



Public Health
England

Protecting and improving the nation's health

Cost-effective commissioning of end of life care

Understanding the health economics of
palliative and end of life care

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1. Introduction and acknowledgements

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Introduction

In 2015, Public Health England (PHE) commissioned a programme of work to enable clinical commissioning groups (CCGs), local authorities, and other decision makers to better understand the health and economic case for increasing investment in prevention and early intervention. One of the areas that was identified as a priority were the services and care provided to patients who were diagnosed as being or nearing the end of their lives, as a result of a terminal illness.

Optimity Advisors were commissioned to undertake this analysis, which involved the following:

- a consideration of the wider policy context to which this analysis contributes
- a review of the available literature on the costs and effectiveness of different initiatives and schemes designed to improve patients and carers experiences at the end of the patient's lives
- a health economic model designed to inform commissioners when making commissioning decisions

This work has followed a number of workshops held between September 2014 and March 2015 with members of the Strategic Clinical Networks (SCNs) and the National End of Life Care Intelligence Network (NEoLCIN), which identified key issues and the top priorities raised by the SCNs.

This report brings together existing evidence in palliative and end of life care which was identified by an evidence review undertaken using a systematic and robust search and appraisal methodology. Early findings from this review as well as identified gaps in the evidence base and priorities for addressing those gaps were presented at a workshop, which gathered health economists, academic and clinical experts, patients and local government representatives. As a consequence, additional studies and information were added to the findings.

Section two of this report describes the wider policy context of palliative care and end of life care, and outlines some of the key initiatives supporting the end of life care in England.

Section three of the report describes the methods and findings of the evidence review of the cost-effectiveness of end of life care.

And finally, section four describes the economic tool which has been developed as part of this project. The tool was developed to help inform commissioners in their decision-making for end of life care services. Due to the nature and extent of the evidence on the costs and impacts of interventions and services for patients at the end of their lives, it was agreed that a tool that explored the trade offs between different types of end of life care would be the most useful. The analysis helps the user explore whether there were genuine financial and efficiency savings available from shifting such care out of secondary services and describes interventions that might be deployed to achieve such savings. Where evidence of the effectiveness (for example in reducing the use of acute care beds) of specific interventions is available, the tool allows users to model the impact of these interventions on their local data, to provide an estimate of the return on investment (ROI) associated with that intervention.

2. Policy context

This project was commissioned within a policy context (in England) where numerous other initiatives for end of life care are taking place.

These initiatives largely follow on from the first end of life care strategy in England in 2008, which found from public surveys (among many other things) a major disconnect between people's preferences for where they wanted to die and their actual place of death, and set out a vision to transform end of life care.

Following that report, the Government's publication in 2012, 'Liberating the NHS: No decision about me, without me' reiterated the government's commitment to offering people and their families the choice to die at home.

For facilitating the dissemination of best practices, NICE has developed a quality standard encompassing the entire end of life care pathway^[1]. It comprises 16 quality statements providing guidance on:

- patient support and communication
- workforce training and organisation
- family and bereavement support

In 2013, the independent review of the Liverpool Care Pathway (LCP) found evidence that the LCP was not being consistently and correctly applied and recommended that it be replaced within six to 12 months by an end of life care plan for each patient and condition-specific good practice guidance^[2]. Following this, the NICE quality standards have been amended and the Leadership Alliance for the Care of Dying People, a coalition of 21 national organisations, including Public Health England, published their approach to caring for dying people in 'One chance to get it right'^[3]. This document articulates five priorities for care of the dying person. These priorities are (when it is thought that the person may die within the next few days or hours):

- this possibility is recognised and communicated clearly, decisions made and actions taken in accordance with the person's needs and wishes, and these are regularly reviewed and decisions revised accordingly
- sensitive communication takes place between staff and the dying person, and those identified as important to them
- the dying person, and those identified as important to them, are involved in decisions about treatment and care to the extent that the dying person wants
- the needs of families and others identified as important to the dying person are actively explored, respected and met as far as possible
- an individual plan of care, which includes food and drink, symptom control and psychological, social and spiritual support, is agreed, co-ordinated and delivered with compassion

More recently, in 2015, ‘A Review of Choice in End of Life Care’ was published, following a wide public engagement exercise. Their recommendations included setting a specific date for a national choice offer in end of life care and investing an additional £130 million in community based care and services at the end of life^[4]. This report highlighted several main themes, as shown in Figure 1.

In 2015, a partnership of 27 national organisations committed to promoting palliative and end of life care published the ‘Ambitions for Palliative and End of Life Care’, a national framework consisting of six ambitions as shown in Figure 1^[5].

In response to the Review and drawing on the Ambitions document, in July 2016, the government made a commitment that ‘every person nearing the end of their life should receive attentive, high quality, compassionate care, so their pain is eased, their spirits lifted and their wishes for their closing weeks, days and hours are respected’^[6]. This document set out a list of actions to deliver the government’s commitment as shown in Figure 1.

Figure 1: Government’s response to the review of End of Life and the Ambitions for End of Life Care Partnership

Choice Review - 7 main themes	Government Commitment – 7 actions	Ambitions for Palliative and End of Life Care: - 6 ambitions
I want to be cared for and die in a place of my choice	We will develop more personalised care for people approaching the end of life	Each person is seen as an individual
I want involvement in, and control over, decisions about my care	We will put in place measures to improve care quality across different settings	Each person gets fair access to care
I want access to high quality care given by well trained staff	We will identify and spread innovating in the delivery of high quality care	Maximising comfort and wellbeing
I want access to the right services when I need them	We will lead on end of life nationally and provide support for local leadership, including commissioners, to prioritise and improve end of life care	Care is coordinated
I want support for my physical, emotional, social and spiritual needs	We will ensure we have the right people with the right knowledge and skills to delivery high quality personalised care	All staff are prepared to care
I want the right people to know my wishes at the right time	We will work together with system partners and the voluntary sector to deliver this commitment	Each community is prepared to help
I want the people who are important to me to be involved in my care	We will strengthen accountability and transparency to drive improvements	

Health and care professionals will be expected to reflect these commitments in their work, and new measures will be developed and implemented to ensure that local health and care leaders are meeting the standards expected of them.

Two enabling elements for the government to achieve its commitment are access to accurate and timely data as well as commissioning where end of life care is explicitly valued and prioritised.

Research on end of life care has started to be more targeted on specific population groups. In December 2015, NICE published guidelines on care of adults in the last two to three days of life^[7]. Also, a guideline specifically targeting children has been published in December 2016 on the planning and management of end of life care for infants, children and young people with life-limiting conditions^[8]. Quality standards on care in the last day of life and on end of life care for children are expected to be published in 2017^[9].

Data

Currently, the National Council for Palliative Care collects the minimum data set (MDS) for specialist palliative care services on an annual basis [10]. This is the only data available nationally which covers patient activity in specialist services in the voluntary sector and the NHS in England. While this is a rich source of data, it is voluntary, and therefore not complete and does not provide the level of granularity needed for the development of a new currency and payment system for palliative care.

Commissioning

In 2015, NHS England published a set of developmental currencies for palliative care for both children and adults. This followed recommendations from the Palliative Care Funding Review of 2011 to address concerns that the lack of transparent cost and activity data meant that providers were not incentivised to care for more patients and evidenced-based discussions were difficult^[11]. A national currency could address these concerns and reduce variation in funding and access to services by introducing a 'common language' to collect uniform data. The developmental currencies were defined using data from the palliative care funding pilots, and these currencies have been further tested over the past year.

Early this year, NHS England is expected to publish final currencies and associated guidance on how commissioners might apply this guidance. Notably, NHS England has recently indicated that a 'per-patient tariff', the original model as proposed by the Palliative Care Funding Review of 2011, may not be the only, or most suitable, funding model for palliative care^[12]. NHS England will be engaging with stakeholders to review and consider various approaches to palliative care funding for children and adults. However, they note that any approach may involve the use of the palliative care currencies as the 'building blocks' for a funding model.

3. Evidence review

3.1 Objectives of the study and review questions

PHE commissioned Optimity Advisors to undertake a research project in the area of palliative and end of life health and social care services, with the following overarching aims:

- to collate and review the existing evidence of interventions and delivery models associated with end of life and palliative care, in the primary, secondary and community settings
- to propose approaches for improving outcomes, and where possible, generating cash releasing savings
- to identify, where possible, any gaps in the evidence base;
- to identify whether there are specific patient or disease groups that will benefit from different models, or where there is potential for greater benefits and/or cost-savings
- to explore the incentive structures facing commissioners with regard to shifting care provision away from the acute sector to the primary, community and social care sectors

An evidence review of the cost-effectiveness of end of life care services was undertaken in order to collate information to support better decision-making, by improving patient outcomes, and potentially generating financial savings. A consequence of this review will also be an assessment of any gaps in the evidence base.

3.1.1 Review questions

The review aimed to answer the questions of what is the current evidence base and what gaps exist regarding the economics of palliative and end of life care. The review also tried to address the following issues:

- identifying the outcomes/benefits to patients and their families of models of care
- compiling existing evidence on the cost-effectiveness, value for money and return on investment of models of care
- modelling the timing of costs and outcomes for different parties across the care pathway associated with shifting patterns of care, bearing in mind the defined 'optimal pathway'
- highlighting incentive issues operating across the health and social care system;
- presenting what is understood to be the optimal approach to end of life management (care pathway)

3.1.2 Definitions

The following definitions from the report 'One chance to get it right' were used in the review^[3].

Palliative care: Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. Palliative care:

- provides relief from pain and other distressing symptoms
- affirms life and regards dying as a normal process
- intends neither to hasten or postpone death
- integrates the psychological and spiritual aspects of patient care
- offers a support system to help patients live as actively as possible until death
- offers a support system to help the family cope during the patient's illness and in their own bereavement
- uses a team approach to address the needs of patients and their families
- enhances quality of life and may also positively influence the course of illness
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, and includes those investigations needed to better understand and manage clinical complications

Palliative care can be provided by a range of health and social care staff and may take place alongside treatment intended to reverse particular conditions.

End of Life: Patients are 'approaching the end of life' when they are likely to die within the next 12 months. This includes patients whose death is imminent (expected within a few hours or days) and those with:

- advanced, progressive, incurable conditions
- general frailty and coexisting conditions that mean they are expected to die within 12 months
- existing conditions if they are at risk of dying from a sudden acute crisis in their condition
- life-threatening acute conditions caused by sudden catastrophic events

In the General Medical Council guidance, the term 'approaching the end of life' also applies to those extremely premature neonates whose prospects for survival are known to be very poor, and to patients who are diagnosed as being in a persistent vegetative state (PVS) for whom a decision to withdraw treatment may lead to their death.

Economic analysis: When reviewing the papers, it has been considered that an ideal economic analysis would look at the cost of an end of life care intervention/model of care versus the potential savings for the NHS, and also for other types of care such as social and community care, specialist palliative care, voluntary care and informal care

performed by families. An economic evaluation should also include the potential extra costs incurred on all care settings as a result of a shifting of care (e.g. decreasing costs and activity in one setting might increase costs and activity in another setting).

3.2 Overview of included studies

Table 1 below provides an overview of the included studies with their respective critical appraisal score. The quality assessment of studies has been undertaken by adapting the economic evaluation appraisal checklist developed by NICE^[13]. The scores assigned to studies are:

- very serious limitations: the study fails to meet one or more quality criteria and this is very likely to change the conclusions about cost-effectiveness
- potentially serious limitations: the study fails to meet one or more quality criteria and this could change the conclusions about cost-effectiveness
- Minor limitations: the study meets all quality criteria, or fails to meet one or more quality criteria but this is unlikely to change the conclusions about cost-effectiveness

The checklist has been included in Appendix 6.

Table 1: Overview of included studies

Number of studies in the category	Type of study	Sources (Critical appraisal)	Brief description
2	Randomised control trial	Higginson et. al., 2009 ^[14] (Potentially serious limitations); Higginson et. al., 2014 ^[15] (Potentially serious limitations);	One randomised control trial analysed the impact of a multi-professional palliative care team on patients with multiple sclerosis conditions ^[14] . The other trial reported the impact of a breathlessness support service on patients at their end of life with refractory breathlessness and advanced disease.
5	Study comparing outcomes before and after an intervention	Sue Ryder, 2013 ^[16] (Potentially serious limitations); York Health Economic Consortium, 2016 ^[17] (Potentially serious limitations);	Three studies reported the outcomes ^[16;17] or costs ^[18;17] before and after a palliative care intervention (Partnership for Excellence in Palliative care – PEPS ^[16] , a modified Appreciative Inquiry intervention ^[18] , the Gold Line system ^[17]). Other reports that have been provided by the Gold Standard Framework compare the outcomes of GSF accredited GP practices

		<p>Amador et. al., 2014 [18] (Potentially serious limitations);</p> <p>Clifford et. al., [19] (Very serious limitations) ;</p> <p>Stobbart-Rowlands, 2015 [20] (Minor limitations);</p>	<p>[19] and GSF certified/trained Care Homes [20] before and after the implementation of the GSF training.</p>
4	Evaluation/descriptive report	<p>Gandy, 2010 [21] (Potentially serious limitations);</p> <p>Noble et al., 2012 [22] (Very serious limitations);</p> <p>The National Gold Standards Framework (GSF) Centre in End of Life Care, 2015. [23] (Very serious limitations);</p> <p>The National Gold Standards Framework (GSF) Centre in End of Life Care, 2016. [24] (Very serious limitations)</p>	<p>Four reports are just descriptive or evaluate the outcomes of an intervention (Staff training for Liverpool care pathways and Gold Standard Framework (GSF) [21], the Midhurst Palliative Care Service - MMS [22] and the GSF training programme only [23; 24]) without having any clear comparator.</p>
2	Comparative studies of patients receiving or not an intervention	<p>Wye et. al., 2012 [25] (Minor limitations);</p> <p>Chitnis et. al., 2012 (Minor limitations) [26]</p>	<p>Two studies compared the outcomes of patients joining or not a specific initiative (Delivering Choice Programme - DCP [25] and Marie Curie Cancer Service - MCCS [26]).</p>

1	Comparative study/ before and after study	Addicott et. al., 2008 (Minor limitations) ^[27]	This study combines both comparing outcomes of the overall patients before and after the intervention and an analysis of the outcomes of the patients who joined the programme (Marie Curie Cancer Service - M CCS)
4	Observational retrospective studies (without any interventions)	<p>Gardiner et. al, 2014b ^[28] (Potentially serious limitations);</p> <p>Abel et. al., 2009 ^[29] (Potentially serious limitations);</p> <p>The Balance of Care Group, 2008 ^[30] (Potentially serious limitations);</p> <p>Bekelman et. al., 2016 ^[31] (Potentially serious limitations);</p>	Some studies look at the death data from a hospitals and assess the percentage of patients who would not have need to be at the hospital to receive palliative cares ^[28; 29; 30] . One study used retrospective data to compare place of death and hospital expenditure in seven developed countries with diverse modes of healthcare and delivery ^[31] .
1	Impact analysis on healthcare pathways	Deloitte LLP, 2012 ^[32] (Very serious limitations)	One report is presented in the form of case studies. British Red Cross Schemes (two covering Accident & Emergency (A&E) hospital schemes, and four focused on community and individual resilience) had been applied in six different sites. The impacts of the schemes on each healthcare pathway has then been estimated.
2	Economic modelling (Markov	National Audit Office, 2008 ^[33] (Potentially	Two reports estimated the economic benefits of shifting palliative care from hospital to other place of care (three stages

	model)	serious limitations) Hatziandreu et. Al., 2008 ^[34] (Minor limitations)	incorporated in both models: community care, inpatient hospice and hospital acute care).
11	Costing studies	Wood et. al., 2013 ^[35] (Minor limitations); Marie Curie Cancer Care, 2012 ^[36] (Minor limitations); Macmillan Cancer Support, 2013 ^[37] (Potentially serious limitations); Hughes-Hallet et. al., 2011 ^[38] (Potentially serious limitations); Georghiou et. al., 2014 ^[39] (Minor limitations); Roberts et. al., 2013 ^[40] (Minor limitations); Georghiou et. al., 2012 ^[41] (Very serious limitations); Burbeck et al., 2014 ^[42] (Minor limitations);	Six studies mainly report outcomes related to costs. They outline the costs for different palliative care settings and establish how cost-savings can be made. The study/report would for example compare the costs of end of life care in hospital with the cost of equivalent care at the community level (eg hospice, care home, care at home) and would explain that shifting costs from hospital to community care could reduce the overall total cost of end of life care ^[35; 36; 37; 38; 39; 40; 41] . Some reports mention costs in term of staff and compare the type of staff in different settings (eg volunteers and paid staff in statutory and non-statutory service) ^[42] . One report is more a scenario planning and encourage the NHS to invest in community care to increase the availability of services. It explains that the overall cost would slightly increase but for a far better service with a reduction in hospital admission ^[43] . Other reports assess the costs of care (formal and informal care) for different conditions/ different stages of the disease ^[44; 45] .

		<p>The Choice of End of Life Care Programme Board, 2015 ^[43] (Potentially serious limitations);</p> <p>McCrone, 2009 ^[44] (Very serious limitations);</p> <p>Round et. al., 2015 ^[45] (Minor limitations)</p>	
1	Cost benefit analysis	NHS Improving Quality, 2013 ^[46] (Minor limitations)	One study used a cost benefit analysis approach by analysing costs and benefits of an intervention (Electronic palliative care coordination system).
11	Evidence review	<p>Gott et. al., 2011 ^[47];</p> <p>Dixon et. al., 2015 ^[48];</p> <p>Gomes et. al., 2013 ^[49];</p> <p>Zimmermann et al., 2008 ^[50];</p> <p>Smith et. al., 2014 ^[51];</p> <p>May et. al., 2014 ^[52];</p> <p>Evans et. al., 2013 ^[53];</p> <p>García-Pérez et. al., 2009 ^[54];</p> <p>Gomes et., al., ^[55];</p>	The evidence reviews retrieved have found very limited evidence of cost-effectiveness of different models of care at end of life stage, which is in line with the results of our evidence review. As the studies did not provide enough cost-effectiveness evidence, the critical appraisal checklist was not applied to these studies.

		National End of Life Care Programme., 2012. ^[56] ; Douglas et. al., 2003 ^[57]	
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3.3 Findings

Main review question: what is the current knowledge and what are the gaps in the economic evidence regarding palliative and end of life care?

It is well established that there is a mismatch between the location in which care takes place at the end of life and individual's preferred place of care. Whereas many people at their end of life would prefer to be cared for at home, around 90% of people spend time in hospital in their final year of life according to a literature review carried out by Gott et al. It also reports that there is still an excessive number of hospital admissions that could be avoided if patients were offered high quality community support^[47]. This discrepancy between individuals' preferences and actual service provision presents a potential opportunity to reconfigure care in a way which achieves better alignment with the preferences of those at the end of life and relieves pressure on the hospital sector. However, the cost implications of shifting care from one setting to another are not fully understood. Any reduction in costs of hospital care to the NHS may simply be offset by an increase of primary, social, community and informal care costs. To construct a full economic analysis, ideally the costs from a societal perspective would be considered, although this is often not the case.

A recent review by Dixon et al. (2015) from the LSE and the Personal and Social Services Research Unit (based at the Universities of Manchester and Kent, and the LSE) on equity of provision of palliative care in the UK has identified some evidence on costs and cost-effectiveness associated with end of life care^[48]. This is despite a lack of data on the costs of generalist versus specialist care at the end of life, by place of delivery, noted by the Social Care Institute of Excellence^[58]. Most of the evidence found by Dixon et al. (2015) comes from outside the UK. For example, a Cochrane review on the effectiveness and cost-effectiveness of home palliative care for patients with a number of conditions found six economic studies, just one of which had a UK setting^[49;14]. This study compared a fast-track group allocated to receive care by a multi professional palliative care team immediately, and a control group who received usual care for three months, after which they were offered the palliative care team.

All the other economic studies included in the Cochrane review found the interventions to be cost-saving but, in common with the palliative care team study, due to sample sizes, these results were not statistically significant. However, this doesn't necessarily imply that the savings cannot be achieved. An earlier evidence review, using Cochrane

methods, identified seven randomized controlled trials (RCTs) of specialised palliative care, only one of which was conducted in the UK, with only one (a US study) showing significant cost-savings^[50].

A review of moderate and high quality literature identified 46 studies including the UK study by Higginson et al. (2009)^[14], the only cost-effectiveness study in the sample^[51]. The remaining studies were cost analyses, including a second UK study where the difference in costs between the palliative care intervention and control group was negligible^[59]. Among the RCTs, costs were found to be significantly lower in the palliative care arm compared with the control arm in two studies (one of an inpatient palliative care team, the other of a home-based palliative care initiative^[60;61]). Differences in the remaining studies were not statistically significant.

One review of hospital-based specialist palliative care identified in the Dixon et al. (2015) report considered primarily US literature and found that palliative care delivered by trained palliative care staff was less costly than care delivered by generalist or other specialist hospital staff^[62]. A second review, again dominated by US evidence, found that specialist palliative care consultation teams generated cost-savings and improvements in care^[52].

Other literature has considered the available UK evidence. One review from 2008 conducted in conjunction with the National Audit Office identified four UK studies including three RCTs^[34]. Based on the UK and international evidence, it was estimated that costs in the last year of life were 30% lower for palliative care patients than for other patients. Specific UK initiatives have been evaluated in a number of studies.

The Marie Curie Nursing Service (MCNS), a community-based palliative nursing service, has been found to have lower non-MCNS costs from first contact until death, compared with a matched control group. Cost-savings were achieved through reduced hospital admissions. Meanwhile, a second study estimated a potential cost-saving, including MCNS costs, of around £500 per person relative to usual end of life care^[39].

The average acute and community services costs of the Marie Curie Delivering Choice Programme, comprising a rapid response team and discharge community link nurses for those who wish to be cared for and die at home, were found in one study to be similar to those of a control group^[27]. An evaluation of the Midhurst Macmillan Specialist Palliative Care Service, consisting of an early referral programme and a multidisciplinary team of specialist palliative care professionals linking with primary healthcare, community services, social services, care organisations and voluntary bodies, estimated that costs could be reduced by 20% in the last year of life with this approach^[63].

Performing cost-effectiveness analysis for end of life care interventions is challenging as the conventional use of quality Adjusted life year (QALY) is not optimal. A QALY is a generic measure capturing the extra quantity and quality of life lived by a patients. However, end of life care services from the review do not intend to extend the life of the patients who are dying but to optimise both the quality of care and the costs of care. As

defined by the working definition of the National Council for Palliative Care, end of life care aims to: 'help all those with advanced, progressive, incurable illness to live as well as possible until they die', and 'enables the supportive and palliative care needs of both patient and family to be identified and met throughout the last phase of life and into bereavement. It includes management of pain and other symptoms and provision of psychological, social, spiritual and practical support.'

This definition explains why in the review, the quality of care is not assessed quantitatively but through qualitative data and by the underlying assumption that patients' preferred being cared in the community rather than in a hospital setting. A detailed review of the outcomes used for measuring the effectiveness of end of life care is further developed in sub-question 2. Because the outcomes are not quantitative, it is challenging to perform with a robust methodology a cost-effectiveness analysis.

Sub-question 1: What are the outcomes/benefits to patients and their families of different models of care?

The studies that include other measures of success than cost savings usually report tangible outcomes that do not directly affect patients' well-being. Below is a list of all outcomes identified in the studies reviewed.

Outcomes related to place death

It has been identified by a few studies that a possible outcome to measure the efficiency of palliative care programme is to report the place of death. Some studies compare the actual place of death of patients with their desired place of death^[20; 21; 22; 23; 46]. Others just assume that patients home, nursing home or hospice are preferred places of death by patients in comparison to hospital^[17; 25; 26; 29; 30; 32;35]. Therefore, the objective and outcomes measured of many palliative programmes relate in shifting the number of death away from hospital to other care setting and ultimately at home (or usual place of residence). All studies measuring the place of death report an increase in death in the usual place of residence (or away from the hospital) as a result of an end of life care intervention.

Outcomes related to reductions in use of acute care:

Other studies measure the effectiveness of palliative care programmes by:

- reporting the number of emergency admissions and identifying the reduction of admission after the implementation of the end of life care intervention^[25;16;34;17]
- reporting the number of A&E attendances and identifying the reduction of attendance after the intervention^[25;32]
- measuring the time spent in acute care or reporting the reduction in time spent in hospital stay^[16;27;35;32]
- reporting hospital admissions and re-admissions that have been prevented^[28;32]
- estimating the extra number of days spent at home (instead of hospital)^[39]

Outcomes related to care-giver burden:

Few studies reported outcomes related to care-givers burden ^[14].

Outcomes related to patient improved quality of life:

One randomised control trial reports the utility (at the end of life as an outcomes. Besides the common EQ-5D utility score, the study reported the palliative care outcomes scale which is a utility measure that have been specifically developed for use among people with advanced diseases ^[15].

Sub-question 2: what is the existing evidence on the cost-effectiveness, value for money and return on investment of models of care?

As shown in 'Error! Reference source not found'. few studies present cost-effectiveness measures of end of life care across different settings or models of care. There is only one randomised control trial with a clear scientific methodology that assessed the cost-effectiveness of a multi-professional palliative care team for patients with advance multiple sclerosis^[14].

Another randomised control trial^[15] estimated the impact of a breathlessness support service group on patients with advanced disease and refractory breathlessness. Even though the results of this study suggest that breathlessness does not have an impact on the quality of life of the patients (eg EQ-5D scale, palliative care outcome scale), the breathlessness support has however improved breathlessness mastery at no extra costs.

However due to the limited sample size (respective 25 and 53 patients in the experimental group for the multiple sclerosis and breathlessness patients) and specificity of the disease, it cannot be affirmed that cost-effectiveness of this specific form of end of life care would exist in a more general setting.

The attempts to measure the effectiveness of palliative care programmes are often limited by the ability to have a clear comparator. Some studies are just descriptive, without including any comparators^[21; 22; 23]. Other studies attempted to compare the results of an intervention with a 'control group'. For example, Addicott and Dewar (2008) report upon the impact of the Marie Curie Cancer Care programme by assessing the effect of the intervention on patient outcomes without differentiating between those who join the programme or not^[27]. It does not therefore capture any other external factors that could have also impacted the outcomes of the programme (eg one of the impacts of an end of life care programme is a reduction in A&E admissions; an epidemic might have increased the number of A&E admissions and therefore would underestimate the impact of the programme). To tackle this issue, the study also reported the effect on the patients who joined the programme in comparison with the patients who did not join. In this case, there may be an overestimation of the effect due to the fact that patients were not randomly selected.

The before and after studies as well as the comparative studies give an indication on the benefits of palliative care initiatives, but cannot capture with certainty the extent to which the outcomes observed are related to the programme^[16;17;18; 19; 20; 25; 26]. Even though the studies cannot fully capture the effect of end of life care programmes, they all seem to suggest that the place of care would only have a limited impact on the effectiveness or quality of the palliative care received. The place of care however, may have a greater impact on the quality of life of the patients and on the costs incurred by the health system.

Studies suggesting hospital care to be more expensive than community care:

Based on the reviewed studies, the costs of care per setting or model of care from the public spending perspective are likely to be as follows:

- higher costs for acute care in hospital;
- medium costs for nursing care and hospice care;
- lower costs for care at home (where main healthcare, social and informal care providers are from the community).

This is why most of the studies that evaluate the efficiency of palliative care would analyse the ability of a palliative care intervention to reduce hospital admissions and hospital deaths. How the costs from reduced admissions are transferred into the community care is not always clearly reported. Few studies reported the economic impact of potentially avoidable hospital admissions by estimating the cost of providing support in alternative place of care^[28; 34; 35; 39]. The report by Georghiou and Bardsley (2014) is a typical example of a study with a good methodology on cost-shifting^[39]. The authors estimated the cost transferred to the community after the implementation of the Marie Curie nursing service (costs per patient during their last three months of life):

- running the Marie Curie nursing service would cost around £581 at the community level
- the authors estimated that the Marie Curie nursing service would decrease costs incurred by secondary care through a reduction in emergency admissions (£1,140 less spent in secondary care)
- this reduction in admissions would necessitate a higher support from alternative care (primary, community and social care); the extra cost incurred to alternative care was estimated at £72

Pulling all these numbers together, the authors concluded that the extra cost of the Marie Curie Nursing service (because of the extra investment and of the shift of care), should be outweighed by the savings made in secondary care. They found a potential net saving of £487 per person during their last three months of life by shifting care from the hospital to the community.

Other studies discussing costs of end of life in hospital and at the community level:

One study however suggests that increasing care at the community level might not be a cost-saving solution from a societal perspective. Roberts and Hurst (2013) compare the costs and staff activity of an NHS palliative care ward and a charitable hospice ward and conclude that charitable hospice is more expensive but delivers better quality of care than the hospital^[40]. The difference in the results compared to the previous section, could be due to the contextual difference of the studies, the intervention or the perspective, and the way informal care costs are calculated. Roberts and Hurst (2013) compare staff activity in a charity and a non-charity setting but their method of valuing volunteering work, which has no direct wage data associated with it, might not be estimated in the same way than in the other studies.

Only one study from Burbeck et al. (2014) gives a detailed national picture of volunteer activity in palliative care services^[42]. They compare the contribution from volunteers and paid staff and the results reveal an important variation in numbers and activities across statutory and voluntary palliative care services. Perspectives of costs need to be considered. From an NHS perspective, voluntary hospice care would be less expensive than a NHS palliative care ward because the main source of funding of a voluntary hospice is not from the NHS but charitable fundraising. This was reported by Hospice UK who estimated that on average adult hospices received only 32% funding from the government in 2013. The rest of the funding mainly comes from charitable giving^[64].

Finally, one intervention, the Gold Line, seems to have increased the unit cost of non-elective admission. The Gold Line is a telephone service acting as a single point of contact for patients and carers. It allows access to help and advice 24 hours a day, seven days a week and aims to support patients when possible in their preferred place of care. Even though this result diverging from the conclusion of most of the evidence could be partially explained by the limitation in the methodology, the paper suggests that the Gold Line increased the unit cost of hospital care. The paper argues that the Gold Line enabled the patients with serious unmet needs to reach out the hospital, driving up the average cost of non-admission^[17].

From a societal perspective, the importance of informal care (volunteering but also that from family of the patients) is often missed in costs studies. While the savings to the NHS are usually correctly calculated, additional costs (or additional savings) to the informal care setting is not often considered. This is likely to overestimate the potential cost-savings of shifting care from hospital to home.

Sub-question 3: Modelling the timing of costs and outcomes for different parties across the care pathway associated with shifting patterns of care

No strong evidence was found on modelling the timing of costs and outcomes across the care pathway. Two studies used Markov modelling to estimate the potential saving of shifting patterns of care by using transition probabilities of patients moving from one care setting to another^[34;35]. The issues of these studies, however, is that they simplify

models of care available at the end of life as they only consider costs from the perspective of the tax payer and do not include informal care costs. For instance, Hatziandreu et al. (2008) estimated the costs of care across settings for a cohort of patients in their last year of life, with cancer or with organ failure. They found that cancer patients and patients with organ failure would spend 94% and 89% of their time at home, 1% and 0% in hospice and 5% and 11% in hospital, respectively. This type of modelling enabled to estimate the current costs incurred in the three settings and to establish some scenarios when some elements of patient care are shifted from hospital to the community.

The model estimated the potential savings of shifting care from the hospital to the community of all patients with cancer and organ failure in England (estimated from the England deaths register, 2006). The hypothetical cohort used in the model is made of 126,779 and 29,440 cancer and organ failure patients respectively. The authors' main findings are the following:

- on average, a one-day reduction in the mean hospital length of stay implies a £26 and £16 million reduction in the total end of life cost for all cancer patients and patients with an organ failure, respectively (£205 and £126 per person)
- a 5% reduction in emergency admission implies a £16 and £13million reduction in the total end of life cost for cancer patients and patients with an organ failure, respectively (£126 and £441 per person).

Another study from Georghiou and Bardsley (2014) described in sub-question 1, estimates the extra costs incurred to the community (Primary care, Social and Community care) of a reduction in 2.5 days stay in hospital^[39].

Sub-question 4: Highlighting incentive issues operating across the health and social care system.

No direct evidence was found to answer this question from the published literature. However, there is a range of evidence around how commissioners and providers are addressing the resource challenges, which include how incentives can be structured.

Financial challenges: pressure of urgent care system flow:

As a result of the ageing population, more people are expected to die at an older age and will be more likely to have complex needs and multiple comorbidities. This will increase the level and intensity of end of life care required in the UK and is likely to put even more pressure on the urgent care system flow. Alongside the demographic pressure, financial pressures might not allow CCGs to invest significantly in the redesign of end of life care provision.

The increasing multimorbidities at the end of life requires, however, a change in funding regimes towards a more integrated approach aiming to create incentives that bring commissioning partners together for delivering agreed outcome measures^[65].

Integrated commissioning:

Because service provided at the end of life comes from a range of sectors with various funding regimes, CCGs are encouraged to consider joint commissioning and the possibility of pooled budgets with the different commissioning partners. To make this funding mechanism work, providers would have to agree on joint outcomes that would be measured across the sector (eg monitoring patients' and carers' experience of the new service). This joint commissioning approach is necessary for ensuring all care providers have the right incentive to deliver a high quality service. For instance, if a social care organisation invests in improving the end of life care of its patients, the extra costs will be paid by the social care services but financial savings will happen in secondary care through reduction in admissions. The social care provider needs to ensure that investing in end of life care services would lead to some benefit within its organisation and not solely in the secondary sector^[65].

Practicalities for redesigning services:

Many initiatives have been put in place to redesign commissioning services. The ultimate goal would be to agree on a currency that would group patients at their end of life according to their clinical and resources need. This is ongoing work from NHS England, which in 2015 developed 28 currency units for adults at their end of life based on patients clinical health (eg stable, unstable, deteriorating and dying stages)^[66].

Additionally, commissioners have a set of tools and framework available from Commissioning and Quality for Innovation (CQUIN) and Quality, Innovation, Productivity and Prevention (QIPP) scheme that are not focused on end of life but provide a template on how commissioning focusing on patients' outcomes can be put in place and how the transition from the current to more integrated commissioning can be as smooth as possible^[65].

Case study

A hospice in the south-east of England functions as the 'prime contractor' for a range of local hospice based and community services. The hospice provides the in-patient hospice care and day hospice service, sub-contracts the community nursing (hospice care at home) and co-ordinates the 24/7 advice line, which receives more than 3,000 calls per month from people at end of life and their carers, and clinicians seeking specialist advice on palliative care. This arrangement supports the commissioners in reducing overheads related to multiple contracts with several providers, helps meet objectives related to co-ordinated care across different services, as well as meaning the hospice can maintain a central overview of provision and need in the area^[67].

Input from the workshop: discussion about the optimal approach to end of life management (care pathway)

In a stakeholder workshop held on 9 February 2016, preliminary findings of the review were presented, followed by a discussion about optimal approaches to end of life management.

There are a number of standards and frameworks that set out general best practice for care provision for patients at the end of their lives. NICE developed a quality standard that encompasses the whole end of life care pathway^[1]. It aims to offer high quality care that, when delivered collectively, should contribute to improving the effectiveness, safety and experience of care for adults approaching the end of life and the experience of their families and carers. The NICE Quality Standard emphasises the importance of having integrated and co-ordinated services across all relevant health and social care agencies, including specialist palliative care. The Quality Standard is made of 16 quality statements encompassing the entire end of life care pathway: from the identification of a patient at the end of life and communication with patients and families to bereavement support^[1].

The Gold Standard Framework (GSF), inspired by the NICE Quality Standard, was introduced at the stakeholder workshop as a potential effective approach to end of life care, although, to date, no peer reviewed publication has demonstrated its effectiveness. The GSF team has delivered training to thousands of doctors, nurses and carers who provide care for patients in their final years of life. It operates in any care setting (eg home, care home and hospital), and provides tools, resources and support for facilitating changes in local implementation and for measuring the progress of end of life care within an organisation.

The documents extracted present evidence supporting ten existing GSF training programmes^[28], the GSF Care Home (GSFCH) training programme^[20; 21; 24] and the GSF Primary Care Accreditation quality hallmark awards Accredited and GSF primary care accreditation GP^[45].

The methodological quality of the above studies have serious limitations (in several cases the methodology has not been explained in detail), therefore the results and conclusions reported need to be taken with caution.

The improvement of outcomes for quality of care might change per settings/types of programme but globally the GSF aims to achieve the following outcomes:

- increase the number of people recognised to be at their last year of life^[19; 23]
- provide and record Advance Care Planning (ACP) discussions between patients, family, friends and healthcare providers^[19; 20; 23]
- increase the number of patients who die in their preferred place of death (fewer deaths in hospital and more deaths in care home)^[19; 20; 21; 23]
- increase the number of discharges home from acute and community hospitals^[23]
- decrease hospital/crisis admissions^[20; 21; 23]
- increase the overall staff confidence and quality of care^[19; 20; 21; 23]

We cannot however conclude with certainty the extent to which these objectives have been achieved after GSF training sessions and if it provided a real improvement in the quality of life of patients and family.

Critical appraisal of the evidence (applicability and limitation)

The critical appraisal of the studies included in the review is based on the NICE methods guidelines^[13]. They assess two domains:

- applicability: to what extent the results and conclusions of the economic evaluation are applicable to the current UK situation
- limitations: to what extent the methodological quality of the economic evaluation is likely or unlikely to change the conclusions about cost-effectiveness

The studies are generally applicable as all studies retrieved are based on UK population. The frequent methodological limitations encountered in the studies are listed below:

Study design and comparator data:

As expected, few studies have a clear design enabling to assess with certainty the causality between place of care/interventions and patients' outcomes. Except for the two randomised control trials^[14;15] and studies reporting outcomes before and after the implementation of an intervention^[16;17;18; 19; 20; 27], the comparator used for evaluating an end of life model/setting tend to be unclear or absent. Some studies also compare outcomes of patients joining or not a specific initiative. While they are informative, they would most of the time have some selection biases as patients would not be allocated randomly but would decide to join a specific programme.

Sample size and statistical significance:

Even when studies overcame the issues related to design and comparators, they tend to have a limited sample size or they do not always report statistical significance of their results. Beside the size of the sample, there is sometimes an issue considering the representativeness of the population. Some studies target a specific clinical condition or healthcare setting which does not always enable to extrapolate the results to the wider population (eg patients with dementia from care home).

Transparency of the methodology:

Most of the evidence related to the impact of an intervention on a model of care comes from grey literature. Usually, in reports written by charities and public organisations, the evidence do not clearly express the method of recruitment and data collection, the comparator and other baseline data and the method of measurement which complicate the assesment of the robustness of the studies (as compared to peer reviewed studies which have usually a methodology and limitation section) .

Good methodological study but not completely answering the right question:

Some studies do not evaluate an intervention but provide useful information on cost data between care settings and on the postential costs that could be saved by shifting care from secondary care to the community. While these study are informative, they do not inform the influence of the place of care/type of care on patients' outcomes.

3.4 Conclusion

Even though none of the studies reviewed in this and previous reviews performed a robust cost-effectiveness analysis of end of life care, where authors have done an economic analysis, the evidence seem to suggest that the existing breadth of palliative and end of life care interventions in the primary, social and community care settings are potentially cost-saving or cost-effective. It is possible that this conclusion is informed by the types of outcomes that these studies tend to focus on, such as service use or place of death.

The Palliative care outcomes scale (POS) has been used as an alternative to the EQ 5D scale for assessing utility and quality of life at the end of life in few effectiveness studies^[68]. Only one study which assesses the effectiveness and cost of a breathlessness support intervention used this scale^[15]. It would be desirable if, in the future, economic evaluations would assess the quality of life of patients at the end of life using the POS scale such as in the ongoing study on Short-term Integrated Palliative Care Services (SIPC)^[69].

Most of the other studies consider that the use of 'less costly' services (ie community and home care) are preferred by the patients and would improve their quality of life, models shifting care to the community could be cost-effective in situations where the patient can receive same levels of medical care outside the hospital. However, the assumption of less costly community care compared to hospital care does not always hold, notably for patients with complex needs. No strong analysis on actual patient quality of life per care settings has been reported and the distinction between place of death and place of care is not always clearly made by the studies that tend to use both terms interchangeably. In costing studies and studies that attempted to model the timing of costs shifting patterns, the role of informal care is often omitted or underestimated. A patient cared for at home imposes an extra cost on the family in terms of time, well-being and opportunity costs (eg hours of employment lost by carer). Because of this limitation, the extent of the cost-savings cannot be determined with confidence when care is shifted into the community.

End of life care is complex and there is no clear evidence yet on the optimal care pathway. The only certainty is that models of care should be more integrated to ensure a smooth transition for patients when they change from one care setting to another. This is one of the challenges faced by CCGs who need to consider some sort of joint commissioning across settings to ensure that all organisations are driven by the same goal.

Throughout the review, it has been identified end of life care interventions that could potentially improve patients outcomes or impacts on health care costs (interventions are listed in Appendix 8). These interventions have been used as a starting point to build the economic analytical tool presented in the next section.

4. End of life care economic analytical tool

4.1 Introduction

The aims of the economic tool is to provide users with a simple data analytical tool that can help inform commissioner's decision-making for end of life care services, and assess whether additional costs incurred in the primary, community and social care sectors (due to activity and cost-shifting) outweighed any potential savings from reductions in activities in the secondary care setting. After presenting a literature review to the steering group, it was agreed that the economic tool would explore the trade-offs associated with shifting care from an acute setting to a primary, community and/or social care setting, due to the uncertainty around the costs and impacts of alternative interventions and services for patients at the end of their lives.

The interventions do not have complete information on effect or cost-saving and only two interventions have some incomplete information available. The tool is therefore not designed to provide commissioners with a definitive answer regarding which interventions should be commissioned or is the tool designed to assess the practicality of implementing given interventions; elements such as other existing policies, capacity, process and people must also be considered. Instead, it presents the user with an assessment of the potential net financial implication of interventions that shift activities away from the acute care setting to primary, social and/or community settings.

There are several main reasons for using this end of life economic tool when considering whether or not to commission given interventions. This tool provides the opportunity to assess the net financial implication to each organisation that will be affected when the interventions are implemented, whilst taking into account the funding arrangements of the services, thereby providing the opportunity to assess the financial feasibility of co-financing arrangements for several primary, community and social care services. This may be useful when considering co-commissioning opportunities and incentives across organisational boundaries. Measures such as current expenditure from the number of days spent in hospitals arising from emergency and non-emergency admissions, the number of deaths, and the percentage of deaths in hospital provide context.

Furthermore, this tool provides information on the magnitudes of potential increases in primary, community and social care demands and costs, which give an indication of whether existing infrastructure or other resources can manage such increases in activities. The potential financial implication for patients and/or their families has also been incorporated, illustrating how the actions of service providers (NHS England, CCGs, local authorities, and voluntary organisations) can impact on patients and/or their families. This aspect emphasises the importance of considering wider incentives rather than purely focusing on financial incentives for public sector organisations alone.

This tool is made up of two components:

The first is a summary of the costs, impacts and wider issues associated with different interventions and services for providing care and support for patients at the end of their lives. This is a summarised form of the interventions that were encountered during the literature review, which is presented above in section 3 (Appendix 8) and therefore does not represent an exhaustive list of existing interventions.

The second component is a tool, that enables the user to explore the potential trade-offs associated with shifting resources and activity away from (assumed more costly) secondary care into (assumed less costly) primary, community and social care settings; since it is uncertain whether this is indeed the case.

4.2 Intervention summary

This section of the tool provides a summary of the information that has been retrieved via the literature review, on a range of services and care, presenting interventions for patients who have been classified as being at or near the end of their lives. The full list of interventions can be found in Appendix 8. The user selects an intervention from a menu, and the following information, if available, will appear:

- category of the selected intervention (eg IT, training, etc)
- a description of the intervention
- the activities associated with the intervention
- reference number(s) of the intervention (a list of references is on a separate tab)
- type of output and outcomes
- quantification of the output
- characteristics of the outcome
- required investment and estimated cost-savings

4.3 Economic analysis: activity and cost-shifting analysis

The activity and cost-shifting analysis component allows the user to explore the potential financial implication of shifting activity from the secondary care sector to the primary, community and social care sectors, whilst providing the opportunity for decision-makers to estimate the change in financial position of each affected organisation who funds these services, this includes patients and/or their families. This tool also estimates the scale of increase in the number of activities and costs in primary, community and social care.

In the activity and cost-shifting analysis part of the tool, the key parameters are the expected decrease in secondary care utilisation, the expected increase in primary, community and social care utilisation, and the unit cost of each service.

The secondary care activities considered are broken down into:

- number of emergency and non-emergency admissions

- average length of inpatient stays (in days) arising from emergency and non-emergency admissions,

The primary, community and social care activities considered were:

- GP consultations
- out-of-hours GP Consultations (urgent and emergency)
- district nurse visits
- care at home provided by a home care worker
- informal care (spouse, family, etc)
- inpatient days in hospice care
- residential home care
- nursing home care
- community palliative nursing contacts (eg as provided by Marie Curie)
- specialist community palliative care contact team visits (community based hospice care)
- voluntary care from a third sector organisation.

Whilst this list of activities is unlikely to be exhaustive, it is designed to provide a broad range of activities (and potential funding sources) that could divert end of life care provided in a secondary care setting.

4.4 Methodology

To begin, a geographical area needs to be selected (eg a CCG or England as a whole) as well as an illness category, and the time period concerned (i.e. the number of years between when the benefits were expected to come on stream and when the interventions are expected to end). The baseline activity is assumed to grow at a given annual growth rate and the expected percentage decreases in secondary activities is applied on a yearly basis.

The monetary value associated with this reduction in secondary care activities is calculated by multiplying the volume of activity with the reference unit cost of the relevant activity. For the reductions in both the number of emergency and non-emergency hospital admissions, the number of admissions are converted into the number of inpatient days averted using the current average length of stay.

To bring about this reduction in secondary care utilisation, it is possible that there will be some additional investment/spending in other aspects of the health and social care system. These costs are broken down into two, a one-off initial investment and an estimated yearly cost. If there is no additional investment, existing resources are expected to absorb the activity diverted from the secondary care sector.

The expected reduction in secondary care utilisation, and how this diverted activity, i.e. the number of inpatient days avoided, is expected to be split between the following care settings: home, residential home, nursing home, and inpatient days in hospice care. In

addition, for the days expected to be spent at home, information is required on the expected demand for primary, community and social care services.

The total increase in the cost of delivering additional primary, community and social care services are apportioned by the percentage of financial contribution by each funding organisation, including patients and/or their families.

When estimating the financial implication, the tool assumes that the costs of activity decreases in secondary care and activity increases in primary, community and social care, are the costs of delivering these services. Other assumptions are:

- the expected percentages of secondary care utilisation reduction and the expected increases in primary, community and social care utilisation are assumed to be achieved
- the savings from reduced secondary care utilisation is directly transferable to primary, community and social care settings

4.5 Illustration: an indicative case study

This section provides an illustration of how a given locality might use this tool to gauge the potential impact of shifting activity from the secondary care sector to the primary, community and social care sectors. It is important to note that this is an indicative scenario. The activity and cost-shifting analysis provides insights on a local level and, for the purpose of this illustration, data for a specific CCG has been used and the illness category is circulatory diseases, including heart disease and stroke.

4.5.1 Current statistics

The number of deaths in in the health economy for circulatory diseases is 1,372 in the year 2013-2014, 51% of which occurred in hospitals. From 2013 to 2015, the average yearly number of emergency admissions is 1811, the average length of stay arising from emergency admissions is 10 days, the average yearly number of non-emergency admissions is 410, and the average length of stay arising from non-emergency admissions is 25 days.*

4.5.2 Activity and cost-analysis

The following section illustrates the types of scenarios that the tool can model. If we assume the funding organisations in the health economy plan to implement an intervention to lead to a 10% reduction in the number of emergency admissions on a yearly basis, with the expected reduction to come on stream two years after the intervention's implementation, and there is funding for four years. The reduced number of inpatient days avoided arising from reduced number of emergency admissions at the

* Based on latest available data for all CCGs; individual CCGs may have more up to date local data.

year when the benefits are expected to come on stream will be 3742 inpatient days, with a yearly activity growth of 3%.

It is anticipated that 50% of patients spend this ‘extra’ time out of hospital at home, 30% of patients spend time in residential homes, and 20% of patients spend time in nursing homes.

For these extra time spent at home, whilst there are no additional residential costs, it is expected that there will be additional services accessed by the patient. In this instance the user expects these to be as follows:

For patients who avoid emergency admissions completely, each patient is expected to have five extra days out of hospital on average, and their access to primary, community and social care services is expected to be as indicated in the following table.

For a Typical Patient Staying at HOME Who Avoided Admissions, the Additional Services to be utilised during the 5 day(s)	Number of Visits	Number of Hours
GP Consultations	1	
Out-of-Hours GP Consultations (Urgent and Emergency)	2	
District Nurse		5
Care at Home provided by a Home Care Worker		10
Informal Care (Spouse/Family etc.)		2
Community Palliative Nursing Contact (e.g. as provided by Marie Curie)		2
Specialist Community Palliative Care Contact Team (Community-Based Hospice Care)		
Volunteer from a Third Sector Organisation		

For patients who are discharged from hospitals earlier than they previously would have been, each patient is expected to be out of hospital for less than one day on average. Hence, it is anticipated that there would not be any additional demand in primary, community and social care.

The required investment in this particular case: the expected initial one-off investment costs to NHS England, the CCG and the local authority is £100,000 each, and estimated yearly operational costs are £50,000 each.

Based on the user’s input, the increase in primary, community and social care activities are as follows:

Primary, Community and Social Care Service	Expected average monthly activity increase for all patients in the 4 years during which the intervention(s) will be implemented	Expected average annual activity increase for all patients in the 4 years during which the intervention(s) will be implemented	Expected total increase in activity (cumulative) for all patients in the 4 years during which the intervention(s) will be implemented	Total increase in cost (cumulative) for all patients in the 4 years after the implementation of intervention(s)
Home	23	275	826	£0
Residential Home (Local Authority-Funded)	7	83	248	£115,898
Residential Home (Self-Funded)	7	83	248	£150,011
Nursing Home (Local Authority and NHS England-Funded)	5	55	165	£100,542
Nursing Home (NHS England and Self-Funded)	5	55	165	£123,284
Inpatient Days in Hospice Care	0	0	0	£0
GP Consultations	16	198	594	£23,561
Out-of-Hours GP Consultations (Urgent and Emergency)	33	396	1,188	£73,858
District Nurses	82	990	2,969	£208,833
Care at Home provided by a Home Care Worker	165	1,980	5,939	£128,512
Informal Care (Spouse/Family etc.)	33	396	1,188	£7,711
Community Palliative Nursing Contact (e.g. as provided by Marie Curie)	33	396	1,188	£82,462
Specialist Community Palliative Care Contact Team (Community-Based Hospice Care)	0	0	0	£0
Volunteer from a Third Sector Organisation	0	0	0	£0

The net financial position of NHS England, the CCG, and the local authority as a whole will have saved £1,164,547. Using the default funding contribution amongst various

organisations, the model generates estimates for the overall change in financial position for these organisations over the four-year period:

- NHS England will have an increased expenditure of £0.42 million
- the CCG will have saved £2.34 million
- the local authority will have an increased expenditure of £0.75 million
- the voluntary sector will have increased expenditure of £0.06 million
- patients and/or their families will have an increase in their time commitment, which is valued at £0.33 million

Four years after the implementation of the intervention, the system as a whole will have a net present value (change in financial position) of £0.78 million, given the investment made, reduced secondary care inpatient days, and activity increase in the primary, community and social care.

4.6 Interpretation of results

It is important that the user understands what this tool does and does not say about the economics of end of life care.

For a range of defined information ie:

- local information provided (CCG, illness category and time frame)
- a user-defined expected reduction in secondary services
- a projected impact on the primary, social and community care sectors
- national cost data

The tool informs the user whether an intervention designed to reduce secondary care utilisation in the provision of palliative care demonstrates value for money, given the expected transfer of care to other settings.

It is, however, important to reflect on the financial and economic interpretation of savings resulting from a reduction in activity (in secondary care services). There are three potential consequences here:

The first is that a reduction in activity by a provider (and hence a reduction in the payment made by CCGs to a provider) may not reflect an actual reduction in the costs incurred by the provider themselves. The cost base, and the nature of fixed and variable costs, may mean that the secondary care provider, although seeing a reduction in the volume of activity may not (immediately) be able to reduce expenditure. The consequences of this might be that whilst CCGs can reduce their contracted expenditure through reduced activity, the providers' financial position may worsen if they are unable to reduce costs.

The second point is more of an economic than a financial one - if the level of activity of an organisation is reduced, then a reduction in expenditure may not be the appropriate, or indeed the desired, action. Notwithstanding the issues raised in the point above, one option to an organisation might be to "cash in" the savings arising from the reduction in

activity, by releasing resources and reducing expenditure. However, an alternative might be to reallocate the released resources to the next best alternative (which given competing pressures in the NHS might be the socially optimal course of action). In this case, there are no financial savings, but benefits are realised in a different form, i.e. improved/increased care provided in the next best alternative use of the freed up resources. What actually happens in this context, is of course, dependent on the CCG. However, the point to be raised is when faced with a reduction in activity, an organisation can either reduce costs, or reallocate expenditure.

Finally, the third course of action is that savings are not cashed in by the provider, resources are not redirected to the next best new use, but that the resources are absorbed at the same cost but at a reduced level of output, and productivity falls. This is, of course, the most undesirable course of action.

The results produced by the tool are based on the simplistic assumption that released resources in the secondary care setting can be cashed within the provider and reallocated to other care settings. However, users should be aware that in reality there are a number of choices available to decision makers with regard to 'cashability'.

This information can be used by commissioners alongside local data about current expenditure and activities to inform local strategies and discussions about future commissioning plans for end of life care services.

What the tool does not do is tell commissioners where resources should be allocated, and what are the most cost-effective, or cost-saving, interventions for patients at the end of their lives. This would be the outcome of a more detailed model, the data for which is, at present, non-existent. This more detailed model would also require detailed data about baseline levels of local service provision at a CCG level, which would be time-consuming and resource-intensive to collect, and likely to be out-of-date extremely quickly.

In addition, decision-makers need to consider the potential improvement, or indeed the potential decline, in the quality and safety of care, and patient experience, in conjunction with the net financial implication, when considering the implementation of interventions. A neutral or positive net financial implication alone should not be the only determinant. Moreover, it is essential for decision-makers to consider whether or not the current capacity of care provision can adequately cope with a potential influx of primary, community and social care activities.

The current tool provides the user with a further piece of evidence about the potential financial trade-offs associated with transferring activity from the secondary care sector to the primary, community and social care sectors based on a defined reduction in emergency and ordinary admissions and/or their associated average length of stay.

5 Conclusion

By compiling existing evidence on the cost-effectiveness of end of life care services, this analysis helps to better understand the health economics of end of life care.

The evidence suggests a desire from patients and carers for end of life care to be moved away from secondary medical care settings to other settings, either at home or in the community. Theoretically, this could represent significant savings from shifting end of life care away from secondary care.

As reported in the literature, a number of interventions, such as the home based end of life nursing care described in Georghiou and Bardsley (2014), have demonstrated that such impacts are possible since shifting care from 'more costly' services (hospital) to 'less costly' services (community and home care) could reduce the overall total cost of end of life care^[39]. It is important, however, to highlight the fact that informal care is not always considered appropriately in the calculation of cost-effectiveness and that the perspective (ie NHS or society) of the analysis is prime in economic analysis.

Within the model produced alongside this report, we have included the costs of informal care. Additionally, no strong analysis on actual patient quality of life per care settings has been reported. Generally in the literature it is assumed that patients dying in the setting of their choice is correlated with 'better care'. However, there is no objective evidence proving this, only the assumption that given the care is provided in the preferred setting of the patient/carer. Furthermore, often in the literature, the distinction between place of death and place of care is not always clearly distinguished and are sometimes assumed to be synonymous. This further limits our ability to draw strong conclusions from the literature.

Additionally, the interpretation of savings resulting from a reduction in activity needs to be considered carefully. Shifting activities could result in savings to (one part) of the NHS but the impact of shifting activities to other areas of the NHS (eg district nursing) or community and social care needs to be recognised and accounted for. As articulated in the literature review, the uncosted impact on the voluntary care, including carers and families, is not frequently considered. The tool produced alongside this report does include the possibility of examining the impact on the informal care provision.

The economic tool gives some indication to commissioners on the consequences of shifting expenditure, but this does not give the final answer to commissioners as to where to allocate resources. Rather it can help commissioners to explore the potential for moving care from one setting to another and understand the cost implications and the likely relative trade-offs, even if activities in secondary care can be reduced.

6 Appendices

Appendix 1: Methodology

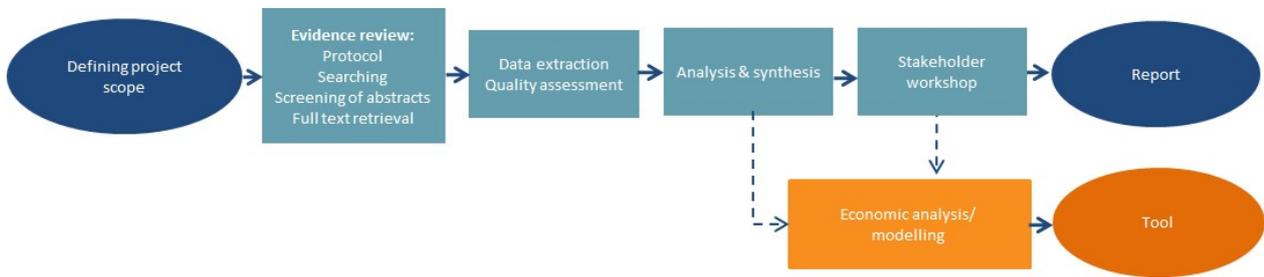
The key features of the rapid evidence review methodology are summarised in Table 2.

Table 2: Steps of the rapid evidence assessment

Steps	Description
1. Developing the protocol	Developing and submitting a protocol for the evidence reviews based (including draft search strategy and search strategy) for PHE approval.
2. Searching and retrieving	Developing targeted, focused strategies to locate evidence that might be relevant to the review questions.
3. Selecting and screening	Using clearly defined inclusion criteria to determine which of the located studies are relevant to the review questions.
4. Extracting and collating the data	Using comprehensive data extraction tools to capture all necessary data, including study context, population, intervention content, and effectiveness and cost-effectiveness findings.
5. Assessing the quality	Assessing the quality of the studies using a standard checklist.
6. Synthesising the data	Synthesising the data by identifying trends and drawing conclusions across the body of evidence reviewed.
7. Reporting the evidence	Summarising our findings in the requested reports in a clear and accessible manner.

A diagrammatic overview of the process for conducting the evidence review is given in Figure 2.

Figure 2: Evidence review overview for this project



In order to select the studies to be included in the review, database searches were conducted. The search protocols and the list of databases consulted are included in the appendices. The websites of relevant organisations were searched for additional studies. Additional papers, reports and resources were identified at the workshop ‘Understanding the economics of palliative and end of life care’ held on 9 February 2016.

The diagram in ‘**Error! Reference source not found.** below represents the flow of literature for this review.

Figure 3: Flow of literature for this review



32 studies and reports and 11 systematic evidence reviews have been included in the review. The overview of the studies included is presented in the next section. The list of included studies is presented in Appendix 2 and summaries of all the included papers are presented in Appendix 3. Although the rapid evidence review is based on a robust and thorough method, the list of studies is not an exhaustive one.

Appendix 2: Summary of included studies

[14] Higginson I, McCrone P, Hart SR, Burman R, Silber E, Edmonds PM. 2009. Is Short-Term Palliative Care Cost-Effective in Multiple Sclerosis? A Randomized Phase II Trial. *Journal of Pain and Symptom Management*; 38:6: 816-826.

Higginson and colleagues (2009) have evaluated the cost-effectiveness of a palliative care service for patients with multiple sclerosis (MS). The study compared a group of patients who received multi professional palliative care team treatment (fast track) to a control group who received usual care for three months and then received multi professional palliative care team treatment. The study found that the mean service costs for the fast-track group (inpatient care and informal care) over the 12 weeks follow-up were £1,789 lower than the costs of the control group. Lower community costs in the fast track group were observed compared to the non-fast track group. There were no differences in cost of informal care. The authors concluded that short-term palliative care for patients severely affected by MS and their caregivers will be cost-effective.

[15] Higginson, I., Bausewein, C., Reilly, C., Gao,W., Gysels,M., Dzingina,M., McCrone,P., Booth,S., Jolley,C., Moxham,J., 2014. An integrated palliative and respiratory care service for patients with advanced disease and refractory breathlessness: a randomised controlled trial. *The Lancet*.

This randomised trial analyse randomly allocated adults with refractory breathlessness and advanced disease to receive either a breathlessness support service or usual care. The breathlessness support service was a short-term, single point of access service integrating palliative care, respiratory medicine, physiotherapy, and occupational therapy. Mastery in the breathlessness support service group improved compared with the control (mean difference 0.58, 95% CI 0.01–1.15, $p=0.048$; effect size 0.44). Survival rate from randomisation to six months was better in the breathlessness support service group than in the control group (50 of 53 [94%] vs 39 of 52 [75%]). The authors concluded that the breathlessness support service improved breathlessness mastery for the patient without any extra costs.

[16] Sue Ryder. 2013. Partnership for Excellence in Palliative Support (PEPS). Evaluation of pilot. Sue Ryder Evaluation Series: Report No. 2.

This study evaluates the impact of PEPS (Partnership for Excellence in Palliative Support) over 12 month pilot programmes. PEPS provides a 24 hours telephone point of access for palliative care services and a single point of contact for patients and their carer. 1,051 patients from NHS Bedfordshire were enrolled in the programme, of whom 620 patients have died. The emergency admissions prior to referral to PEPS were 256, however, after referral to PEPS were 178. Of the 256 admissions before referral to PEPS the average length of stay was 10.1 days compared to 6.9 days during PEPS. The average length of stay during the final four months of life was 8.8 days. The

average cost per admission during the final four months of life was £3,359. This figure was higher before referral to PEPS (£3,388) compared to during PEPS (£3,075).

[17] York Health Economic Consortium, 2016. Economic Evaluation of the Gold Line: Health Foundation Shared Purpose project, Airedale NHS Foundation Trust.

This report presents findings from the evaluation of the Gold Line system to enhance and improve end of life care in Airedale, Wharfedale and Craven, incorporating both economic findings from York Health Economics Consortium and other qualitative findings from work carried out by the University of Bradford. The Gold Line started operating in November 2013 for Airedale, Wharfedale and Craven CCG and in April 2014 for Bradford CCGs, and is a single point of contact for patients and carers, allowing access to help and advice 24 hours a day, seven days a week.

The authors compared the place of death and number of non-elective admissions before and after the implementation of the Gold Line and found a 23% reduction in admissions equivalent to a reduction of 390 bed days in a sample of 70 patients. They reported a slight decrease in hospital deaths falling from 36.8% to 35.3% and an increase in deaths in usual place of residence from 52.4% to 54.3%.

Cost results are more mitigated:

Even though the number of admissions is reduced, the total costs of unplanned admission is higher in the intervention group because the average cost per admission was higher in the intervention group (£7,607 in the intervention group versus £6,632 in the control). The paper suggests that the difference in admission cost may be due to inflation of the payment by result tariff but this is unlikely to account for such large differences in cost and it could be due to many reasons such as patients with unmet need being identified and admitted appropriately to hospital.

The paper however also multiplied a national average cost of elective admission (£2,350) with the number of elective admission before and after the intervention. This led to a potential saving of £443,000 or the full set of patients who used the Gold Line and died (n=347).

[18] Amador, S., Goodman, C., King, D., Ng, Y.T., Elmore, N., Mathie, E., Machen, I., Knapp, M., 2014. Exploring resource use and associated costs in end-of-life care for older people with dementia in residential care homes. *Int J Geriatr Psychiatry* 29, 758–766.

This study aims to compare the end of life care costs of older people with dementia (OPWD) who are residents in care homes (CHs) before (phase 1) and after (phase 2) the implementation of a modified Appreciative Inquiry intervention. In this study, data have been collected for 133 OPWD in six residential care home before and after the intervention. Outputs from the intervention included a script for discussing end of life wishes with relatives based on materials developed by the Dying Matters Coalition set

up by the National Council for Palliative Care, a tool to support discussions with emergency and out-of-hours (OOHs) services and a GP-led implementation and audit of advanced care planning. The costs reported for each resident in Phase 1 were about £2,800 per month (including service, accommodation and medication). As a result of the intervention, the total service costs fell by 43% and hospital care costs fell by 88%. Besides cost-savings, the intervention was perceived as having a positive impact on working relationships between CHs and visiting health care practitioners.

Conclusions: Results presented here represent early work in an under-researched area of care.

[19] Clifford, C., Thomas, K., Armstrong-Wilson, J. End of Life Care in Primary Care: The Gold Standards Framework, Going for Gold service improvement programme and Accreditation process (Paper currently in publication)

This study compares the outcomes of the 10 first GP practices that undertook Gold Standard Framework (GSF) 'Going for Gold' training in primary care and progressed to GSF RCGP Accreditation. The outcomes reported are:

- earlier identification rates of patients in the last year of life, average 0.54% (with a range of 30-60%)
- increased non-cancer patients on their register (18%-47%),
- increased numbers of care homes residents (22%-40%)
- efforts to increase the numbers offering and recording advance care planning discussions showed significant increases with an average of 46% (range 26%-62%)
- greatly improved systematic carer support offered (17%-72%)
- more dying in their preferred place of care (44%-59%)

The study however has very serious methodological limitations as the methodology is not explained and there is a mismatch in the figures presented.

[20] Stobbart-Rowlands., 2015. Bradford, Airedale and Craven GSF Care Homes Training Programme Evaluation Report.

This is an evaluation report of the GSF Care Home training programme in Bradford, Airedale and Craven. The evaluation presents data from a survey with the 30 participating Care Homes, with an 80% response rate. Main findings of the survey are as follows:

- improvement in quality of care: level of attendance care planning, before: 65%; after: 92%
- increased confidence of staff: confidence level increased by 8.9%
- increase in advance care planning and recorded PPC (ADA - After Death Analysis): advance care planning discussions increased from around 47% to 71%;
- reduction in crisis admissions in last stages of life (ADA): crisis admissions in the last six months of life, from the 16 homes that completed both base line and follow up

ADAs showed a significant reduction of around one third from 33 admissions for 70 resident deaths to 24 admissions for 72 deaths.

- reduction in hospital deaths: more dying in their usual place of residence (ADA): home death rate, before: 84.3%; after 88.9%; preferred place of care recorded increased by around 10% to 78%.

[21] Gandy, R., 2010. Economic appraisal of an end-of-life care training initiative for care homes with dementia patients. *Journal of Care Services Management* 4, 321–330.

Gandy (2010) performed an evaluation of an education and training initiative that has been developed by Greater Manchester Strategic Health Authority for care staff in four care homes (with nursing) and one NHS mental health ward. The initiative encompasses end of life care tools, such as the Gold Standards Framework and the Liverpool Care of the Dying Pathway.

The initiative aimed at improving the quality of end of life care received by older people with dementia. The results indicated that the proportion of patients who died in their preferred place of death increased following the initiative. All of the patients who stated 'home' as their preferred place of death (60%) died in their home, and all those who stated 'hospital' (27%) died in hospital. The remaining four cases (13%) did not have an answer recorded and all of them died in hospital.

The overall cost of the initiative equated to approximately £131,000 per annum. It is equivalent to £26,200 per home, £916 per available bed or £956 per occupied bed/patient. Dividing the costs by the number of patient deaths gives a figure of £4,094. The study then discusses that the only way in which a primary care trust (PCT) will save money is if patients who wish to die in their nursing home do actually die there, and are not admitted to hospital. Nursing home charges will be the same irrespective of whether a patient is admitted to hospital and the length of stay at hospital would impact the costs of the hospital trust and not the cost of the PCT.

[22] Noble, B., King, N., Hughes, P., Winslow, M., Melvin, J., Brooks, J., Bravington, A., Ingleton, C., Bath, P. (2012) Evaluation of the Midhurst Macmillan Specialist Palliative Care Service (Real Choice Project): A community consultant-led palliative care service

This report made for Macmillan Cancer Support is an after death analysis that aims to assess whether the Midhurst service meets the original aims of the palliative care initiative. The Midhurst Palliative Care Service (MMS) is a consultant led multi-disciplinary team that aims to provide 'hands on' care and advice at home, in community hospitals and in nursing/residential homes. Its efficiency has notably been assessed in comparison with the Hospice at Home (H@H) intervention – another consultant led multi-disciplinary team that existed before MMS. The Midhurst Palliative Care Service receives referrals for patients in the population served by 19 general practices. The total size of the population is about 155,000 and 389 referrals were received in 2012, of

which about 85% are patients with cancer. The main outcome of interest is the number deaths that happened in the preferred place of death. Relatives of dead patients had been surveyed. One hundred of the 102 respondents reported that their relative had spent time at home in their last three months. The mean cost of the Midhurst service itself is about £3,000 per patient referred (based on a service cost of £1,200,000). Overall cost of the service is divided evenly between grants from Macmillan Cancer Support and the NHS.

[23] GSF - Overview of the work of the National GSF Centre in End of Life care

The report presents all the Gold Standard Framework projects across the UK and gives details of the existing 10 GSF training programmes. It presents the attainments of GSF Accredited Teams at GP practices, hospitals and care homes, although the methodology for obtaining the results is not explained. According to the paper, the GSF results are as follows:

- early recognition of patients (identification in the last year of life): GP practices: 70%; Acute Hospitals: 35%; community hospitals: 45%; accredited care home: 100%
- Advance Care Planning discussion offered to every person: GP practices: 75% offered ACP; Acute Hospitals: 85%-100% offered ACP; community hospitals: 98% offered ACP; accredited Care home: 95% uptake
- decreased hospitalisation and improved carers support: GP practices: halving hospital deaths, 65% carers support; acute hospitals: reduced length of stay, improved carers support; community hospitals: improved carers support; accredited care home: halving hospital deaths and admissions and 97% carer support
- dying where they choose using personalised care plan in final days: GP practices: 63% die where they choose; 75% using 5P plan final days; acute hospitals: increase in home discharges; 80% 5Ps care final days plan; community hospitals: increase home discharges; 97% 5Ps care final days plan; care home accredited: 84% died where they choose; 90% using 5Ps care plan

[24] National GSF Centre, 2016. Gold Standards Framework Care Homes (GSFCH) Training programme

www.goldstandardsframework.org.uk/cdcontent/uploads/files/GSF%20Care%20Home%20Evidence%20Summary%20Jan%202016.pdf

The paper summarises evidence describing the value and impact of the Gold Standard Framework (GSF) care homes training and accreditation programmes in three outcome areas: quality of care, co-ordination and collaboration and reducing hospitalisation. The evidence, collected since 2004, includes both local evaluations, audits, area-wide reports and peer reviewed papers evaluating GSF.

The evidence included shows that the GSF Care Homes Programme improves the following outcomes:

Quality of Care through:

- transforming the culture of care (attitudes, awareness and ethos in line with core values)
- helping people live well until they die
- developing staff confidence, morale and motivation
- improving job satisfaction, staff recruitment and retention
- encouraging an open, realistic approach to discussing dying and quality of care for dying
- facilitating proactive care and anticipatory care planning
- promoting more personalised care in line with person centred approach
- improving standards of care through governance

Co-ordination and collaboration through:

- earlier identification of patient needs
- enhancing collaboration with teams and between teams; providing a framework to enhance; patterns of working, structures and processes
- enhancing team working and information sharing within staff teams
- promoting collaborative working with GPs, District Nurses, Palliative Care and other specialists
- improving documentation, recording, and communication with all care homes staff

Outcomes including reducing hospitalisation:

- enabling cost-effectiveness and cost-savings for the NHS
- reducing hospitalisation
- enabling more to live and die in the place of their choosing;
- significant reduction in numbers of hospital deaths (e.g. halved) and crisis hospital admissions
- reduced length of stay in hospital
- fewer crises calls out of hours
- improving effective assessment and management of symptoms, including anticipatory planning and management

In terms of the reduction in hospital admission from care homes, the GSF evidence supports the drive to reduce inappropriate admissions with hospital deaths in GSF care homes being more than halved (13% in GSF Care Homes compared to 28.1% in the Non-GSF homes. The paper suggests that for a CCG with 50 care homes, the programme could achieve potential savings to the NHS of £1-2 million per year through reduced admissions to hospital from care homes and reduced lengths of stay. Also, the comparison pre and post programme has shown reduced crisis events and crisis admissions to hospital from 37.8% to 26.3%.

[25] Wye L, Lasseter G, Percival J, Simmonds B, Duncan L, Purdy S. 2012. Independent Evaluation of the Marie Curie Cancer Care Delivering Choice Programme in Somerset and North Somerset. University of Bristol

Delivering Choice Programme (DCP) was developed by Marie Curie Cancer Care and aims to develop services to ensure that the patients at the end of life die in their place of their choice. The DCP was implemented in Somerset and North Somerset. Following the implementation of the programme in North Somerset, it was found that patients under the DCP were 67% less likely to die in the hospital compared to the patients not receiving the DCP. The numbers dying in the hospital are even lower in Somerset (80% less likely to die in the hospital). In North Somerset, emergency hospital admissions have reduced in the last month of life (51% lower) and the last week of life (78% lower) following the DCP. In Somerset, emergency hospital admissions have reduced in the last month of life (39% lower) and the last week of life (68% lower) following the DCP. A&E attendances in the last month of life were also lower by 59% in North Somerset among patients enrolled in the DCP. In the last week of life the attendances were also lower, by 78% in-patients enrolled in the DCP compared to the patients not enrolled in the DCP. A&E attendances in the last month of life were also lower by 34% in Somerset among patients enrolled in the DCP.

In the last week of life the attendances were also lower, by 68% in-patients enrolled in the DCP compared to the patients not enrolled in the DCP. Delivering the DCP in North Somerset was estimated at £368,000 and indicative hospital costs (i.e. rough estimate) avoided were calculated at £151,609 over 12 months. In Somerset the cost of the DCP was £325,955 and indicative hospital costs avoided were calculated at £289,335 over 12 months. The impact of delivering the DCP on community costs were not calculated due to a lack of data.

[26] Chitnis X, Georghiou T, Steventon A, Bardsley M. 2012. The impact of the Marie curie Nursing Service on place of death and hospital use at the end of life.

Chitnis et al. (2012) made a comparative study between the patients who receive the Marie Curie Nursing Service (MCNS) and those who did not. Of patients who received the MCNS, 76.7% died at home and 7.7% died in hospital. These results are better than the patients who did not receive the MCNS where 35% died at home and 41.6% died in hospital. Emergency admissions to hospital decreased in-patients who received the MCNS; 11.7% had an emergency admission compared to 35% in the control group. MCNS also had a positive impact on A&E attendance; only 7.9% of MCNS had an A&E attendance compared to 28.7% in the control group. The authors also compared the costs of any hospital activities and concluded that the costs are cheaper for patients part of the MCNS programme; the total hospital costs for patients enrolled in MCNS was £1,140 per person less than for the control group.

[27] Addicott R, Dewar S. 2008. Improving choice at end of life; A descriptive analysis of the impact and cost of the Marie Curie Delivering Choice programme in Lincolnshire. King's Fund

The report by King's Fund analysed the impact and costs of a Marie Curie Cancer Care programme: Delivering Choice in Lincolnshire. The programme aims to increase choice at the end of life; it provides two discharge nurses (based in the acute sector) who facilitate speedy discharge of patients receiving end of life care to their preferred place of care. This programme is designed to provide services for both cancer and non-cancer patients.

The study found that the overall rate (people who accessed and have not accessed the programme) of home deaths have significantly increased after the implementation of the programme, from 19% to 23% for all patients (cancer and non-cancer patients). However, the figure was not statistically significant for non-cancer patients. If only people who accessed the programme are considered, then the percentage of deaths at home have increased from 19% to 42%. There are however some limitation in the methodology as there is no clear control group against which to undertake a more meaningful comparison.

The report also looked at acute admissions and length of stay. The findings, however, were not statistically significant. The average cost of acute care for patients with cancer in the final eight weeks of life before the programme implementation was calculated at £3,066. Following the programme implementation the cost was estimated at £3,019. The cost of acute care for people who were involved in the programme was estimated at £3,067. The report outlined that for patients who received services by the rapid response team incurred significantly lower costs, however, the cost was higher for patients who received services by the discharge community link nurses. For patients who received the care from both the rapid response team and the discharge community link nurses there was no statistical difference.

The report also tried to assess the cost of community services and concluded that 'While extra community support was being provided by programme services and community nurses, there was also a reduction in the number of GP contacts, 999 ambulance journeys and out-of-hours visits. Overall, there was no statistically significant change in the cost profile for community services.' The report compared the cost of acute and community services for patients enrolled in the programme and for patients not enrolled in the programme. The average overall cost of the programme was £5,401 and for non-programme user it was £5,324. The difference, however, was not statistically significant.

[28] Gardiner, C., Ward, S., Gott, M., Ingleton, C., 2014b. Economic impact of hospitalisations among patients in the last year of life: an observational study. *Palliat Med* 28, 422–429.

In their observational retrospective study, Gardiner et al. (2014) aim to determine the extent of potentially avoidable hospital admissions and costs amongst patients admitted to hospital in the last year of life. They performed an after death analysis in two large acute hospitals in the North of England where 483 patients died within one year of admission to hospital. Of 483 admissions, palliative medicine consultants classified 7.2% of them as potentially avoidable. Among the admissions that could have been avoided, the alternative places of care suggested were: nursing home (for 80% of the cases), patient home (for 11.4% of cases) and hospice (for 8.6% of cases). The main health conditions were: Bronchitis/pneumonia (for 31.4% of cases), frailty/old age (for 22.9% of cases), dementia (for 11.4% of cases), renal failure (for 8.6% of cases) and cancer (for 8.6% of cases). Avoiding these admissions and caring for the patients in alternative locations would have reduced the costs of the two hospitals by £5.9 million per year. They assume a reduction of length of stay in all 483 patients by 14% concluded that reducing length of hospital stay in palliative care patients may offer the potential to achieve higher hospital cost-savings than preventing avoidable.

[29] Abel, J., Rich, A., Griffin, T., Purdy, S., 2009. End-of-life care in hospital: a descriptive study of all inpatient deaths in 1 year.

This is an observational retrospective study that aims to estimate how many patients who died in a district general hospital in England might have been able to be cared for at home or in their usual place of residence (nursing home, other hospital, residential home, sheltered housing, EMI (mental health nursing home) and to calculate the savings in hospital admissions that could be used for the development of community services. Data came from a district general hospital in the south west of England. Among the 599 cases reviewed, 152 (26%) patients were clearly in the last year of life and 110 (18%) patients had significant comorbidities and could probably have been recognised as being in the last year of life. At least 119 (20%) clearly and 75 (13%) probably could have stayed at home. 69% (39 for sure and 14 maybe) of those admitted from nursing home (total: 77) could have stayed in the nursing home to die. Of the 440 patients who has been admitted from home, 61 could have died at home for sure 47 may have been able to die at home. The mean cost of admission was £3173 per patient. This paper concludes by suggesting that it is possible to calculate how many extra patients may need community care packages and the cost that could be redistributed from hospital to community for these services.

[30] The balance of care group. 2008, Identifying Alternatives to Hospital for People at the End of Life.

www.nao.org.uk/wpcontent/uploads/2008/11/07081043_alternatives.pdf

The report presents the findings of a retrospective study undertaken with Sheffield health and social care organisations, in conjunction with the National Audit Office value for money study on the delivery of end of life care (EoLC) services in England. The aim of the project in Sheffield was to explore the potential for change in care pathways for people at the end of life, assessing whether some of the patients who died at hospital could have received care in another setting. The study assessed the hospital records of 210 adults in Sheffield PCT who died in October 2007. Using Gold Standard Framework categories, the underlying cause of death of these patients was frailty (42%), cancer (30%), chronic disease (20%) and died 'unexpectedly'(8%).

According to the authors of the study, deaths in hospital that could have been avoided:

- surveyors identified alternatives to dying in hospital for 80 out of 200 surveyed (40%)
- overall for those with alternatives, about 40% could have been at home, 40% in a care home and 20% in hospice
- above average numbers of admissions from care homes, especially nursing homes were thought to be avoidable.

The 61% of care home residents dying there could be as high as 80% if alternative care pathways were followed.

- in terms of Length of Stay, the total bed days occupied by patients who died in hospital was 3367, equivalent to an average 109 occupied beds.

The 80 patients for whom alternatives were identified used 1501 bed days, equivalent to 48 occupied beds.

- cancer patients mainly needed palliative care, while frail patients needed services involving general or specialist nursing, with some palliative care as part of their overall end of life care.

For chronic disease patients' alternatives were only identified for 7 out of 44 patients dying in hospital (16%).

The authors of the study assert that, assuming a cost per inpatient day of £250, the 'avoidable' part is worth £375,250 (=1501*250) for what is in effect a month's costs. They also claim that if a similar number of bed days could be avoided on average throughout a year, this would gross up to about £4.5million (equivalent say to the running costs of two wards). Finally, the authors consider that given that Sheffield accounts for 1% of England population, similar reductions in proportions dying in hospital across the country could potentially release revenue of £450 million for investment in alternatives to hospital. These figures need to be considered with caution as the study was published in 2008. Nevertheless, from a methodological point of view, this study has only minor limitations.

[31] Bekelman, J. E., Halpern, S. D., Blankart, C. R., et al. 2016. Comparison of Site of Death, Health Care Utilization, and Hospital Expenditures for Patients Dying With Cancer in 7 Developed Countries. JAMA 315(3) 272-83

The study compared place of death, inpatient health care utilisation and hospital expenditure of patients at their end of life in seven different countries; The United States, the Netherlands, Canada, Belgium, England, Germany and Norway. These nations were selected because they had diverse modes of health care financing and delivery and available high-quality sources of administrative claims and registry data.

The results are provided below for patients older than 65 years who died with Cancer. The United States (cohort of decedents aged >65 years, N = 211 816) and the Netherlands (N = 7216) had the lowest proportion of decedents who died in acute care hospitals (22.2% and 29.4%, respectively). A higher proportion of decedents died in acute care hospitals in Belgium (N = 21 054; 51.2%), Canada (N = 20 818; 52.1%), England (N = 97 099; 41.7%), Germany (N = 24 434; 38.3%), and Norway (N = 6636; 44.7%).

In the last 180 days of life, mean per capita hospital expenditures were higher in Canada (US \$21 840), Norway (US \$19 783), and the United States (US \$18 500), intermediate in Germany (US \$16 221) and Belgium (US \$15 699), and lower in the Netherlands (US \$10 936) and England (US \$9342).

[32] Deloitte. 2012. The economic impact of care in the home services; A report commissioned by the British Red Cross. British Red Cross

The report by Deloitte for the British Red Cross (BRC) estimates the economic benefits to commissioners (for health and social care settings) across six BRC schemes. Two schemes cover A&E hospital and four focusses on individual resilience and community. It was estimated that these schemes can help to save commissioners £8million. The overall return on commissioners' expenditure as estimated between 40% and 280%. The report presents a simple illustration of different pathways for the service user with an option of social admission or the BRC assisted discharge. The BRC service was tested across six sites and depending on a site, savings per used from the scheme was estimated between £168 and £704. These savings have resulted from prevention of hospital admissions/readmissions, reduction in hospital stay, A&E admissions and reducing or prevention the use of costly domiciliary and residential care.

[34] National Audit Office (2008) End of Life Care. National Audit Office.

www.nao.org.uk/wp-content/uploads/2008/11/07081043.pdf

The National Audit Office developed a Markov model to test the impact of service use redistribution for cancer patients across different scenarios. It was estimated that the PCTs spent £245million on specialist end of life care in 2006-07. The cost of the NHS and social care services was estimated at £1.8billion per annum in the last year of life. The cost of hospice care was estimated at £0.5billion. The NAO report estimated that a

shift of patients with cancer diagnosis to palliative would result in 20% fewer emergency admissions and five fewer bed-days per person and would save £171 million per year. A shift of patients with heart failure and pulmonary disease to palliative care would result in 20% fewer emergency admissions and five fewer bed-days per person that would save £112 million per year.

[35] Hatziandreu E, Archontakis F, Daly A. 2008. The potential cost-saving of greater use of home- and hospice-based end of life care in England. Technical report. National Audit Office

Rand Europe calculated the cost last year of life to the NHS and social care services by performing a Markov modelling. The overall end of life care cost is estimated to be at £1.8billion for patients with cancer diagnosis or £14,236 per patient. For patients with organ failure the cost of care was estimated at £553million in the last year of life or £18,771 per patient. Rand also modelled the impact of reduction in unplanned admissions and length of stay for cancer patients and found that potentially £42 to £171 million per annum can be saved. The research concludes that there is a real potential for palliative care services to reduce expenditures associated with hospitalisation while at the same time accommodating the expressed preferences of patients.

[35] Wood C, Salter J. 2013. A time and a place; what people want at the end of life. Sue Ryder

This document is an evaluation conducted by the Sue Ryder Hospice that aims to define the perception of patients for dying in different settings of care (hospice, community care, palliative inpatient care in hospital and care at home, hospice at home). It provides cost data on the different care settings and found that running the hospice inpatient care at the end of life for 15-20 beds costs around £5,500 per day (£275-£367 per bed/per day). This cost of hospice care is thought to be more expensive than home care (estimated cost for a day of community care at the end of life: £145), but cheaper than hospital inpatient care (Estimated costs for a specialist palliative inpatient bed day: £425). It was found that the hospice at home services can affect the number of people who can die at home; the number of patients who die at home increase with the hospice at home services from 28% to 74%. The cost of the hospice at home services is estimated £152 serving 90,000 people per year. It was thought that this service has a potential to reduce the cost of £20 million a year that the NHS spends on hospital care for end of life. The document also reports data on an initiative (A Partnership for Excellence in Palliative Support) developed by Sue Ryder and NHS Bedfordshire. The Partnership for Excellence in Palliative Support (PEPS) service provides a single point of contact for patients and their carers. The programme run over 12 months and enrolled 1,051 patients (of whom 620 patients have died). In the last four months of life, among PEPS users there were 30% fewer emergency hospital admissions and hospital length of stay has been reduced by 30% (estimated reduction

in cost per admission is £300) compared to before PEPS service use. Overall, the service was well received by healthcare professionals.

[36] Marie Curie Cancer Care. 2012. Understanding the cost of end of life care in different settings. Marie Curie Cancer Care

The report by Marie Curie Cancer Care found that most of the costing studies are theoretical and have a number of limitations. The report also concluded that “to date, there are no ‘gold standard’ randomised controlled trials comparing the costs and outcomes of ‘usual care’ with the costs and outcomes of enhanced community services.” However, there were a number of costs presented in the report and they have been summarised below. The cost of community care at the end of life is estimated at £145 per day per patient, whereas the cost for a specialist palliative in-patient bed day at hospital was calculated at £425 per day per patient (2009-10 prices). These costs are based on unit costs of health and social care. Moving patients from hospital care to community care can result in cost-saving of £280 per day per patient. Reducing the cost of hospital stay (moving patients to community care from hospital care) could potentially save £34million per year. This calculation is based on 4 days of hospital days avoided for 30,000 patients per year. The report by Marie Curie Cancer Care also summarised a number of case studies on shifting care among the services. If the emergency admissions are reduced by 10% and hospital length of stay are reduced by three days, potentially £104million can be redistributed to community services. Marie Curie Cancer Care also reported a Balance of Care Group study; the Balance of Care Group found that of 200 people who died in the hospital, 40% of them did not require hospital services and could have been cared for elsewhere. It was estimated that in Sheffield PCT alone around £4.5 million could be shifted to community services for the end of life care if all patients who did not required the hospital care were cared for in the community. Another study calculated that the cost of 14 days of end of life treatment at the hospital would cost £4,200 (£374 per day), however, the cost of an intensive community support for 14 days would cost £2,500. This would result in saving of £1,700 per person if the patients were cared for in the community.

[37] Macmillan Cancer Support. 2013. There’s no place like home; Making the case for free social care at the end of life. Macmillan Cancer Support

The report by Macmillan Cancer Support has demonstrated the cost-saving potential of care settings for end of life treatment. The report stated that the cost of end of life care in the final few months of life can be as high as £90,000 per person. However, the cost of social care and home care can be cheaper as well as and predictable and constant. The report cited the figure by the National End of Life Care Programme and said that potential net saving per person who died in the community rather than in the hospital could be £958. Macmillan also argues that providing free social care would free up the NHS services and result in money saving. They have concluded that this approach would generate £2.24 of monetised benefits to the healthcare system per £1 invested.

[38] Hughes-Hallet T, Craft A, Davies D, Mackay I, Nielsson T. 2011. Funding the Right Care and Support for Everyone; Creating a Fair and Transparent Funding System; the Final Report of the Palliative Care Funding Review. Palliative Care Funding Review

This paper sets out a vision for a new funding mechanism for palliative care in England. It mainly discusses how much Primary Care Trusts (PCTs) spend on palliative care by and how much could be avoided if we had a reduction of death in hospital. Recognising palliative care needs and optimising provision of services outside the hospital setting could potentially reduce deaths in hospital by up to 60,000 a year by 2021. This reduction in hospital deaths has a potential to save £180million per year. The calculation is based on a number of cases avoided (60,000) and a cost of per hospital death at £3,000. The report also quotes the Department of Health's cost of adult palliative care for the PCT at £460million in 2010/11. The report also states that there is a variation on amount of money spent on specialist palliative care; the cost varied from £186 per death to £6,213. 'A total of 61% of all PCTs spend less than £1,000 per death in their PCT'. However, the methodology of this study is poorly described and could potentially lead to biases as all numbers used for calculating costs savings are based on assumption.

[39] Georghiou T, Bardsley M. 2014. Exploring the cost of care at the end of life; Research report. Nuffield Trust

The report by Nuffield Trust calculated the cost of various services used by people in the last 90 days of life. The study aims to assess whether the costs saved from hospital are still outweighed when transferred to the community care. They use for that the data of the nursing services provided by Marie Curie Cancer Care. The costs were calculated for the following services: primary care (GP consultations), community care (district nurse care), local authority funded social care, inpatient hospice care, secondary care (acute hospital).

Primary care:

It was calculated that the average number of visits to the GP over 90 days was 4.6 per person. The average cost of the GP services for the patients in the final 90 days of life was calculated at £147. The report also estimated the cost for the patients with the cancer diagnosis at a cost of £365 per person. For people with no cancer diagnosis the cost was estimated at £137 per person. The calculations take into account the average number of visits at a cost of £32 per consultation.

Community care:

The cost of the community care (district nursing only) was calculated at average cost of £278 per person. For patients with cancer diagnosis, the cost was estimated at £588 per person compared to £249 for those not diagnosed with cancer. The calculations are

based on district nurse time spent during the final 90 days of life (on average 214 minutes). The cost of the district nurse per hour was estimated at £78.

Social care:

The average cost per person of social care provided by local authority for people who died was £1,010 per person. For patients with cancer diagnosis, the cost was estimated at £444 in the last three months of life per person compared to £1,222 for those not diagnosed with cancer. It was thought that the difference in cost could be due to a greater access to hospice care for patients with cancer diagnosis.

Hospice care:

In-patient hospice care per bed/day cost was broadly calculated at £400 with an average stay of 14 days (total cost of £5,600). Based on a number of assumptions, the report calculated the average hospice cost over all people who died. It is very broadly estimated to be around £550. The cost of care in final 90 days per person on average was estimated at £4,580. This figure is slightly higher for cancer patients (£5,890). For non-cancer patients the cost is lower at £3,785 per person.

Simulation:

The paper also reports a modelled cohort of patients who received Marie Curie nursing services compared to a cohort of patients who did not receive the service (normal care). It was assumed that the only difference between the groups was in the number of days at home (for the Marie Curie group, patients would spend 2.5 extra days at home in the final 90). For primary care, community care and social care the cost of nursing service was slightly higher (£10-£41) than the normal care. Hospice in-patient care cost was lower in Marie Curie nursing services by £476 per person compared to normal care. The cost of the secondary care was also lower in the nursing group £1,140 per person. Marie Curie nursing service cost was estimated at £581 per person. More estimation of costs is reported in the report.

[40] Roberts, D., Hurst, K., 2013. Evaluating palliative care ward staffing using bed occupancy, patient dependency, staff activity, service quality and cost data. *Palliat Med* 27, 123–130.

Roberts et al. (2013) analyses palliative care staffing in different settings. The main aims of the study were to adapt the workforce planning method used extensively in the UK National Health Service (NHS) for use in hospices and to compare hospice and NHS palliative care staffing establishments. The authors collected data in 16 hospice and seven NHS palliative care ward and compared the type and quantity of staff in UK hospice and NHS palliative care wards. They compared bed occupancy, patient dependency, staff activity, nursing quality, sick leave taken by staff and their activity for both settings.

The actual full time employment (FTE) per bed was estimated at £156 in palliative care ward and £288 (min: 130 - max: 312) in hospice ward. They concluded that hospice wards are better staffed, are more expensive to run and have fewer patients than palliative care ward but staff deliver higher-quality care (measured using an established service quality audit) despite facing heavier workloads.

[41] Georghiou,T., Davies,S., Davies, A., Bardsley,M., 2012 Understanding patterns of health and social care full report final. Nuffield Trust.

This report from the Nuffield Trust created and analysed a linked dataset between social care (founded by local authorities) and health care users who are in their last year of life. Georghiou et al.(2012) performed an after death analysis of 73,243 people who died across seven sites. The methodology of this report is unclear but presents a good amount of data on utilisation and costs of social and acute care. Summing all services' costs in the final year of life, the author found that the total hospital care costs across all 73,243 people were £486.6m - this equated to an average of £6,644 per person who died. The total social care costs accounted for slightly more than half the total hospital costs at £255.3m - this equated to an average of £3,486 per person who died. The authors also reported data on users of both services, social care and healthcare that have not been reported here.

[42] Burbeck, R., Low, J., Sampson, E.L., Bravery, R., Hill, M., Morris, S., Ockenden, N., Payne, S., Candy, B., 2014. Volunteers in specialist palliative care: a survey of adult services in the United Kingdom. J Palliat Med 17, 568–574.

The study aims to describe current involvement of volunteers (with direct contact with patients or family) compared to the involvement of paid staff for providing palliative care. An online survey was sent to 290 UK adult hospices and specialist palliative care services involving volunteers. The survey had a 67% response rate (153 voluntary sectors services and 41 statutory services). The number of paid staff and volunteers vary across palliative care services. In statutory services, there were around 30 paid staff members (Range: 1–110), 60 volunteers (Range: 1-270) and 45 volunteers with direct patient or family contact (Range: 1-255). In voluntary services, there were around 96 paid staffs (Range: 2-485), 200 volunteers (Range: 7-4,300) and 99 volunteers with direct patient or family contact (Range: 2-1,110). This comprehensive survey of volunteer activity in U.K. specialist palliative care provides an understanding of the role of volunteer for providing palliative care. Volunteers were most commonly involved in day care and bereavement services and there were per service, approximately one-and-a-half volunteers for every paid member of staff (including office, care, and clinical staff, excluding 'bank' or agency nurses).

[43] The Choice of End of Life Care Programme Board. 2015. What's important to me: A Review of Choice in End of Life Care.

A recent report by the Choice in End of Life Care programme board established that the cost of end of life care in the final year of life in England is around £3.9billion. This cost covers both NHS specialist and non-specialist services and social care. The majority of the money is spent on NHS services, followed by the voluntary services (hospices for example) and social care services provided by local authorities. Around £430million is spent on social care by individuals who require care.

This study compares the impact on costs spent by NHS, charity, social care and patient for 3 different options under three different modelled scenarios (scenario one: no change in current pathway, scenario two: assumes decrease in hospital deaths by 20% and scenario three: assumes decrease in hospital deaths by 40%). The report found that moving from baseline services (option one) to option two (increased service availability that would enable choice and improve care) will enable to reduce hospital unit costs and reduce A&E admissions. The option three is the same as option two with even better service availability and extra services (such as the use of telecare and telehealth). The authors concluded by stating that the scenarios under option two offer a realistic level of improvement in end of life care. These scenarios feature a relatively modest overall increase in spending from the NHS, and a sliding scale of increasing spending on social care as more people are treated in community settings.

[44] McCrone, P., 2009. Capturing the costs of end-of-life care: comparisons of multiple sclerosis, Parkinson's disease, and dementia. J Pain Symptom Manage 38, 62–67.

This study compares the costs of end of life care of three conditions (Dementia, MS and Parkinson's disease) at different stages of the disease and in different settings of care (formal and informal services). McCrone (2009) concluded that the characteristics of end of life care are likely to differ across conditions and also within them. Overall, the costs of informal care appears higher than the costs of formal care; the study concluded therefore that measuring informal care is complex and that further work is needed to estimate accurately the cost of all the relevant services.

[45] Round, J., Jones, L., Morris, S., 2015. Estimating the cost of caring for people with cancer at the end of life: A modelling study. Palliat Med 0269216315595203.

This study estimates the direct and indirect costs for lung, breast, colorectal and prostate cancer patients at the end of life (from the start of strong opioids to death) in England and Wales. Round et al (2015) use a modelling-based approach to estimate the costs of care. Data were estimated from the literature and publicly available data sets. To reflect the uncertainty in model estimate, they performed a probabilistic sensitivity analysis. The total costs for treating people with these four cancers at the end of life were estimated at £641 million. Breast and prostate cancer patients have the highest expected cost per person at £12,663 (95% credible interval (CI): £1249 -

£38,712) and £14,859 (95% CI: £1391-£46,424), respectively. The authors concluded that the cost to society of providing care to people at the end of their lives is significant. Approximately one-third of this cost is borne by informal care givers.

[46] NHS Improving Quality. 2013. Economic Evaluation of the Electronic Palliative Care Co-ordination System (EPaCCS) Early Implementer Sites. NHS Improving Quality

The author estimated the potential saving of electronic palliative care based on four pilots' studies. Electronic Palliative Care Co-ordination Systems are developed to co-ordinate people's choices about the place of death and care and support they need. The cost of system was estimated at £21,000 to set-up and £8,000 recurrent cost per 200,000 population per year. The evaluation found that the system can save £133,200 per 200,000 population per annum. The calculation is based on cost of deaths in usual place of residence. The report also calculated that the net benefit over four years for 200,000 population would be around £270,000; after four years it is thought that the saving for each year could be £100,000 per annum. There were a number of scenarios tested and the estimates of benefit varies between £124,000 and £1.1million for a population of 200,000 people over four years.

Appendix 3: Search protocols

Terms for palliative and end of life care † :	
<ol style="list-style-type: none"> 1. death, dying, deathbed 2. terminally ill* 3. terminal or terminal care or phase* 4. palliative care or therapy 5. (palliati* or terminal or end or final or last) stage* 6. "end of life" 7. ((last or final) (hour* or day* or minute* or week* or month* or year* or moment*)). 	OR

And

Economic filters for non-economic databases ‡ :	
<ol style="list-style-type: none"> 1. economic* 2. cost* or cost analysis 3. fee* or charges 4. budget* 5. price* or pricing* 6. cost* (effective* or utilit* or benefit* or minimi* or unit* or estimate* or variable*) 7. financ* 8. value 9. money or monetary 10. return on investment, ROI 	OR

† To build upon the review that NICE has recently published on end of life care (NG31), we will base the search strategy for health economics studies already undertaken for the new guidelines and expand to other databases and update the searches carried out for the guidelines.

‡ Economic filters will be applied by NICE protocols to search economic evidence

Appendix 4: Sources and number of hits

Electronic databases

Database	Host	Date	Hits
Medline and Medline in Process	Ovid	20/1	783
Embase	Ovid	21/1	1,598
AMED	Ovid	21/1	319
HMIC	Ovid	21/1	238
PsycInfo	Ovid	21/1	741
Econlit	EbscoHost	21/1	50
BNI	Proquest	21/1	220
Cochrane Library		28/1	Cochrane Reviews 61 Economic evaluations 8
TOTAL			4,018

Web searches: list of websites and resources - grey literature

- UK government
- PHE
- NICE
- National End of Life Care Intelligence Network
- OECD
- WHO int/Europe
- Marie Curie
- Nuffield
- Sue Ryder
- OpenGrey
- Association for Palliative Medicine of Great Britain and Ireland

- Association of Hospice and Palliative Care Chaplains
- Brainstrust
- College of Occupational Therapists
- Compassion in Dying
- English Community Care Association
- Gold Standards Framework
- Hospice UK
- Macmillan Cancer Support
- National Care Forum
- National Council for Palliative Care
- National End of Life Care Programme
- Pancreatic Cancer UK
- Patients' Association
- Progressive Supranuclear Palsy Association (PSPA)
- Resuscitation Council (UK)
- Sarcoma UK
- Social Care Institute for Excellence
- UK Community Advisory Board (UK-CAB)

Number of studies/reports found: 44

Other sources

Citation chasing, workshop, steering group

**51
studies (2
duplicates)**

Appendix 5: Inclusion criteria and checklist

Study types

The aim is to identify relevant economic and cost studies, including the following study types:

- cost-benefit analyses (CBA)
- cost-effectiveness studies (CEA)
- cost-utility analyses (CUA)
- cost-consequence analysis (CCA)
- cost analysis
- any other cost analysis (eg return on investment).

Systematic reviews may be identified which include any of the study types listed above. Systematic reviews will be used as a source of further economic studies – or primary studies that include an economic focus - rather than be included in their own right.

Inclusion criteria

Population: Adults as the focus is on health inequalities, evidence broken down by population subgroups will be synthesised where available, as well as by different types of patients and disease groups.

Interventions: Palliative and end of life care models (home and community models vs. hospital), generalist and specialist palliative care services.

Comparator: No intervention, usual practice, or comparison of two or more intervention types.

Outcomes: All possible outcomes related to palliative care, for example physical care, management of pain and other symptoms and provision of psychological, social care, spiritual and practical support.

Settings: Any settings (eg hospital, hospice care, care home, patient home).

Limits:

- time period: from 1999
- geography: UK only, however literature from OECD countries may be included if applicable to the UK context or fills a gap
- language: only material written in English will be included

Inclusion/exclusion criteria checklist

	Criteria	Code	Notes
Q1	Date: Is the study published after 1 January 1999	If NO – exclude 1_EX Date	
Q2	Language: Is the study report published in English?	If NO – exclude 2_EX Language	
Q3	Country: Was the study conducted in the UK? Relevant studies conducted§ in OECD countries have been identified for the economic model and tool	If NO – exclude 3_EX Country	
Q4	Population: Is the study relevant for population groups?	If NO – exclude 4_EX Population	Adults, as the focus is on health inequalities, evidence broken down by population subgroups will be synthesised where available, as well as by different types of patients and disease groups.
Q5	Topic: Does the study report palliative care end of life care interventions or service model?	NO – exclude 6_EX Topic	Palliative care models (e.g. hospital, hospice care, care home, patient home), generalist and specialist palliative care services.
Q6	Outcomes: Does the study report relevant	NO – exclude 7_EX	All possible outcomes related to palliative care, for example physical care,

§ **OECD countries:** Australia; Austria; Belgium; Canada; Chile; Czech Republic; Denmark; Estonia; Finland; France; Germany; Greece; Hungary; Iceland; Ireland; Israel; Italy; Japan; Korea; Luxembourg; Mexico; Netherlands, Norway; New Zealand; Poland; Portugal; Slovak Republic; Slovenia; Spain; Sweden; Switzerland; Turkey; United Kingdom, United States.

	outcomes?	Outcomes	management of pain and other symptoms and provision of psychological, social care, spiritual and practical support.
Q7	Economic: Does the study report economic analysis or costs?	NO – exclude 8_EX Economic	Exclude papers that report only effectiveness data.
Q8	Study design: Cost-benefit analysis; Cost-effectiveness studies; Cost-utility analyses; Cost-consequence analysis; Cost analysis; Any other cost analysis (eg return on investment); Primary research study including relevant economic information (eg unit costs); Systematic reviews any of the above studies.	Studies that are an economic evaluation include as: 9_IN.ECON Studies that report useful cost and resource data include as: 10_IN.COST Systematic reviews that include any of the study types include as: 11_IN.SYSTREV	

Appendix 6: Quality assessment template

Quality assessment of included studies has been carried out in accordance with Appendix H of the NICE methods manual^[13]. These checklists are as follows:

Study identification Include author, title, reference, year of publication		
Checklist completed by		
Section 1: Applicability This checklist should be used first to filter out irrelevant studies.	Yes/ partly/ no/ unclear/ not applicable	Comments
1.1 Is the study population appropriate for the review question?		
1.2 Are the interventions appropriate for the review question?		
1.3 Is the system in which the study was conducted sufficiently similar to the current UK context?		
1.4 Are the perspectives clearly stated and what were they?		
1.5 Are all direct effects on individuals included, and are all other effects included where they are material?		
1.6 Are all future costs and outcomes discounted appropriately?		
1.7 Is QALY used as an outcome, and was it derived using NICE's preferred methods? If not, describe rationale and outcomes used in line with analytical perspectives taken (item		

1.4 above).		
1.8 Are costs and outcomes from other sectors fully and appropriately measured and valued?		
1.9 Overall judgement: directly applicable/partially applicable/not applicable		
There is no need to use section 2 of the checklist if the study is considered 'not applicable'.		
Other comments:		
Section 2: Study limitations (the level of methodological quality) This checklist should be used once it has been decided that the study is sufficiently applicable to the context of the guideline	Yes/ partly/ no/ unclear/ not applicable	Comments
2.1 Does the model structure adequately reflect the nature of the topic under evaluation?		
2.2 Is the time horizon sufficiently long to reflect all important differences in costs and outcomes?		
2.3 Are all important and relevant outcomes included?		
2.4 Are the estimates of baseline outcomes from the best available source?		
2.5 Are the estimates of relative intervention effects from the best available source?		
2.6 Are all important and relevant costs included?		

2.7 Are the estimates of resource use from the best available source?		
2.8 Are the unit costs of resources from the best available source?		
2.9 Is an appropriate incremental analysis presented or can it be calculated from the data?		
2.10 Are all important parameters whose values are uncertain subjected to appropriate sensitivity analysis?		
2.11 Is there any potential conflict of interest?		
2.12 Overall assessment: minor limitations/potentially serious limitations/very serious limitations		
Other comments:		

Appendix 7: List of interventions identified by the evidence review

Intervention Discussed in Paper	Reference Name	Reference Number
British Red Cross Schemes	Deloitte. 2012. The economic impact of care in the home services; A report commissioned by the British Red Cross. British Red Cross	27
Consultant led multi-disciplinary team (Example from Midhurst)	Noble, B., King, N., Hughes, P., Winslow, M., Melvin, J., Brooks, J., Bravington, A., Ingleton, C., Bath, P. 2012. Evaluation of the Midhurst Macmillan Specialist Palliative Care Service (Real Choice Project): A community consultant-led palliative care service.	17
Electronic Palliative Care Co-ordination Systems (EPaCCS)	NHS Improving Quality. 2013. Economic Evaluation of the Electronic Palliative Care Co-ordination System (EPaCCS) Early Implementer Sites. NHS Improving Quality	41
Gold Standards Framework (GSF) training: All 10 existing programmes	GSF - Overview of the work of the National GSF Centre in End of Life care.	18
Gold Standards Framework (GSF) training: Care Home (example from Bradford, Airedale and Craven)	Stobbart-Rowlands, 2015. Bradford, Airedale and Craven GSF Care Homes Training Programme Evaluation Report.	15
Gold Standards Framework (GSF) training: Primary care	Clifford, C., Thomas, K., Armstrong-Wilson, J. End of Life Care in Primary Care: The Gold Standards Framework, Going for Gold service improvement programme and	14

	Accreditation process (Paper currently in publication).	
Hospice at home (Example from Leckhampton Court Hospice at home service)	Wood C, Salter J. 2013. A time and a place; what people want at the end of life. Sue Ryder	30
Marie Curie Delivering Choice Programme (DCP) (Example from Lincolnshire)	Addicott R, Dewar S. 2008. Improving choice at end of life; A descriptive analysis of the impact and cost of the Marie Curie Delivering Choice programme in Lincolnshire. King's Fund	22
Marie Curie Delivering Choice Programme (DCP) (Example from Somerset)	Wye L, Lasseter G, Percival J, Simmonds B, Duncan L, Purdy S. 2012. Independent Evaluation of the Marie Curie Cancer Care Delivering Choice Programme in Somerset and North Somerset. University of Bristol	20
Marie Curie Nursing Service (MCNS)	Georghiou T, Bardsley M. 2014. Exploring the cost of care at the end of life; Research report. Nuffield Trust	34
Marie Curie Nursing Service (MCNS)	Chitnis X, Goerghiou T, Steventon A, Bardsley M. 2012. The impact of the Marie Curie Nursing Service on place of death and hospital use at the end of life; Research report. Nuffield Trust	21
Modified Appreciative Inquiry intervention (example from 6 residential care homes in the East of England)	Amador, S., Goodman, C., King, D., Ng, Y.T., Elmore, N., Mathie, E., Machen, I., Knapp, M., 2014. Exploring resource use and associated costs in end-of-life care for older people	13

	with dementia in residential care homes. <i>Int J Geriatr Psychiatry</i> 29, 758–766.	
Multi-professional palliative care team (PCT) for people with multiple sclerosis (Example from South East London)	Higginson I, McCrone P, Hart SR, Burman R, Silber E, Edmonds PM. 2009. Is Short-Term Palliative Care Cost-Effective in Multiple Sclerosis? A Randomized Phase II Trial. <i>Journal of Pain and Symptom Management</i> ; 38:6: 816-826	10
Partnership for Excellence in Palliative Support (PEPS)	Sue Ryder. 2013. Partnership for Excellence in Palliative Support (PEPS). Evaluation of pilot. Sue Ryder Evaluation Series: Report No. 2	11
Partnership for Excellence in Palliative Support (PEPS) (Example from initiative led by Sue Ryder and NHS Bedfordshire)	Wood C, Salter J. 2013. A time and a place; what people want at the end of life. Sue Ryder	30
The Gold Line (Example from Airedale, Wharfedale and Craven CCG area).	York Health Economic Consortium, 2016. Economic Evaluation of the Gold Line: Health Foundation Shared Purpose project, Airedale NHS Foundation Trust	12

Appendix 8: Bibliography

- [1] NICE, 2013. End of life care for adults: Quality standard. (Available at: www.nice.org.uk/guidance/qs13)
- [2] Independent Review of the Liverpool Care Pathway (2013). More care, less pathway: A review of the Liverpool Care pathway.
- [3] Leadership Alliance for the Care of Dying People (2014). One chance to get it right: Improving people's experience of care in the last few days and hours of life.
- [4] Choice in End of Life Programme Board. 2015. What's important to me. A Review of Choice in End of Life Care.
- [5] National Palliative and End of Life Care Partnership. 2015. Ambitions for Palliative and End of Life Care: A national framework for local action 2015-2020.
- [6] Department of Health. 2016. Our Commitment to you for end of life care: The Government Response to the Review of Choice in End of Life Care.
- [7] NICE, 2015. Care of dying adults in the last days of life. (Available at: www.nice.org.uk/guidance/ng31)
- [8] NICE, 2016. End of life care for infants, children and young people with life-limiting conditions: planning and management. (Available at: www.nice.org.uk/guidance/ng61)
- [9] NICE, 2016. End of Life Care. (Available at: www.nice.org.uk/guidance/service-delivery--organisation-and-staffing/end-of-life-care)
- [10] National Council for Palliative Care. Minimum Data Set (MDS) for Specialist Palliative Care Services. (Available at: <http://www.ncpc.org.uk/minimum-data-set>)
- [11] NHS England, 2015. Developing a new approach to palliative care funding.
- [12] Public Health England, 2016. Joint statement from NHS England and Public Health England: update on development of the Palliative Care Clinical Data Set and Palliative Care Currencies.
- [13] NICE. 2014. Developing NICE guidelines: the manual appendix H. (Available at: www.nice.org.uk/process/pmg20/resources/developing-nice-guidelines-the-manual-appendix-h-2549711485)
- [14] Higginson I, McCrone P, Hart SR, Burman R, Silber E, Edmonds PM. 2009. Is Short-Term Palliative Care Cost-Effective in Multiple Sclerosis? A Randomized Phase II Trial. *Journal of Pain and Symptom Management*; 38:6: 816-826.
- [15] Irene J Higginson, Claudia Bausewein, Charles C Reilly, Wei Gao, Marjolein Gysels, Mendwas Dzingina, Paul McCrone, Sara Booth, Caroline J Jolley, John Moxham. 2014. An integrated palliative and respiratory care service for patients with advanced disease and refractory breathlessness: a randomised controlled trial. *The Lancet*.

- [16] Sue Ryder. 2013. Partnership for Excellence in Palliative Support (PEPS). Evaluation of pilot. Sue Ryder Evaluation Series: Report No. 2.
- [17] York Health Economic Consortium, 2016. Economic Evaluation of the Gold Line: Health Foundation Shared Purpose project, Airedale NHS Foundation Trust.
- [18] Amador, S., Goodman, C., King, D., Ng, Y.T., Elmore, N., Mathie, E., Machen, I., Knapp, M., 2014. Exploring resource use and associated costs in end-of-life care for older people with dementia in residential care homes. *Int J Geriatr Psychiatry* 29, 758–766.
- [19] Clifford, C., Thomas, K., Armstrong-Wilson, J. End of Life Care in Primary Care: The Gold Standards Framework, Going for Gold service improvement programme and Accreditation process (Paper currently in publication).
- [20] Stobbart-Rowlands, 2015. Bradford, Airedale and Craven GSF Care Homes Training Programme Evaluation Report.
- [21] Gandy, R., 2010. Economic appraisal of an end-of-life care training initiative for care homes with dementia patients. *Journal of Care Services Management* 4, 321–330.
- [22] Noble, B., King, N., Hughes, P., Winslow, M., Melvin, J., Brooks, J., Bravington, A., Ingleton, C., Bath, P. 2012. Evaluation of the Midhurst Macmillan Specialist Palliative Care Service (Real Choice Project): A community consultant-led palliative care service. *Macmillan Cancer Support*.
- [23] The National Gold Standards Framework (GSF) Centre in End of Life Care. 2015. The gold standards framework: Overview of the work of the National GSF Centre in End of Life care.
- [24] The National Gold Standards Framework (GSF) Centre in End of Life Care. 2016. Care Homes Training programme.
- [25] Wye L, Lasseter G, Percival J, Simmonds B, Duncan L, Purdy S. 2012. Independent Evaluation of the Marie Curie Cancer Care Delivering Choice Programme in Somerset and North Somerset. University of Bristol.
- [26] Chitnis X, Georghiou T, Steventon A, Bardsley M. 2012. The impact of the Marie Curie Nursing Service on place of death and hospital use at the end of life; Research report. Nuffield Trust.
- [27] Addicott R, Dewar S. 2008. Improving choice at end of life; A descriptive analysis of the impact and cost of the Marie Curie Delivering Choice programme in Lincolnshire. King's Fund.
- [28] Gardiner, C., Ward, S., Gott, M., Ingleton, C., 2014b. Economic impact of hospitalisations among patients in the last year of life: an observational study. *Palliat Med* 28, 422–429.
- [29] Abel, J., Rich, A., Griffin, T., Purdy, S. 2009. End-of-life care in hospital: a descriptive study of all inpatient deaths in 1 year. *Palliative Medicine*, 23(7):16-22.

- [30] The Balance of Care Group. 2008. Identifying alternatives to hospital for people at the end of life. National Audit Office.
- [31] Bekelman, J. E., Halpern, S. D., Blankart, C. R., et al. 2016. Comparison of Site of Death, Health Care Utilization, and Hospital Expenditures for Patients Dying With Cancer in 7 Developed Countries. *JAMA* 315(3) 272-83.
- [32] Deloitte LLP. 2012. The economic impact of care in the home services; A report commissioned by the British Red Cross. British Red Cross.
- [33] National Audit Office (2008) End of Life Care. National Audit Office. www.nao.org.uk/wp-content/uploads/2008/11/07081043.pdf
- [34] Hatziandreu E, Archontakis F, Daly A. 2008. The potential cost-saving of greater use of home- and hospice-based end of life care in England. Technical report. National Audit Office
- [35] Wood C, Salter J. 2013. A time and a place; what people want at the end of life. Sue Ryder.
- [36] Marie Curie Cancer Care. 2012. Understanding the cost of end of life care in different settings. Marie Curie Cancer Care.
- [37] Macmillan Cancer Support. 2013. There's no place like home; Making the case for free social care at the end of life. Macmillan Cancer Support.
- [38] Hughes-Hallet T, Craft A, Davies D, Mackay I, Nielsson T. 2011. Funding the Right Care and Support for Everyone; Creating a Fair and Transparent Funding System; the Final Report of the Palliative Care Funding Review. Palliative Care Funding Review.
- [39] Georghiou T, Bardsley M. 2014. Exploring the cost of care at the end of life; Research report. Nuffield Trust.
- [40] Roberts, D., Hurst, K., 2013. Evaluating palliative care ward staffing using bed occupancy, patient dependency, staff activity, service quality and cost data. *Palliat Med* 27, 123–130.
- [41] Georghiou,T., Davies,S., Davies, A., Bardsley,M., 2012 Understanding patterns of health and social care full report final. Nuffield Trust.
- [42] Burbeck, R., Low, J., Sampson, E.L., Bravery, R., Hill, M., Morris, S., Ockenden, N., Payne, S., Candy, B., 2014. Volunteers in specialist palliative care: a survey of adult services in the United Kingdom. *J Palliat Med* 17, 568–574.
- [43] The Choice of End of Life Care Programme Board. 2015. What's important to me: A Review of Choice in End of Life Care. The Choice of End of Life Care Programme Board.
- [44] McCrone, P., 2009. Capturing the costs of end-of-life care: comparisons of multiple sclerosis, Parkinson's disease, and dementia. *J Pain Symptom Manage* 38, 62–67.

- [45] Round, J., Jones, L., Morris, S., 2015. Estimating the cost of caring for people with cancer at the end of life: A modelling study. *Palliat Med* 0269216315595203.
- [46] NHS Improving Quality. 2013. Economic Evaluation of the Electronic Palliative Care Co-ordination System (EPaCCS) Early Implementer Sites. NHS Improving Quality.
- [47] Gott, M., Ward, S., Gardiner, C., Cobb, M., Ingleton, C., 2011. A narrative literature review of the evidence regarding the economic impact of avoidable hospitalizations amongst palliative care patients in the UK. *Progress in Palliative Care* 19, 291–298.
- [48] Dixon J, King D, Matosevic T, Clark M, Knapp M., 2015. Equity in the provision of palliative care in the UK: review of evidence. London: London School of Economics and Political Science.
- [49] Gomes B, Calanzani N, Curiale V, McCrone P, Higginson IJ, de Brito M. 2013. Effectiveness and cost-effectiveness of home palliative care services for adults with advanced illness and their caregivers (Review). *The Cochrane Library*; 6: i-280.
- [50] Zimmermann C, Riechelmann R, Krzyzanowska M, Rodin G, Tannock I (2008). Effectiveness of specialized palliative care: a systematic review. *JAMA* 299 (14): 1698–709.
- [51] Smith S, Brick A, O'Hara S, Normand C., 2014. Evidence on the cost and cost-effectiveness of palliative care: a literature review. *Palliative Medicine*, 28(2): 130–150.
- [52] May P, Normand C, Morrison R. S., 2014. Economic impact of hospital inpatient palliative care consultation: review of current evidence and directions for future research, *Journal of Palliative Medicine* 17(9): 1054–63.
- [53] Evans, C.J., Harding, R., Higginson, I.J., MORECare, 2013. “Best practice” in developing and evaluating palliative and end-of-life care services: a meta-synthesis of research methods for the MORECare project. *Palliat Med* 27, 885–898.
- [54] García-Pérez, L., Linertová, R., Martín-Olivera, R., Serrano-Aguilar, P., Benítez-Rosario, M.A., 2009. A systematic review of specialised palliative care for terminal patients: which model is better? *Palliat Med* 23, 17–22.
- [55] Gomes, B., Calanzani, N., Higginson, I.J., 2014. Benefits and costs of home palliative care compared with usual care for patients with advanced illness and their family caregivers. *JAMA* 311, 1060–1061.
- [56] National End of Life Care Programme. 2012. Reviewing end of life care costing information to inform the QIPP End of Life Care Workstream. Whole Systems Partnership.
- [57] Douglas, H. R., Halliday, D., Normand, C., et al. 2003. Economic evaluation of specialist cancer and palliative nursing: Macmillan evaluation study findings. *International Journal of Palliative Nursing* 9(10) 429-38.
- [58] Social Care Institute for Excellence (2013). SCIE Guide 48: Dying well at home: the case for integrated working. London: NHS Improving Quality.

- [59] Douglas H R, Normand C E, Higginson I J, Goodwin D M, Myers K., 2003. Palliative day care: what does it cost to run a centre and does attendance affect use of other services? *Palliative Medicine* 17 (7): 628–637.
- [60] Gade G, Venohr I, Conner D, McGrady K, Beane J, Richardson R H, Williams M P, Liberson M, Blum M, Della Penna R., 2008. Impact of an inpatient palliative care team: a randomized control trial. *Journal of Palliative Medicine* 11(2):180–190.
- [61] Brumley R, Enguidanos S, Jamison P, Seitz R, Morgenstern N, Saito S, McIlwane J, Hillary K, Gonzalez J., 2007. Increased satisfaction with care and lower costs: results of a randomized trial of in-home palliative care. *Journal of the American Geriatrics Society* 55(7):993–1000.
- [62] Simoens S, Kutten B, Keirse E, Berghe PV, Beguin C, Desmedt M, Deveugele M, Léonard C, Paulus D, Menten J., 2010. The costs of treating terminal patients, *Journal of Pain and Symptom Management* 40(3):436–48.
- [63] Thiel V, Sonola L, Goodwin N, Kodner D., 2012. *Midhurst Macmillan Community Specialist Palliative Care Service: Delivering end-of-life care in the community*. London: The King's Fund.
- [64] Hospice UK, 2014. *Hospice accounts: Analysis of the accounts of UK independent voluntary hospices for the year ended 31 March 2013*.
- [65] Royal College of General Practitioners, 2013. *Commissioning Guidance in End of Life Care*.
- [66] NHS England, 2015. *Developing a new approach to palliative care funding*.
- [67] Case study provided by Hospice UK in response to their Commissioning and Statutory Funding survey.
- [68] The palliative care outcome scale. (Available at: <http://pos-pal.org/maix/pos-and-ipos-summary.php>).
- [69] Evaluation of the clinical and cost-effectiveness of Short-term Integrated Palliative Care Services (SIPC) to OPTimise CARE for people with advanced long-term Neurological conditions. Ongoing study available at: www.nets.nihr.ac.uk/__data/assets/pdf_file/0005/148640/PRO-12-130-47.pdf.