriate study design
Pardon 2009[619]	No relevant outcome
Pardon 2012[620]	Inappropriate study design
Park 2010[621]	Inappropriate study design
Parkes 1978[622]	Inappropriate study design
Partridge 2009[623]	Inappropriate study design
Patrick 2007[624]	Not review population
Pattison 2015[625]	Not review population
Pautex 2008[626]	Inappropriate study design
Payne 1994[629]	inappropriate study design
Payne 2007[628]	No relevant outcomes
Payne 2017 [627]	Not relevant to PICO
Pearlman 2000[630]	Inappropriate study design
Pearlman 2005[631]	Inappropriate study design
Peck 2018[632]	Not review population
Peeters 2010[633]	Inappropriate study design
Peinado-Gorlat 2015[634]	Not review population
Periyakoil 2015[635]	Not relevant population
Periyakoil 2016[636]	Not relevant population
Perry 1996[638]	Inappropriate study design
Perry 2001[639]	No relevant outcome
Perry 2003[637]	Inappropriate study design
Peters 2006[640]	Inappropriate study design
Pfeifer 1994[641]	Not relevant population
Phillips 2006[642]	Not relevant population
Phipps 2003[645]	Not relevant population
Phipps 2003[643]	No relevant outcomes
Phipps 2004[644]	Inappropriate study design
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Phongtankuel 2016[646]	Inappropriate study design
Phongtankuel 2017[647]	Not relevant outcomes
Piamjariyakul 2013[650]	Not relevant outcome
Picot 2015[651]	Inappropriate study design
Pidgeon 2017[652]	Inappropriate study design
Pierce 1999[653]	No relevant outcome
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Pincombe 1996[655]	No relevant outcomes
Pleschberger 2011[656]	Not review population
Ploeg 2001[657]	No relevant outcome
Pockett 2010[658]	Inappropriate study design
Porensky 2008[659]	Inappropriate study design
Powazki 1999[660]	Inappropriate study design

Powers 2011[661]	Not relevant population
Powis 2004[662]	Inappropriate study design
Price 2016[663]	Not relevant population
Prince-Paul 2008[664]	No relevant outcomes
Prosser 2012[665]	Not relevant population
Pugh 2009[666]	Inappropriate study design
Pungchompoo 2013[667]	Not peer reviewed
Radcliffe 2015[668]	Not relevant population
Radhakrishnan 2017[669]	Not relevant population
Rahemi 2016[670]	Inappropriate study design
Raijmakers 2015[671]	No relevant outcome
Rainer 2002[672]	Inappropriate study design
Rainsford 2017[673]	Inappropriate study design
Ratkowski 2015[674]	Inappropriate study design
Ratner 2001[675]	Inappropriate study design
Raudonis 1993[676]	No relevant outcomes
Ray 2014[677]	No relevant outcomes
Raynes 2000[678]	No relevant outcome
Reblin 2014[679]	Inappropriate study design
Reese 2015[680]	Not relevant population
Reinke 2011[681]	Inappropriate study design
Rhee 2013[682]	Not relevant population
Rhodes 1999[683]	No relevant outcome
Richards 2011[684]	No relevant outcome
Richter 1995[685]	Not relevant population
Riesenbeck 2015[686]	Not relevant population
Rietjens 2006[687]	Inappropriate study design
Rigby 2010[688]	Inappropriate study design
Riggs 2014[689]	No relevant outcomes
Ringdal 2007[690]	Inappropriate study design
Robinson 2000[692]	No relevant outcomes
Robinson 2013[696]	Not relevant population
Robinson 2014[695]	Inappropriate study design
Robinson 2015[694]	No relevant outcome
Robinson 2015[693]	No relevant outcome
Robinson 2016[691]	No relevant outcomes
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Rocker 2008[698]	Inappropriate study design
Rodenbach 2017[699]	Inappropriate study design
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Rosemond 2017[702]	Not relevant outcomes
Rosenberg 2015[703]	Not review population
Rosenfeld 2000[704]	Not relevant population
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Ross 2014[706]	Not review population
Roth 2000[707]	Inappropriate study design

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Running 2009[710]	Inappropriate study design
Ryan 2009[711]	Not relevant population
Ryan 2012[713]	Not review population
Ryan 2017[712]	Not review population
Sahlberg-Blom 2000[714]	No relevant outcomes
Sanchez-Garcia 2017[715]	Not English language
Sanchez-Tomero 2011[716]	Inappropriate study design
Sanders 2008[717]	Not relevant population
Sandsdalen 2015[719]	No relevant outcome
Sandsdalen 2016[718]	Inappropriate study design
Sarmento 2017[720]	No relevant outcome
Sato 2012[721]	Inappropriate study design
Sautter 2014[722]	Inappropriate study design
Scheerens 2018 [723]	Not review population
Schenker 2014[724]	Not relevant population
Schofield 2006[725]	Inappropriate study design
Schoot 2017[726]	Not review population
Schreibeis-Baum 2016[727]	Not review population
Schwartz 2004[728]	Inappropriate study design
Scott 2015[729]	Inappropriate study design
Scott 2016[730]	No relevant outcome
Seamark 2014[731]	No relevant outcome
Sekse 2017[732]	Not review population
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Sellars 2018 [733]	Not relevant population
Selman 2007[735]	Not review population
Seltzer 1992[737]	Inappropriate study design
Sessanna 2010[738]	not relevant population
Seymour 2010[739]	Not relevant population
Shahidi 2010[740]	Inappropriate study design
Shanley 2011[742]	Not relevant population
Shanley 2017[741]	Not review population
Shield 2005[743]	No relevant outcome
Shih 2015[744]	Inappropriate study design
Shope 1993[745]	Inappropriate study design
Shyu 2000[746]	Not relevant population
Siegel 2006[747]	Not peer reviewed
Silva 2016[748]	Inappropriate study design
Silveira 2012[749]	Not relevant population
Simms 2011[750]	Inappropriate study design
Simon 2002[751]	No relevant outcomes
Sims 1997[753]	Inappropriate study design
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Snow 2009[764]	Inappropriate study design
Snyder 2013[765]	Inappropriate study design
Sommerbakk 2016[766]	Not relevant population
Song 2011[768]	Inappropriate study design
Song 2012[767]	Inappropriate study design
Southwell 2010[769]	Inappropriate study design
Spence 2009[770]	Not relevant population
Stajduhar[774]	No relevant outcomes
Stajduhar 2008[772]	Inappropriate study design
Stajduhar 2011[773]	Not relevant population
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Stein 2008[776]	Inappropriate study design
Stein 2013[777]	Inappropriate study design
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Stevens 2011[779]	Inappropriate study design
Strachan 2009[781]	Inappropriate study design
Street 2005[782]	Not relevant population
Stuart 2008[783]	Inappropriate study design
Sudore 2013[785]	Inappropriate study design
Sudore 2016[784]	Inappropriate study design
Taggart 2012[786]	Not relevant population
Takada 2014[787]	Inappropriate study design
Tammelleo 2000[788]	Inappropriate study design
Tang 2009[789]	Inappropriate study design
Taubert 2010[790]	Not relevant population
Taylor 2003[791]	Inappropriate study design
Tedder 2017[792]	Inappropriate study design
Temkin-Greener 2009[793]	Inappropriate study design
Teno 2004[794]	Inappropriate study design
Thomas 2002[797]	Inappropriate study design
Thomas 2007[796]	Inappropriate study design
Thomas 2010[795]	Not relevant population
Thomas 2017[798]	Inappropriate study design
Thompson 1998[799]	Study withdrawn
Thoonsen 2016[800]	Not relevant population
Thoresen 2016[801]	No relevant outcomes
Thorpe 2006[802]	Inappropriate study design

Threapleton 2017[803]	Inappropriate study design
Thurston 2012[804]	Not relevant population
Tiernan 2002[805]	Inappropriate study design
Torres-Vigil 2012[807]	Inappropriate study design
Toye 2012[808]	Inappropriate study design
Train 2005[809]	Not review population
Travers 2016[810]	Inappropriate study design
Travis 2002[811]	Inappropriate study design
Trees 2017[812]	Not relevant to PICO
Treloar 2009[813]	No relevant outcomes
Turner 2016[814]	No relevant outcomes
van der Steen 2017[815]	Not relevant outcomes
van Eechoud 2014[816]	No relevant outcomes
Van Meter 1985[817]	Inappropriate study design
van Riet Paap 2014[818]	Not relevant population
van Wijmen 2014[819]	Not relevant population
Vander Laan[820]	Not peer reviewed
Vandervoort 2014[822]	Inappropriate study design
Vandervoort 2014[821]	Inappropriate study design
Vassal 2011[823]	Inappropriate study design
Vedel 2014[824]	No relevant outcome
Veigh 2017[825]	Not relevant to PICO
Veloso 2016[826]	Inappropriate study design
Venkatasalu 2015[827]	Not relevant population
Ventura 2014[828]	Inappropriate study design
Virnig 2006[829]	Inappropriate study design
Wahid 2017[830]	Not relevant to PICO
Walczak 2013[833]	Inappropriate study design
Waldrop 2011[834]	No relevant outcome
Waldrop 2012[835]	Inappropriate study design
Wallace 2015[836]	Inappropriate study design
Wallace 2016[837]	Inappropriate study design
Wallerstedt 2014[838]	No relevant outcome
Walsh 2010[839]	Not review population
Walsh 2011[840]	Not relevant population
Walshe 2008[841]	Not relevant population
Wanicha 2016[842]	No relevant outcomes
Ward 2009[843]	Not review population
Waters 2001[844]	Not review population
Weibull 2008[845]	No relevant outcomes
Wentlandt 2012[846]	Inappropriate study design
Wentlandt 2016[847]	Not relevant population
Wiegand 2006[849]	Inappropriate study design
Wiese 2009[850]	Not relevant population
Wiese 2012[851]	Not review population
Wilkinson 1999[853]	Inappropriate study design

Wilkinson 2017[852]	Not review population
Willard 2006[854]	Not review population
Williams 2011[855]	Inappropriate study design
Williams 2012[857]	Inappropriate study design
Williams 2015[856]	Not relevant to PICO
Wilson 2011[858]	No relevant outcomes
Wilson 2012[859]	No relevant outcome
Wilson 2013[860]	Inappropriate study design
Winter 2012[861]	Inappropriate study design
Witkowski 2004[862]	No relevant outcome
Wittenberg-Lyles 2010[863]	Inappropriate study design
Wittenberg-Lyles 2010[864]	No relevant outcomes
Wittenberg-Lyles 2013[865]	Inappropriate study design
Wittich 2013[866]	No relevant outcomes
Wladkowski 2016[867]	Unable to locate
Wodehouse 2009[868]	Not relevant population
Wolkowski 2017[869]	Not review population
Woodman 2016[870]	Not review PICO
Woodward 2004[871]	Not relevant population
Worth 2006[872]	No relevant outcome
Wu 2010[873]	Inappropriate study design
Wu 2015[874]	Not review population
Wye 2014[875]	Inappropriate study design
Xafis 2015[876]	Not relevant population
Yabroff 2004[877]	Inappropriate study design
Yamagishi 2012[878]	Inappropriate study design
Yang 2012[880]	Inappropriate study design
Yang 2012[879]	No relevant outcome
Yap 2017[881]	Not review population
Young 2006[882]	No relevant outcomes
Young 2008[883]	Inappropriate study design
Yung 2010[884]	Inappropriate study design
Zaider 2009[885]	Inappropriate study design
Zallman 2003[886]	Inappropriate study design
Zapart 2007[887]	No relevant outcomes
Zhang 2012[888]	Inappropriate study design
Zimmerman 2015[889]	Inappropriate study design
Zimmermann 2016[890]	No relevant outcome

F.2 Excluded economic studies

There were no excluded economic studies for this review.

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