

Palliative Care Funding Review

The right care and support for everyone

Interim Report December 2010

“We need a funding system which is fair, delivers what people want and need, and encourages the provision of high quality services in all settings.”

Palliative Care Funding Review Interim Report December 2010

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www.palliativecarefunding.org.uk

Executive Summary

The Challenge

The past 30 years have seen huge advances in medical care, with a consequent increase in life expectancy. In addition, demographic changes mean that in the future there will be increasing numbers of older people needing access to palliative care services.

Along with improvements in care has come a recognition of the importance of caring for people at the end of life when cure is no longer possible. There is now a real recognition of the importance of end of life care, and end of life care strategies for children, young people and adults have been developed.

Whilst there has been some improvement to services over the recent past, there has been real difficulty in translating these strategies into action. We know that the current system does not adequately meet everyone's needs. It is often poorly coordinated and difficult for patients and families to navigate.

The coalition government has recognised the importance of this, and has made a commitment to introducing a new per-patient funding system for providers of palliative care, in order to help turn the existing strategies into action.

The Secretary of State for Health, Andrew Lansley, has therefore asked the Chief Executive of Marie Curie Cancer Care, Tom Hughes-Hallett, to chair an independent review with the specific remit of recommending a funding system which enables dedicated palliative care to be available for all people in England who require it.

The Secretary of State has requested an interim report in autumn 2010 with final recommendations by summer 2011. The review started work in July 2010, and has been collecting evidence by a variety of consultation methods.

Respondents to the review consultation have told us that although the current system does not work for everyone, we should not be 'reinventing the wheel' but should learn from current models of best practice. They have said that we need:

- 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.

The current system is overcomplicated, difficult to navigate and not joined-up enough. There are, however, many committed, effective organisations and

individuals who are doing excellent work, who should be supported and who we can learn from. Above all, services need to be designed around the needs of patients, families and carers, rather than the criteria of different agencies or organisations or professional boundaries.

Palliative care is a diverse market, with services provided by the statutory, voluntary and private sector. This richness of provision, while supportive of innovation, has evolved in an ad hoc way and this has led to large variations in the levels of state funding provided.

There has never been a review of the funding systems for children, young people and adult palliative care at the same time, or a definition of what services the state should be providing for people at the end of life. This lack of clarity about how and what services are funded impedes commissioners and providers from making the most effective use of resources and providing transparent services.

Defining Dedicated Palliative Care

In response to our consultation we have been told that the focus of the statutory responsibility should be on the key services which will allow people to be cared for and die in a place of their choosing.

We consider the services which fall within the definition of dedicated palliative care to be:

- **Specialist palliative care services – care delivered by specialist providers e.g. specialist in-patient facilities.**
- **Core palliative care services – care delivered by people whose primary focus is palliative care e.g. 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.**

To ensure that good end of life care is provided to everyone, in our final report we will make recommendations on what the core components of dedicated palliative care that should be funded by the NHS as a statutory responsibility are. We will also explore how these are balanced with services that are funded or supported by society.

Developing a New Funding Mechanism

The development of this new funding mechanism is a big challenge, and is made even harder by the lack of availability of robust information on current palliative care spending. The Department of Health's 2008 *End of Life Care Strategy* states: "It is difficult, if not impossible to calculate the cost of end of life care in this country"¹. But it is also a challenge the country cannot afford to ignore, and presents us with a great opportunity to improve the system for people.

¹ DH 2008a.

We envisage a national funding system which is delivered locally

- **Across health and social care services.**
- **Through packages which are based on people's needs rather than on their disease or age; a well coordinated system which people can dip into and out of as appropriate.**
- **Commissioned at a local or sub-national level, depending on population size and frequency of occurrence.**

Investing Now for Better Outcomes and Efficiencies

But that does not mean we should wait for a new funding system before investment in the community begins. Time and again the review team have heard the phrase 'If there was one thing I would do to improve palliative care services it would be the provision of 24/7 community services'. Lack of 24/7 access to care is a major barrier to delivering the most effective, efficient services and we urge the government to take steps to address this need immediately.

We recommend a clear signal is given to providers in the forthcoming NHS Operating Framework and NHS Outcomes Framework that 24/7 community services are a priority.

We know that by reducing the amount of time that people approaching the end of their lives spend in hospital, we could make resources available which could be better used to support them to receive care in their preferred place. As the National Audit Office (NAO) have reported, by reducing emergency hospital admissions by 10 percent and the average length of stay following admission by three days for cancer patients in the last year of life, £104 million could be redistributed to meet people's preferences for place of care.²

A relatively small investment in community services now will enable commissioners to deliver improved outcomes for patients, as well as ensuring services are delivered in the most cost effective way.

Tom Hughes-Hallett
Chair

Professor Sir Alan Craft
Review Team

Catherine Davies
Review Team

² NAO 2008.

1. Introduction

In the document *The Coalition: Our programme for Government*, the government made a commitment to introducing per-patient funding for palliative care. Given that putting this system in place will take several years, the government has set up an independent review to examine dedicated palliative care funding for adults and children in England, and to make recommendations on the way forward.

Under the terms of reference (see Annex 1), phase one of this review should offer a definition of dedicated palliative care services, together with some indicative costs, by autumn 2010. This interim report is the review team's response to this challenge.

The review team was established in the summer, and its first task was to set up a process by which the review could engage with the sector. This report has been informed by the responses to the engagement (through questionnaires and consultation events) and views which have been expressed to the review team in meetings and evidence sessions. We would like to thank all the people and organisations who have taken the time to speak to us and respond to our questionnaire. (See Annex 2 for a list of organisations).

Consultation Event

The review consultation commenced on the 3rd September 2010, with a launch event in London. A selection of over 100 key stakeholders gathered together to hear the aims of the review and how it will progress over the coming months. In addition, the delegates discussed the three key questions for the first phase of the review:

1. What are dedicated palliative care services?
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?
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?

A report summarising the event and key outcomes has been produced by the review team and is available at <http://palliativecarefunding.org.uk/Report.pdf>

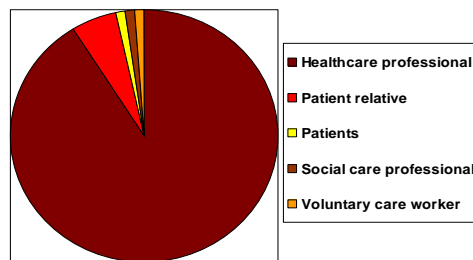
Website and Online Questionnaire

A website, www.palliativecarefunding.org.uk, has been developed to support the engagement process. Also launched on 3rd September, it is designed to provide background to the review, the reasons why it is taking place and the

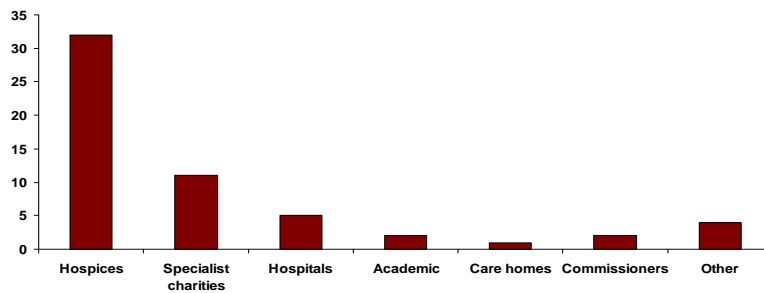
opportunity to contribute to the review team’s work. People are able to send comments, opinions and evidence via an online questionnaire, which includes the three key questions for the first phase of the review (outlined above). People were asked to submit responses to inform this report by 29th October 2010. The website content will be refreshed following the publication of this report and throughout the duration of the review.

Summary of Website Respondents

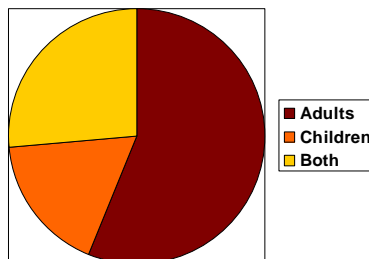
90 responses to the questionnaire were received³, and of these 52 allowed us to show their feedback on the website. These were uploaded over the course of the consultation. The respondents were predominately healthcare professionals⁴ (82 respondents), five were relatives of patients, one patient, one social care professional and one voluntary care worker.



57 questionnaires (63 percent) were submitted on behalf of organisations; these came from a total of 54 different organisations. The remainder were from individuals. Of the submissions from organisations, 32 were from hospices⁵, 11 from specialist charities/ umbrella organisations, five from hospitals, two from academic institutions, one from a care home, two from PCTs and four from other organisations.



Of the submissions by organisations 32 were from adult services, 10 from children’s services and 15 from services which deal with both adults and children.



³ Three were submitted as separate reports and not in the standard questionnaire format (by Help the Hospices, National Council for Palliative Care and Marie Curie Cancer Care).

⁴ Based on job title and organisation. This includes clinical as well as non-clinical.

⁵ 30 different hospices are represented.

2. Setting the Scene

One System for Children, Young People and Adults

The review team is delighted that for the first time the government is considering the needs of both children and adults within the same review. We know that there are strong commonalities in need for palliative care services for both adults and children. In both cases patients often have chronic illnesses and the key challenge identified to meeting their needs is the access to 24/7 support services. In addition we believe that by developing one transparent funding system, the journey from children's to adult services will be clearer and the challenges of making this transition will be improved.

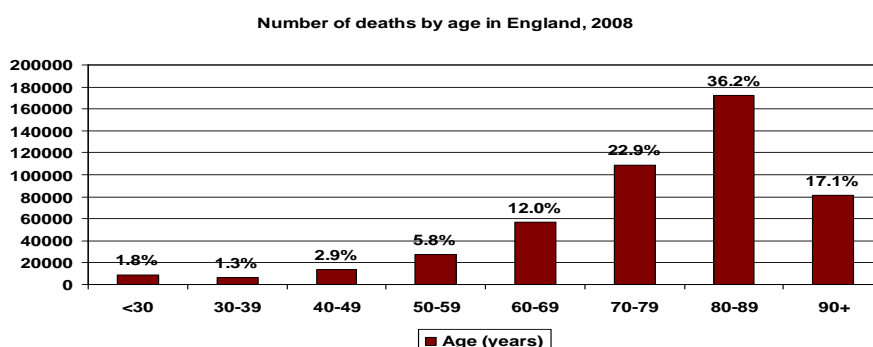
Changing Society

We know that more people will need care and support at the end of their life in the future. A number of factors will contribute to this, but key changes are that the age at which people die is increasing and that demographic changes in England mean that there will be more older people needing care in the future.

There were a total of 459,241 deaths in England in 2009 (including neonatal deaths).⁶ Population estimates show that annual numbers of deaths fell by 8% from 1974 to 2003, but are expected to rise by 17% from 2012 to 2030.⁷

Advances in medical care mean children with palliative care needs are living longer and subsequently requiring more palliative care services. For example, advancements in treatment of cystic fibrosis have led to a much longer life expectancy than 20 to 30 years ago, when many people with cystic fibrosis died in their teenage years. Today the median age of survival is more than 37 years, according to the Cystic Fibrosis Foundation.

Adults are also living longer. Population estimates show that the number of people aged over 85 is likely to double between 2008 and 2033, and the number of people aged over 100 is set to increase more than sevenfold in the same time.⁸ This will lead to more people living with the complications of old age and long term illness, increasing the need for end of life and palliative care.



Source: South West Public Health Observatory from ONS data.⁹

⁶ ONS 2010.

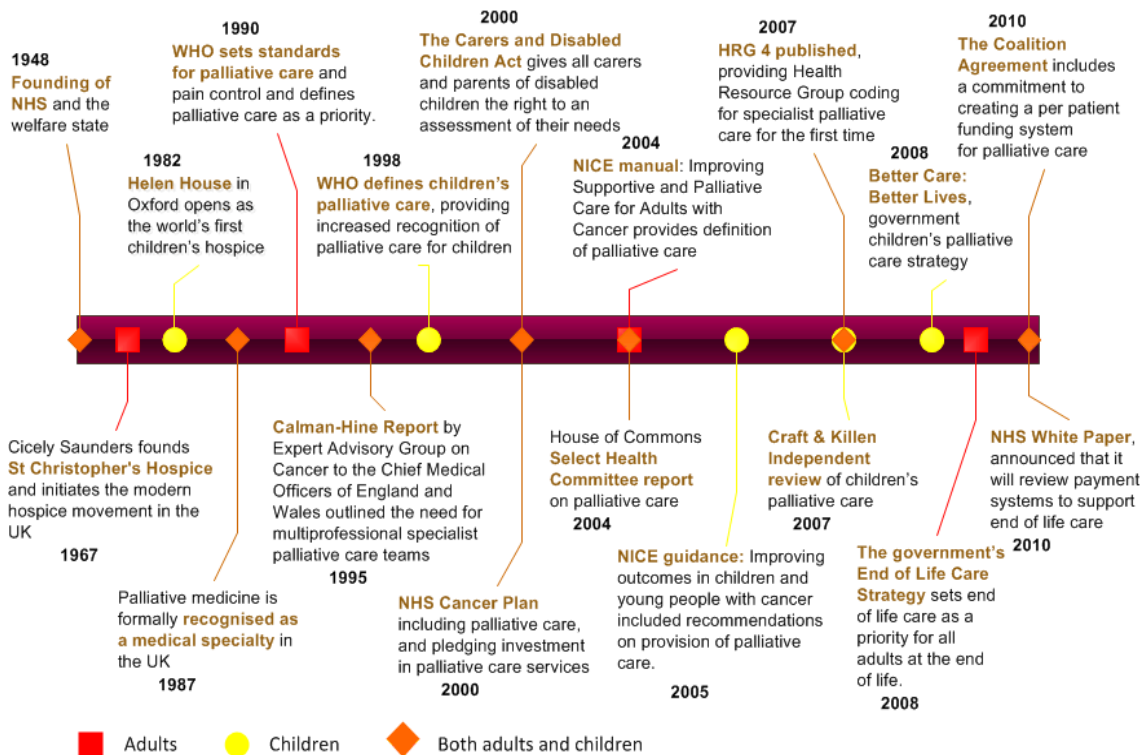
⁷ Gomes & Higginson 2008.

⁸ ONS 2009.

⁹ NEoLCIN 2010.

Current System

The provision of palliative care services by the NHS has evolved over time. Its origins are derived from the modern hospice movement, beginning with Dame Cicely Saunders and the opening of St Christopher's Hospice in 1967.



The diagram above sets out some of the key milestones in the evolution of palliative care services. The review team is seeking to build on this work and sees the 2007 Craft/Killen Report, the Department of Health's 2008 *Better Care: Better Lives Strategy* and the Department of Health's 2008 *End of Life Care Strategy* as providing the baseline for the way adult and children's services should be delivered in England. The review is not seeking to rewrite these strategies, but rather to suggest the financial levers which should be developed to ensure their effective implementation.

How Services are Delivered

NHS Services are currently provided by statutory, voluntary and private sector providers across a number of different settings, including hospital, community, care homes and hospices. On some occasions, palliative care services are also needed in other locations, such as prisons, hostels for the homeless and independent living homes for people with learning disabilities.

A large proportion of end of life care is also provided by informal carers. 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.¹⁰

¹⁰ Carers UK 2007.

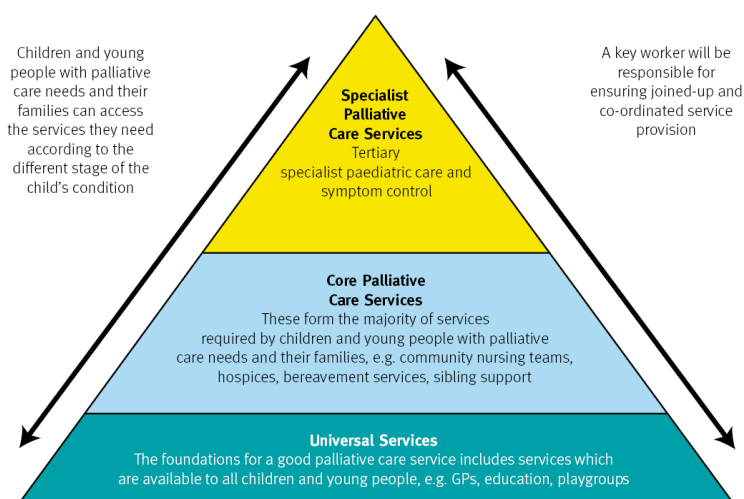
Hospice and Palliative Care In-patient Units in England							
NHS inpatient units	Voluntary sector units	Total units	NHS beds	Voluntary sector beds	Total beds	Children's units	Children's beds
40	133	173	490	2139	2629	36	269

Hospice and Palliative Care Community and Hospital Support Services				
Home care teams	Hospice at home services	Day care centres	Hospital support nursing services	Hospital support teams
226	95	225	25	228

Source: Help the Hospices' Hospice & Specialist Palliative Care Directory.¹¹

2007 Palliative Care Services for Children and Young People in England

The Craft/Killen review sets out a more sustainable way of developing and funding services for children and young people as well as looking at the availability and accessibility of these services. Its suggestions for the important elements of a good palliative care service for children and young people are captured in the triangle below:



The approach is based upon the Association for Children's Palliative Care (ACT) Care Pathway, involving access not only to specialist palliative care services as required, but also to those universal services that are available to all children.¹²

2008 Better Care: Better Lives

The previous government accepted the recommendations in *Palliative Care Services for Children and Young People in England* and built on these in

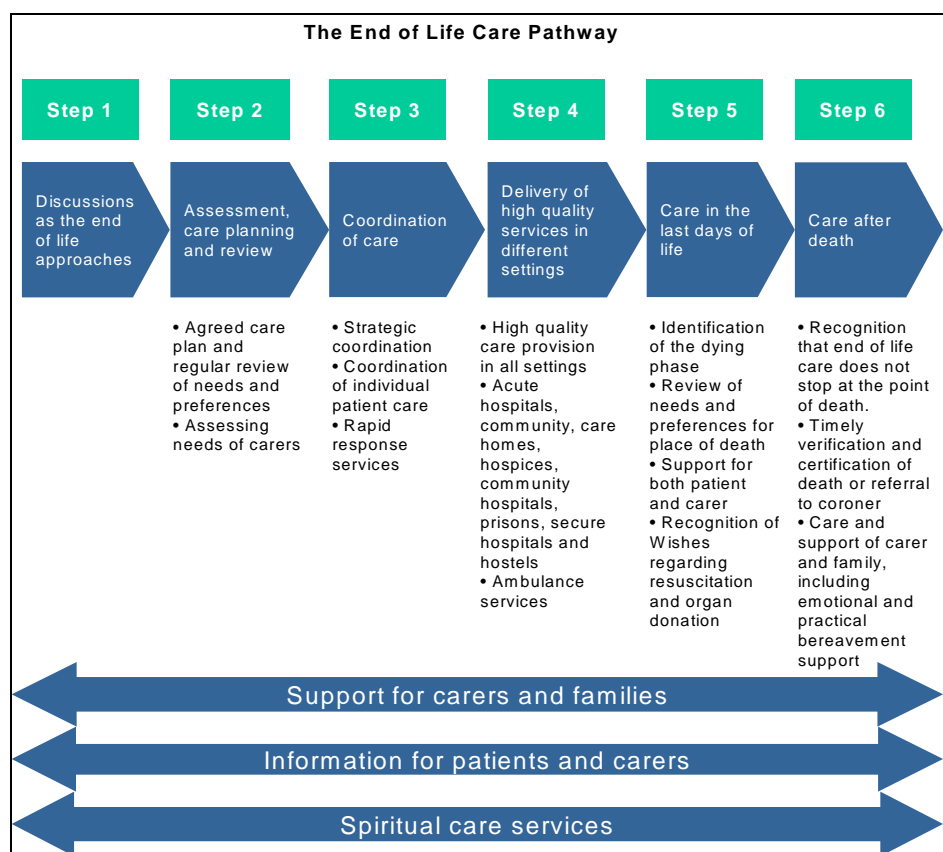
¹¹ HtH 2009.

¹² Craft & Killen 2007.

Better Care: Better Lives which set out the future direction for children's palliative care services and the systems in which these sit.¹³

2008 End of Life Care Strategy

Also in 2008, the previous government published the *End of Life Care Strategy*, which sets out a framework for improving access to high quality care for all adults approaching the end of life. It sets out a recommended end of life care pathway for adults which, whilst recognising people's needs may be different, outlines the six key steps on the journey.¹⁴



How Services are Funded

There have been a number of attempts to quantify spend on end of life and palliative care but a lack of data has made this very challenging. The Department of Health estimates that across health and social care, the overall cost of end of life care is measured in billions of pounds.¹⁵

A RAND Corporation report from 2008 estimated that the annual cost to NHS and social care services in England of providing care to cancer patients in the 12 months prior to death (27 per cent of deaths) is approximately £1.8 billion. Results of a similar analysis by RAND for organ failure patients (heart and respiratory), provided an estimated annual cost of £553 million.¹⁶

¹³ DH 2008b.

¹⁴ DH 2008a.

¹⁵ DH 2008a.

¹⁶ RAND Corporation 2008.

State Support

While this country has some of the best hospice and palliative care services in the world, they have evolved in an ad hoc way over time which has meant that the funding of these services by the state has not been clearly defined, and there are large variations in the levels of state funding provided. In a survey of Primary Care Trusts (PCTs) by the Department of Health in 2008, palliative care expenditure across PCTs ranged from £154 to £1,684 per death.¹⁷

“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

Voluntary Sector Support

A large number of hospice and palliative care services are managed and predominantly funded by the voluntary sector.

A survey of expenditure by Primary Care Trusts on hospice/specialist palliative care services for the year 2006/07 highlights the extent of support provided by the voluntary sector to these services:

NHS and voluntary sector expenditure on specialist palliative care services in 2007

Expenditure by PCTs on NHS services £million	Expenditure by PCTs on voluntary services £million	Expenditure by voluntary services from voluntary income (excluding income received from PCTs). £million	Net Expenditure 2007 £million
114.32	134.79	286.71	535.82

Source: Peter Tebbit's Benchmarking analysis for the National Council for Palliative Care.¹⁸

An additional challenge is the way voluntary sector services are funded by the state. As described earlier, currently there is lack of uniformity and fairness, both across the sector and within PCTs, in the way payment is made to hospices and other providers. On average, adult hospices in England received 34 percent of their running costs from government funds in 2009.¹⁹ The actual percentage of state funding for local charitable hospices around the country varies considerably – from zero to 62 percent of their costs.²⁰

“Affluent areas tend to be able to offer a more diverse range of service due to increased charitable funding, poor areas offer poorer levels of choice.” **Chief Executive of a Hospice**

Government funding for children's hospices is typically much lower than for adult hospices, and is on average 15 percent of running costs. It would be even lower but for a programme of emergency funding by the Department of

¹⁷ DH 2008c.

¹⁸ Tebbit 2009.

¹⁹ HtH 2010a.

²⁰ NAO 2008.

Health, distributed as an ongoing annual £10 million grant to children's hospices under Section 64.²¹

97 percent of independent hospices responding to an NAO survey stated that the funding they received from PCTs did not fully cover the costs of the NHS services they provided.²²

Additionally, most hospices are currently funded through block grants or contracts from the NHS, 70 percent of which are only one year contracts. These arrangements do not allow payment to be based on quality, or incentivise evidence-based interventions that demonstrate quality. This can impede commissioners from performance-managing the service as well as leading to difficulties for hospices with long-term planning.²³

Funding for NHS Services

As a major provider of end of life care, hospitals support many patients with palliative care needs. It is likely that hospitals will continue to be the single largest provider of end of life care, so the system needs to provide incentives for them to do it well. However, we know that not all patients who die in an acute setting should be treated there. In a detailed examination of patient records in one PCT, the NAO found that 40 percent of patients who died in hospital in October 2007 did not have medical needs which required them to be treated in hospital, and nearly a quarter of these patients had been in hospital for over a month. Alternative places of care for these patients identified by the work were equally split between home based alternatives (in a patient's own home or a care home) and bed based care in a hospice.²⁴

A further complication for hospitals is that there is currently no national tariff for end of life care services, 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.

²¹ HtH 2010b.

²² NAO 2008.

²³ NAO 2008.

²⁴ NAO 2008.

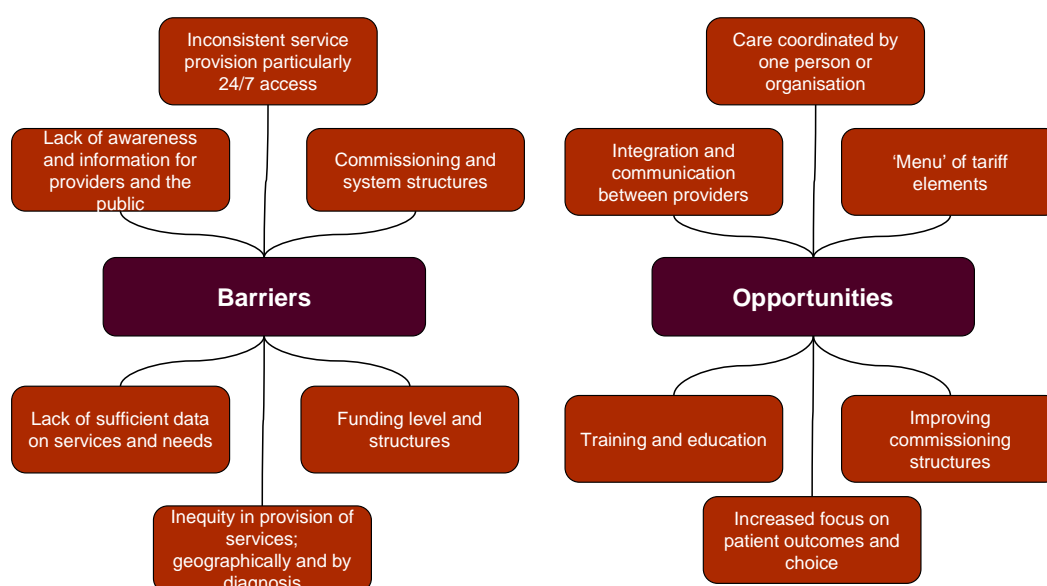
3. Building on Best Practice to Improve Outcomes for People

Challenges Arising from the Current System

We asked for views from the sector on what we can learn from the way services are currently provided, and how we ensure we build on best practice to improve outcomes for people.

The key points people raised can be summarised as follows. There needs to be:

- 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.



Stimulating Investment in Community Services

A shortage of community services and a lack of integration between health and social care contribute to keeping people in hospital beds, preventing good outcomes and increasing costs. We need to build on the expertise of the sector, for instance in the hospice movement and the provision of care for cancer, and stimulate the growth of high quality services in the community.

24/7 Access to Community Services

A key theme amongst respondents was the need to offer services within the community, in particular nursing services, 24 hours a day, seven days a week. This is a particularly important part of supporting patients to be cared for and

die at home. The condition of those reaching the end of life can change rapidly, thereby requiring an urgent response. Adequate and timely provision of services and medicines is vitally important in the provision of high quality care.

It is essential that there is access to palliative care services to support people in the community at all times; access to these services will prevent unnecessary emergency admissions to hospitals and deliver improved outcomes for people.

Research has also highlighted that 24/7 access to care is lacking in many parts of the country. Macmillan Cancer Support surveyed 125 out of 152 PCTs, and found that a full service of 24/7 community nursing was only available in 56 percent of PCTs. Of the remaining 44 percent, most provide 24/7 care to some but not all residents. Of these, 20 PCTs (16 percent) did not specify any plans to provide a full service.²⁵

“The most common cause of a patient bouncing back into hospital is because there is a lack of care to support them at home 24/7. With adequate resources to cover this, the patients if they choose to could stay at home.” **Healthcare Professional**

A number of respondents felt that respite care/short breaks were an important service for both adults and children, enabling patients to remain at home and carers to ‘keep going’.

“Respite care has immense value to the patient and their family, enabling them to carry on where otherwise they could fall apart and require far greater statutory sector crisis intervention.”
Chief Executive of a Children’s Hospice

Better Integration of Services across Health and Social Care and Coordinated Care Packages

This was a key theme amongst responses, with many people pointing to the fact that improved integration and coordination would improve services, streamline (and reduce) costs, reduce confusion and improve outcomes for patients. The Marie Curie Cancer Care Delivering Choice Programme has demonstrated significantly improved outcomes for patients and families due to increased integration of services in a number of locations.²⁶

Respondents also highlighted that health and social care services are funded by different mechanisms and this can lead to confusion for people when the boundaries between the two systems are not transparent.

“Funding should encourage shared working between social services and health.” **Medical Director of a Hospice**

²⁶ King’s Fund 2010.

Respondents were concerned that personal health budgets would be overly cumbersome for end of life patients and difficult to manage given the uncertainties on life expectancy for many end of life patients. They can work well in long term conditions, and may work for children's services but parents would need to have the freedom to use the funds as they see fit.

There was a consensus among respondents that patients (and their families/carers) should not have to coordinate their own end of life care. There were a number of suggestions about where the coordination of services should lie: some felt that this should sit with district nurses, others with hospices, others with a dedicated palliative care team. Whichever team they are from, the coordinator needs to be clearly identified, widely supported and well educated.

“Without improving the organisation and coordination of care provided by generalists, more people fall through the net and end up in hospital, dying in a way that is not aligned to their wishes and preferences and is not cost effective for the NHS.” **National Clinical Lead**

An Increased Focus on Outcomes and Patient Choice

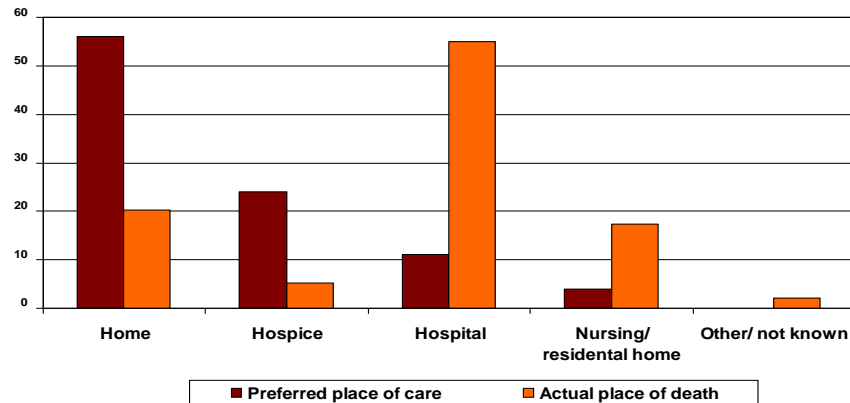
Respondents felt that positive patient outcomes should be a priority for end of life care. The needs of the patient must come first; they should be provided with options and enabled to access the services of their choice. There should also be enough flexibility within the system to respond quickly and effectively to any changes in a patient's needs. Patients should be supported so that they can be cared for and die in a place of their choice, even if they have no family or carer to support them.

“We need to truly explore what are improved outcomes for people, to build our knowledge of patient reported outcomes, rather than focusing on service outputs.” **Relative of a Patient**

Research consistently shows that most people say that they would like to be cared for and die in their own home (for some this would be their care home): between 56 percent and 74 percent in different studies for adults. This trend in preferred place of care also relates to children with palliative care needs, and their families. For many parents, the home provides the security and comfort of a familiar environment, and children generally prefer to be at home among their own toys, pets, family members and friends.²⁷

However the proportion of people achieving this wish is very small with most deaths in England occurring in NHS hospitals (55 percent), followed by home (20.3 percent), care homes (17.4 percent), hospices (5.2 percent) and 2.0 percent in other locations. The following table highlights this contrast.

²⁷ Craft & Killen 2007.



Source: Irene Higginson 2003: *Priorities and preferences for end of life care combined with ONS mortality data for England 2009.*²⁸

A Reduction of Inequities in the System

The ‘postcode lottery’ within palliative care means that patients with the same diagnosis in different geographical locations can expect very different levels of service, and this was attributed to differing levels of funding. The diagnosis of the patient also creates inequalities; respondents felt that palliative care services should be assigned based on need rather than diagnosis (while understanding that in some cases different diagnoses will mean that there are great differences in need).

“Current services tend to be cancer orientated. Palliative care is about preparing any patient and their family/ loved ones for a dignified and comfortable death in a place of the patient's choosing irrespective of diagnosis.” **Chief Executive of a Hospice**

Research by the National End of Life Care Intelligence Network highlights significant variations in where people die depending on their age, sex, diagnosis and socioeconomic status.²⁹ These variations may not necessarily be caused by inequity in access to services, but this is likely to be at least a contributing factor.

There is also evidence that deprivation may affect the resources needed to achieve community palliative care and death. A report for the London Regional Strategy Group for Palliative Care in 2000 showed that to achieve similar levels of home death rates, twice the resources were needed in deprived areas.³⁰

Improved Education and Training on Palliative Care Services

Training and education were felt by respondents to be key areas for investment and support given their great importance when seeking to improve services. Staff should be trained on care and communication skills, awareness of the issues surrounding palliative care and specialised needs of palliative care patients with particular needs, such as mental health, learning

²⁸ Higginson 2003 & ONS 2010.

²⁹ NEoLCIN 2010.

³⁰ Tebbit 2009.

disabilities or dementia. It was highlighted that hospices, given their expertise, may be well placed to provide education and training to other organisations. Disseminating developments in good practice should also be a priority.

“The range of specialist palliative services that should be available includes the provision of end of life education and training for all providers of health and social care for whom palliative care is part of their role.”

Chief Executive of a Hospice

A 2007 report by the National Council for Palliative Care and the National End of Life Care Programme highlighting examples of good practice for end of life care in care homes, found that education and training for care home staff can help improve the care of those who are dying as well as combating the sense of isolation many care home staff feel.³¹

³¹ NCPC & NEoLCP 2007.

4. Defining Dedicated Palliative Care

There is a consensus among respondents to the review team's consultation so far that although there are flaws in the current system, we should not be 'reinventing the wheel' but should learn from current models of best practice. The current system is overcomplicated, difficult to navigate and not joined-up enough. There are, however, many committed, effective organisations and individuals who are doing excellent work, who should be supported and who we can learn from. Above all, services need to be designed around the needs of patients and families rather than the criteria of different agencies or organisations, or professional boundaries.

What is Dedicated Palliative Care?

There are a number of definitions for 'end of life care', 'palliative care' and 'specialist palliative care'. This report does not seek to define what palliative care is clinically but to clarify what statutory services should be provided by the state to ensure a good death is made a possibility for everyone.

- **End of Life Care**

One aspect of palliative care is end of life care. The 2008 *End of Life Care Strategy* for England based its understanding of end of life care on the National Council for Palliative Care's definition, which states that end of life care is care that helps all those with advanced, progressive, incurable illness to live as well as possible until they die. It enables the supportive and palliative care needs of both patient and family to be identified and met throughout the last phase of life and into bereavement. It includes management of pain and other symptoms and provision of psychological, social, spiritual and practical support.³²

- **Palliative Care**

According to the National Institute for Clinical Excellence (NICE), palliative care can be defined as: "the active holistic care of patients with advanced, progressive illness. Management of pain and other symptoms and provision of psychological, social and spiritual support is paramount. The goal of palliative care is achievement of the best quality of life for patients and their families. Many aspects of palliative care are also applicable earlier in the course of the illness in conjunction with other treatments."³³

Palliative care for children represents a special, albeit closely related field to adult palliative care. In their 2007 review, Craft and Killen defined children's palliative care as care concerned with the treatment of children with life-limiting or life threatening conditions. It is the need to maintain quality of life, not just in the dying stages, but also in the weeks, months and years before death and is characterised by concern for symptom relief, promotion of

³² DH 2008a.

³³ NICE 2004.

general well-being, and psychological and social comfort for the child and family.³⁴

- **Dedicated Palliative Care**

In response to our consultation several suggested definitions of dedicated palliative care have been submitted to the review team. The respondents' combined views on the elements included in dedicated palliative care can be summarised as follows:

Elements of Dedicated Palliative Care Services

- 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 does 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.

This has been further refined by the National Council for Palliative Care who suggested the following definition:

“Care which enables people with progressive, and/or life threatening conditions or who are approaching the end of life to live according to their wishes and preferences wherever possible. The management of pain and other symptoms of non curable conditions and provision of psychological, social and spiritual support is paramount. It includes support for the person to plan their future care in anticipation of further deterioration and support for the person’s family and loved ones. Dedicated palliative care can be provided in any setting. It is not time bound but may be provided at any stage of the person’s care pathway and that of their carer(s).” **National Council for Palliative Care**

What Should the State be Responsible for?

Respondents suggested that there is a need to define the core components of palliative care that should be funded by the NHS as a statutory responsibility.

Core Components of Dedicated Palliative Care

People felt the focus of this statutory responsibility should be the key services which will allow people to be cared for and die in the place of their choosing.

³⁴ Craft & Killen 2007.

Suggestions for what core services should cover included:

- All specialist palliative care services, including community specialist palliative care nursing
- In-patient, outpatient and care at home hospice services
- Care home palliative care services
- 24/7 community care
- Counselling and psychological services
- Spiritual and social support
- Bereavement support for families and carers
- Education for palliative care professionals
- Telephone advice services
- Domiciliary services
- Respite care and short breaks

The need for realism was clearly articulated, with respondents indicating that the state would not always be able to fund all services. Many respondents felt that there was a need for additional funding to improve services, particularly in the short term (given that investment in community services is likely to provide savings in the acute setting in the longer term). There was also a feeling that the sector would have to be mindful not to waste money in the switch to a new funding system, especially in the current economic climate.

Many felt that NHS funding for core services provided by the voluntary sector would allow charitable funds to be used for innovation, enabling the sector to add value and drive service improvements.

Respondents were keen that the focus on improving community services should not be at the expense of specialist palliative care in hospitals which is a vital part of palliative care as a whole. There was mention that supporting and improving generalist palliative care services would ensure that specialists have a greater availability for patients with specialist needs.

The *End of Life Care Strategy* states that although every individual may have a different idea about what would, for them, constitute a 'good death', for many this would involve:

- Being treated as an individual, with dignity and respect
- Being without pain and other symptoms
- Being in familiar surroundings
- Being in the company of close family and/or friends

High quality care should be available to all irrespective of age, gender, ethnicity, religious belief, disability, sexual orientation, diagnosis or socioeconomic deprivation, and wherever the person may be: at home, in a care home, in hospital, in a hospice or elsewhere.³⁵

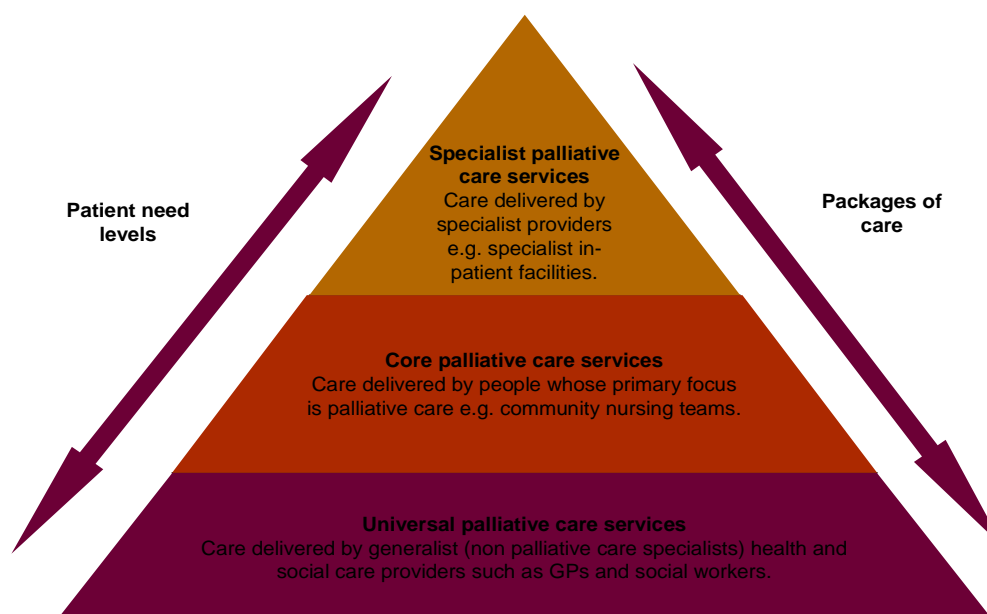
³⁵ DH 2008a.

Elements of Dedicated Palliative Care

Using the basis of the Craft/Killen triangle (see page 9) 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 e.g. specialist in-patient facilities.
- **Core palliative care services** – care delivered by people whose primary focus is palliative care e.g. 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.

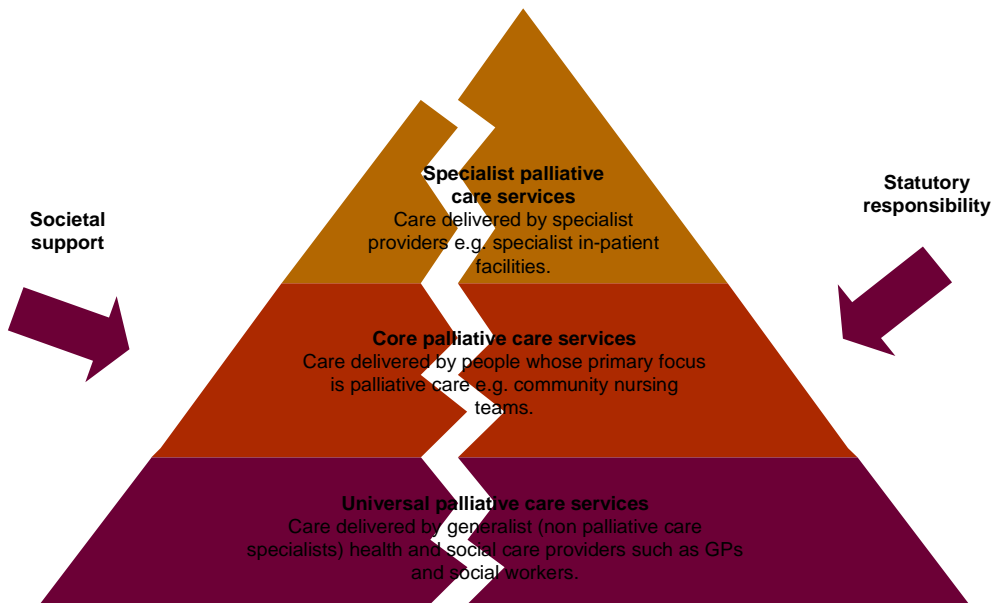
Elements of Dedicated Palliative Care



But, this does not mean that the state should fund all these services. Rather, it should provide the 'core' statutory service, and society – be that through the voluntary sector, private sector or individuals – adding a 'top up'.

This concept is demonstrated in this second version of the triangle.

Statutory responsibility and societal support



This diagram is illustrative and should not be seen as demonstrating exactly where the division between state and society should lie.

Our final report will make recommendations on what the core components of dedicated palliative care that should be funded by the NHS as a statutory responsibility are. We will also explore how these are balanced with services that are funded or supported by society, to deliver a funding mechanism which:

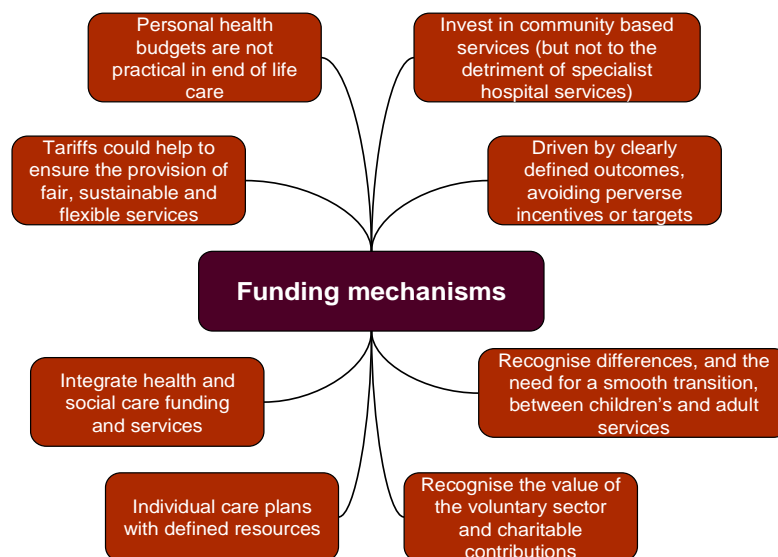
- Is fair to all sectors, including the voluntary sector.
- Encourages the development of community-based palliative care services.
- Supports the exercise of choice by care users of provider and of location of palliative care provision.

5. The Funding Mechanism Challenge

“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

People have told us that the key elements a new funding mechanism needs to consider are:



Fair for All, Stimulating Growth and Supporting Choice

There was a consensus among the majority of stakeholders that tariff-based funding would be the most fair, sustainable and flexible system. The tariff should cover all providers: NHS, local authority, private or voluntary and give parity of funding between these. Tariffs would need to cover a set of services, wherever they are provided, but should be sensitive and flexible enough to meet the needs of individual patients. They should be structured to focus on outcomes but not over-burden organisations with administrative work. Respondents had differing opinions on what the tariff(s) should cover, from ‘full cost recovery’ for all care to ‘units of care’ with a proportion of costs recovered or a contribution towards the costs of voluntary agencies.

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

Chief Executive of a Hospice

Pathway funding is seen by respondents as neither flexible nor person-centred enough for palliative care. It is also seen as cumbersome, time-consuming to administer and is currently untried in palliative care.

“Activity (or per patient) based funding seems inevitable and appropriate but it needs to be administered equitably.”

Chief Executive of a Hospice

In order to ensure services provided are of a high quality, respondents feel that there needs to be an increased focus on outcomes for patients. Outcomes should focus on patient satisfaction (for instance from survey criteria) rather than counting numbers. It was stated that there should be a robust system of checking that providers are meeting agreed standards. If providers do not meet these standards it was suggested that there should be financial penalties, with the provider made accountable.

“Any new funding mechanism should provide incentives for providers to continually improve the quality of care and support, in direct response to people’s needs.” **End of Life Care Charity**

In order to maximise the effectiveness of budgets and bring sectors together, many respondents felt that the funds for palliative care across health, social care and the voluntary sector should be pooled and managed jointly. In order to ensure that local needs are met, adult services should be commissioned locally. Due to lower numbers of children requiring palliative care however, in order to obtain cost savings, children’s services should be commissioned regionally or nationally. The need to consider the role of continuing health care in any new funding mechanism was also raised.

There was a feeling amongst many respondents that a move towards either activity-based or per-patient funding is likely and appropriate but must not be overcomplicated and must be administered equitably. Many respondents outlined the need for services to be flexible and responsive to need, and some felt that a way to achieve this would be to base funding on availability of services (e.g. number of beds available) rather than activity. A minority felt that per-patient funding was not the right way 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 of a Hospice

In order to protect patients from being pressured to move on inappropriately, respondents felt that there should not be inappropriate caps on stay length and that there should also be no caps on admissions (experience shows that caps on admissions to palliative care services results in inappropriate admissions to acute services so there is no saving). Other areas of concern include penalties for failed discharges from hospital, which may discourage hospitals from sending patients with a short life expectancy or high symptom burden home and therefore undermine patient choice. It was highlighted that we need to facilitate a system which ensures a speedy discharge from hospitals, and is not hampered by bureaucracy. We must also be careful of providing perverse incentives in which a tariff for end of life care would generate income for hospitals and could encourage the trend of people dying in hospital.

“There is a danger that if a tariff was agreed for palliative care provided in a hospital setting this becomes an income generator for hospitals so we are never going to reverse the trend of people dying in hospital rather than their own home.” **Healthcare Professional**

6. The Way Forward

Many respondents felt that we need to learn from the current funding system, both the good and the bad. They pointed out that much work on developing costs and new funding systems has already been done (for instance in the work already undertaken to try and develop a tariff under the payment by results system). It was also stressed that we need to move away from annual funding agreements and one-off pots of money, as these stifle service development due to uncertainties on future funding.

The review team will consider all these challenges going forward. In particular we agree that the most effective way of creating a new system is by building on the best work and information already available.

We would highlight at this point in our work that we think the new funding mechanism should be a national system which is implemented locally:

- Across health and social care services.
- Through packages which are based on people's needs rather than on their disease or age - a well coordinated system which people can dip into and out of as appropriate.
- Commissioned at a local or sub national level depending on population size and frequency of occurrence.

We will spend the next six months developing this new funding mechanism in conjunction with the sector, in order to deliver our final report by summer 2011. With the current paucity of data in this field, we will need to undertake some detailed analytical work to define the currencies and develop a new system which can be taken forward with confidence at a national level.

We will update our website and set out how people can continue to engage with the review over the coming months.

Action Needed Now

But we also think more can be done now to invest in the community. Reducing the amount of time people approaching the end of their lives spend in hospital could make resources available which could be used to better support people in their preferred place of care. The NAO estimates that £104 million could be made available for investment into meeting people's preferences for place of care by reducing emergency hospital admissions by 10 percent and the average length of stay following admission by three days (a reduction of around 25 percent in the current average length of stay).³⁶

This startling evidence shows how resources could be released and be put to better use within the system. 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

³⁶ NAO 2008.

delivered in the most cost effective way. As mentioned earlier in the report, this is a particularly important part of supporting patients to be cared for and die in their preferred place of care. The condition of those reaching the end of life can change rapidly, thereby requiring an urgent response. Adequate and timely provision of services and medicines is vitally important in the provision of high quality care. It is essential that there is access to palliative care services to support people in the community at all times. This will prevent unnecessary emergency admissions to hospitals and deliver improved outcomes for people.

We urge the government to take steps to address this need immediately, and recommend a clear signal is given in the forthcoming NHS Operating Framework and NHS Outcomes Framework to providers that 24/7 community services are a priority.

The Palliative Care Funding Review Team

**Tom Hughes-Hallett (chair),
Professor Sir Alan Craft,
Catherine Davies,
Isla Mackay, and
Tilde Nielsson**

www.palliativecarefunding.org.uk

**Palliative Care Funding Review
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.

Annex 2

Organisations who have taken part in the review process so far

<ul style="list-style-type: none">• Acorn Children's House• ACEVO• ACT• ADASS• Age UK• Ashgate Hospice• Association for Children's Palliative Care (ACT)• Association for Palliative Medicine of Great Britain and Ireland• Barnsley Hospice• Bath and North East Somerset PCT• Bolton Hospice• British Heart Foundation• Butterwick Hospice• Canterbury Christ Church University• Camden PCT• Care Quality Commission• Carers• Central London Healthcare• CHASE Hospice Care for Children• Child Bereavement Trust• Children's Hospices UK• Children's Hospice South West• Children's National Oversight Group• Crossroads• Cruse Bereavement• Demos• Department of Health• Derian House• Dorothy House Hospice• Douglas Macmillan Hospice• Dove House Hospice• Earl Mountbatten Hospice• East Anglia Children's Hospices• East Cheshire Hospice• East of England SHA• Ellenor Lions• English Community Care Association• Every Disabled Child Matters• Forum of Chairmen of Independent Hospices• General Medical Council• Great Ormond Street Children's Hospital• Greenwich & Bexley Cottage Hospice• Grove Hospice• Guys & St Thomas' Hospital	<ul style="list-style-type: none">• National Clinical Director for Dementia• National Clinical Director for Primary Care• National Council for Palliative Care• National End of Life Care Programme• National End of Life Care Board• National GSF Centre CIC• National Voices• NHS Alderhey• NHS Devon• NHS Oxfordshire• NHS Plymouth• NHS South Central• Norfolk & Norwich University NHS Foundation Trust• Nuffield Trust• Oakhaven Hospice Trust• Overgate Hospice• Parents and relatives of patients• Prince of Wales Hospice• Princess Alice Hospice• Queen Elizabeth Hospital• Rainbow Trust• Reiki Council• Richard House Children's House• Rotherham Hospice• Rowcroft Hospice, Devon• Royal College Nursing• Royal College of General Practitioners• Royal College of Physicians• Royal Marsden Hospital• Severn Hospice• South East Coast SHA• Saint Francis Hospice• Saint Michael's Hospice and Just'B' Bereavement Support Services• St Andrew's Hospice, Grimsby• St Anthony's Residential Home• St Barnabas Hospice, Lincolnshire• St Catherine's Hospice, Preston• St Catherine's Hospice, Scarborough• St Christopher's Hospice, London• St Clare's Hospice, Tyne and Wear• St Cuthbert's Hospice• St Elizabeth's Hospice, East Suffolk
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<ul style="list-style-type: none"> • Hartlepool and District Hospice • Heart of Kent Hospice • Help the Hospices • Hertfordshire PCT • Hospice Care for Burnley & Pendle • Hospice of St Francis • Hospiscare, Exeter, Mid and East Devon • Isabel Hospice • Islington PCT • Julia's House Dorset Children's Hospice • Keech Hospice Care • Kings College London • Kirkwood Hospice • Leeds Teaching NHS Trust • Lindsey Lodge Hospice • Macmillan Cancer Support • Marie Curie Cancer Care • Marie Curie Hospice (Newcastle) • Martin House Hospice CYP • Maypole Trust • MENCAP • Middlesbrough, Redcar & Cleveland Community Services • Motor Neurone Disease Association • Mount Vernon Cancer Network • Mount Vernon Hospital • MS Society • Naomi House Children's Hospice • National Audit Office • National Clinical Director for Cancer • National Clinical Director for Children, Young People and Maternity Services 	<ul style="list-style-type: none"> • St Gemma's Hospice, Leeds • St Giles Hospice • St Helena Hospice, North East & Mid Essex • St John's Hospice, Wirral • St Luke's Hospice, Plymouth • St Oswald's Hospice, Newcastle • St Peter & St James' Hospice, East and West Sussex • St Teresa's Hospice, Darlington • Sue Ryder Care • Surrey PCT • Teesside Hospice Care Foundation • The Children's Trust • The Implementation Board for Palliative Care Strategy in Wales (Welsh Assembly Government) • The Legacy Rainbow House • The Martlets Hospice, Brighton & Hove • United Kingdom Homecare Association Ltd • University College London • University Hospital of Wales • Wakefield Hospice • Wallsall PCT • Warwickshire PCT • WellChild • Wigan & Leigh Hospice • Willow Burn Hospice • Wisdom Hospice • Yorks and Humber PCT
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