

Palliative Care Funding Review

Funding the Right Care and Support for Everyone

Creating a Fair and Transparent Funding System; the Final Report of the Palliative Care Funding Review

An independent review for the Secretary of State for Health by
Tom Hughes-Hallett, Professor Sir Alan Craft and Catherine Davies

Funding the Right Care and Support for Everyone

Creating a Fair and Transparent Funding System; the Final Report of the Palliative Care Funding Review

July 2011

The review team:

*Tom Hughes-Hallett
Professor Sir Alan Craft
Catherine Davies
Isla Mackay
Tilde Nielsson*

Contents

Executive Summary	6
Report summary	11
Chapter 1 - Our approach to the review	14
1.1 Purpose of the review	14
1.2 How the review team collected evidence	14
1.3 Regional stakeholder events	15
1.4 Stakeholder meetings	15
1.5 Who gave evidence?	15
1.6 What we asked and heard	16
Chapter 2 - The current funding system	20
2.1 Background	20
2.2 Wide variation in services and sources of funding	21
2.3 The challenges for patients, commissioners and providers	23
2.4 Current PCT spend on palliative and end of life care	23
2.5 Funding arrangements for the acute sector	24
2.6 Funding arrangements for the community sector	25
Chapter 3 - How to create a new funding system	30
3.1 A unique challenge requires an innovative approach	30
3.2 We need to build a system around meeting people's needs	31
3.3 We commissioned new research to help develop solutions	31
3.4 Getting a better understanding of the needs of patients	32
3.5 Developing a classification system	34
3.6 Definitions of the criteria	38
3.7 Testing the proposed classification system	40
3.8 How the palliative care tariff will work	40
3.9 We need to collect more cost information to build a tariff	42
Chapter 4 - How to support the funding mechanism to deliver better outcomes for patients	44
4.1 Levers to support a new funding mechanism	44

Chapter 5 - Creating the dedicated palliative care package	49
5.1 Integrated care packages	49
5.2 Assessment of the needs of the patient	51
5.3 Coordination of the care of the patient	52
5.4 Clinical care of the patient	52
5.5 Social care	54
5.6 Drugs and pharmacy services	55
5.7 Complementary therapies	56
5.8 Bereavement	56
5.9 Respite care and short breaks	57
5.10 Psychiatric care	59
5.11 Spiritual support	59
5.12 Education and training	60
Chapter 6 - How many people need palliative care and how many are not getting it?	62
6.1 Expected trends in the need for palliative care	62
6.2 Changing demographics	64
Chapter 7 - Creating a new system which is cost effective and provides value for money	65
7.1 How much will the new system cost?	65
7.2 The cost of universal services	67
7.3 How the system would provide value for money	67
7.4 Projecting the impact of improving palliative care provision	68
7.5 Social care costs	70
7.6 The impact on charitable funding	71
Chapter 8 - Building the system	72
8.1 A managed transition	72
8.2 Creating the new system	72
Annex 1 Terms of Reference	75
Annex 2 List of stakeholders	76
Annex 3 International comparisons	85
Annex 4 Glossary of terms	92
Annex 5 Example of possible cost buckets	93
Annex 6 Services included in the costings work commissioned from King's College London and their partners	94
Annex 7 Definition of the elements of dedicated palliative care	95
Annex 8 List of references	96

Executive Summary **Funding the right care and support for everyone**

We want to ensure everyone is able to live well until they die. Like birth, death is a part of life - something no one can avoid. But, unlike the beginning of life where it is clear what the state will provide, the evolution of palliative care has led to a lack of transparency about how the state funds a good, safe death.

About the Review

In July 2010, the Secretary of State for Health commissioned an independent review of the funding of dedicated palliative care for adults and children in England.

The review was asked to develop, for the first time, a per-patient funding mechanism for palliative care. No other country in the world has introduced such a system for both adults and children, so this step is bold but necessary.

Britain is a world leader in palliative care and the hospice movement internationally owes its current strength to its beginnings here. There are many highly committed professionals who are doing their best to provide high quality palliative and end of life care. Yet their expertise does not reach all who need their care. Access to good services is inconsistent and the absence of sufficient provision of 24/7 community services is stark.

Our work shows that up to 457,000 people need good palliative care services every year but around 92,000 people are not being reached.

It is also a timely decision. After decades of declining death rates, we now face the dual demographic challenges of these increasing and people living longer with more complex needs as they approach the end of life. Leading academics have forecast that this could lead to 90,000 more people dying in institutions by 2030 (Gomes & Higginson 2008).

We know that the current system is confusing and does not help people get the care and support they need, or provide them with meaningful choice. Research consistently shows that most people would like to be cared for and die in their own home; between 56% and 65% for adults (Higginson 2003; YouGov 2008). But the great majority of us still die in hospital and arguably at a higher economic cost.

Evidence shows us that incentivising the provision of palliative care leads to better outcomes for patients, supports choice and is the most cost effective way of using NHS resources. We need to remove the barriers within the current system to enable this to happen.

We are delighted to have been commissioned to undertake this review. The consequence of doing nothing is clear: ever widening inequities; more and more people not receiving the care they need; and a financial system which

results in too many people being cared for in hospitals. This is not what patients want, and is an unnecessary economic burden on the NHS.

The review's recommendations have three key aims:

- To create a fair and transparent funding system
- To deliver better outcomes for patients
- To provide better value for the NHS

These aims should be achieved by developing:

- an NHS palliative care tariff which is based on need
- a funding system which incentivises good outcomes for patients, irrespective of both time and setting
- the commissioning of integrated care packages which stimulate community services

Creating an NHS palliative care tariff

We are all different and the health service is built on variation. So the challenge is to develop a system which captures the variations of the many different people that need palliative care, at any stage of their journey.

Current evidence identifies the phase of illness (stable, unstable, deteriorating and dying) as the key driver of need. We recommend an initial needs classification system led by phase of illness which can further be refined by capturing other main cost drivers such as provider type, problem severity, functional status and age.

Basing the funding model on a needs classification system would ensure that the funding follows the patient in a fair and transparent way, as the level of funding provided to a service would be determined by the complexity and level of need of the patients.

The tariff would not replace other funding for the patient's disease, and would in effect operate as a top-up to any other tariffs which may already cover the non-palliative aspects of the patient's care needs. For example, we would anticipate that for children, following the conversation and assessment of them being diagnosed as life limited, any palliative care needs the child has would be met through the tariff.

What levers can we use to ensure successful outcomes?

- A clear statement from the Government describing the palliative care support and services that patients, families and carers can receive from the NHS if they need them
- A per-patient funding model which applies equally to all providers across all settings
- Every Clinical Commissioning Group to maintain an end of life locality register

- Removing the need for social care means assessment for patients on an end of life locality register enabling prompt discharge from hospital and the creation of an appropriate health and social care package
- A lead provider for palliative care identified in every Clinical Commissioning Group to coordinate palliative care services.
- Services commissioned on the basis of quality not price and that meet agreed quality standards and markers
- Outcome measures developed which are supported by the newly created dataset (for the tariff) and the NHS outcomes framework
- Integrated care packages commissioned across appropriate populations. We recommend that the commissioning levels for palliative care services per population for adults and children should be set at a minimum population level of 300,000, and up to 1.5m
- A standard contract for commissioning NHS palliative care services
- Access to 24/7 community services in every Clinical Commissioning Group

What should the NHS fully fund in the new system?

We recommend, through the palliative care tariff:

- An assessment, on a regular basis, of the needs of a patient
- All the clinically assessed palliative care needs of a patient irrespective of setting, as in any other branch of clinical care
- A coordinator for the patient who will guide them through their journey, signposting patients and families to the full range of services including those provided by society and not funded by the state
- At the end of life, as an addition to the tariff, the social care needs of a patient after they are added to an end of life locality register

In addition:

We recommend that the Department of Health commits funds to support the transition and implementation of the new funding system. The NHS should continue to fund drugs and pharmacy services in all settings and the NHS Commissioning Board should fund palliative care education and training for NHS professionals.

We also recommend that commissioners must continue to provide appropriate support for patients, families and carers, ensuring they commission services which support their needs. In particular we highlight the importance of bereavement services, respite care, short breaks, carer support and spiritual care. Evidence demonstrates that the absence of such services can lead to deteriorating health in those closest to the patient, and on whom the patient depends.

What will the NHS not fund through the palliative care tariff?

- Episodes of care by either type or duration which are not assessed as a clinical need
- Support for families and carers

We do not include in the tariff: bereavement care (except for a pre-bereavement assessment), spiritual care, complementary therapies, support for carers and families, information and advice, respite care for adults, play therapy, and other similar interventions. These services can continue to be supported by either the state or society as they are now, outside the palliative care tariff.

How have we reached these recommendations?

- They are based on evidence from more than 760 individuals and 380 organisations who we met through our review consultation. We also commissioned work from King's College London and their partners to support the review
- We have road tested them in simulations with groups of providers and commissioners
- A similar system has been tried and tested in Australia over a number of years and is working well

But

There is a stunning lack of good data surrounding costs for palliative care in England.

And

This is the first time a per-patient tariff for community services is being created for any health care intervention in England. Only Australia has developed such a tariff for palliative care for adults and none exist for children internationally.

We are pathfinders, but we approach the task with passion not fear. For all of these reasons, we recommend that our funding system is tested in at least five pilot sites to collect better data and refine the proposals.

How much will this cost the state?

Our contention based on modelled evidence is that our funding system could be cost neutral to the state, and if implemented effectively **we project that delivering improved recognition of palliative care needs, as well as optimised provision of services outside the hospital setting, could potentially reduce deaths in hospital by up to 60,000 a year by 2021.** Using the QIPP estimate of £3,000 per hospital death, **this would translate to a potential reduction in hospital costs of £180m per annum.**

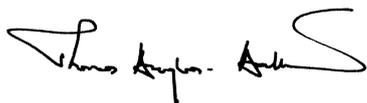
We would wish to proof these figures through the pilots we have proposed.

Added value can be created by using palliative care networks, simplifying tender processes, introducing a standard contract, and incentivising partnership working between providers and commissioners. Training will lead to better care and less reliance on specialist staff in the longer term.

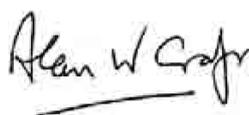
Our recommendations should:

- Support the implementation of the End of Life Care Strategy for England 2008 and the Children's Palliative Care Review for England 2007
- Apply equally to adults and children not least to improve care for those moving from childhood to adulthood
- Support reasonable choice and good outcomes for patients
- Create a funding system designed on patient need rather than on age or disease
- Enable coordinated care to be available where and when it is needed by patients without delay - towards the end of life delay becomes unethical
- Help patients, carers and families know what they can expect the NHS to fund and provide signposting to other services supported by charitable and/or private funding
- Provide a funding system which promotes equity for patients irrespective of where they live or indeed which month their care is needed. The current system all too often allows rationing of care towards the end of the NHS financial year
- Ensure payments are only made for patient care. Contracts that are not related to activity should cease
- Be fair to all providers and follow the patient across all settings; hospital, care home, hospice, or home
- Avoid increasing the number of people dying in hospital and incentivise the development of community services, providing better value to the taxpayer as well as better care to the patient
- Incentivise earlier recognition of palliative care patients
- Enable regular assessment of patients and better coordination of services and patient care leading to better care and less stress for patients and families
- Enable providers to demonstrate what additional support they bring to palliative care services through their fundraising

In summary our recommendations, if implemented, will create a fair and transparent funding system, which provides better outcomes for patients and better value for the NHS.



Tom Hughes-Hallett
Chair



Professor Sir Alan Craft
Review Team



Catherine Davies
Review Team

Report summary

This report sets out a vision for a new funding mechanism for palliative care in England.

Chapter 1 – Our approach to the review

Explains how we met with and heard evidence from over 760 individuals and 380 organisations from across the sector. A further 334 contributions were received via responses through our website. It also provides a summary of the key issues stakeholders raised.

Chapter 2 – The current funding system

Highlights the challenges of the current funding system. The lack of a clearly defined funding model has led to a wide variation in the level of state funding provided to services. A recent survey by the Department of Health estimates that PCTs spent £460m on adult palliative and end of life care in 2010/11, with one PCT spending around £0.2m on specialist palliative care alone, and another around £21m. This variation means that one PCT spent approximately £186 per death on specialist palliative care, while another spent £6,213 and 61% of all PCTs spend less than £1,000 per death.

The lack of a clearly defined funding model and any national tariff, means that block contracts with some spot purchasing are the most common funding mechanisms currently employed in palliative care services. This means that payments do not follow the patients, and providers are paid regardless of activity, impeding commissioners from performance-managing services. The current system does not therefore ensure best possible value for money.

Chapter 3 – How to create a new funding system

The review was asked to develop, for the first time, a per-patient funding mechanism for palliative care for adults and children in England. Palliative care is an emerging field, and models for funding it are still being developed.

The main criterion identified as shaping palliative care needs is phase of illness (stable, unstable, deteriorating and dying). An initial needs classification system is therefore proposed, led by phase of illness. This initial classification system can further be combined with a system to capture the other main cost drivers identified (provider type, problem severity, functional status and age). Based on these criteria, we recommend a needs classification system with a total of 25 classes – 13 for adults and 12 for children. We recommend attaching tariffs to each of these classes.

Basing the funding model on a needs classification system would ensure that the funding follows the patient in a fair and transparent way, as the level of funding provided to a service would be determined by the complexity and level of need of the patients.

Chapter 4 – How to support a the funding mechanism to deliver better outcomes for patients

An important part of any funding mechanism are the funding levers which can be put in place to support the tariff structure and bring about improvements in the quality of services provided to patients.

Stakeholders have told us that the funding levers in the current system are unclear and are used inconsistently in different areas. In this chapter we suggest a set of levers to be implemented in the system, to support the best possible outcomes and quality services for patients.

Chapter 5 - Creating the dedicated palliative care package

In this chapter we set out our recommendations on what services should be included in the NHS palliative care tariff and what services the state should continue to support alongside society.

The review is clear that any new funding system needs to recognise the huge support society currently provides to these services and we need to ensure that we incentivise and support society to continue to contribute. By developing a per-patient funding system based on needs, we need to ensure that the important role families and carers have in both delivering and supporting palliative care patients is not forgotten. We think this is a vital part of society’s role in supporting the state to deliver the best care for people.

Chapter 6 - How many people need palliative care and how many are not getting it?

We know that in England, approximately 470,000 people currently die each year. Not all of these people will need palliative care. **Our work shows the total palliative care needs of the population in England is around 355,000 people (with a maximum of 457,000) requiring care every year.** Comparing this with the people who currently receive specialist palliative care, around 171,000, and accounting for the possibility that a proportion of this group are having their needs met by universal services, **we estimate that around 92,000 people per year have unmet palliative needs.**

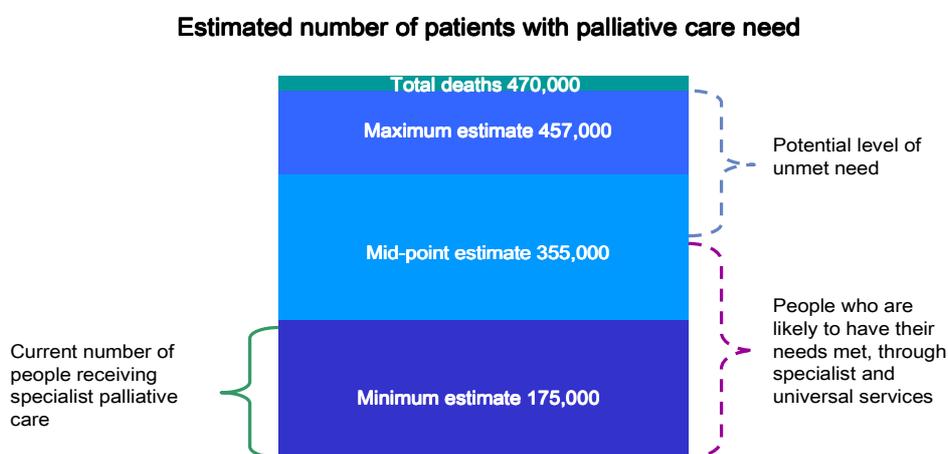


Figure 1 – estimated levels of palliative care needs

Changing demographics, with an ageing population, longer chronic disease trajectories, and greater co-morbidity, provide further incentives to improve and expand palliative care provision.

Chapter 7 - Creating a new system which is cost effective and provides value for money

The commissioned work to support the review estimates that **the total cost of providing the elements of specialist and core palliative care, which are proposed to be covered by the tariff, to be around £411m for adults.**

It is estimated that hospital admissions in the last year of life for adults costs the NHS in the region of £1.3bn. The cost for children is estimated to be in the region of £18.2m. Savings could potentially be achieved on these hospital costs in the last year of life, which would free up resources to provide palliative care and care in the community. **We project that delivering improved recognition of palliative care needs, as well as optimised provision of services outside of the hospital setting, could reduce deaths in hospital by up to 60,000 a year by 2021.** Using the QIPP estimate of £3,000 per hospital death, **this would translate to a potential reduction in hospital costs of £180m per annum.**

Chapter 8 - Building the system

Currently, there is no national funding mechanism for palliative care. Given the need to build up an informed evidence base to support the move to a more equitable funding system we envisage that a transitional phase will be needed to allow for the transfer from the current system to the new system to take place. New data collection systems need to be set up. We recommend pilots are established to test the model and gather data to build the tariffs. Comparable work undertaken to develop mental health tariffs indicated that this would cost in the region of £1.5m to £2.5m.

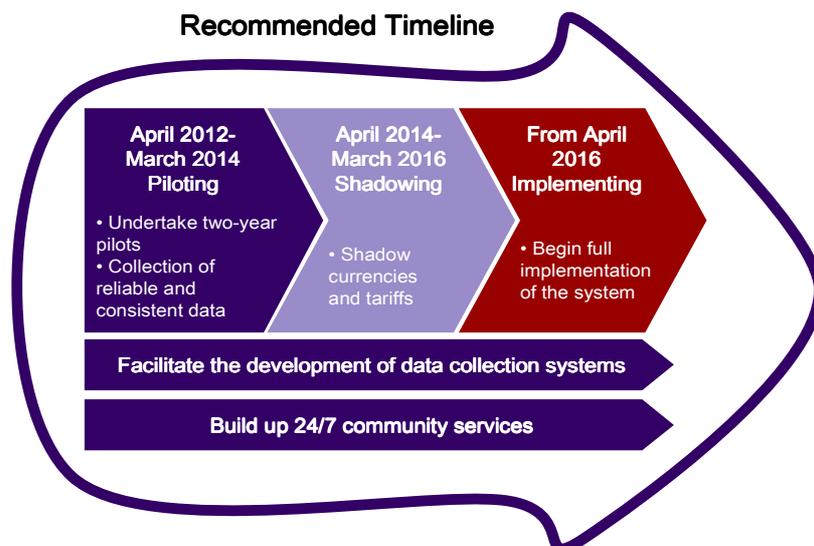


Figure 2 – Recommended Timeline

Chapter 1 **Our approach to the review**

Chapter summary

We know that there is a wealth of experience and expertise in the palliative care sector, and a key aim of the review has been to build on existing work and knowledge. In addition, the patient is at the heart of the work of the review so we have been keen to meet with patients and carers as often as possible.

We have met with more than 760 individuals from over 380 organisations and have reached even greater numbers through our website. We met with and heard from representatives from the NHS, hospices, the private sector, professional bodies, government, local authorities, spiritual care representatives, think tanks, academics, the third sector and patient and carer representatives. The consultation was divided into two phases, the first of which informed our interim report, the second has been key in developing this final report.

1.1 Purpose of the review

In the coalition agreement the Government made a commitment to introduce per-patient funding for palliative care. The Government set up this independent review to examine dedicated palliative care funding for adults and children in England, and to make recommendations on the way forward (see Annex 1 for copy of the Terms of Reference).

1.2 How the review team collected evidence

Following the announcement of the review in the summer 2010, the team started its engagement work with a stakeholder conference presenting the aims and objectives of the work to a range of professionals working in the palliative care sector. Following this event the team launched a website and outlined the key questions for the first stage of the review. They asked stakeholders to feedback on these via a questionnaire on the website and through meetings with organisations and individuals. This initial consultation formed the basis of the interim report, published in December 2010 and met the first part of the terms of reference of the review.

The second stage of the review, which followed the publication of the interim report, included a second website consultation, evidence sessions and regional stakeholder events. In addition, following a tendering process, a collaborative team led by King's College London was commissioned to develop a classification system for palliative/end of life patients according to need and to cost the delivery of services to meet these levels of needs.

Finally the review team refined their conclusions through a series of testing sessions with representatives from across the palliative care field. These

concluded with a final stakeholder event in June 2011, shortly before the publication of this final report.

1.3 Regional stakeholder events

From February to April 2011, the review team travelled the country to meet with stakeholders and to hear their views on the key questions for the review. In total more than 450 individuals from 270 organisations attended these events.

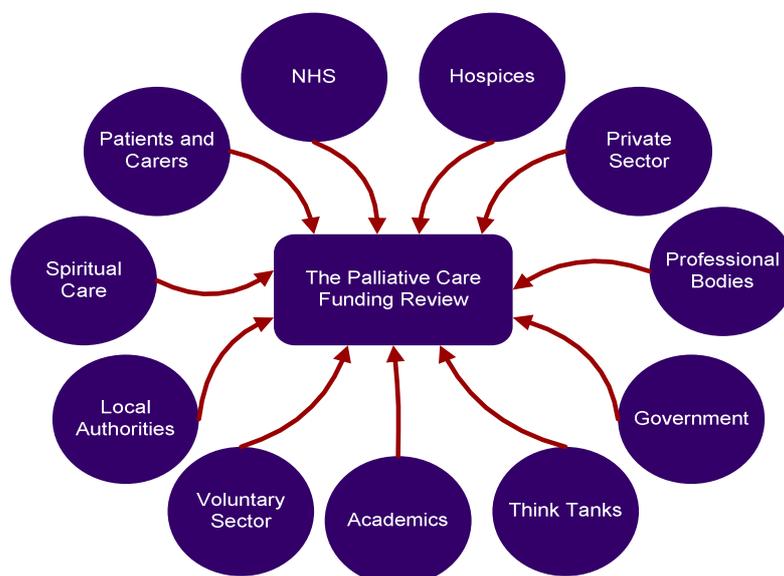
Events were organised either through local organisations which invited the team to visit or through regional end of life care leads. A wide selection of stakeholders from the state, voluntary and private sectors and across children's and adult services were invited. Attendees included GPs, commissioners, social workers, hospital managers, consultants, ambulance service managers, care home managers and a range of voluntary sector organisations.

1.4 Stakeholder meetings

In addition to the regional events, the team met with a number of organisations and individuals separately, to discuss key questions for the review in order to gain their different perspectives. We met with patients and carers, government departments, GPs, hospices, NHS organisations, private sector organisations, professional bodies, social care providers, academics, think tanks and the voluntary sector. In total we held evidence sessions with more than 310 individuals from 110 organisations.

1.5 Who gave evidence?

In total the review team met with more than 760 individuals from 380 organisations. In addition, for our online questionnaires, we received 90 responses to the first and 244 to the second (see Annex 2 for a list of all the stakeholders who engaged with the review). Overall, we met with and heard from representatives from the following:



1.6 What we asked and heard

Phase one of the stakeholder engagement

In phase one of the review the team asked three questions:

1. What do you think are “dedicated palliative care services”?

In response to our consultation on this question, several suggested definitions of dedicated palliative care were submitted to the review team. The respondents’ combined views on the elements included in dedicated palliative care can be summarised as follows:

- Individualised and holistic care and symptom control for patients who have a life-limiting or life threatening illness, and their families/carers
- Not age, diagnosis, place or time specific and do not involve disease modifying treatments
- Based on patient needs and wishes, and promote community based care
- Include community services, respite and day care and 24/7 access to care
- Include care and support for families and carers, including psychological and bereavement support
- Involve health, social care and the voluntary sector working together; including hospitals, nursing services, hospices, care homes, psychological therapies, social services and spiritual support
- Include education of professionals and the general public
- Interact with other services such as geriatric services and dependent on core generalist services to be functional, including community teams

2. What can we learn from the way services are currently provided, and how do we ensure we build on best practice to improve outcomes for people?

On this question, respondents felt that it was important to ensure:

- 24/7 access to community services
- Better integration of services across health and social care and coordinated care packages
- An increased focus on outcomes and patient choice
- A reduction of inequities in the system, be they geographical, funding, or access to services for patients with different diagnoses
- Improved education and training on palliative care services

3. How can we develop a funding mechanism which:

- **Is fair to all sectors, including the voluntary sector?**
- **Encourages the development of community-based palliative care services?**
- **Supports the exercise of choice by care users of provider and of location of palliative care provision?**

On this question, respondents felt that the funding mechanism must:

- Ensure investment in community based services (but not to the detriment of specialist hospital services)
- Be driven by clearly defined outcomes, avoiding perverse incentives and targets
- Recognise the differences, and the need for a smooth transition between children's and adults services
- Recognise the value of the voluntary sector and charitable contributions
- Encourage the use of individual care plans with defined resources
- Integrate health and social care funding and services
- Ensure the provision of fair, sustainable and flexible services

More information on the feedback in phase one can be found in our interim report, available on the review website (www.palliativecarefunding.org.uk).

Phase two of the stakeholder engagement

In phase two of the consultation we asked two further questions:

1. The review team recommend that the core components of dedicated palliative care to be funded by the state should be those which ensure people achieve an acceptable level of quality of life, thereby enabling them to be cared for and die in a place of their choosing.

- **What services are required to meet this?**
- **Should these services be 100% funded?**
- **Which services should be supported by society?**

Respondents felt that a range of services are required in order to provide good palliative care to meet the needs of patients and families/carers.

- A majority felt that an assessment of the needs of the patient, coordination of the care of the patient, in-patient and out-patient care, community care, rehabilitation support and education and training should be supported by the state.
- A majority of respondents also felt that social care, respite and short breaks, bereavement, psychological and psychiatric care and spiritual care should be supported by a combination of the state and society.
- The majority felt that complementary therapies should be supported by society alone.

Respondents argued passionately about the relative importance of each of these components of palliative care. A full summary of their views is available in our stakeholder engagement report which is available on the review website (www.palliativecarefunding.org.uk).

2. In addition to funding streams, an important part of any funding mechanism is the funding levers which can be used to bring about improvements in the quality of service provision.

- **What do you think are the current funding levers and how well are they working?**
- **In the new system, what levers do you think we should use to meet the needs of patients? How would these work? Are there any risks that new levers could impact in an unhelpful way on the delivery of quality care for patients?**

On this question, respondents told us that:

- Funding levers are currently unclear and used inconsistently in different areas
- Levers in the new system should include:
 - A clear definition of the responsibility of the state in providing palliative care
 - A tariff, including costs
 - A clear set of guidelines and outcomes which services should be commissioned and provided against, these should be based on meeting the needs and wishes of patients

In addition there should be financial incentives (either rewards or penalties) in the system to focus on:

- Providing high quality, dignified, safe symptom managed care to all, regardless of setting or provider (including assessments, care planning, coordination of care, medical care and emotional and spiritual care)
- Ensuring that people are cared for and die in a place of their choosing and which is appropriate to their needs (including avoiding inappropriate admissions, increasing the speed of discharges and integrated working between providers)
- Educating generalists, specialists and commissioners to agreed standards
- Focusing on the quality of services as well as value for money

The overall process of the review can be summarised as follows:

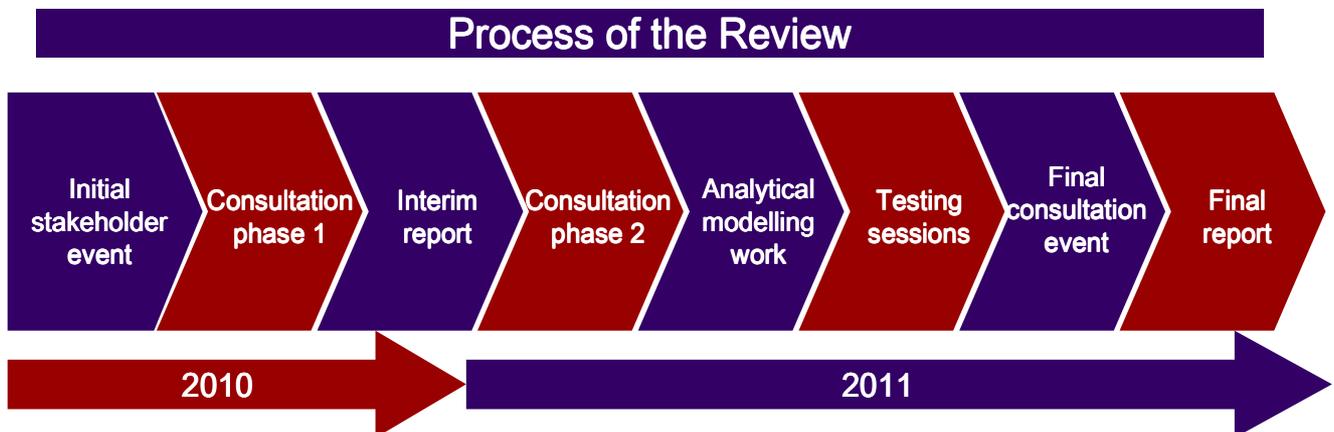


Figure 3: Review Timeline

Chapter 2 **The current funding system**

Chapter summary

From our research and stakeholder engagement, it is clear that while this country has some of the best hospice and palliative care services in the world, there are still significant challenges to address. Palliative care in England is provided by a plurality of providers from both the NHS and the voluntary sector. There is a lack of integration and coordination between services, and the provision of palliative care varies between geographical areas.

The lack of a clearly defined funding model and any national tariff, means that block contracts with some spot purchasing are the most common funding mechanisms currently employed in palliative care services. This means that payments do not follow patients, and providers are paid regardless of activity, impeding commissioners from performance-managing services. The current system does not therefore ensure best possible value for money.

A recent survey by the Department of Health estimates that PCTs spent £460m on adult palliative and end of life care in 2010/11, with one PCT spending around £0.2m on specialist palliative care alone, and another around £21m. This variation means that one PCT spent approximately £186 per death on specialist palliative care, while another spent £6,213. A total of, 61% of all PCTs spend less than £1,000 per death in their PCT.

2.1 Background

The palliative care sector in England has evolved in an ad hoc way over time which has meant that the state's role in funding these services has not been clearly defined. As a result, there are large variations in the levels of state funding provided, geographically as well as between services.

“There are areas of excellent practice with relatively little in others, so equity of provision needs to be high on the agenda.”

Consultant in Palliative Medicine

Reviewing the current system for funding palliative care in England highlights the fact that it is overly complicated, difficult to navigate and not joined-up enough, leading to a lack of fairness and transparency for commissioners, providers and patients. The system is focused on providers and **not** patients. The review team is therefore convinced that changes must be made swiftly to the system, as doing nothing and continuing with the current mechanisms will only compound these challenges.

2.2 Wide variation in services and sources of funding

Part of the challenge in addressing the funding of palliative care in England is the huge variety of services involved, and their various sources of funding. This can be illustrated in the following diagram:

Main funding flows for end of life/palliative care:

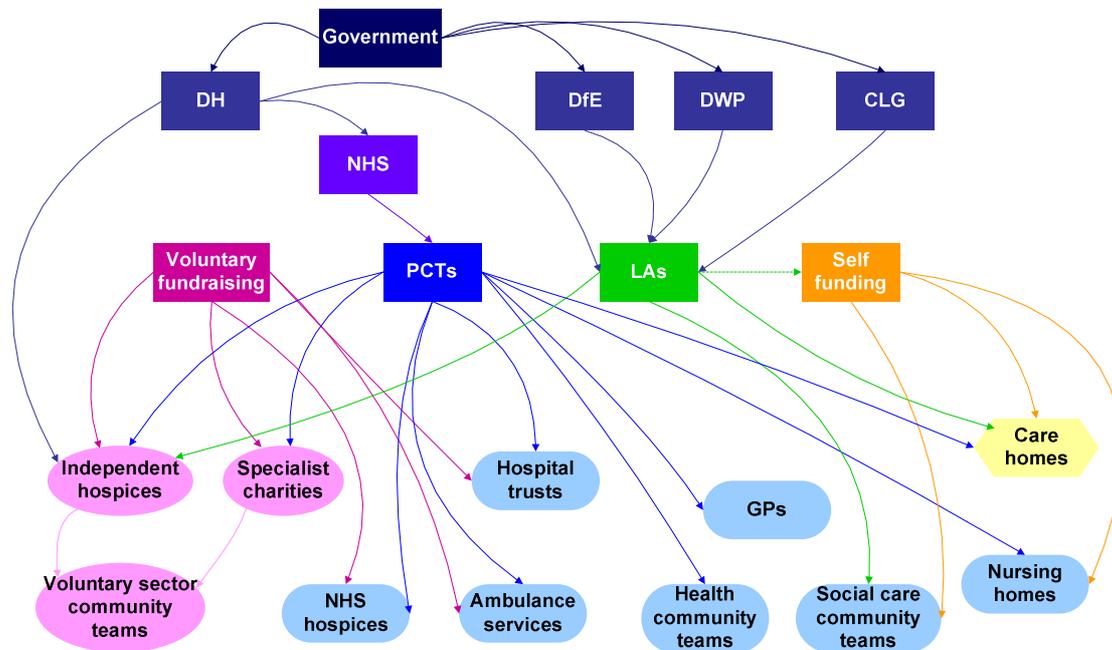


Figure 4: Main funding flows for palliative care

This overview is not exhaustive, but it does give an idea of the complexity of current funding streams within palliative care.

Alongside this complexity of funding streams, the actual arrangements for how state funding is provided and regulated are not robust or well defined. Whilst some pioneers have developed and are using local tariffs, there is no national tariff for palliative care in either acute or community settings, and no defined national funding model.

The lack of a clearly defined funding model and any national tariffs, means that block contracts with some spot purchasing are the most common funding mechanisms currently employed in palliative care services, as illustrated in the following diagram of the major state funding streams:

State funding sources and forms in the four main settings for end of life/palliative care:

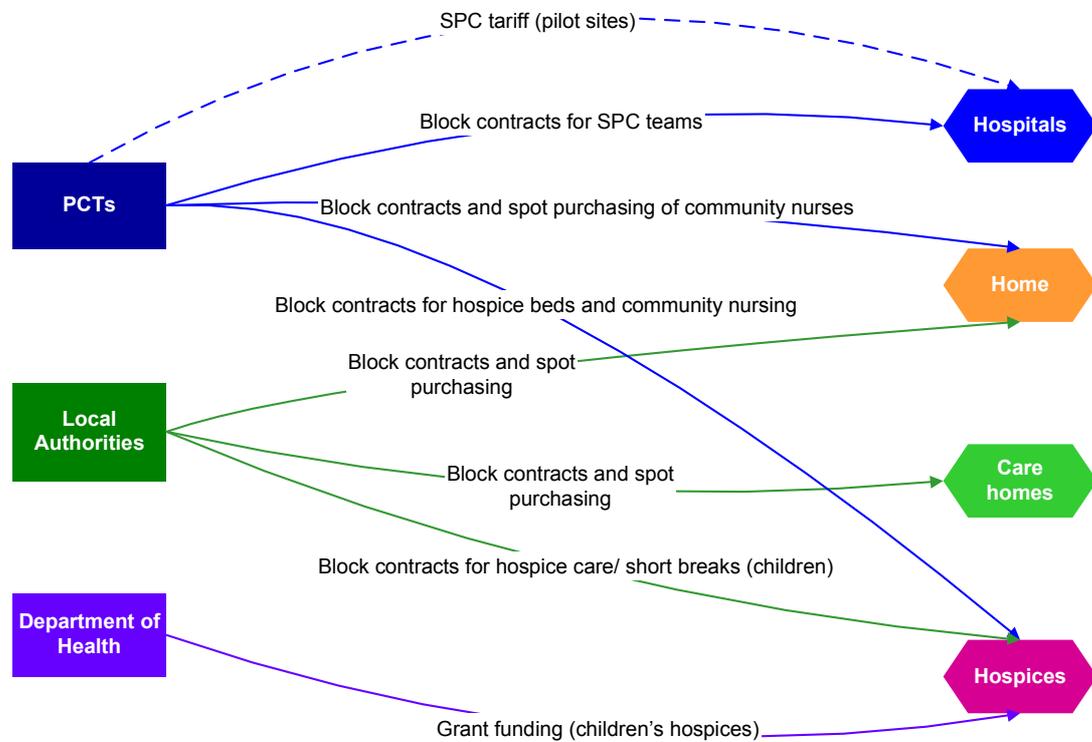


Figure 5: State funding methods

The current funding system therefore leads to a lack of transparency and fairness in the way services are funded.

2.3 The challenges for patients, commissioners and providers

The current funding system provides challenges for patients, commissioners and providers.

Patients: the current system means that the palliative care services that patients need are provided by a mixture of state and voluntary sector services, in a mixture of free at the point of delivery and means tested services. This leaves patients unclear as to what services they can reasonably expect to receive, as well as who is responsible for funding the services, impeding the exercise of choice by patients. Further, the ad hoc nature of the current system does not ensure that the services are tailored to actual need in an area or a population, which means that services are unlikely to reach all patients who may require palliative care.

Commissioners: the use of block contracts means commissioners have few options to incentivise evidence-based monitoring of services to demonstrate quality. Providers are paid regardless of activity. This impedes commissioners from performance-managing services, and does not allow them to ensure best possible value for money.

Providers: spot purchasing and short-term block contracts provide little security regarding future funding, and therefore do not enable providers to plan ahead to employ staff and provide high quality, sustainable services. This also impedes innovation and service developments. Further, block contracts fail to provide a clear division between which parts of the providers' services are paid for by the state, and which are paid for through voluntary fundraising, leaving providers without a clear message regarding the funding of their services.

2.4 Current PCT spend on palliative and end of life care

A recent survey by the Department of Health estimates that PCTs spent £460m on adult palliative and end of life care in 2010/11.

This figure relates to PCT expenditure on all services that are specifically focused on end of life and palliative care, but excludes generic services where palliative care is only one element of the services, such as district nursing.

The survey also underlines the variation of spend on specialist palliative care alone between PCTs, as the following table shows:

PCT spend on specialist palliative care 2010/11 ¹		
Minimum spend	Average spend	Maximum spend
£0.2m	£3.1m	£21m

Table 1: PCT spend on specialist palliative care

This huge variation in spend can be partly explained by the variation in PCT size, but it does lead to a ‘postcode lottery’, where PCTs are spending very different amounts of money on specialist palliative care per death in their area. This variation means that one PCT spent approximately £186 per death on specialist palliative care, while another spends £6,213. A total of 61% of all PCTs spend less than £1,000 per death in their PCT.

Notably, these figures cover PCT expenditure only, and do not take account of the significant expenditure by voluntary sector sources on specialist palliative care services. The reported figures are for adults only, as there is no data on PCT spend on children’s palliative care services.

2.5 Funding arrangements for the acute sector

There is currently no national Payment by Results (PbR) tariff for palliative care in hospitals, despite efforts by the Department of Health to develop one. Healthcare Resource Groups (HRGs) for specialist palliative care have been developed, and this has enabled some trusts to develop their own local tariffs in designated pilot sites. The 10th version of the International Classification of Diseases (ICD-10) offered a code relating to palliative care for the first time; the *Z51.5 - Palliative care*. Use of this code by hospitals is very varied, and there is no national tariff attached to the code, although some hospitals may have negotiated local tariffs for its use. National guidance on the use of this code states that it cannot be used in place of a primary diagnostic code and, therefore must always be coded in a secondary position (Corcoran & Gandy 1997).

Where there is no tariff for services, PCTs are likely to have block contracts with the acute trusts for the specialist palliative care team, although there may be some spot purchasing as well. There is no central register of what these block contracts or spot purchasing arrangements cover, as commissioning arrangements are a local responsibility.

Our research has shown that specialist palliative care teams in hospitals may operate as a loss generating service for the trust, with their costs covered through the income from profit generating services in the trust. Some income for these teams may also be generated through the voluntary fundraising income of the trust. In certain cases, the teams also have locality specific funding agreements with hospices or PCTs, such as community visit tariffs or phone consultation tariffs. The lack of

¹ Figures derived from survey to be published shortly by the Department of Health. Not all PCTs replied to this survey, so actual spend may be higher.

a clear funding structure for these teams means that their continued operation may be at risk.

2.6 Funding arrangements for the community sector

Hospices

A large number of hospice services in England are managed and predominantly funded by the voluntary sector, operated either as independent hospices or by national specialist charities.

The funding which voluntary sector organisations receive from the state does not normally cover their full running costs. On average, adult hospices in England received 34% of their running costs from government funds in 2009 (HtH 2010a). The actual percentage of state funding for local charitable hospices around the country varies considerably – from zero to 62% of their costs (NAO 2008a). Government funding for children’s hospices is typically much lower than for adult hospices, and is on average 15% of running costs (HtH 2010b).

The large national charities such as Marie Curie Cancer Care and Sue Ryder Care also generate the majority of their funding through fundraising.

Without a clear statement of what the state will provide to meet people's palliative care needs, the percentage of the services provided by voluntary organisations which should be funded by the state is unclear. But we know that 97% of independent hospices responding to an NAO survey felt that the funding they received from PCTs did not fully cover the costs of the NHS services they provided (NAO 2008d).

There is no national tariff for hospice care. Some work has been undertaken in various areas to develop local hospice tariffs, but so far these have not been implemented to any great extent. A PCT survey from 2008 showed that out of 135 PCTs reporting that they commissioned beds from voluntary hospices, the majority (80%) used block contracts.

Methods used by PCTs to commission hospice services		
Commissioning method	No of PCTs using commissioning method	Percentage of PCTs using commissioning method²
Block contract	109	80.7
Spot purchase	26	19.3
Other	27	20.0

Table 2: Commissioning methods (NAO 2008b).

For voluntary sector hospices, 70% of these contracts are one year contracts (NAO 2008a).

² The total number of PCTs was 135. Some PCTs reported using more than one commissioning method, and the numbers therefore add up to more than 100.

Children's hospices receive a large proportion of their state funding through a programme of emergency funding by the Department of Health, distributed as an ongoing annual £10 million grant to children's hospices under Section 64 of the Health Services and Public Health Act 1968 (HtH 2010b). This grant has so far been renewed every three years, but the future of this arrangement is unclear. Children's hospices also receive a proportion their funding to deliver short breaks. Short breaks funding comes through Local Authorities and the NHS. Department for Education ministers announced £800m for short breaks in December 2010. In addition, to help improve the way short breaks are provided, the Department for Education is also providing £40 million of capital investment in 2011-12.

In addition to the voluntary sector hospices, there are around 40 NHS run hospices in England, providing care for adults. While these hospices do receive the majority of their funding directly from the state, generally through block grant arrangements; most supplement this income with voluntary fundraising from the local communities which they serve. We know that some NHS hospices are raising 50% of their funding from voluntary sources.

Community nursing services

Community nursing services have historically been funded through block contracting arrangements – a fixed sum of money for a broadly specified service. The requirements for data collection and quality assessments of these services vary greatly between PCTs. The Department of Health publication, *Currency and Pricing Options for Community Services* (January 2009), signalled a shift away from these arrangements through a commitment to the development of tariffs under the Payment by Results system, though currently no currencies or tariffs for community services have been fixed.

HRGs for specialist palliative care in hospitals have been developed, and these could theoretically be applied to community service beds. But, it is clear that the use of these is currently not widespread.

GPs

GPs are funded through PCTs, on a surgery or practice basis. Around half of practice income comes from a global sum that is based on the number of patients within a practice, weighted according to their age profile, gender, levels of deprivation and ill health and the costs of recruiting staff in each locality.

The second major chunk of funding comes from the Quality Outcomes Framework (QOF) system. The QOF has an indicator set for palliative care, including:

- That the practice has a complete register of all patients in need of palliative care irrespective of age
- That the practice has regular (at least three-monthly) meetings where all patients on the register are discussed

GPs receive three QOF points for achieving each of these. There are no specific guidelines on funding for the palliative care indicators, and the use of registers varies between GP practices. But the purpose of the points system is to pay them accordingly (DH 2008a).

Thirdly, practices can enter into Enhanced Service agreements, either with Government or with their local Primary Care Trust. These secure payment for meeting specific requirements, such as flu and childhood immunisations or targets that have been defined to meet a specific local need.

Residential care

Nursing and care homes are generally funded partly through NHS, partly through Local Authorities and partly from patients themselves. The funding arrangements for the Local Authority contributions to funding care homes range from block contracts to per-patient funding arrangements, with the majority of care homes receiving block contracts from their commissioning Local Authority. Whilst we do not know the exact number of state funded places in these homes, according to a NAO care home survey from 2008, 50% of places in the care homes that responded to the survey were fully state funded, while 29% were privately funded and 21% were mixed funded (NAO 2008c).

NHS continuing healthcare

One form of funding for care in the community is also provided to meet people's palliative care needs through NHS continuing healthcare budgets. For adults, NHS continuing healthcare is the name given to a package of care which is arranged and funded solely by the NHS for individuals outside hospital who have ongoing healthcare needs. Patients can receive continuing healthcare in any setting, including their own home or a care home.

Anyone assessed as having a certain level of care needs may receive NHS continuing healthcare. It is not dependent on a particular disease, diagnosis or condition, or on who provides the care or where that care is provided. If, following an assessment process, a patient's overall needs show that their *primary need* is a health need; they should be eligible for NHS continuing healthcare.

NHS continuing healthcare assessment can be a lengthy process, unless the individual is judged to qualify for the fast-track assessment. The fast track tool has been developed for cases where the patient is rapidly deteriorating, entering a terminal phase or has an increasing level of dependency. This tool is primarily used for people approaching the end of life.

NHS Continuing Healthcare (CHC) – the carer perspective

Healthcare professionals, patients and families have told us of the difficulties that they have faced in navigating the continuing health care system. From the patient and carer perspective the system is poorly understood, highly bureaucratic and not responsive enough. One carer highlighted their case to us where the fast track continuing healthcare assessment took over three weeks to arrange, during which time the emotional and financial burden on the family placed a great strain on them, at an already very difficult time. They struggled to know who to contact and what action they should take and felt that the staff they came into contact with also had a poor understanding both of their situation and the continuing healthcare processes. This was both frustrating and upsetting for the family at a time when they wanted to be able to focus on their final few weeks with their father.

Continuing care for children and young people is organised differently from care for adults. A continuing care package will be required when a child or young person has needs arising from disability, accident or illness that cannot be met by existing universal or specialist services alone (see Annex 7 for our definitions of specialist, core and universal palliative care services). Continuing care does not cover children and young people with care needs that may be met appropriately through existing universal or specialist health services. In this instance, their needs should be addressed using a case management approach.

However, childhood and youth is a period of rapidly changing physical, intellectual and emotional maturation alongside social and educational development. All children of compulsory school age (5 to 16) should receive suitable education, either by regular attendance at school or through other arrangements. There may also be social care needs. Most care for children and young people is provided by families at home, and maintaining relationships between the child or young person, their family and other carers, and professionals, is a particularly important aspect.

This means that a wider range of agencies is likely to be involved in the case of a child or young person with continuing care needs than in the case of an adult. Children and young people's continuing care needs are best addressed holistically by all the agencies that are involved in providing them with public services or care: predominantly health, social care and education. It is likely that a continuing care package will include a range of services commissioned by PCTs, local authority children's services and sometimes others. PCTs are responsible for leading the continuing care process for children.

Social care services

Social care services contribute greatly to palliative care through social care

community teams. A study undertaken by the Nuffield Health Trust found that on average 30% of the people studied used some form of Local Authority-funded social care service in the 12 months prior to death (Nuffield 2010).

Local Authorities run community teams providing needs assessed social care in people's homes, including palliative and end of life care. These teams are generally funded directly by the Local Authority.

We know that some hospices also have social care workers as part of their palliative care teams. These are not generally funded by the state, but are often covered through the hospices' voluntary fundraising.

Most funding for Local Authority funded social care comes from central government through the Revenue Support Grant, but a substantial proportion of social care spending also comes from finance raised by local councils themselves. Unlike healthcare, social care services are subject to means-testing and charging. A person with total assets worth more than a given capital threshold (this is updated annually and currently stands at £23,250) receives no public financial support.

The assessment of social care needs, as well as the means testing system, is currently a lengthy process and is undertaken separately from the health care system. This impedes the coordination of the services and the delivery of an integrated service for patients.

For children, policy responsibility for social care has passed to the Department for Education (DfE), which funds and regulates children's social care service provided through Local Authorities.

Chapter 3

How to create a new funding system

Chapter summary

The review was asked to develop, for the first time, a per-patient funding mechanism for palliative care for adults and children in England. Palliative care is still an emerging field, and models for funding it are still being developed, not just in England but also internationally.

We are all different and the health service is built on variation. So the challenge is to develop a system which captures these variations and can classify the many different people who need care and support.

The main criterion identified as shaping palliative care needs is phase of illness (stable, unstable, deteriorating and dying). An initial needs classification system is therefore proposed, led by phase of illness. This initial classification system can further be combined with a system to capture the other main cost drivers identified (provider type, problem severity, functional status and age). Based on these criteria, we recommend a needs classification system with a total of 25 classes – 13 for adults and 12 for children. We recommend attaching tariffs to each of these classes.

Basing the funding model on a needs classification system would ensure that the funding follows the patient in a fair and transparent way, as the level of funding provided to a service would be determined by the complexity and level of need of the patients.

3.1 A unique challenge requires an innovative approach

A review of international models for funding palliative care shows that the only country which has implemented a full per-patient funding model for palliative care is Australia³. This review is a great opportunity to introduce a palliative care tariff for the first time in England, and at the same time deliver the first community tariff in the country. As the Australian model is for adults only, there is no existing per-patient funding system for children's palliative care in the world, so the delivery of a system for children would be a world first.

'First - good luck. This question has been kicked into the long grass too many times before because of its complexity - but it deserves an answer. Second, don't throw out the baby with the bathwater. Despite the current system's problems, it has produced an improvement in care in the last few decades.' **Chief Executive, Hospice**

³ A brief summary of the Australian system and other international models reviewed is provided in Annex 3.

Palliative care is unlike many other fields of care in that it delivers complex, patient and family centred interventions to those with life-limiting conditions, which are driven by professionals' recognition of needs, and the patient's (and often family's) awareness, preferences and priorities. This complex combination of perspectives is highly challenging for the development of a successful per-patient funding model and has required the review to consider a new approach to building a funding model.

3.2 We need to build a system around meeting people's needs

The review was asked to develop a per-patient funding mechanism for palliative care for adults and children in England. Stakeholders have told us we also need to consider what a new tariff system can offer for people, in terms of addressing inequities, capturing patient-based outcomes, and driving high quality care in the place of choice. We believe the first step in doing this is to understand patient needs by developing a patient classification system which organises patients based on characteristics of care needs and similarity in resource use.

“Any funding mechanism will need to recognise intensity and complexity of palliative care interventions going beyond the conventional standards and targets such as bed occupancy, length of stay etc.”

Consultant in Palliative Medicine

We are all different and the health service is built on variation. So the challenge is how we develop a system which captures these variations and can classify the many different people who need care and support, and which meets their palliative care needs at any stage of their journey.

3.3 We commissioned new research to help develop solutions

With the current paucity of data in this field, the team commissioned a piece of detailed research to support our work and enable us to develop evidence-based solutions. In it we asked tenderers to consider options and develop proposals for:

- 1. A classification system categorising palliative/ end of life patients according to level of need**, which is capable of categorising palliative and end of life patients into meaningful groups based on comparable intensity of care needs and similarity in resource use.
- 2. Costings of the delivery of services necessary for each of the levels of need in the classification system.** Calculations of the cost, for a set time frame, of the services necessary to meet the identified needs at each level of the classification system developed in part 1.

We were delighted to award this contract to a collaborative team led by Dr Fliss Murtagh, Dr Claudia Bausewein, and Professor Irene Higginson, from King's College London (KCL), working with Julia Verne from the South West Public Health Observatory (SWPHO) and Peter Lacey from Whole Systems Partnership (WSP). The recommendations we put forward in this chapter are informed by the evidence and conclusions of their work.

3.4 Getting a better understanding of the needs of patients

The first step towards developing a per-patient needs based system is to gain a better understanding of patient needs, by examining the key cost and resource drivers in the last year of life.

As part of the work undertaken for the review by KCL and their partners, a literature review was conducted to consider the factors which affect the level of care needed in the last year of life. There is limited evidence available, and much of it is from a non-UK setting, but some preliminary findings can be presented:

Drivers of need in palliative care for adults

- Older age is associated with reduced overall costs, although home, nursing home, and hospice care costs specifically are higher for older people
- Black and ethnic minority background is associated with lower overall costs, but increased hospital costs
- Lower socio-economic status is associated with lower hospital costs and higher home care, nursing home, and hospice costs
- Living alone drives increased overall costs, while higher income drives hospital costs up specifically
- An urban setting for care provision also tends to drive up overall costs.
- In terms of illness, poorer functional status, proximity to death, and co-morbid conditions all increase costs across settings
- Palliative care interventions decrease costs across settings, and particularly reduce hospital costs

For children, the evidence is even less clear, but there are some indications and trends, as shown in the following table:

Drivers of need in palliative care for children

- Diagnosis and trajectory of illness affect the pattern of costs (longer trajectories are associated with higher costs, and some chronic conditions are associated with lower in-patient and higher outpatient costs. Cancer-related costs peak around diagnosis and then again towards death)
- Older children may have lower outpatient costs
- Black and ethnic minority background is associated with different patterns of costs (higher hospital but lower hospice costs).
- Rural location is associated with different patterns of costs (greater in-patient and lower outpatient costs)

As part of the review work, the Department of Health undertook an analysis of hospital use in the last year of life for people with conditions that may indicate a need for palliative care⁴. The analysis shows that almost a third (32.6%) of all hospital admissions for adults with conditions that may require palliative care in the last year of life occur in the last 30 days before death.

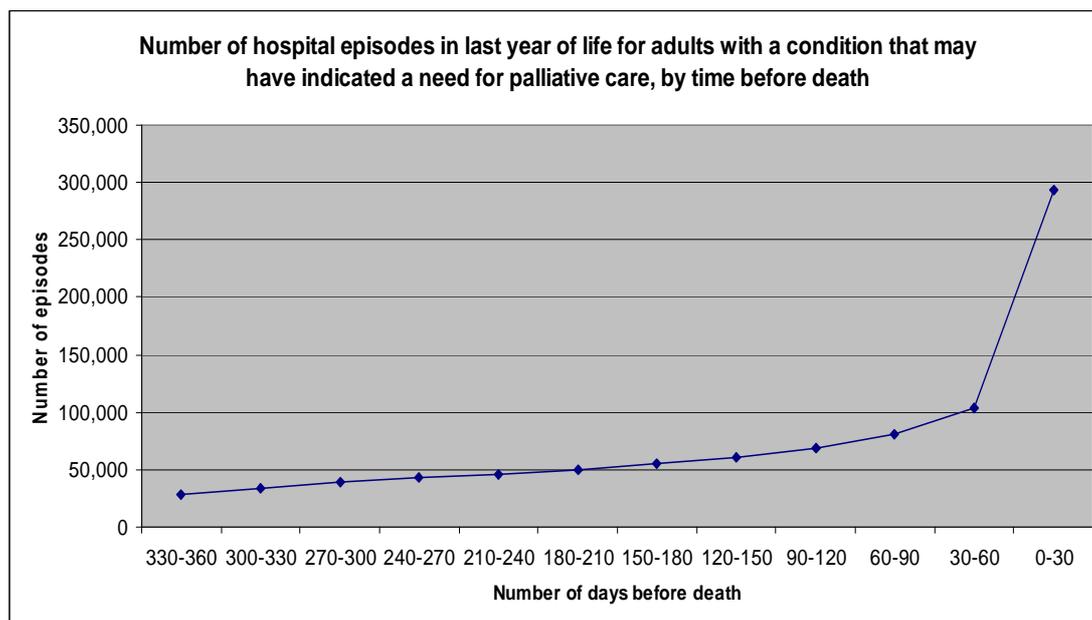


Figure 6: Hospital episodes for adults

⁴ This analysis constitutes an update of the Cochrane work from 2007 (Cochrane et al 2007). The original analysis covered children only. The updated version refreshes this, and also extends the methodology to adults using a different list of conditions, derived from the Rosenwax work (Rosenwax et al 2005). The data used for this analysis are derived from a linked dataset of ONS mortality data from 2009 and The Information Centre for health and social care Hospital Episode Statistics (HES) data from 2008 and 2009. The resulting dataset enables conclusions to be drawn about the hospital episodes of a person in the last year of life.

For children, there is a similar pattern, with more than four times as many episodes occurring in the 30 days before death as in the penultimate 30 days.

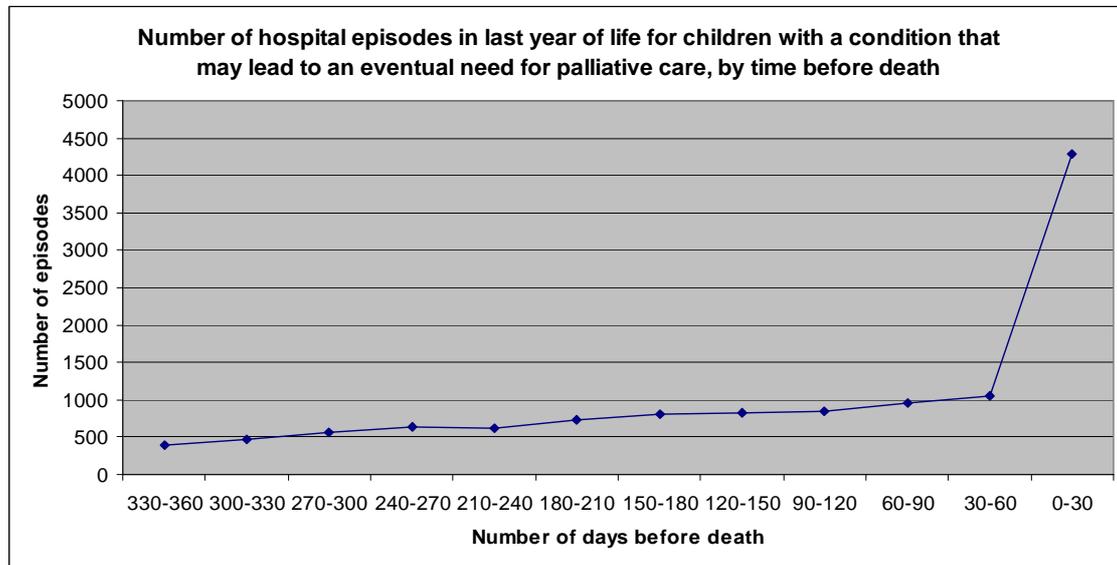


Figure 7: Hospital episodes for children

The number of episodes also increases with age for adults, and there is a relationship between higher episode numbers and more deprived areas for both adults and children.

Finally, the KCL/SWPHO/WSP team also undertook a review of international work on palliative care, and found that the Australian National Sub-acute and Non Acute Patient classification system provided the only prospective work undertaken to classify and understand patient needs in palliative care. The Australian work identified that the criteria used successfully in classification systems for acute care, such as *diagnosis*, *procedures*, *age*, and *disposition* were ineffective in classifying resource use and level of need in palliative care. Instead, *phase of illness* was identified as the best indicator of resource use (see below in paragraph 3.6 for a definition of the four phases of illness identified). Further, regression analysis revealed *age*, *functional status*, and *problem severity score* as the best additional predictors of cost (Eagar et al 1997). (See Annex 3 for more details on the Australian model).

The Australian model found that there was still a degree of variation which could only be explained by the difference in the provider type. The Australian team therefore included provider type as a variable, although this was a provider-level rather than patient-level variable, and not regarded as ideal for inclusion in a needs-driven classification system (Eagar et al 1997).

3.5 Developing a classification system

The cost drivers identified for palliative care are therefore different from the main cost drivers in acute care which are mainly diagnosis driven, and which as a consequence are the main determinants for the current PbR system. However, they resonate with the clinical reality of palliative care.

Based on the findings from the literature review, the Department of Health analysis and the review of international models, the commissioned work from KCL and their partners delivered a detailed proposed classification system for understanding and classifying patient need. These recommendations are based on the evidence outlined above, and have been discussed with a number of clinicians in both adult and paediatric palliative care, and refined accordingly.

The term used to describe this type of patient level classification system within healthcare funding is ‘casemix’. Casemix is a general term which describes any system which classifies patients into groups based on their level of need and the resources they use.

The main driver of need was found to be the **phase of illness**. We would therefore recommend an initial classification system which is based on phase of illness:

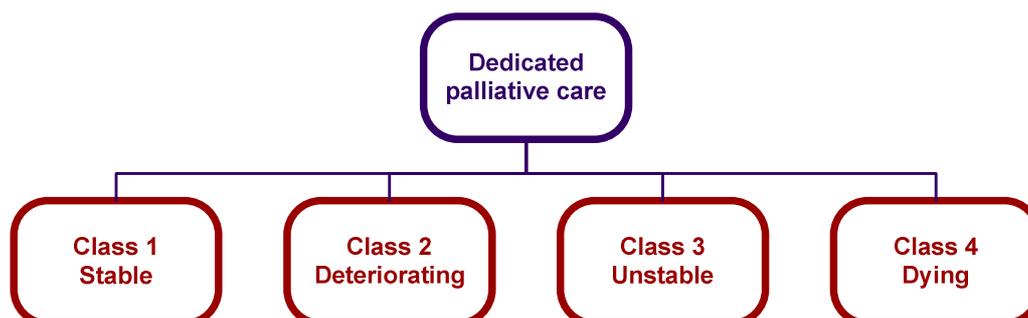


Figure 8: Initial classification system

This initial classification system can further be combined with a system to capture the other main cost drivers identified (provider type, problem severity, functional status and age), which would allow for further refinement of the classification system going forward. We envisage that for accuracy and ease of use, the system would need to be split between adults and children. **Building on the criteria and the evidence from KCL and their partners, and simplifying their proposal somewhat, we have developed an initial proposal for a needs classification system with a total of 25 classes – 13 for adults and 12 for children.**

Proposed detailed classification system for adults						
Phase	Provider type	Problem severity	Functional status	Age		CLASS
Stable	Non-specialist	-	-	-	➡	1
Stable	Specialist	-	-	-	➡	2
Unstable	Non-specialist	-	Low-mod impaired	≥60	➡	3
Unstable	Non-specialist	-	Low-mod impaired	≤59	➡	4
Unstable	Non-specialist	-	High impairment	-	➡	5
Unstable	Specialist	Low/ mod	-	-	➡	6
Unstable	Specialist	High	-	-	➡	7
Deteriorating	Non-specialist	-	-	-	➡	8
Deteriorating	Specialist	Low	-	-	➡	9
Deteriorating	Specialist	High	Low-mod impairment	-	➡	10
Deteriorating	Specialist	High	High impairment	-	➡	11
Dying	Non-specialist	-	-	-	➡	12
Dying	Specialist	-	-	-	➡	13

Figure 9: Classification system for adults

Proposed detailed classification system for children				
Age	Phase of illness	Problem severity		CLASS
0-1 years	-	Low or moderate	➡	1
0-1 years	-	High	➡	2
2-13 years	Stable	Low or moderate	➡	3
2-13 years	Stable	High	➡	4
2-13 years	Unstable/ deteriorating	Low or moderate	➡	5
2-13 years	Unstable/ deteriorating	High	➡	6
2-13 years	Dying	-	➡	7
14-25 years	Stable	Low or moderate	➡	8
14-25 years	Stable	High	➡	9
14-25 years	Unstable/ deteriorating	Low or moderate	➡	10
14-25 years	Unstable/ deteriorating	High	➡	11
14-25 years	Dying	-	➡	12

Figure 10: Classification system for children

As such, the following five key criteria are used to classify palliative care need for adult patients:

Key classification criteria proposed for adults

- **Phase of illness**
- **Provider type**
- **Problem severity**
- **Functional status**
- **Age**

Or, to put it another way, when a clinician assesses a patient's needs, the five key questions they would ask are:

- Which phase of illness is the patient currently in?
- Which provider type will need to be involved in delivering the care?
- How severe are the problems the patient is experiencing?
- What is the current functional status of the patient?
- What age is this patient?

For children, functional status and provider type was believed by clinicians to be less important, and the main criteria was found to be age rather than phase of illness.

Key classification criteria proposed for children

- **Age**
- **Phase of illness**
- **Problem severity**

Or to put it another way, when a paediatric clinician assesses a patient's needs, the three key questions they would ask are;

- What age is this patient?
- Which phase of illness is the patient currently in?
- How severe are the problems the patient is experiencing?

Case study:

The Lincolnshire model

The Lincolnshire end of life model has evolved over the last eight years. This programme, whilst delivering five discrete projects, more importantly, provided the foundations on which a strong partnership has been built between palliative care providers and commissioners in health, social care and the third sector. During the last four years, a number of different end of life initiatives have supported the evolution of the Lincolnshire model.

Most recently, a new development has ensured that end of life patients have their needs identified and matched to the correct staff with the required competences. Working together St Barnabas Hospice, Marie Curie Cancer Care, NHS Lincolnshire, Lincolnshire Community Healthcare Services NHS Trust and local agencies have implemented, a locally developed, responsiveness needs tool that has allowed this to happen. This development has been a result of an integrated approach to service development and delivery.

The responsiveness tool identifies whether the patient requires a stable (planned), deteriorating (rapid) or urgent (immediate) response based on their physical and emotional needs and their phase of illness. Although the pilot still has two months to run, early indicators suggest some very encouraging results:

- Those patients with the greatest need have received care from the right staff at the right time
- 100% of patients who have been through the pilot have died in their preferred place of death
- Feedback from relatives and clinicians has been positive

The full evaluation report will be due in early autumn and will be used to inform future commissioning and provision of responsive palliative care services in the community.

3.6 Definitions of the criteria

Phase of illness

Phase of illness refers to a phase in the patient's illness reflecting the type and level of care needed. Four main phases can be identified:

- **Stable:** symptoms controlled, needs met by current care plan, family situation stable
- **Deteriorating:** symptoms gradually or steadily worsening over weeks, or development of new but expected problems over days/weeks, with need for adaptation of care plan and regular review, with worsening family distress and/or social/practical burden (note that rapidly or unpredictably deteriorating would fall into the next category)

- **Unstable:** new severe problem(s) or rapid increase in existing severe problem(s) over days, and urgent or semi-urgent change in intervention(s) needed to meet needs
- **Dying:** death anticipated in a matter of days, requiring frequent, usually daily, review

Throughout the course of a disease a patient will experience several phases. There is no sequential order of the phases and a patient can be in the same phase several times during their disease trajectory. Phases can vary in length from days to weeks to months.

Provider type:

In line with the Australian findings, provider type is further proposed to be included in the classification system, at least as a transitional measure, defined by specialist or non specialist provision as this fits with existing English models of palliative care. We propose that specialist provision is defined based on existing definitions, in terms of the multi-disciplinary team nature of the care provided and the additional specialist training undertaken. The inclusion of this criterion constitutes something of a compromise between being needs-led and accommodating existing models of palliative care, but the patient criteria are still the core components of the model.

Problem severity

Problem severity relates to the number of domains of need, together with their interaction and unpredictability which together determine clinical complexity. We recommend that a Palliative Care Complexity scale, similar to that used by the AN-SNAP study or to the Rehabilitation Complexity scale developed for a similar purpose in rehabilitation, is developed. Problem severity could be calculated using established outcome measures, providing these are multi-dimensional and short, and can be completed by clinicians in practice.

Functional status

Functional status or dependency can be captured by short scales, such as the modified Karnofsky scale and the Barthel index. These are relatively simple scales which can be scored within a short time, and which are already in common usage in the UK.

Age

Age group for children have been categorized into 0-1 yrs (up to second birthday), 2-13 yrs (up to 14th birthday), 14-25 yrs (up to 26th birthday), and ≥ 25 yrs. An age cut off of 60 years has also been employed for some of the adult classes. The age cut off for the children's categories has been extended to 25, in order to capture the transition group. **We recommend that the age cut offs between the adult and children's classification systems should be used in a flexible way, to best suit the needs of the patient.** For example, a child living with a life-limiting illness from early in life should not be immediately transferred to an adult tariff when turning 18 if their needs are still better covered by the children's tariffs. Vice-versa a young adult under 18 who

is diagnosed with a life threatening condition, could be placed on the adult tariff if deemed more suitable by the assessing clinician.

3.7 Testing the proposed classification system

The evidence shows that developing a patient classification system, a balance needs to be struck between the level of detail captured and the level of effort required to capture them. At one extreme, a classification system would have a class for each and every patient, as every patient is different. At the other extreme, there is one class only which covers all patients. There is a direct trade-off between accuracy of classification and criteria which is not too difficult for providers and commissioners to use in practice. **We believe that the level of detail included in the classification system proposed here strikes the right balance, but this should be tested and refined going forward.**

“Don’t over-complicate any funding structure. Level of complexity may well seem an appropriate method of defining how much should be paid.”

Chief Executive, Hospice

The proposed classification system has been adapted from the Australian system, combining some of the classes and integrating the in-patient and community classification systems, to achieve a less complicated model. Testing and piloting the system is necessary, to determine whether the proposed criteria can be reliably measured and are effective in delivering sufficiently homogeneous classes. This is especially critical for the paediatric components, since the Australian work was exclusively focused on adults, and there is very limited evidence on cost drivers for palliative care for children and young people.

3.8 How the palliative care tariff will work

We recommend the development of a funding model based on the presented classification system. This will ensure that the funding follows the patient in a fair and transparent way, as the level of funding provided to a service is determined by the complexity and level of need of the patients. **To achieve this, we recommend that each class in the classification system is assigned a tariff based on their relative resource use. These would be set as national tariffs, but commissioned and delivered locally.**

The level of tariff attached to each class would be determined through establishing the relative resource use for each class. The tariff level would therefore be weighted by the needs of patients. For example, adult class 11 (deteriorating patient with specialist input, high problem severity and high impairment) would be likely to have a significantly higher cost than adult class 1 (stable patient requiring non-specialist input).

The tariffs will follow the patient, and will be available to pay for palliative care in all settings, including hospitals, care homes, hospices or the patient’s own home, and regardless of provider.

The tariff will be available to cover the palliative care needs of all patients assessed as needing palliative care. The episode tariffs would therefore be available to cover a patient's palliative care needs throughout their journey. For example, we would anticipate that for children, following the conversation and assessment of them being diagnosed as life limited, any palliative care needs the child has would be met through the tariff. The tariff would not replace other funding for the patient's disease, and would in effect operate as a top-up to any other tariffs which may already cover the non-palliative aspects of the patient's care needs. This can be illustrated in the following diagram:

The palliative care top-up tariff

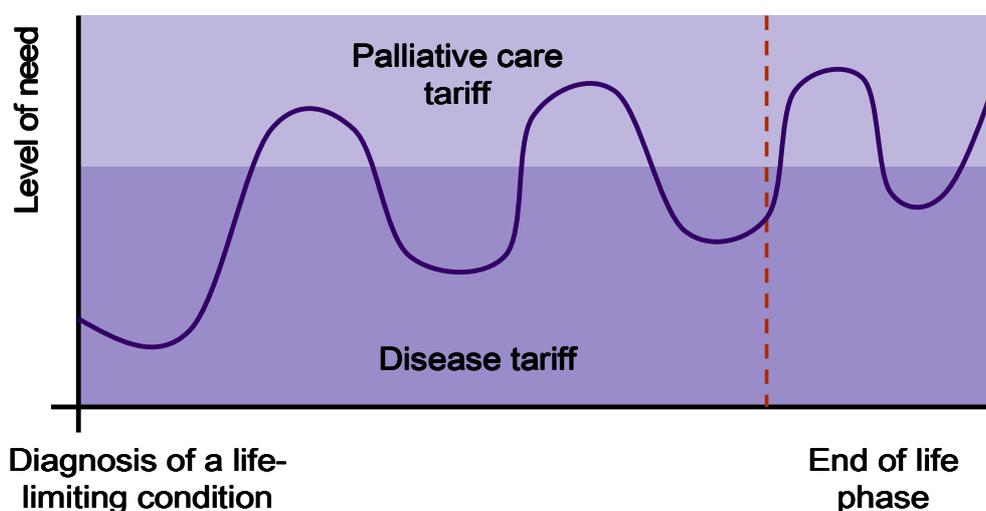


Figure 11: The palliative care top-up tariff

As such, a patient would not need to be in the dying or end of life stage of their trajectory to access the palliative care tariff. Patients would be able to dip in and out of the system as and when they have a palliative care need.

We recommend one tariff structure which works across all settings and providers. This will ensure that the funding follows the patient in a fair and transparent way, as the level of funding provided to a service is determined by the complexity and level of need of the patients. We recommend that the exclusion of accommodation costs from the tariff needs to be tested through the pilots to understand the impact and fairness for all providers, before it can be concluded with any certainty that they should not be included in the tariff.

How will it work in practice for patients, commissioners and providers?

Patients, once they are assessed as needing palliative care, will know that there is a tariff available to cover their palliative care needs in all settings, including hospitals, care homes, hospices or the patient's own home.

Commissioners will have a tariff by which to purchase palliative care services based on activity, using a system which is weighted based on complexity of patient need. They would be able to commission to quality and outcomes, and would be able to monitor activity closely and plan future services accordingly.

Providers will be paid for the care they provide to patients on an activity basis. The level of payment will be dependent on the complexity and resource use of the patient cases, providing a fairer payment for the services provided.

We propose that payments are structured as *episode payments for each phase of illness*, rather than per-diem payments. They should be based on the average length of a phase of illness, and the length will therefore vary between classes. This means that a new unit or episode is counted whenever the patient moves between the phases of illness used in the classification system. This allows a new episode of care to start when it is clinically meaningful.

Any funding model that includes an element of episode payments needs to consider how best to fund patients whose episodes are of exceptionally short or long duration in relation to the average length of stay (Eagar et al 1997). See Annex 3 for details on how this is addressed in the Australian model.

In order to address the current problems for palliative care patients relating to the boundaries between health and social care, as well as the inconsistency in the application of the CHC system, **the review recommends that once a patient reaches the end of life stage, and are put on the end of life locality register, all health and social care should be funded by the state and free at the point of delivery (see Chapter 4 and 5 for more detail on this argument). We recommend that this is implemented as a 'clip-on' to the main palliative care tariff, which can be added on once a patient has been added to the end of life locality register. We recommend that the social care clip-on tariff should not include accommodation costs.**

3.9 We need to collect more cost information to build a tariff

One of the major challenges for this review has been the lack of consistent cost data. Providers have very different methodologies for reporting and presenting their cost data, which makes it difficult to draw comparisons. **In**

order to inform this proposed per-patient funding model, it is necessary to collect data on services provided to patients, as well as the actual costs of delivering these services, in a consistent manner across providers.

“A tariff that is equal for all providers; NHS, private or voluntary, enables better planning and development of services.”

Chief Executive, Hospice

Detailed data should, therefore, be collected on patient characteristics, staff time, and all costs accrued in delivering palliative care to these patients. This is necessary to identify mean and variance in resource use, understand what patient characteristics best correspond to different levels of resource use, and from this analysis, refine the proposed classification system to correspond most accurately to resource use.

In order to ensure that the data collected is comparable across providers, it is important to develop an agreed methodology for classifying and reporting cost data. One way of ensuring this is to use the ‘cost bucket’ approach applied in the Australian work, but modifying the cost buckets to suit the England setting.

In this approach, all costs are categorised into cost groups or ‘buckets’, representing the different components of costs. This is to aid understanding of costs and cost variance between services and service providers, and to allow for exclusion in the analysis of those elements which are not included in the tariff. (See Annex 5 for a list of possible cost buckets). Some cost drivers which are difficult to capture at patient level are not built into the system. In order to ensure the tariff system is fair to all providers, **we recommend weighting the tariffs by in socio-economic factors which are not picked up in the direct tariff costs.**

We recommend that a prospective study is undertaken to verify and refine the proposed classification system as well as understand resource use at a patient level. Such a study is already in development by King’s College London. We also recommend the establishment of pilots to test the model and gather data to build the tariffs. See Chapter 8 for more details on our recommendations around the transitional phase.

Chapter 4

How to support the funding mechanism to deliver better outcomes for patients

Chapter summary

An important part of any funding mechanism are the funding levers which can be put in place to support the tariff structure and bring about improvements in the quality of services provided to patients.

Stakeholders have told us that the funding levers in the current system are unclear and are used inconsistently in different areas. In this chapter we suggest a set of levers to be implemented in the system, to support the best possible outcomes and quality services for patients.

4.1 Levers to support a new funding mechanism

The following diagram illustrates what patients, families, commissioners and providers have told us they want from the new funding mechanism:

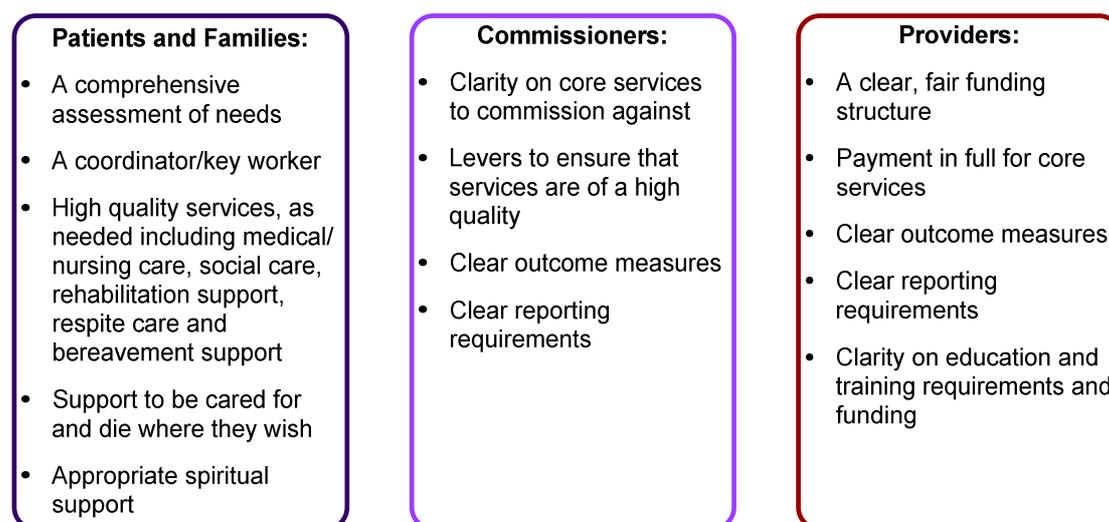


Figure 12: What stakeholders want.

In addition to the tariff system, an important part of any funding mechanism is the funding levers which can be used to support the tariff structure in bringing about improvements in the quality of service provision.

Stakeholders have told us that the funding levers in the current system are unclear and are used inconsistently in different areas. We therefore recommend that a set of funding levers are implemented in the system, to support the funding mechanism to achieve the best possible outcomes and quality services to be provided for patients.

We recommend:

- **Implementation of a per-patient funding model based on the presented classification system** (see Chapter 3). This will ensure that the funding follows the patient in a fair and transparent way, as the level of funding provided to a service is determined by the complexity and level of need of the patients. The use of a tariff for both adults children's, supported by the provision of a care coordinator for all patients, would facilitate the transition from children's to adult services. To support this, we recommend that the age cut offs between adult and children's classification systems should be used in a flexible way, to best suit the needs of the patient (see paragraph 3.6 above).
- The development of a **statement by the Government describing the palliative care support and services that patients, families and carers can receive, if they need them, from the NHS**. A version of this is currently on available NHS Choices, but this needs to be updated and strengthened.
- **A lead provider for palliative care is identified in every Clinical Commissioning Group, to coordinate all palliative care services, including those not funded by the NHS**. Furthermore, consideration should be given to the commissioning of integrated care packages which include services not funded by the NHS, to prevent cherry picking and allow for best patient outcomes. The lead provider must identify a person/organisation that will coordinate care for patients.
- **Every Clinical Commissioning Group (or at commissioning network level) should be required to hold an end of life locality register**, to support the capture, storage and sharing of electronic patient records.

Case study:

End of Life Care Locality Registers

In the End of Life Care Strategy 2008, the Department of Health recommended that 'PCTs create locality-wide registers for people approaching the end of life, so that they can receive priority care'. Locality registers capture, store and share electronic patient records for all people in a given area who are identified as approaching the end of life.

Information stored on the registers includes core information such as diagnosis (or diagnoses), DNARs, contact information (for patients and carers) and advanced care plan information. Through locality registers information may be shared between hospital teams, GPs, out of hours services, ambulance services, community teams, hospices and care homes. The information captured is designed to enable teams to improve the coordination of the care of the patient and outcome reporting.

Locality registers have been piloted in eight sites in England, which adopted a variety of approaches and technologies. One pilot site, covering the Devon-wide area, provides a coordination hub for a population of 1.6m people with an average annual death rate of over 12,000. With the patient's consent, their information, including an assessment of their needs, symptom management information and their preferences, as outline in their advanced care plan, is shared with all agencies, including GPs, consultants and care homes. To date this has resulted in 63 percent of patients dying in their preferred place of death. In addition, only 9 percent of patients to date have died in an acute setting, with the remaining 91 percent dying in a non-acute setting.

The service is currently being expanded to host the children and young people's palliative care register.

- **When a patient is put onto the end of life locality register the NHS will meet all their needs (both health and social care). A patient can only be put onto the register after:**
 - they have had a conversation with a healthcare professional that they are at the end of life
 - an assessment of their needs has been undertaken and a care plan has been drawn up, which is shared with all providers in the area

- **Services should be commissioned on the basis of quality not price and meet:**
 - CQC standards
 - NICE End of Life Care Quality Standard for adults (in development)
 - National Quality markers (devised from the end of life care strategy)

- **Outcomes measures are developed which are supported by the newly created dataset for the tariff and the NHS outcomes framework.** Currently, there are no clear outcomes to use for measuring and benchmarking palliative care provision. To strengthen the funding mechanism, and maintain a focus on quality and patient outcomes, **we recommend that a set of specific outcomes measures for palliative care be developed.** This could be based on the Australian work on a set of patient reported outcomes measures (see Annex 3 for details), as well as the existing work on the Palliative care Outcomes Scale (POS) undertaken by the Cicely Saunders Institute for Palliative Care. The outcomes measures should be structured to fit with the classification system, to ensure ease of collection and monitoring.
- **Guidelines for the right commissioning levels are implemented, for both adults and children,** in order to support commissioners in planning and commissioning the right service mix for their population. Commissioning services with the proposed classification system will not work if the population is too small, because of a natural variation in need. **We recommend that the commissioning levels for palliative care services per population for adults and children should be set at a minimum population level of 300,000, and up to 1.5m.** For children at least, this is likely to be closer to the maximum than the minimum level. **There is a benefit to commissioning levels being co-terminus with catchment areas of other organisations or structures, as this supports makes joint working.**
- **A standard contract for commissioning NHS palliative care services is established.** Currently, there is no standard contract template specifically for palliative and end of life care services, and many providers are required to use the Community Services Contract, which is not always fit for purpose. We think the Department of Health or the NHS Commissioning Board should develop a standard contract template for palliative care services, which sets out the specific requirements related to palliative care. We recommend that the contract should be a three-year contract, instead of the current one-year contracts which most voluntary sector providers have with PCTs (see Chapter 2).
- **Community services should be built up, to provide 24/7 access to community care across the country.** Availability of 24/7 care in the community is crucial to enable people to be cared for at home if they wish to do so. In 2010, a Macmillan Cancer Support survey found that a full service of 24/7 community nursing was only available in 56% of PCTs. Of the remaining 44%, most provide 24/7 care to some but not all residents. (Macmillan 2010). Some investment in developing additional community services is therefore needed.

'This (community care) was invaluable, however the worst part of the last few days was that there was no emergency contact for the night nurse from 4pm until 6pm. The telephone number given was not used by the nurse.' **Relative of Patient**

We know that a relatively small investment in 24/7 community services now will enable commissioners to deliver improved outcomes for patients as well as ensuring palliative care services are delivered in the most cost effective way. This would also support the potential hospital cost savings from palliative care, as described below (see paragraph 7.4). Some investment has already been made in this area. Under the End of Life Care Strategy, the Department of Health announced an extra £88m for PCTs in their 2009-10 budgets, and £198m in 2010-11. The resources were designated to expand provision, including rapid response community services for adults approaching the end of their lives, and to improve training for all health and social care staff who come into contact with people who are dying. By introducing a tariff for palliative care community services, and implementing the full recommendations of this review, there will be a growth in the provision of palliative care in the community.

Case study:

Marie Curie Delivering Choice Programme

The Delivering Choice Programme was launched by Marie Curie in 2004. The programme aims to double the number of people with a terminal illness who are cared for and spend their final days at home. It does this by helping local providers and commissioners of care to develop the best possible local services for palliative care patients, regardless of diagnosis, so that they can be cared for in the place of their choice.

The programme works with the NHS and social services, voluntary and independent sectors to develop integrated patient-centred 24/7 services. The benefits include improved patient choice in place of care and death, a reduction in the strain on acute services and increased learning across providers.

The programme has a total of 18 projects (some of which have been concluded, with various services being sustained for the long term by local providers). A toolkit and expert advice service is available through the programme website.

Results from the first project in Lincolnshire published by the King's Fund in 2008 showed that by improving community care better patient outcomes were achieved at no extra cost. The evaluation also showed that deaths at home for patients have more than doubled.

Chapter 5

Creating the dedicated palliative care package

Chapter summary

In this chapter we set out our recommendations on which services should be included in the NHS palliative care tariff and which services the state should continue to support alongside society.

The review team recommends that the palliative care patient package should contain the following elements:

- **Assessment of the patient**
- **Coordination of the care of the patient**
- **Clinical care needs of the patient**
- **Social care needs of the patient at the end of life**

The review is clear that any new funding system needs to recognise the huge support society currently provides for these services and we need to ensure we incentivise and support society to continue to contribute. By developing a per-patient funding system based on needs, we need to ensure that the important role families and carers have in both delivering and supporting palliative care patients is not forgotten. We therefore think this is a vital part of society's role in supporting the state to deliver the best care for people.

5.1 Integrated care packages

We described in Chapter 3 how a classification system can be set up for palliative care and how this can be built into a per-patient tariff. In this chapter we are now exploring what should be included in this tariff; what should the dedicated palliative care package funded through an NHS tariff be?

The review is clear that any new funding system needs to recognise the huge support society currently provides for these services and we need to ensure we incentivise and support society to continue to contribute.

Whilst the tariff will not include all palliative care services which are currently delivered by both the NHS and the voluntary sector, it should cover the elements needed to enable patients to live well until they die, and to have a good, safe death.

We envisage a system which recognises the whole of the children's palliative care pathway and the adults' end of life care pathway. Commissioners should work with providers to ensure adequate services are there to support these pathways. They should work jointly with providers to plan and commission integrated care packages which cover services provided by the state,

voluntary or private sector. However, the totality of these services will not automatically be funded by the state.

By developing a per-patient funding system based on needs, we must ensure that the important role families and carers have in both delivering and supporting palliative care patients is not forgotten. Research by the Motor Neurone Disease Society estimates that in the last year of life each patient with motor neurone disease receives informal care which would cost £101,000 to provide professionally (Carers UK 2007). It is important for the Government to continue to support these vital roles, in particular through implementation of the 2010 Carers Strategy. We also think support for carers is a vital part of society's role in supporting the state to deliver the best care for people.

Whether the services are provided by state or society, the patient is at the centre of the package:

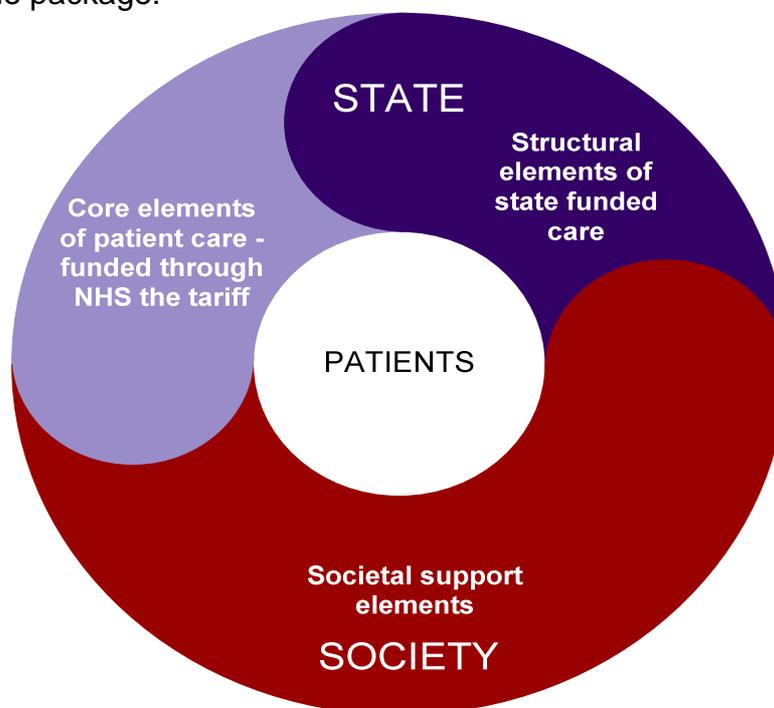


Figure 13: The integrated care package

The team has consulted widely and asked people what they think the core elements of dedicated palliative care which the state should fund through a tariff should be, and what they think society should contribute.

The review team recommends that the palliative care patient package should contain the following elements:

- Assessment of the patient
- Coordination of the care of the patient
- Clinical care needs of the patient
- Social care needs of the patient at the end of life

5.2 Assessment of the needs of the patient

Stakeholders felt that assessment (and reassessment as needed) is absolutely core in providing good palliative care to patients. They felt that assessment should be the responsibility of the state because it is key to understanding the needs of the patient; it helps to ensure that patients get the right services from the right people at the right time; and state funding will help ensure high quality and consistent assessments across the country.

Reassessments should be undertaken in response to a change in the level of need of the patient; this will ensure that as conditions and symptoms change, the packages of care and support can be adapted to meet the changing need.

People highlighted that a good assessment should:

- be undertaken by someone who has good communication skills and is competent and experienced enough to have a good understanding of the needs of the patient, what services are available across both health and social care and how different providers link together
- cover the needs of the families and carers
- signpost wider services such as housing, benefits and education (for children with palliative needs)
- be followed up by the development of a care plan; this is essential in ensuring that the needs of the patient are met. The care plan should:
 - be personalised and signpost all services required, signposting to non-state services should also be included
 - be standardised so that they can be easily understood by all who come into contact with the patient (for instance, ambulance teams may cover large geographic areas with differing care plans, all of which need to be fully understood)
 - be quickly followed by access to services for patients; delays are unacceptable for palliative patients

'While actual care components may be delivered in a variety of settings, provided by a range of organisations and funded from multiple sources, the assessment of needs and coordination of the care plan must sit within statutory funded services and be the responsibility of an NHS key worker' **Hospice Chief Executive**

A number of stakeholders mentioned the frustrations of patients and families in having to repeat the same information to different sets of assessors and in having to complete 'endless' forms. In particular, divisions between health and social care were mentioned as leading to a number of different assessments. One assessment should be used to cover all of the needs of a patient, and if patients have a long term condition, the palliative care assessment should build on previous assessments.

The review recommends that assessment is included in the palliative care tariff.

5.3 Coordination of the care of the patient

An organisation or individual to coordinate the care of the patient was seen by stakeholders as a core element in providing good palliative care. Stakeholders felt that this should be a responsibility of the state because it ensures improved access to services, would enable patients to more rapidly be transferred home from hospital and would ensure that the patient is less likely to 'bounce back' into hospital. The role of the coordinator is essential but is more complex than it may appear; they will need to work across organisational boundaries, give advice on services and ensure that patients and families get all of the care and support that they need. In addition, it is essential that the coordinating organisation or individual is listened to and respected by all agencies; the role would not be effective without this.

'To my mind after nearly 20 years of caring for a life limited child with a degenerative condition, the key component missing in care coordination has been a key worker.' **Relative of a Patient**

The review recommends that the coordination of the care of the patient is included in the palliative care tariff.

5.4 Clinical care of the patient

A majority of respondents felt that all clinical care, based on a needs assessment, should be the responsibility of and funded by the state. This is true for all other conditions and respondents strongly felt that this should be the case in palliative care. In particular, clinical care should not need to be funded by voluntary providers (as is currently the case in some areas). Funding of clinical care should be the same, regardless of the provider, and all providers should be subject to the same quality standards (such as CQC inspections). If there are multiple providers in one area then communication and coordination between providers is essential.

'The state provide in-patient/out-patient care for other elements of medicine, however in-patient and out-patient palliative and end of life care has fallen predominantly to the independent/charitable provision with full cost recovery applied to the minimum of services' **Director of Nursing, Hospice**

Relatives of patients mentioned that it was invaluable for them to know that if their relative deteriorated then there would be an in-patient bed available to them and that they would be cared for. The needs and wishes of a dying patient may change rapidly. Initially they may have wished to be cared for at home, but as their condition worsens they may prefer to be cared for in a hospital or hospice. This should be made possible for them so that they feel safe and cared for.

Respondents who felt that in-patient and out-patient care could be funded by a combination of the state and society generally felt that this is a key area where the voluntary sector can add value. For instance, the state could fund the clinical care, with voluntary contributions enhancing the setting of the care. An example given was that independent hospices provide day care for patients with clinical and other support, including creative therapy. The clinical support could be a responsibility of the state, but the other elements are akin to psycho/social/spiritual support, supported through voluntary sector contributions. Indeed a number of respondents felt that state funded day care should focus on the provision of clinical services and addressing issues around the health and social care needs of the patient, while society may wish to provide other services alongside this.

'A patient requiring a cardiology appointment would expect to have the appointment funded through the NHS - a patient requiring specialist palliative care should be able to expect the same.' **Healthcare Professional**

Respondents highlighted the fact that rehabilitation support is funded by the state for other patients and this should be the same for palliative patients. It should be a priority for the state to fund services which will enable patients to live well and die in the place of their choice, thereby enhancing their quality of life. Rehabilitation support will also expedite discharge home, prevent readmissions due to falls and injuries and reduce the burden on the carer so is likely to save the state money in the long run. It often helps to address the complex social and psychological needs of patients as well as their physical needs; the realisation that palliative patients can do something to improve their wellbeing is of great psychological benefit.

Rehabilitation should be available regardless of diagnosis: dementia, Parkinson's and those with a short life expectancy were mentioned by a number of respondents as diagnoses which often lead to a lack of rehabilitation support. Respondents highlighted that in many areas there are currently few rehabilitation teams working in the community; this needs to be addressed.

The review supports the NICE Guidance 2004 for adults, which highlights that rehabilitation attempts to maximise patients' ability to function, to promote their independence and to help them to adapt to their condition, and this is increasingly being seen as integral to patient care. Services are provided by a range of allied health professionals, including appliance officers, dieticians, lymphoedema therapists, occupational therapists, oral health specialists, physiotherapists, psychosexual counsellors, speech and language therapists, stoma therapists and therapy radiographers. NICE recommends that all patients who need rehabilitation services should have access to them when and where they are needed and that they should be provided without delay. The NICE Guidance 2005 for children echoes this and suggests that in addition, neurology, endocrinology and psychology (including neuropsychology) may also contribute.

The review considers clinical care to include all medical care, nursing care and rehabilitation support (including physiotherapy). The review recommends that all clinical care of the patient should be included in the tariff, irrespective of the setting of the provider. We recommend that the exclusion of accommodation costs from the tariff needs to be tested through the pilots to understand the impact and fairness for all providers, before it can be concluded with any certainty that they should not be included in the tariff.

‘Patients with terminal illnesses need to feel that they are achieving the most from their lives; these (rehabilitation) therapies support them to do this. It is an essential part of the funding.’ **Healthcare Professional**

5.5 Social care

Stakeholders felt that social care plays a fundamental role in ensuring that patients can be cared for and die in the community setting, be it in their own homes or in care or nursing homes. Timely, effective social care is likely to provide cost savings to the system as it will enable patients to be discharged more quickly from hospital, ensure that they are able to remain in their home and prevent unnecessary admissions to hospitals and/or care homes.

‘The emphasis on increased care in the community must make this a priority and there needs to be an incentive to discourage in-patient admissions and encourage discharges. If affordable, this should be a priority for providing an acceptable level of quality of life.’ **Director of Finance, Hospice**

The current funding system for social care often creates barriers for social care professionals and delays them in providing responsive services to help people to get home from hospital and to stop them from being readmitted. Means testing creates delays and NHS continuing healthcare was mentioned by many as being a key cause of inequities in England; the guidelines (in particular for the fast track) are interpreted differently in different areas.

At the end of a patient’s life, care (based on a needs assessment) should be available quickly and without a requirement for means testing or a continuing care assessment: if a patient is dying, meeting their needs should be the primary concern.

Care homes are vital in caring for people approaching the end of life and they should be supported to provide high quality palliative care and to enable patients to die there. Stakeholders suggested that other providers could support care homes through GP visits, nursing or consultant clinics within the care home or partnerships with community provider organisations, such as hospices.

The review recommends that the social care needs of a patient are included in the tariff at the end of life, as a ‘clip-on’ tariff to the main palliative care tariff (see Chapter 7 for more details).

The Department for Education is currently holding a consultation on support for children and young people with special educational needs and disabilities. The consultation is focusing on supporting the child and the family and makes a number of proposals as to how best to do this. The consultation highlights that many children with life-threatening conditions have complex needs and that this group is included in the consultation. A number of proposals in the consultation document resonate with the recommendations of this review, including an integrated assessment of the needs of the child and collaborative working between education, health and care teams. The results of the consultation will be taken forward to a testing stage with any necessary legislative changes being taken forward from May 2012.

In addition to these four key areas, stakeholders also commented on other palliative care services:

5.6 Drugs and pharmacy services

A number of respondents raised the issue of equitable payments for drugs within palliative care. Currently in hospices these are 100% funded by the NHS, in line with executive letters EL94(14) annex B and EL95(22); the funding for drugs is often ring fenced by PCTs, with allocated budgets and respondents felt that a similar system should continue in the future but were concerned about the practicalities of this in a new commissioning landscape. Respondents also highlighted the important role that pharmacists play in palliative care and emphasised that this service must be available 24/7.

‘With the current level of knowledge and understanding, the PCPN committee members would, most likely, favour retaining the model of a citywide “ring-fenced” budget for drugs and palliative care pharmacy services for voluntary hospices, instead of devolving the budget to individual consortia. We are acutely aware that this funding stream needs to be put on the local and national agenda’ **Palliative Care Pharmacists Network**

The review team recommend that these services do not fall into the tariff but should continue to be funded by the NHS as now.

5.7 Complementary therapies

According to the NICE 2004 Guidelines, complementary therapies are used alongside orthodox treatments with the aim of providing psychological and emotional support through the relief of symptoms. Therapies may be considered as self-care approaches (meditation, for instance), as techniques (massage) or as interventions with a range of clinical applications (homeopathy). All are used in this context in addition to, rather than in place of, orthodox cancer treatments to help with symptom control and to enhance general well being. NICE recommends that patients should be empowered to make their own decisions about complementary therapies and therapists through the provision of high quality information.

Respondents to the review felt that these therapies can be hugely beneficial to some patients, but that medical benefits are largely unproven. It is important to acknowledge the great psychological benefits that these therapies may have in helping patients and families to feel valued, relax and take their minds off the difficult reality of their present circumstances. Indeed they are often viewed by patients and families as some of the most important services that they receive. A lack of evidence for their clinical effectiveness, coupled with a realistic view of the current financial climate however, led many to suggest that this may be a key area where individuals and the voluntary sector can fund these beneficial 'extras'.

'We believe it is important to note this is not just about "touchy feely" massages. Complementary therapies are actually some patients' preferred choice of pain relief. We believe that acupuncture should be 100 percent state funded but would accept an argument that otherwise complementary therapy should be society funded. If anything has to be removed from the dedicated palliative care definition we would concede that this would be it.' **Chief Executive, Hospice**

It is important that the potential benefits of complementary therapies are highlighted in an assessment of need and that patients and families are signposted to services; indeed many respondents felt that the state's responsibility should lie in signposting these services but not funding them.

The review team recommends that complementary therapies are not included in the tariff.

5.8 Bereavement

Respondents expressed a range of views on bereavement support and more general psychological care. Many feel that pre-bereavement support is an absolutely essential part of palliative care and should be fully funded by the state. Also of great importance is information for families and carers on the services that are available; currently many do not receive this information so do not know that there is support available to them. A number felt that bereavement care should be supported by society because death is a normal

part of life.

Equity of access was highlighted by stakeholders as a key issue in bereavement services; if a patient dies in a hospice their family is much more likely to receive bereavement support than if they die in hospital. Not everyone will want or need bereavement support, but for those who do they should be given the information on services and access to these services.

‘The lion’s share of bereavement support for children and young people is provided by their families, communities and wider society. While these groups will continue to respond to children’s day to day needs, we need greater and more consistent state funding to lever in and underpin this support, so that all bereaved children get help at the level they need, when they need it.’ **Childhood Bereavement Network**

Regardless of the provider, staff must be adequately trained; and standards for competencies must be set and enforced.

In the case of younger patients, when the care may have been provided over many years, the carers have given up their careers, their aspirations, their friendships, and devoted their lives to the care of their child. Their loss is indescribable and there is often nothing to fill the days and help them move on as their life was focussed on providing care; state funded bereavement support is crucial in these cases.

Evidence presented to the review team demonstrates that bereavement services for bereaved children are not universal, with only 65-70% of Local Authority areas having an ‘open access’ service available to any bereaved child in the area. Whilst we have not included bereavement support in our proposed per-patient tariff, we do think it is important that universal access to these services is available for everyone if they need them.

Respondents felt that bereavement and psychological support for professionals is also key and should be state funded.

The review team recommends that a pre-bereavement assessment is included in the tariff, but that bereavement support continues to be supported by both the state and society, outside the palliative care tariff.

5.9 Respite care and short breaks

Respite care or the provision of short breaks may have two distinct purposes. The first is planned in-patient care to monitor the clinical needs of the patient and to make any necessary adjustments to their care. We feel that this falls under clinical care as outlined above and should be fully funded by the state according to the needs of the patient.

The second form of respite/short breaks is to provide a break for carers and

families from the often challenging demands placed on them through caring. Stakeholders felt that this form of respite is a vital service which can reduce emergency admissions to hospital, prevent family breakdown and save the NHS money in the long run. Children with life limiting conditions are living longer and while this is welcome, it increases the strain on families caring in the long term so respite care is becoming increasingly important.

Short breaks for life-limited and life threatened children and young people will often not be possible unless the healthcare needs of the child are provided for. This is the duty of the state. Even where the break is not primarily for a medical reason, nursing and other specialist healthcare is still essential.

The nature of life-limiting and life threatening conditions, their complexity and instability, means that children and young people require medical, nursing and other specialist support to not only access the short break but to also make sure that it is a positive and meaningful experience for the child.

'Specialist short breaks are a critical element of palliative care for children and young people and must be included in the funding model, if it is to genuinely take account of their needs as well as those of adults. Short breaks for children who are life limited are often different from purely social care respite, they are in effect specialist short breaks, designed to manage the symptoms of the child or young people as well as provide an important opportunity for parents to have a break from the demands of caring and to spend time with other siblings. They have an important healthcare dimension, often involving high-levels of clinical involvement and therefore need to be delivered by specialist staff.'

Children's Hospices UK

It is important to recognise that a child does not exist without their family and therefore services must be commissioned with their needs in mind. The multiple strains placed on families caring for a life limited child, often leading to higher levels of family breakdown, acute hospital admission and mental health issues for parents and siblings underline the importance of clarity in the commissioning and provision of appropriate short breaks both Sat home and in short break facilities, including children's hospices

For many families, this should be met through the Breaks for Carers of Disabled Children Regulations 2011, which impose a duty on Local Authorities to provide breaks from caring to assist parents and others who provide care for disabled children.

The Department for Education's accompanying Advice for Local Authorities is explicit that the NHS has a direct funding duty for breaks for children with complex needs, which includes the funding of children's hospice provision. It states at 2.10, *"Health services have multiple roles to play in the provision of short breaks for disabled children in their areas. They will directly provide and*

commission some services, for example, short breaks for children with complex health needs. (For some children, this may involve spending some time in a hospice.)”

The review team recommends the following:

- 1. Short breaks which represent planned in-patient and/or community care (for example, to monitor the clinical needs of the patient and to make any necessary adjustments to their care) fall under clinical care as outlined above and should be funded through the palliative care tariff, according to the needs of the child or young person.**
- 2. Short breaks which provide respite for the carers and families of children requiring palliative care should be funded by local authorities and the NHS under their respective legal short breaks duties.**

These "duties" refer to the short breaks duty on local authorities (Breaks for Carers of Disabled Children Regulations 2011) and the legal precedence which establishes that the NHS is responsible for short breaks where the 'scale and type of nursing care' is such that it is outside that which can be provided by the local authority (R (T,D and B) v Haringey LBC).

- 3. Respite care for adults continues to be supported by both the state and society as it is now, outside the palliative care tariff.**

5.10 Psychiatric care

Patients needing psychiatric care have a medical need so this should be fully funded by the state as it would be for all patients with psychiatric needs. Psychological care of a certain level is currently funded by the state and this should continue to be the case. If patients or families have an assessed psychological need whether due to a palliative condition or not, then their treatment should be funded by the state. Respondents highlighted the need for early assessment and intervention by Mental Health services in providing support before mental illness occurs; investment in appropriate support at the right time is needed.

The review team recommends that these services should be fully funded by the state as they are now through current Mental Health funding mechanisms.

5.11 Spiritual support

Spiritual support was recognised by a majority of respondents as a key part of palliative care; many felt that spiritual support should be provided by all people working in palliative care, regardless of location. Spiritual care is key to delivering good care and encompasses self esteem, dignity, peace and acceptance. A number of respondents felt that spiritual support should be a key part of the training for anyone working in palliative care. A minority of respondents felt that spiritual support is less important than other services so

should not be funded by the state. Spiritual care is vital for all people whether or not they have a religious faith. It is essential as people reach the end of their life and wonder about the meaning of life, afterlife and have they led a "good" life. Staff working in palliative care should also have access to spiritual support when needed.

The state currently funds many hospital chaplaincy posts, and these chaplains play a key role in good end of life care in hospitals. This support is important to a range of patients; hospital chaplains will talk to and help patients regardless of their religion or spiritual beliefs. This spiritual support is part of the NHS constitution, and many respondents argued strongly that this should continue. Spiritual care in the community varies greatly. It is usually funded by society and through voluntary funding, and some respondents felt that if spiritual care is supported by the state in hospitals, this should also be the case in the community.

Respondents highlighted that where spiritual care is being provided "from the cradle to the grave" the present arrangements may be outside the remit of this review. A number of respondents highlighted a specific concern that should the palliative care funding review recommend that funding for spiritual care be reduced, this may result in spiritual care across the NHS being cut and that this would be of great detriment to the wellbeing of patients.

'Spiritual care and support is an intrinsic part of good palliative care, and not an add-on optional extra. It is not exclusively religious, but is essential in ensuring that people achieve an acceptable quality of life, because spiritual care addresses the existential questions of meaning and purpose and the sense of self which inevitably arise following a terminal diagnosis and during the final phase of life. Spiritual care includes, but is not exclusively about, people's faith and religion. The End of Life Care Strategy published by the DoH in 2008 regards it as an essential element of all stages and aspects of care.' **Healthcare Professional**

The review team recommends that spiritual support should continue to be supported by both the state and society as it is now, outside the palliative care tariff, and that hospital chaplaincy teams should continue to be funded by hospitals as they currently are.

5.12 Education and training

Respondents felt that education and training are absolutely essential parts of providing palliative care. Both generalists and specialists should be trained on palliative care and this training should be regular and ongoing; it should be a core part of professional training programmes, not an add-on. The key challenges for education and training are funding and time.

Respondents felt that there should be national standards for education and training, and that providers should have to demonstrate the competency of their workforce in order to be commissioned (Skills for Health and Skills for Care competencies both at a large organisational level and an individual supervisor/supervisee level were suggested as potential guidelines). Respondents suggested that state funding should be used to train those working within state-run services only, and that providers should be expected to fund the training of their workforce. Many respondents highlighted the need for a 'cascade of knowledge' from specialists to generalists and that all palliative care staff should have a responsibility to train others and pass on their knowledge.

Respondents felt that a number of areas should be prioritised in education and training on palliative care. These included the 'bedside manner' and how to work with dying patients and their families, communication skills and spiritual support. There should also be a focus on standards of care, inappropriate admissions and the integration/collaborative working of services and providers.

The general public should also be able to access training and advice in palliative care, in order to both increase the understanding and acceptance of care, and to help people if the time comes for themselves to either need palliative care, or to care for a person who needs palliative care.

The review team recommends that the NHS Commissioning Board should fund palliative care education and training for NHS professionals. All other professionals should be trained to standards which should be outlined in the standard contract for commissioning NHS palliative care services and should be funded by the provider organisation.

'Infection control is mandatory but care of the dying is not. There are competing demands for what is on the mandatory list in our trust, and I am a realist, but there should be an inclusion of end of life care in the overall mandatory expectation of front line clinical workers.' **Consultant in Palliative Medicine**

Chapter 6

How many people need palliative care and how many are not getting it?

Chapter summary

We know that in England, approximately 470,000 people currently die each year. Not all of these people will need palliative care. Using data on underlying cause of death in the ONS Annual Public Health Mortality Extract, the total palliative care needs of the population in England have been estimated at around 355,000 people requiring palliative care every year.

Comparing this with an estimated mean group of around 171,000 who currently receive specialist palliative care, and accounting for the possibility that a proportion of this group are having their needs met through universal palliative care services, we estimate that around 92,000 people per year have an unmet palliative care need.

Changing demographics, with an ageing population, longer chronic disease trajectories, and greater co-morbidity, provide further incentives to improve and expand palliative care provision.

6.1 Expected trends in the need for palliative care

The commissioned work from KCL and their partners provides indicative estimates of the number of people in England who are likely to need palliative care in any one year.

We know that in England, approximately **470,000 people currently die each year**. Not all of these will need palliative care, because their cause of death is sudden, either through unpredictable onset of disease or an external cause. Recent analysis of all deaths in England by the National End of Life Care Intelligence Network estimate that at least 25% of all deaths in England are unexpected deaths from sudden causes (Blackmore, Pring & Verne 2011; Pring & Verne 2011; Osinowo & Verne 2011).

Using data on underlying cause of death in the ONS Annual Public Health Mortality Extract, and refining the Rosenwax method for estimating palliative care needs for a population (for adults) (Rosenwax et al 2005), combined with the Cochrane list of causes likely to require palliative care for children (Cochrane et al 2007), the KCL/ SWPHO/ WSP team estimated total palliative care needs of the population in England for both adults and children, providing a minimum, maximum as well as a set of intermediate estimates.

Estimated number of patients with palliative care need per year		
Approach	Number of patients with palliative care needs	Percentage of all deaths
Minimal estimate	174,969	37%
Low estimate	297,985	63%
Intermediate estimate (lower limit)	326,685	69%
Intermediate estimate (upper limit)	387,067	82%
Maximal estimate	456,767	97%
Total deaths	472,784	100%

Table 3: Expected number of patient with palliative care needs

These estimates can be compared with current levels of palliative care provision, to get an understanding of their validity. Using adjusted data from the existing Minimum Data Set for specialist palliative care, the KCL/SWPHO/WSP team estimates that the total number of people seen by specialist palliative care services is around 171,000⁵. Also, the Department of Health's updated analysis of the Cochrane work showed that around 245,000⁶ people who died in 2009 were admitted to hospital in their last year of life with conditions that may have led to a need for palliative care. Given the likely extent of people who may receive only non-specialist palliative care, this comparison suggests that the 'low' population estimate may be too low – the intermediate estimates may be more realistic in reflecting actual population-wide palliative care needs.

It is therefore estimated that between 70 and 80% of all deaths are likely to need palliative care input. The mid-point between these two, 75% of deaths, would equate to **around 355,000 people requiring palliative care every year.**

These projections from the commissioned work from KCL and their partners allow for a rough estimate of the current unmet need for palliative care. Using the intermediate estimate of 355,000 people needing palliative care, and comparing this with an estimated mean group of around 171,000 who currently receive specialist palliative care, there is a group of around 184,000 people who need palliative care, but who are not receiving specialist palliative care input at present. If the maximum estimate of palliative care needs is used, this increases to 285,000. It is likely that a proportion of this group are having their needs met through universal palliative care services (see Annex 7 for our definitions of specialist, core and universal palliative care services).

⁵ The total reported figure is 253,900, of which 10% are expected to not be in the last year of life. The KCL/ SWPHO/ WSP team have also estimated the potential overlap between the community services in the MDS. This gives a figure of 141,000-201,000 receiving specialist palliative care, with a mean number of 171,000. Making the assumption that all in-patient specialist palliative care admissions are also known to the specialist palliative care community teams, we have employed these figures here as all people seen by specialist palliative care services.

⁶ 3,100 children and 241,500 adult patients.

Presuming that this accounts for up to 50% of the group who do not receive specialist palliative care, this would indicate that **around 92,000 people per year have an unmet palliative care need, or up to 142,500 if using the maximum estimated need.**

Estimated number of patients with palliative care need



6.2 Changing demographics

‘A new funding model must take into account the ageing demographic, the scale and complexity of need generated by patient populations and the need to jointly commission health and social care efficiently.’

The British Geriatrics Society

Changing demographics, with an ageing population, longer chronic disease trajectories, and greater co-morbidity, provide further incentives to improve and expand palliative care provision.

From 2016, there will be a steady rise in the annual number of deaths in England, and forecasts have been made that an additional 90,000 hospital or other beds would be required by 2030, unless alternatives are provided through an increase in community services (Gomes & Higginson 2008).

Using ONS population projections (2008-based) alongside mortality rates, the KCL/ SWPHO/ WSP team produced an expected number of deaths by age for each year between 2011 and 2031.

Expected number of deaths by age band 2011 to 2031					
Age band	2011	2016	2021	2026	2031
18 to 24	1,847	1,429	1,148	1,072	1,070
25 to 64	74,054	68,362	67,521	65,359	60,919
65+	370,814	370,739	380,996	407,738	448,507
All adults	446,714	440,530	449,665	474,169	510,496

Table 4: Expected number of deaths

Chapter 7

Creating a new system which is cost effective and provides value for money

Chapter summary

The commissioned work from KCL and their partners to support the review estimates the total cost of providing the elements of specialist and core palliative care, which are proposed to be covered by the tariff, to be around £411m for adults.

It is estimated that hospital admissions in the last year of life for adults cost the NHS in the region of £1.3bn. The cost for children is estimated to be in the region of £18.2m. Savings could potentially be achieved on these hospital costs in the last year of life, which would free up resources to provide palliative care and care in the community.

We project that delivering improved recognition of palliative care needs, as well as optimised provision of services outside the hospital setting, could potentially reduce deaths in hospital by up to 60,000 a year by 2021. Using the QIPP estimate of £3,000 per hospital death, this would translate to a potential reduction in hospital costs of £180m per annum.

7.1 How much will the new system cost?

The commissioned work from KCL and their partners to support the review provides an estimate of the total cost of providing the elements of specialist and core palliative care, which are proposed to be included in the packages and covered by the tariff, *at the current level of provision*. This has been undertaken for *adults only*, as the data to undertake a similar analysis for children is not presently available. The estimate has been designed to include only those services which the review is suggesting should be funded through the tariff (see Annex 6 for a full list of the services included in the analysis). The calculations are based on a set of unit costs developed from data provided to the review by a number of providers, including some of the largest voluntary sector providers, combined with information from the Minimum Data Set on activity levels⁷.

Taking the unit costs provided by palliative care providers, and using the level of activity reported in the most recent MDS for the included services, the total mean estimate of the cost of providing the elements of specialist and core palliative care services included in the packages (see Annex 7 for our

⁷ Reliable and usable cost data in palliative care is scarce. For this reason, the KCL/ SWPHO/ WSP work used all available cost data, including reference costs and costs derived from different individual providers. There are problems with this approach, because of the limited data on which reference costs are based, and also the lack of comparability of individual provider data; however it represents a best estimate with the best data available.

definitions of specialist, core and universal palliative care services), derived through this piece of research is:

Estimated total cost of the packages of care for adults ⁸		
Minimum	Mean	Maximum
£240.4m	£411.3m	£781.4m

Table 5: estimated cost of packages

These are not additional costs to the existing PCT spend of £460m (see Chapter 2), but provide an illustration of the level of funding which would be likely to be redistributed through the tariff system. Note that these figures do also not necessarily cover the same set of services and the £460m PCT spend, and so cannot be directly compared to this figure.

The maximum estimate is likely to be too high, as it is based on the very high reported costs from some voluntary sector providers, which we anticipate the state would not want to cover fully. These figures include the elements which this review is proposing should be funded by the state through the tariff, and excludes any services which the review is recommending should be supported by society or funded by the state through other means than the per-patient tariff.

We recommend that the exclusion of accommodation costs from the tariff needs to be tested through the pilots to understand the impact and fairness for all providers, before it can be concluded with any certainty that they should not be included in the tariff. We estimate that excluding accommodation costs could reduce in-patient costs by a third, bringing the total mean estimate to £318.3m. This figure needs to be tested as the review team feel this total figure is very low.

These estimated costs do not include the cost of universal services or social care. It gives an indication of the amount of funding which would be redistributed through the new tariff system if the level of provision was to remain the same.

For children, the only cost data on specialist palliative care is the data from children's hospices. So we have been unable to build an estimate for these services. Figures from Children's Hospices UK indicate that **a total of £77m per year is spent on children's hospice care, for both in-patient and community care.** It is important to note that the majority of this funding is likely to come from the voluntary sector, as children's hospices currently receive around 15% of their funding from the state (HtH 2010b).

⁸ The wide variation between the minimum and maximum estimate is due to marked variation in the reported unit costs from different care providers.

7.2 The cost of universal services

There is no data directly on the cost of delivering universal services (see Annex 7 for our definitions of specialist, core and universal palliative care services), however the commissioned work from KCL and their partners provides an informed estimate of what it may cost to provide universal palliative care. The approach assumes that anyone receiving specialist palliative care will also have universal palliative care needs, and that there is an additional group who are only receiving universal palliative care. This gives a low estimate of 203,971 and an upper estimate of 323,892 people receiving universal services. The estimate considers primary and community care teams only, so it only includes those who die at home or in care homes. The whole population figures are therefore adjusted to represent only those dying in places other than hospital, giving a low estimate of 85,668 and an upper estimate of 136,034. Combining these population figures with the estimated workforce costs provided by the East Midlands Functional Analysis⁹, **the KCL/ SWPHO/ WSP team were able to estimate that somewhere between £208m and £518m are spent on universal palliative care provision by primary and community providers, annually.**

7.3 How the system would provide value for money

An analysis by the Department of Health of ONS mortality data from 2009 linked with HES data¹⁰ provides information about the hospital episodes of a person in the last year of life. The analysis includes those people in the last year of life who have been admitted to hospital with a condition that may indicate a need for palliative care¹¹. Different condition lists are used for children and adults, as the conditions that may require palliative care are different for these two groups. **The analysis estimates that the total cost of hospital admissions in the last year of life for adults admitted with a primary diagnosis indicating a palliative care need is in the region of £1.3bn. The estimated cost for children is estimated to be in the region of £18.2m.**

These estimated costs to the NHS far outweigh the cost of providing palliative care as they take into account all types of care, not strictly palliative care. Evidence suggests that savings could potentially be achieved on these hospital costs in the last year of life, which would free up resources

⁹ £155 per assessment, £102 per week for on-going community support, and £898 for care in the last days of life. Assuming an average of two assessments or reassessments, one episode of 'last days' care, and an average of 12 weeks on-going community support, this equates to £2,432 per patient. Assuming an average of three assessments, plus 24 weeks of on-going support, plus last days care, this would equate to £3,811 per patient.

¹⁰ The data used for this analysis are derived from a linked dataset of ONS mortality data from 2009 and The Information Centre for health and social care Hospital Episode Statistics (HES) data from 2008 and 2009.

¹¹ Palliative care service use is difficult to determine and as such, proxies have been used where necessary. To estimate palliative care need in adults, HES data for patients aged 18 and above with a primary diagnosis from a list of conditions which may indicate palliative care need (adapted from Rosenwax et al 2005). For children and young people aged under 18 years an alternative list of conditions that may indicate a need for palliative care is used (see Cochrane et al 2007).

to provide palliative care and care in the community. Several studies provide evidence that provision of palliative care can in fact help reduce overall healthcare costs.

For example, a systematic review on cost and non-clinical outcomes from the US indicates that a modified palliative care presence and control over the clinical care of the patient is associated with fewer hospitalisations, fewer intensive care hospital days and lower costs (Smith & Cassel 2009). A large-scale US study specifically showed that patients receiving palliative care in US hospitals had an adjusted net saving of \$1,696 in direct costs per admission when the admission ended in discharge, or \$4,908 in direct costs per admission when they died in hospital. This was mainly attributed to significant reductions in pharmacy costs, laboratory tests and intensive care costs (Morrison et al 2008). Further, a study comparing early diagnosed metastatic non-small-cell lung cancer patients who received either early palliative care integrated with standard oncologic care or standard oncologic care alone, showed that the intervention group not only had better quality of life and reduced symptom burden, but also less aggressive care, and therefore lower costs, as well as longer survival rates (Temel et al 2010).

There is also some early evidence that these savings apply in a UK setting. A short-term palliative care intervention in multiple sclerosis patients showed cost savings of about £1,800 after 12 weeks follow-up, including in-patient care and informal care costs (Higginson et al 2009). A recent evaluation of the 'Macmillan Midhurst Specialist Palliative Care Service', shows that early referral to a specialist palliative care service is associated with patients spending fewer nights in a hospital setting and having fewer A&E attendances. It is also associated with fewer deaths occurring in a hospital setting.

Ensuring availability of palliative care in hospital and community settings, and supporting early referral to palliative care, could therefore potentially lead to significant cost savings for the NHS on hospital costs in the last year of life.

7.4 Projecting the impact of improving palliative care provision

While it is not possible to say exactly how much could be saved by improving and expanding palliative care provision, using the Whole Systems Partnership model it is possible to provide a set of reasonable projections, based on changes in *hospital death rates* only, based on improved recognition of palliative care needs, as well as improved provision of services outside of the hospital setting.

Using the mid-point of the population estimate, approximately 355,000 people per year will need palliative care. On current estimates of 55% of deaths taking place in hospital, this means that approximately 195,000 people needing palliative care would die in hospital each year. The national QIPP for end of life care has adopted a figure of £3,000 per hospital death as the basis

for improvements in productivity in this area. This gives a total cost for hospital deaths in people with a palliative care need alone of **£585m**.

Based on the research findings, the following table gives an overview of the potential changes in hospital death rates in people with palliative care needs, based on improved recognition of need alone, as well as improved recognition combined with improved provision of care in the community:

Approximate number of hospital deaths under different scenarios				
	2011	2016	2021	2031
Demographic changes only	195,000	195,000	195,000	215,000
Improved recognition of palliative care needs, with sub-optimised provision of alternatives	195,000	160,000	160,000	175,000
Improved recognition and full optimisation of alternative place of care provision	195,000	145,000	135,000	150,000

Table 6: projected number of deaths in hospital

If no action is taken, by 2031, the hospital death figure in people with palliative care needs is projected to rise to 215,000. The model projects that delivering improved recognition of palliative care needs, as well as optimised provision of services outside of the hospital setting, could potentially reduce deaths in hospital by up to 60,000 a year by 2021. **Again using the QIPP estimate of £3,000 per hospital death, this would translate to a potential reduction in hospital costs of £180m per annum¹².**

Notably, these projections of the impact of alternative scenarios for population palliative care needs and any associated cost savings relates to hospital *deaths* only, and do not take account of the potential for reducing total hospital *admissions* during the last year of life. The estimated figure may therefore be conservative.

The potential cost saving indicated does not take account of the resources required to provide support to the people who have been shifted to the community.

As described above (see Chapter 6), the commissioned work from KCL and their partners provides an estimate that around **92,000** people per year have an unmet palliative care need. Using the total cost estimates outlined above, for the services included in the tariff, **it is possible to give some indication of the increase in expenditure if the specialist palliative care services were to be expanded to reach a larger group of people than they do presently.** For example, using the mid-point numbers for population

¹² It should be noted that demographic changes during the subsequent decade to 2031 would net off ~15,000 of these deaths (at a corresponding cost of £45m).

estimates, **reaching an additional 60,000 people would lead to a rise in the total mean cost estimate to £555.5m (or £430m when reducing in-patient costs by a third); this would therefore require an approximate additional investment of £144.2m (£111.7m) compared with the current level of provision.** Note that this estimate assumes that the additional 60,000 people would receive the same level of palliative care as the current recipients, including in-patient and community care.

While this evidence all points to possible cost savings, and supports our recommended direction of travel, without additional, robust information on costs we cannot draw any definite conclusions.

7.5 Social care costs

Social care is an integral part of the support necessary for people with palliative or end of life care needs, and has a role in ensuring that people are able to be cared for and die in a place of their choosing. Social care may play a role in preventing unnecessary admissions, as well as facilitating timely discharge from hospital. At present, NHS provided care is free at the point of need, while social care services are means tested, leading to complicated assessment procedures and care not being linked up. For those reaching the end of their life, we think that there is a strong case for all services to be free at the point of delivery. At this time, the last thing individuals and families should be facing are arguments over funding of the care they need and delays in the provision of care due to complex systems and procedures.

In order to address the current problems for palliative care patients relating to the boundaries between health and social care, and to improve consistency in the NHS continuing healthcare system, **the review recommends that once a patient reaches the end of life stage, and is put on the end of life locality register, all health and social care should be funded by the state and be free at the point of delivery** (see Chapter 4 and 5). We recommend that this is implemented as a 'clip-on' to the main palliative care tariff, which can be added on once a patient has been added to the end of life locality register. Evidence indicates the current time frame for people to be recognised as being end of life, and be put on an end of life register, is less than 12 weeks.

We recognise this recommendation could potentially lead to some additional costs to the state, by providing free social care to a group of people who would otherwise self-fund their own care, although it is likely that the majority of people on an end of life locality register would already be receiving state funded social care. We do not recommend that the social care clip-on tariff includes accommodation costs.

A large proportion of patients on end of life locality registers will already have their social care paid for through local authority funded social care. Using a recent Nuffield Health Trust study on social care and hospital use at the end of life (Nuffield 2010), the KCL/SWPHO/WSP team was able to estimate a projected total cost of Local Authority funded social care for people in the last year of life. In the Nuffield report, 16,479 people died, and of these 30.2%

accessed some form of social care¹³. **Using the total deaths for England, the KCL/SWPHO/WSP team estimates that 142,781 people¹⁴ annually will need social care in their last year of life across England.** Using the cost data provided in the report from the Nuffield Trust, **the average annual cost of Local Authority funded social care for those in the last year of life is estimated at £10,436.50¹⁵, leading to a total cost social care provision in the last year of life of £1.49bn annually.** Note that this is only Local Authority funded social care. More importantly, the estimate for social care provision is based on data from two PCT/Local Authority areas only and cannot necessarily be regarded as representative of England.

Another group of people who are on an end of life locality register may have their social care paid for by the NHS through continuing healthcare funding (CHC). **The available data suggests that overall expenditure by PCTs on NHS CHC is in the region of £2bn**, although it is not known how much of this is for end of life care patients. **National data on ‘fast track’ continuing healthcare funding for 2010/11 indicates that approximately £136m was been spent in the year 2010/11**, for a total of 47,124 people across England. This equates to a cost of £2,883 per person, although there is marked variance in costs. It is not known how much of this ‘fast track’ activity relates to end of life care¹⁶, but there is anecdotal evidence which suggests that a minority of people on fast track NHS continuing healthcare funding survive for significant periods of time (> three months). This leaves a group of people who are on the end of life locality register, and have social care needs, but who are currently self-funding their social care.

The review team have met with the Commission on Funding Care and Support. The Commission is considering the future funding of care and support and will shortly be reporting to the Government on how an affordable and sustaining funding system can be achieved. **We believe our proposals for the future funding of social care in relation to end of life care are compatible with the Commissions proposals.**

7.6 The impact on charitable funding

Voluntary sector organisations felt that clarity on state funding for core palliative care services would not give them reason to reduce their fundraising efforts. The charitable funding that they receive will continue to be a key part of their overall funding and will enable them to continue to provide high quality services, in addition to state-funded services. Suggestions for where charitable funding might be used included additional staffing, non-clinical patient day care, additional bereavement support, complementary therapies, family support and service innovation.

¹³ 7.2% accessed social care alone, while 23.0% accessed both social care and hospital care.

¹⁴ 30.2% of the total 472,784 deaths in 2009.

¹⁵ Using costs from the study’s sites B & C only, as site A appears to be an outlier.

¹⁶ Fast track continuing health care funding is not primarily about end of life/palliative care, but a means to ensure that vulnerable people with complex needs are not delayed in getting the care they need whilst funding arrangements are put in place. The extent of overlap with end of life/palliative care is likely to be significant, but there is no simple way of differentiating this.

Chapter 8 **Building the system**

Chapter summary

Currently, there is no national funding mechanism for palliative care. Given the need to build up an informed evidence base to support the move to a more equitable funding system, we envisage that a transitional phase will be needed to allow for the transfer from the current system to the new system to take place.

We recommend pilots are established to test the model and gather data to build the tariffs. Comparable work undertaken to develop mental health tariffs indicated that this would cost in the region of £1.5m to £2.5m.

8.1 A managed transition

Currently, there is no national funding mechanism for palliative care. Given the need to build up an informed evidence base to support the move to a more equitable funding system we envisage that a transitional phase will be needed to allow for the transfer from the current system to the new system to take place.

Implementing this proposed new funding model will require major changes in existing systems and structures, and the shift therefore needs to be managed carefully, with transitional arrangements in place to support the evolution to a per-patient funding mechanism, and to mitigate the impact on providers. We would recommend recognising the need for a transitional phase spread over a three to five year time frame.

To support implementation and deliver the right outcomes for patients, the new system would need to be supported by additional funding allocated for three separate areas: for testing and structural development of the new system; for developing additional services in the community; and for potential costs in providing free social care to people on end of life locality registers.

We recommend that a leadership board be put in place, with representatives from across both the adult and children's palliative care sector working in partnership with Government to manage and drive forward the transition to the new system.

8.2 Creating the new system

In order to implement a per-patient funding system for dedicated palliative care, substantial improvements in the coverage and quality of existing palliative care information systems are required. A new national data set will need to be developed, with nationally agreed methods to report, collate and analyse palliative care provision.

The only consistent data set for adult services collected at the moment is the hospice and specialist palliative care Minimum Data Set, which is collected voluntarily by the National Council for Palliative Care. For children's services, a Children's Hospices data set is under development by Children's Hospices UK.

The new national data set necessary for the functioning of the per-patient funding model would need to collect data on patient activity from each palliative care provider. This would need to capture key patient characteristics, corresponding to the criteria used in the classification system:

- Age
- Phase of care
- Functional level
- Problem severity
- Provider type (specialist/ non-specialist)

The system would also need to record cost data for services, to allow for benchmarking and tariff calculation.

To build on existing expertise, the national data set could be developed as an aggregated version of the existing data sets for adults and children. These data sets would need to be expanded, and adjusted to collect data at patient level.

Extensive testing and refinement of the classification system will be necessary, and comprehensive costings works will be required to set the final tariffs based on better cost data. A prospective study which can support this is already in developed by King's College London. It will also be important to establish new data collection and system structures.

Setting up a new system requires testing of the proposed model, as well as improved collection of data to refine and adjust the model. The nearest correlation to this testing and implementation process is the current work being undertaken on developing PbR tariffs for Mental Health. For comparison, this work has cost approximately £500,000 per year during its development phase, and has also involved one-off costs of £20,000 to develop a scoring algorithm and £66,000 for Connecting for Health to produce system adjustments, giving a total cost of **£1.5m to £2.5m**.

The review recommends that five pilot sites are selected to test implementation of the new model, and to provide early data to improve and adjust the model. We would recommend a two-year time frame for the pilots, to ensure sufficient data.

Part of these costs would also relate to setting up a data collection system to provide the information needed to develop the classification system further, and to deliver full calculations for the tariffs. One option would be to build on

existing systems and structures for data collection already in operation in the palliative care sector, such as the Minimum Data Set being managed by the National Council for Palliative Care (NCPC) and the Children’s Hospices data set under development by Children’s Hospices UK. Building on these existing initiatives, rather than establishing an entirely new system, would be likely to keep transition costs down.

Our recommended next steps:

- The current minimum data set is expanded to support the tariff and its collation made mandatory for all organisations providing NHS dedicated palliative care services.
- Outcomes measures are developed which are supported by the dataset and the NHS outcomes framework.
- Transition phase to the new system supported by national funding

The following diagram illustrates the recommend timeline for implementation of the review findings:

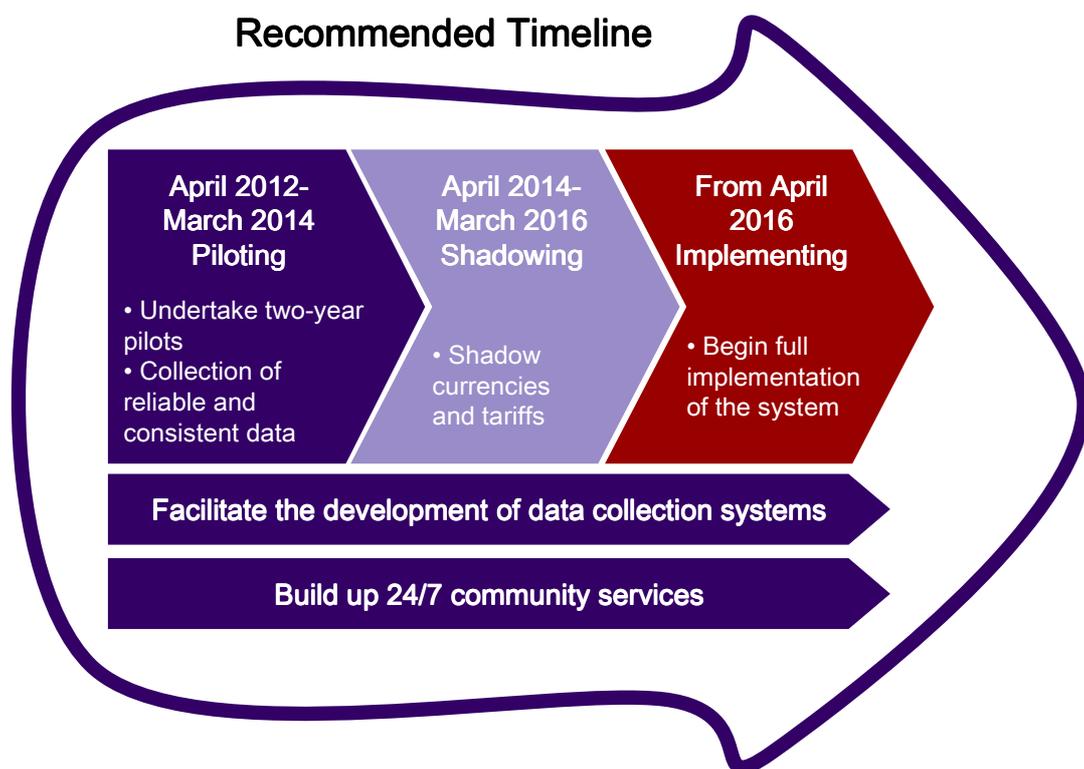


Figure 15 – Recommended Timeline

Terms of Reference

To review the current funding mechanisms for dedicated palliative care for adults and children.

To consider and quantify the impact of changes in funding mechanisms, based on an NHS tariff to meet NHS responsibilities, regardless of the choice of provider, on a per-patient basis.

To make recommendations on a funding mechanism which:

- Is fair to all sectors, including the voluntary sector
- Encourages the development of community-based palliative care services
- Supports the exercise of choice by care users of provider and of location of palliative care provision

Phase one of the review should offer a definition of dedicated palliative care services, together with some indicative costs, by autumn 2010.

Phase two should make detailed recommendations for the mechanisms for funding the core service across all sectors by summer 2011.

List of stakeholders

The review team are so grateful to the many organisations and individuals who have supported their work, through meetings, evidence sessions, stakeholder events, submitting questionnaires, contributing data and through involvement in testing sessions. This input has been an invaluable part of our work and we are grateful to everyone who has contributed.

Organisations and individuals who met with the review:

- Association of Chief Executives of Voluntary Organisations (ACEVO)
- Association of Directors of Adult Social Services (ADASS)
- Age UK
- Aintree University Hospitals NHS Foundation Trust
- Anna Gill (Parent and Carer)
- Association for Children's Palliative Care (ACT)
- Association for Palliative Medicine (APM)
- Association of Palliative Care Social Workers (APCSW)
- Bee Wee (Consultant/Senior Lecturer in Palliative Medicine, Sir Michael Sobell House, Oxford Radcliffe Hospitals NHS Trust, Oxford, and President, Association for Palliative Medicine of Great Britain and Ireland)
- Cambridge University Hospitals NHS Foundation Trust
- Central London Healthcare
- Childhood Bereavement Network
- Children's Hospices UK
- Children's National Oversight Group
- CLIC Sargent
- Demos
- Department for Education
- The Department of Health:
 - Sir David Nicholson (Chief Executive, NHS), David Flory (Deputy Chief Executive, NHS) and David Behan (Director General of Social Care, Local Government and Care Partnerships)
 - QIPP Team
 - Payment by Results Team
 - End of Life Care and Cancer Team
 - GP Consortia Team
 - Continuing Healthcare Team
- Douglas Macmillan Hospice
- English Community Care Association
- Great Ormond Street Hospital
- Healthcare at Home
- Helen McLindon (Consultant)
- Help the Hospices

- Leeds Teaching Hospitals NHS Trust
- Lincolnshire Group – St Barnabas Hospice and NHS Lincolnshire
- Macmillan Cancer Support
- Marie Curie Cancer Care
- National Council for Palliative Care
- National End of Life Care Programme
- National End of Life Care Programme Board
- Newcastle Hospitals NHS Foundation Trust
- Parents and Carers Group - Sarah Dewhurst, Maria Phillips, Tracey Coleman, Maryse Hall, Jan Brown, Natalie Read and Anna Gill
- Peter Tebbit, retired Policy Consultant, NCPG
- Rob Gandy (Independent Management Consultant and Research Associate, Liverpool Business School)
- Professor Rob George, Palliative Care Consultant, Guy's & St Thomas' NHS Foundation Trust and Pan-London Clinical Lead for End of Life Care, Commissioning Support for London
- Rosa Monckton (Parent and Carer)
- SHA End of Life Care Leads Group
- Southampton University Hospitals NHS Foundation Trust
- St Christopher's Hospice, London
- The Commission on Funding of Care and Support
- The General Medical Council
- The Implementation Board for Palliative Care Strategy in Wales (Welsh Assembly Government)
- The King's Fund
- The Nuffield Trust
- The Royal Marsden Hospital
- True Colours Trust

The King's College London (KCL), South West Public Health Observatory (SWPHO) and Whole Systems Partnership (WSP) Research Team:

Our particular thanks to KCL and partners for their detailed research work:

- Dr Fliss Murtagh, KCL
- Dr Claudia Bausewein, KCL
- Iris Groeneveld, KCL
- Yvonne Kaloki, KCL
- Dr Julia Verne, SWPHO
- Peter Lacey, WSP
- Pippa Hodgson, Skills for Health
- Dr Paul McCrone, KCL
- Professor Rob George, Guy's and St Thomas' Hospital NHS Foundation Trust
- Adebawale Osinowo, SWPHO
- Dr Lynne Turner-Stokes, KCL
- Professor Irene Higginson, KCL

Regional Meetings:

Our thanks to the organisations and individuals who helped to arrange and attended these meetings and a particular thank you to the hosts of the meetings who were:

- East Midlands Stakeholder Meeting – St Barnabas Hospice, Lincoln
- East of England Stakeholder Meeting – NHS East of England
- London Stakeholder Meeting – Help the Hospices
- North East Stakeholder Meeting – NHS North East
- North West Stakeholder Meeting – St Catherine’s Hospice, Preston
- South East and South Central Stakeholder Meeting – St Barnabas Hospice, Worthing
- South West Stakeholder Meeting – St Margaret’s Hospice, Taunton
- West Midlands Stakeholder Meeting – Douglas Macmillan Hospice, Stoke-On-Trent
- Yorkshire & Humber Stakeholder Meeting – NHS Yorkshire & Humber

Organisations and individuals who submitted evidence/contributed to the review (our particular thanks to those marked with an * who provided data to the review):

- | | |
|--|---|
| <ul style="list-style-type: none"> • Acorn Children’s Hospice • ACEVO • Age UK • Aintree University Hospitals NHS Foundation Trust • Alder Hey Children’s NHS Foundation Trust* • Anna Gill, Parent and Carer • Archdiocese of Cardiff • Ashgate Hospice, North Derbyshire • Association for Children’s Palliative Care (ACT)* • Association for Palliative Medicine of Great Britain and Ireland • Association of Directors of Adult Social Services • Association of Palliative Care Social Workers • Barking Havering & Redbridge NHS University Hospitals Trust • Barnsley End of Life Strategy Group • Barnsley Hospice, South Yorkshire • Barts and the London NHS Trust • Bluebell Wood Children’s Hospice • Bolton Hospice | <ul style="list-style-type: none"> • Bolton Hospital NHS Foundation Trust • British Anglican Cursillo • British Association of Art Therapists • British Association of Dramatherapists • British Geriatrics Society • British Heart Foundation • Butterwick Hospice, Stockton on Tees • Cambridge University Hospitals NHS Foundation Trust • Canterbury Christchurch University • CARE • Care Quality Commission • Carers UK • Central London Healthcare • Chaplaincy Team Southampton University Hospitals NHS Trust • CHASE Hospice Care for Children • Chestnut Tree House Children’s Hospice • Child Health Development Programme • Childhood Bereavement Network • Childhood Bereavement Charity |
|--|---|

Palliative Care Funding Review

The right care and support for everyone

- Children's Hospice South West
- Children's Hospices across London
- Children's Hospices UK*
- Christian Concern
- Church of England
- Churches Together in Southern Ryedale
- CLIC Sargent*
- Cokermouth Area Team
- College of Occupational Therapists
- Compassion in Dying / Dignity in Dying
- Cornwall Hospice Care
- Countess Mountbatten Hospital
- Crossroads
- Cruse Bereavement Care
- Demos
- Department for Education*
- Department of Health*
- Department of Palliative Care, Cicely Saunders Institute, King's College London
- Derian House Children's Hospice
- Devon Doctors Ltd
- Diocese of Ely
- Diocese of Hereford
- Diocese of Worcester (part of hospital Chaplaincy Team)
- Doncaster Specialist Palliative Care Services
- Dorothy House Hospice
- Douglas Macmillan Hospice
- Dove House Hospice
- Durham University*
- Earl Mountbatten Hospice
- East Anglia Children's Hospices
- East Cheshire Hospice
- East of England Ambulance Service
- Eden Valley Hospice
- EllenorLions Hospice
- English Community Care Association
- Essex County Council
- Every Disabled Child Matters
- Farm Crisis Network
- Forum of Chairmen of Independent Hospices
- Friends of the Elderly*
- General Medical Council
- Gloucestershire Hospitals NHS Foundation Trust
- Gold Standards Framework Centre
- Gosforth Church
- Great Ormond Street Children's Hospital
- Greenwich & Bexley Community Hospice*
- Grove House Hospice
- Guys and St Thomas' Hospital NHS Trust
- Hartlepool and District Hospice
- Haven House Children's Hospice
- Healthcare at Home*
- Heart of England NHS Foundation Trust
- Heart of Kent Hospice*
- Helen and Douglas House
- Helen Findlay, Carer
- Help the Hospices
- Hope House Children's Hospices
- Hospice Care for Burnley & Pendle
- Hospice of St Francis
- Hospiscare, Exeter, Mid and East Devon
- Humber and Yorkshire Coast Cancer Network
- Ian Rennie Grove House Hospice Care*
- Imperial College Healthcare NHS Trust
- Isabel Hospice
- Johnson Community Hospital, Spalding
- Julia's House Dorset Children's Hospice
- Katharine House Hospice, Banbury
- Keech Hospice Care, Bedfordshire
- King's College London
- Kirkwood Hospice, West Yorkshire
- Lancashire and Cumbria Theological Partnership
- Lanercost Parish Church

Palliative Care Funding Review

The right care and support for everyone

- Leeds Palliative Care Operational Group
- Leeds Teaching Hospitals NHS Trust
- Leicestershire & Rutland Organisation for the Relief of Suffering Limited (LOROS)
- Lindsey Lodge Hospice, North Lincolnshire
- Macmillan Cancer Support
- Marie Curie Cancer Care*
- Martin House Children's Hospice, West Yorkshire*
- Maypole Trust
- MENCAP
- Merseyside and Cheshire Cancer Network
- Middlesbrough, Redcar & Cleveland Community Services
- Motor Neurone Disease Association*
- Mount Vernon Cancer Network
- Mount Vernon Hospital
- MS Society
- Naomi House Children's Hospice, Hampshire
- National Audit Office*
- National Care Association
- National Clinical Director for Cancer and End of Life Care
- National Clinical Director for Children, Young People and Maternity Services
- National Clinical Director for Dementia
- National Clinical Director for Primary Care
- National Council for Palliative Care*
- National Deputy Clinical Director for End of Life Care
- National End of Life Care Programme
- National Institute for Clinical Excellence
- National Voices
- Neurological Commissioning Support*
- Newcastle Hospitals NHS Foundation Trust
- NHS Alder Hey
- NHS Barnet
- NHS Bath and North East Somerset
- NHS Berkshire
- NHS Camden
- NHS Devon
- NHS East Midlands
- NHS East of England
- NHS Gloucestershire
- NHS Hertfordshire
- NHS Islington
- NHS Lincolnshire
- NHS London
- NHS Mid-Essex
- NHS North East
- NHS North West
- NHS North Yorkshire and York
- NHS Northamptonshire
- NHS Oxfordshire
- NHS Plymouth
- NHS South Central
- NHS South East Coast
- NHS South West
- NHS Surrey
- NHS Walsall
- NHS Warwickshire
- NHS West Essex
- NHS West Midlands
- NHS Worcestershire
- NHS Yorkshire & Humber
- Norfolk and Norwich University NHS Foundation Trust
- North London Hospice
- Nottingham Children's Hospital
- Nuffield Health Trust*
- Oakhaven Hospice Trust
- Outer North East London Community Services
- Overgate Hospice
- Oxford Radcliffe Hospitals NHS Trust
- Palliative Care Pharmacists Network
- Peabody

Palliative Care Funding Review

The right care and support for everyone

- Peter Tebbit, retired Policy Consultant, NCP
- Phyllis Tuckwell Hospice, Surrey
- Pilgrims Hospices, East Kent
- Plymouth Hospitals NHS Trust
- Portsmouth Diocesan Council for Social Responsibility
- Prince of Wales Hospice, West Yorkshire
- Princess Alice Hospice, Surrey
- Princess Royal Trust for Carers
- Queen Elizabeth Hospital, King's Lynn
- Queens Court Hospice
- Race Equality Foundation
- Rainbow Parish
- Rainbow Trust
- RC Diocese of Lancaster
- Reiki Council
- Reverend Eoin Buchanan
- Richard House Children's Hospice, London
- Rob Gandy, Independent Management Consultant and Research Associate, Liverpool Business School*
- Rosie Gunn, Carer
- Rotherham Hospice, South Yorkshire
- Rowcroft Hospice, Devon
- Royal College of General Practitioners
- Royal College of Nursing
- Royal College of Physicians
- Royal Marsden Hospital
- Severn Hospice
- SLOW Bereaved Parents Group
- Social Action for Health
- South Tees Hospitals NHS Foundation Trust
- South West Public Health Observatory
- Southampton University Hospitals NHS Foundation Trust*
- Southend Hospital
- St Andrew's Hospice, Grimsby
- St Anthony's Residential Home
- St Barnabas Hospice, Lincolnshire*
- St Barnabas Hospice, Worthing
- St Catherine's Hospice, Scarborough
- St Catherine's Hospice, Preston
- St Christopher's Hospice, London
- St Clare's Hospice, Tyne and Wear
- St Cuthbert's Hospice, Durham
- St Elizabeth's Hospice, East Suffolk
- St Francis Hospice, Romford
- St Gemma's Hospice, Leeds
- St Giles' Hospice, Lichfield
- St Helena Hospice, North East and Mid Essex
- St John's Hospice, Wirral
- St John's Church, Barrow
- St Joseph's Hospice Association, Merseyside
- St Joseph's Hospice, Hackney
- St Luke's Hospice, Plymouth
- St Margaret's Hospice, Somerset
- St Mary's Hospital, London
- St Michael's Church
- St Michael's Hospice, Harrogate and Just 'B' Bereavement Support
- St Michaels Hospice, North Hampshire
- St Nicholas Hospice Care, Suffolk
- St Oswald's Hospice, Newcastle upon Tyne
- St Peter & St James Hospice, East and West Sussex
- St Raphael's Hospice, Sutton and Merton
- St Richard's Hospice, Worcester
- St Rocco's Hospice, Warrington
- St Teresa's Hospice, Darlington
- St Wilfrid's Hospice, Chichester
- St Wilfrid's Hospice, Eastbourne
- Sue Ryder Care*
- Teesside Hospice Care
- Teme Valley South Churches
- The Anscombe Bioethics Centre, Oxford
- The Care Forum
- The Children's Trust

Palliative Care Funding Review

The right care and support for everyone

- The Implementation Board for Palliative Care Strategy in Wales (Welsh Assembly Government)
- The J's Hospice, Essex
- The Legacy Rainbow House
- The Martlets Hospice, Brighton and Hove
- The Methodist Church
- The Rowans Hospice, Hampshire
- Trinity Hospice and Palliative Care Services, Blackpool, & Brian House Children's Hospice, Blackpool
- United Kingdom Home Care Association
- University College London
- University Hospital of North Tees
- University Hospital of Wales
- University Hospitals Trust Leicester
- University of Liverpool
- University of Southampton
- Wakefield Hospice
- WellChild
- Wessex Children's Hospice Trust
- Weston Area Health NHS Trust
- Weston Hospice Care*
- Whipps Cross Hospital
- Whole Systems Partnership
- Wigan & Leigh Hospice
- Willow Burn Hospice, County Durham
- Winterton House
- Wisdom Hospice, Rochester
- Woodlands Hospice
- Yorkshire Cancer Network

Individuals who attended the review testing sessions:

- Amy Everton (Assistant Statistician, DH)
- Andrew Fletcher (Director of External Affairs, Children's Hospices UK)
- Dr Bee Wee (Consultant and Senior Lecturer in Palliative Medicine, Oxford Radcliffe Hospitals NHS Trust)
- Dame Barbara Monroe (Chief Executive, St Christopher's Hospice)
- David Strudley (Chief Executive, Acorn's Hospice)
- Debbie Kerslake (Chief Executive, Cruse Bereavement Care)
- Dr Lynda Brook (Children's Palliative Care Consultant, NHS Alder Hey)
- Dr Teresa Tate (Deputy National Clinical Director for Cancer and End of Life Care and Consultant in Palliative Medicine)
- Dwayne Johnson (Executive Director of Social Care, Housing and Health, Halton Borough Council)
- Fiona Boyle (Finance Manager, Southampton University Hospitals NHS Trust)
- Graham Butland (Chief Executive, East Anglia Children's Hospices)
- Helen McLindon (Ex-Commissioner of Children's Services)
- Jane Allberry (Head of Cancer and End of Life Care, Department of Health)
- Jeremy Taylor (Chief Executive, National Voices)
- Jonathan Ellis (Director of Public Policy & Parliamentary Affairs, Help the Hospices)
- Katie Lindsay (Project Manager, National End of Life Care Programme)
- Katrina McNamara-Goodger (Policy Manager, Association of Children's Palliative Care)
- Liz Rogerson (Finance Team, Newcastle Hospitals Foundation Trust)
- Lorna Potter (Ex-Commissioning Manager and Community Development Advisor, National Council for Palliative Care)
- Mandy Thorn (Chief Executive, Marches Care and Vice-Chair of the National Care Association)
- Mark Whiting (Consultant Nurse, Hertfordshire Community NHS Trust)
- Professor Sir Mike Richards (National Clinical Director for Cancer and End of Life Care, Department of Health)
- Rebecca Kingsnorth (Commissioning Manager, NHS Barnet)
- Rebecca Lloyd (Department of Children, Families and Maternity, Department of Health)
- Rob Gandy (Independent Management Consultant and Research Associate, Liverpool Business School)
- Sarah-Jane Mills (Chief Executive, St Barnabas Hospice)
- Sarah Furley (Commissioning Manager, NHS Lincolnshire)
- Sian Heale (Commissioner of Children's Services, NHS Northamptonshire)

- Simon Chapman (Director of Policy and Parliamentary Affairs, National Council for Palliative Care)
- Susan Munroe (Director of Nursing and Patient Services, Marie Curie Cancer Care)
- Suzanne Ibbotson (Policy Development & Costing Manager, Payment by Results DH)
- Tessa Ing (Head of End of Life Care, Department of Health)
- Yvonne Kaloki (Research Assistant, King's College London)

The review team would like to thank the following individuals for their input and support:

- Rebecca Lloyd, Children, Families and Maternity Directorate, DH
- Amy Everton, Children, Families and Maternity Directorate, DH
- Robert Freeman, End of Life Care Team, DH
- Uma Datta, Children, Families and Maternity Directorate, DH
- Suzanne Ibbotson, Payment by Results Team, DH
- Andrew Whitehead, Finance Director, Marie Curie Cancer Care

International comparisons

Australia

In considering approaches to funding palliative care undertaken in other countries, the evidence from Australia stands out because it is derived prospectively – it uses original data to map actual patient-level variables and corresponding costs. In addition, there are sufficient similarities between the palliative care population in England and in Australia, to make direct comparison both feasible and worthwhile.

Before outlining the Australian model for funding palliative care, it is useful to explore how comparable the Australian data is with current English palliative care practice. In-patient length of stay, place of care prior to admission, and outcome of admission can be compared between the Australian AN-SNAP study (see below for details) and the most recent UK Minimum Data-Set statistics:

Comparison of data from AN-SNAP and the UK Minimum Dataset		
Indicator	AN-SNAP study	UK MDS 2008/09
Mean length of in-patient stay, days	13.6	13.9
Proportion of in-patients admitted from home	62%	71%
Proportion of in-patients admitted from hospital	29%	21%
Proportion where episode end/outcome of stay is death	56%	51%

Table 6: Comparison of AN-SNAP and MDS data

A further Australian study on outcomes, PCOC (see below for details) can be compared with the most recent Minimum Data-Set information on number of admissions, as well as the age and diagnosis make up of the patient group can be compared:

Comparison of data from Australian PCOC study and the MDS		
Indicator	PCOC Study	UK MDS 2008/09
Number of patients	6,891	40,800
Total number of admissions	7,923	46,800
Admissions per patient	1.1498	1.1471
<65 years	32.40%	32.70%
>84 years	13.70%	10.90%
Cancer	79.2%	90.0%
Non-cancer	18.60%	8.70%
Length of stay (mean)	12.0 days	13.7 days

Table 7: Comparison of PCOC and MDS data

These statistics are broadly comparable, suggesting that the Australian AN-SNAP and PCOC data does have resonance with current English practice.

The key elements of the Australian model are:

- A national **needs classification system** for palliative care
- A **funding model** based on the classification system
- A set of patient level **outcomes measures** which are linked to the classification and the funding model

The national classification system was developed through a national, prospective study of patient level activities and costs undertaken in 1996, the *Australian National Subacute and Non-acute Patient classification (AN-SNAP)* (Gordon et al 2009). Internationally, the AN-SNAP study is the only piece of prospective work undertaken to develop a robust and patient-based classification system in palliative care. The system covers adults only.

AN-SNAP identified that the criteria used successfully in classification systems for acute care, such as *diagnosis, procedures, age, and disposition* were ineffective in classifying resource use and level of need in palliative care. Instead, a new set of criteria were identified which were able to explain resource use and cost for palliative care (Eagar et al 1997):

Key cost drivers in palliative care identified in the AN-SNAP study

- **Phase of illness**
- **Age**
- **Functional status**
- **Problem severity score**

The Australian model found that the criteria of age, type of phase, and functional status and problem severity score could explain most of the cost variances between patients. However, in the community setting there was still a degree of cost variation which could only be explained by the difference in the provider type. The AN-SNAP team therefore included provider type as a variable, although this was a provider-level rather than patient-level variable, and not regarded as ideal for inclusion in a needs-driven classification system (Eagar et al 1997).

Using these criteria, the AN-SNAP classification system for palliative care is divided into a set of **11 in-patient classes** and a set of **22 ambulatory classes**¹⁷.

Based on the AN-SNAP classification system, the Australian state of New South Wales (NSW) has introduced per-patient funding model for palliative

¹⁷ Ambulatory services are broadly equivalent to the community services term used in the UK.

care, which is currently planned to serve as an example for a nationwide introduction in Australia by 2012.

In the NSW model, palliative care in in-patient and community settings is funded by a **blended payment model**, which combines episode payments with per diem payments. The episode payment can be defined as the 'package payment', and is weighted for the level of need determined for each class in the classification system. The level of the episode payments is therefore determined by the patient characteristics outline above. The length of each episode is also determined by the class.

The per diem payments are not affected by the class, but are standard payments designed to fund those components of care that are independent of case complexity (the 'hotel costs'). These per diem components of the funding model are employed outside of the episode trim points, to ensure that there is no incentive for services to either discharge patient prematurely or to keep them in for longer than necessary.

The Australian work also identified a number of cost areas which were outside direct patient care, and which were therefore problematic to include in a per-patient funding model, including education, research, health promotion and public health.

Further, in the Australian model, the classification system and funding system have been linked with quality and outcomes measures through the Palliative Care Outcomes Collaboration (PCOC), a voluntary quality network that aims to help palliative care services improve practice by demonstrating and improving palliative care outcomes. Under this project, a data collection system for palliative care services has been developed, capturing both service-related information and clinical information.

PCOC Dataset
<ul style="list-style-type: none">• Demographic information about each patient
<ul style="list-style-type: none">• Information relating to the episode of care – where the patient was at the start of the episode and at the end of the episode, and what kind of care was being provided and by whom.
<ul style="list-style-type: none">• Clinical information including:<ul style="list-style-type: none">○ Performance state, phase of care and dependency of the patient using standardised and validated tools including the Australian modified Karnofsky scale.○ A Symptom Assessment Scale covering seven core symptoms: difficulty sleeping, appetite problems, nausea, bowel problems, breathing problems, fatigue, and pain.• Palliative Care Problem Severity scores for each of four aspects of care – pain; other symptoms, psychological and spiritual distress; and family and caregiver issues.

The PCOC initiative offers support to providers on data collection and training of staff to use the tools, a data analysis and benchmarking service that provide reports back to participating palliative care services.

PCOC incorporates a set of national quality markers, with formal targets for services that are performing below the benchmark:

- Time from referral to first contact
- Time in the unstable phase
- Change in pain
- Change in symptoms relative to the national average

Results from the PCOC benchmarking work show that the quality of care has improved across the range of providers. This indicates that outcome measurement can be used to improve the quality of clinical practice.

The strength of the Australian model is therefore that the needs classification system provides a direct link between the funding model and outcomes measures, allowing providers and commissioners to operate with one common dataset for monitoring the funding system and measuring outcomes and potentially allowing funding to be linked directly to outcomes.

Canada

Palliative care in Canada is funded differently, depending on the setting of care. Palliative care at home may be paid for by the provincial health plan as part of a home care programme, but this does not always include the cost of drugs and equipment used at home. Some plans cap the number of paid hours of professional and home support services, and beyond this, people are required to fund privately.

Private insurance may also cover home palliative care services. Provincial health plans usually cover palliative care provided in hospitals, covering most aspects of care including pharmaceuticals, medical supplies and equipment. In long-term care facilities only some of the costs of palliative care are covered and some out of pocket costs need to be paid by residents.

Germany

There has been a rapid development of palliative care in Germany during the last 10 years, both with regard to service provision and funding. Palliative care units are funded by healthcare insurance. Currently, there are two types of funding for palliative care units: per diem funding with varying daily rates, irrespective of the patients' diagnoses or length of stay; or funding in the current DRG (diagnosis-related groups) categories. However, there is no specific DRG for palliative care, and patients are simply classified according to their primary diagnosis and co-morbidities.

In-patient hospices are funded on a per diem rate. Specialist palliative care for adults and children in community-based settings is funded by healthcare insurance. However, funding models vary across the country.

New Zealand

The New Zealand Ministry of Health devolves funding to the 20 District Health Boards (DHBs). DHBs are funded using a population based funding model that applies adjustors for ethnicity, deprivation, age, and rurality. Theoretically this funding includes funding for the provision of palliative care. However, the percentage of palliative care services funded by the state varies.

Aged residential care facilities are predominantly for-profit national organisations with means-tested user charges. Hospices are currently funded at 70% of their 2008/09 costs.

The Ministry of Health has identified the development of a national funding model for adult palliative care as a work plan priority.

Northern Ireland

Health services, including palliative care, are funded by the devolved administration in Northern Ireland. In March 2010 the Health Minister launched a Palliative and End of Life Care Strategy for Adults in Northern Ireland, which recognises that two-thirds of the people in Northern Ireland would benefit from palliative and end of life care prior to and during their last year of life.

As in England, a large proportion of specialist palliative care and end of life care in Northern Ireland is provided, and funded, by voluntary sector organisation. Presently, adult hospices in Northern Ireland receive on average 31% of their costs from the Government.

Scotland

Health services, including palliative care, are funded by the devolved administration in Scotland.

As in England, a large proportion of specialist palliative care and end of life care in Scotland is provided, and funded, by voluntary sector organisation. Whilst it is not possible to provide a figure for the amount of funding that goes to generalist palliative care services given the nature of it, Audit Scotland found that £59m was spent on specialist palliative care in 2006-07. Of this, 44% came from the voluntary sector, whilst NHS Boards spent £15.5m on their own specialist services.

Sweden

In Sweden, voluntary sector involvement in palliative care is very small, and all palliative care is covered by the National Health Care system, predominantly through the regional authorities. This means that all palliative care is funded and there is no fundraising to hospices. Nursing home and primary care-based provision of palliative care is also funded through the regional authorities, so there is no separate funding mechanism for palliative care.

USA

In the USA, there are two main ways of funding palliative care; the Medicare Hospice Benefit and fee for service, and DRG payment for specific reimbursable medical services.

The two major public insurance programs, Medicare and Medicaid, finance the vast majority of end-of-life care. Medicare pays for palliative care (hospice benefit) through capped per diem payments based on the following four categories:

- Routine home care in home or nursing homes.
- In-patient respite care for up to five days to provide carer relief.
- General in-patient care in an in-patient hospice or palliative care unit in hospital.
- Continuous home care – acute care at home with around-the-clock nursing for a crisis that might otherwise lead to in-patient care.

Rates for each of these categories vary by geographic location. Direct patient care by medical practitioners is not part of the per diem payment model but is billed on various fee-for-services type arrangements. A per diem payment is made for each patient enrolled on the benefit at one of these levels for each day of service. 95% of hospice benefit days are at the routine home care level. About 3% are at the general in-patient level and the remainder is under continuous home care and in-patient respite.

However, due to the particular characteristics of palliative care provision in the US, it is difficult to glean useful information to inform any funding model in England.

Wales

Health services, including palliative care, are funded by the devolved administration in Wales. Following the report of the palliative care planning group for Wales, a working group was established, lead by Baroness Finlay.

The Welsh funding model employs a funding formula to distribute central funds for palliative care to the various areas and services in Wales, The formula suggested aims to meet the specialist palliative care needs across Wales, appropriate to both urban and rural settings, for populations of all ages and to take into account the requirements for hospital support teams and those working in cancer centres. In addition, where hospice in-patient beds exist, a funding formula has been developed to guide reimbursement for basic care costs. Where there are no beds, hospice-at-home provision provides an alternative model of care, with funding adjusted pro rata.

This is linked with a detailed service specification or template, which is used to plan services, based on population level needs assessments. This uses information from several previous pieces of work on the number of staff required for a particular population, and was combined with information on

existing provision in Wales to determine the right level of services. This is also linked with detailed quality monitoring measures.

As in England, a large proportion of specialist palliative care and end of life care in Wales is provided, and funded, by voluntary sector organisation.

Glossary of terms

AN-SNAP – Australian National Sub-acute and Non Acute Patient
CHC – Continuing Health Care
CLG – Department for Communities and Local Government
DfE – Department for Education
DH – Department of Health
DWP – Department for Work and Pensions
HES – Hospital Episode Statistics
HRG – Healthcare Resource Group
KCL – King’s College London
LA – Local Authority
LHB – Local Health Board
MDS – Minimum Data Set
NAO – National Audit Office
NCPC – The National Council for Palliative Care
NICE – National Institute for Clinical Excellence
ONS – Office of National Statistics
PbR – Payment by Results
PCT – Primary Care Trust
QIPP – Quality, Innovation, Productivity and Prevention
QOF – Quality Outcomes Framework
SWPHO – South West Public Health Observatory
WSP – Whole Systems Partnership

Example of possible cost buckets

Cost 'buckets'	
Service	Inclusions
Nursing	Clinical nurse consultant or clinical nurse specialist
Physical therapies	Occupational therapy, physiotherapy, speech therapy, therapy aid
Psychosocial services	Social worker, psychologist, chaplain
Other allied	Audiologist, dietician, interpreter, podiatrist, hydrotherapist, care assistant, other
Supplies	Medical and surgical equipment and prostheses, patient transport, external health services
Goods and services	Non healthcare related goods and services
Medical costs	Reported doctor time
Volunteer time	Reported volunteer time
Medical imaging	Cost of type and occurrence of test carried out
Pathology	Cost of type and occurrence of test carried out.
Pharmacy	Cost of type and occurrence of test carried out. Clinical pharmacist costs are included in "other allied staff"
Capital	Costs based on general maintenance, depreciation and capital costs

Table 8: Cost buckets

Annex 6

Services included in the costings work commissioned from King's College London and their partners

Services included in the commissioned work
Specialist palliative care dedicated in-patient beds
Community specialist palliative care
Specific medical, nursing and therapy interventions in specialist palliative care
Extended community services (Hospice at Home and combined community/Hospice at Home)
Hospital-based palliative care support teams
Outpatient attendance for specialist palliative care review (in hospice and hospital)
Core palliative care services such as Marie Curie Nursing and other dedicated provision
Social care specifically related to palliative care
Short term bereavement assessment/ follow-up

Table 9: Services included in costings work

Definition of the elements of dedicated palliative care

Using the basis of the Craft/Killen triangle we would define dedicated palliative care for both children and adults as containing all the following elements:

- **Specialist palliative care services** – care delivered by specialist providers such as specialist in-patient facilities.
- **Core palliative care services** – care delivered by people whose primary focus is palliative care such as community nursing teams.
- **Universal palliative care services** – care delivered by generalist (non-palliative care specialists) health and social care providers such as GPs and social workers.

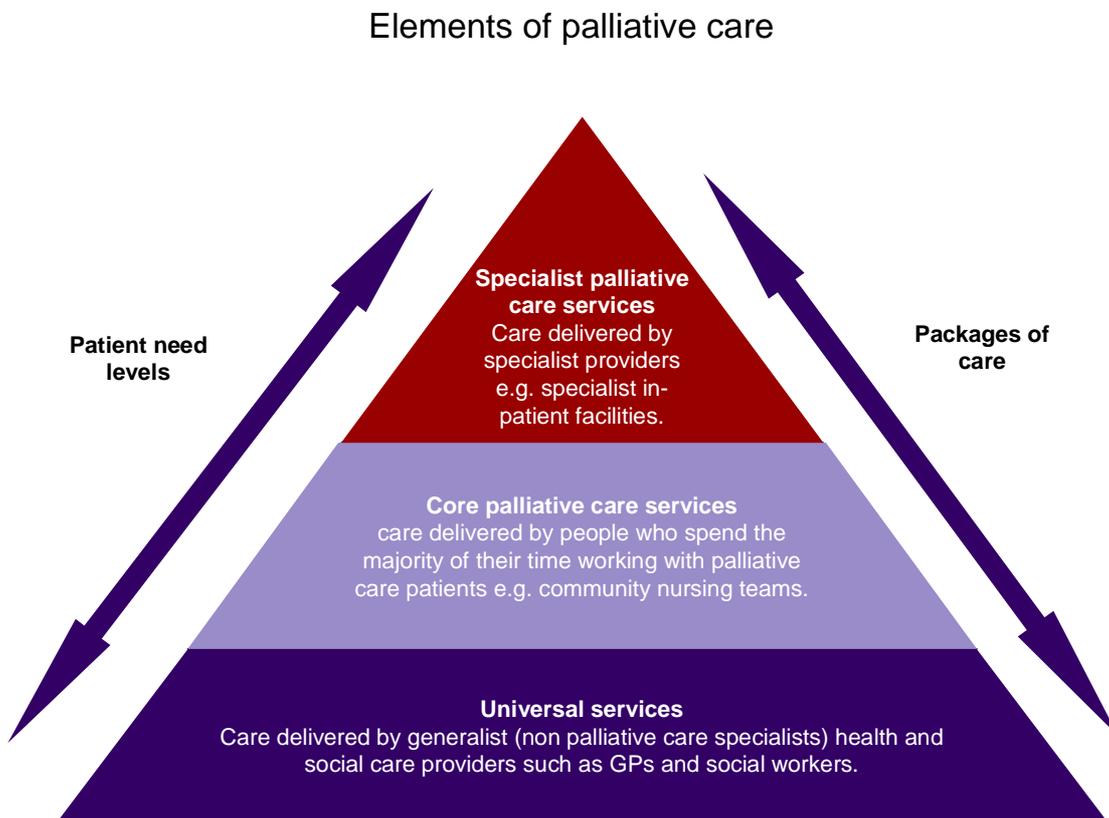


Figure 16: Elements of palliative care

List of references

Blackmore, Pring & Verne 2011 Sara Blackmore, Speciality Registrar Public Health, Andy Pring, Senior Analyst, South West Public Health Observatory, Dr Julia Verne, Director, South West Public Health Observatory: *Predicting Death – Estimating the proportion of deaths that are ‘unexpected’* National End of Life Care Intelligence Network, February 2011.

Carers UK 2007 Carers UK and University of Leeds: *Valuing Carers – calculating the value of unpaid care*, 2007.

Cochrane et al 2007 Cochrane H, Liyange S, Nantambi R: *Palliative care statistics for children and young adults*, Department of Health, England, 2007.

Corcoran & Gandy 1997 Dr Ged Corcoran & Dr Rob Gandy: *Skewed statistics: recoding palliative care*, The British Journal of Healthcare Computing & Information Management October 1997 Volume 14 Number 8, October 1997.

Craft & Killen 2007 Professor Sir Alan Craft and Sue Killen: *Palliative care services for children and young people in England - An independent review for the Secretary of State for Health*, 2007.

DH 2008a Department of Health: *End of Life Care Strategy - Promoting high quality care for all adults at the end of life*, July 2008.

DH 2008b Department of Health: *Better Care: Better Lives - Improving outcomes and experiences for children, young people and their families living with life-limiting and life-threatening conditions*, Best Practice Guidance, February 2008.

DH 2008c Department of Health: *Survey of expenditure by primary care trusts on hospice/specialist palliative care services for the year 2006/07*, July 2008.

DH 2009 Department of Health: *Currency and Pricing Options for Community Services*, January 2009.

Eagar et al 1997 Kathy Eagar and National SNAP Project Team, Centre for Health Service Development, University of Wollongong: *The Australian National Sub-Acute and Non-Acute Patient Classification (AN-SNAP): report of the National Sub-Acute and Non-Acute Casemix Classification Study*, August 1997.

Gomes & Higginson 2008 Barbara Gomes and Irene J. Higginson: *Where people die (1974 2030): past trends, future projection and implications for care*, Palliative Medicine 2008; 22; 33.

Gordon et al 2009 Robert Gordon, Kathy Eagar, David Currow, and Janette Green: *Current Funding and Financing Issues in the Australian Hospice and Palliative Care Sector*, Journal of Pain and Symptom Management Vol. 38 No 1, July 2009.

Higginson et al 2009 Irene J. Higginson, Paul McCrone, Sam R. Hart, Rachel Burman, Eli Silber, and Polly M. Edmonds: *Is Short-Term Palliative Care Cost-Effective in Multiple Sclerosis? A Randomized Phase II Trial*, Journal of Pain and Symptom Management Vol. 38 No. 6 December 2009.

Higginson 2003 Irene J. Higginson: *Priorities and preferences for end of life care*, report prepared for the National Council of Palliative Care, 2003.

HtH 2010a Help the Hospices: *HOSPICE ACCOUNTS - Analysis of the accounts of UK independent voluntary hospices for the year to March 2009*, June 2010.

HtH 2010b Help the Hospices with Children's Hospices UK: *HOSPICE ACCOUNTS - Analysis of the accounts of UK independent voluntary hospices for the year to March 2009 - Children's hospices and hospices operating services for both adults and children*, June 2010.

Macmillan 2010 Macmillan Cancer Support: *Always There? – The impact of the End of Life Care Strategy on 24/7 community nursing in England*, 2010.

Morrison et al 2008 R. Sean Morrison, Joan D. Penrod, J. Brian Cassel, Melissa Caust-Ellenbogen, Ann Litke, Lynn Spragens and Diane E. Meier: *Cost Savings Associated With US Hospital Palliative Care Consultation Programs*, Palliative Care Leadership Centers' Outcomes Group, Arch Intern Med. 2008;168(16):1783-1790.

NAO 2008a National Audit Office: *End of Life Care*, November 2008.

NAO 2008b National Audit Office: *End of Life Care - Results of census of primary care trusts*, 2008.

NAO 2008C National Audit Office: *End of Life Care - Care home survey results*, 2008.

NAO 2008d National Audit Office: *End of Life Care – Results of censuses of Independent Hospices & NHS Palliative Care Providers*, 2008.

NICE 2004 National Institute for Clinical Excellence: *Guidance on Cancer Services - Improving Supportive and Palliative Care for Adults with Cancer - The Manual*, 2004.

Nuffield 2010 The Nuffield Trust; Martin Bardsley, Theo Georghiou and Jennifer Dixon: *Social care and hospital use at the end of life*, 2010

Osinowo & Verne 2011 Adebowale Osinowo, Information Analyst, South West Public Health Observatory, Dr Julia Verne, Director, South West Public Health Observatory: *External causes of death*, National End of Life Care Intelligence Network, February 2011.

Pring & Verne 2011 Andy Pring, Senior Analyst, South West Public Health Observatory, Dr Julia Verne, Director, South West Public Health Observatory: *Deaths Registered as Occurring 'Elsewhere'*, National End of Life Care Intelligence Network, February 2011.

Rosenwax et al 2005 Rosenwax LK, McNamara B, Blackmore AM, Holman CD: *Estimating the size of a potential palliative care population*, PalliatMed. 2005;19(7):556-62.

Smith & Cassel 2009 Thomas J. Smith and J. Brian Cassel: *Cost and Non-Clinical Outcomes of Palliative Care*, Journal of Pain and Symptom Management, Vol. 38 No. 1, July 2009.

Temel et al 2010 Jennifer S. Temel, Joseph A. Greer, Alona Muzikansky, Emily R. Gallagher, Sonal Admane, Vicki A. Jackson, Constance M. Dahlin, Craig D. Blinderman, Juliet Jacobsen, William F. Pirl, J. Andrew Billings, and Thomas J. Lynch: *Early Palliative Care for Patients with Metastatic Non-Small-Cell Lung Cancer*, The New England Journal of Medicine 363;8 august 19, 2010.

YouGov 2008 YouGov survey commissioned by Marie Curie Cancer Care: *Dying at Home*, carried out by YouGov, 2008.

