Palliative Care Funding Programme workshops

An update paper

January 2014
Contents

Introduction ......................................................................................................................... 3
The political and policy context ......................................................................................... 4
  The coalition programme for government ................................................................. 4
Palliative Care Funding Review ....................................................................................... 4
The Health and Social Care Act 2012 ............................................................................ 6
  The current state funding of hospice care in England .............................................. 8
Palliative care funding programme and pilot sites ......................................................... 12
  Aims ............................................................................................................................... 12
  Progress ......................................................................................................................... 13
  The future ...................................................................................................................... 14
Next steps ......................................................................................................................... 14
Introduction

In 2010 the Liberal Democrats and the Conservative Party published a programme for government. The programme included a commitment to introduce a new funding system for hospice and palliative care in England.

This commitment led to the government’s announcement of a review of palliative care funding in July 2010, which it was intended would help inform the development of a new funding system. In July 2011 the review published its final report containing a number of comprehensive recommendations. The report followed an intense round of engagement with statutory, voluntary and commercial providers of palliative care.

A key recommendation of the review was for pilots to be established to collect data on palliative care. After the Department of Health invited expressions of interest from potential sites in autumn 2011 eight pilot sites were announced and came online in spring 2012. Seven of the pilots have since focused on adult palliative care, while one consortia pilot with sites across England has focused on children’s palliative care. To date the pilots have made significant progress in collecting data, which is being collated and analysed by the Palliative Care Funding Programme (PCFP) at NHS England (NHSE).

Help the Hospices remains aware that members hold different views about a new funding system as well as the level of statutory funding for hospice care. This paper provides an update on the policy and political context as well as the current state of funding for hospices in England. It goes on to outline the work of the PCFP and the eight pilot sites.

The paper is informed and shaped by consultation and engagement events we hosted for members in 2010 and workshops we held with Together for Short Lives and NHSE in winter 2013. We would like to thank all of those who engaged with us before, during and after the workshops as it allowed all of the participating organisations to hear the concerns of the sector, which we will be taking forward in the future.

Robert Melnitschuk
Policy and Advocacy Manager
January 2014
The political and policy context

The coalition programme for government

The programme for government, signed in 2010, is a binding agreement between the Liberal Democrats and the Conservative Party, and contains a commitment regarding the funding of hospice and palliative care for adults and children:

“...so that proper support for the most sick children and adults can continue in the setting of their choice, we will introduce a new per-patient funding system for all hospice and providers of palliative care.”

This remains a significant commitment on the part of the two parties, and indicates the importance that the government attaches to changing the way hospice and palliative care is funded.

However, no clear details were provided by the government in its agreement about how a new ‘per-patient’ funding system would work practically but significant work has and continues to be done to inform detailed proposals.

Help the Hospices continues to engage with Ministers about the development of a new funding system, and represent the views and concerns of the hospice sector.

Palliative Care Funding Review

The palliative care funding review was announced by the Department of Health in July 2010. The terms of reference for the review are outlined below.

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

The review asserted that a lack of a defined funding model has led to a significant variation in the level of statutory funding for palliative care services. A comparison of figures, by the review, highlighted for many the need for change to improve care and outcomes for people with a palliative care need:
"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 review was also split into two phases. The first phase constructed a definition of ‘dedicated palliative care services’, which was outlined in the review’s interim report in autumn 2010. The details of the definition are outlined below:

**Definition of ‘dedicated palliative care’**
The definition of ‘dedicated palliative care services’ set out what would be funded by the state or ‘NHS responsibilities’. Other services, it was recommended, should be funded by the state and society, or society alone.

The review outlined its definition of dedicated palliative care services, which included the following elements:

- Assessments of the patient
- Coordination of the care of the patient
- Clinical care needs of the patient (Including all medical and nursing care as well as rehabilitation support such as physiotherapy)
- Social care needs of the patient at the end of life

The second phase made detailed recommendations for a funding mechanism for ‘dedicated palliative care services’ across the statutory, voluntary and commercial sectors in the summer of 2011.

After noting the need to significantly improve the coverage, quality and availability of palliative care data the review recommended that five pilot sites be established to collect data over two years. These sites would collect data which would be used to test and further develop the principles that the review recommended should form the basis of a new funding system.
The Health and Social Care Act 2012

In the same year as the government committed to a new per patient system for palliative care, and in the same month as it launched the palliative care funding review it also published the NHS white paper – *Equity and excellence: liberating the NHS*.

The white paper eventually became the Health and Social Care Bill, which after much debate, coverage and an unprecedented ‘pause’ became the Health and Social Care Act 2012.

The Act constitutes the most radical shake-up of the NHS since it was founded over 65 years ago and has led to several key changes:

- **Reformed commissioning** – Clinical Commissioning Groups (CCGs) have, since 1 April 2013, replaced Primary Care Trusts (PCTs) to commission the majority of NHS services for the people living within the areas they cover. NHS England provides leadership for CCGs but also commissions some NHS services.

- **Reformed payments and pricing** – NHS England is now responsible for payment systems. The remit of Monitor has been expanded to include responsibility for pricing, which is also overseeing an expansion in the development of both nation and local tariffs for NHS services.

- **A focus on patient choice** – Personal Health Budgets continue to be rolled out and people are being greater choice over the provider of their NHS care. Work to introduce a new ‘national choice offer’ for terminally ill people over provider and place of care has been delayed but will be a key focus in 2014.

- **A focus on outcomes** – process targets are being replaced by outcome measures.
Overall, many of the changes that have been ushered in with the Act have been to support the government’s intention to increase choice and competition in health care in England. Part of this process has been to develop ‘a level playing field’ as far as possible in terms of prices and regulations for providers.

While the political commitment to a new funding system for hospice and palliative care appears to remain as strong as it was in 2010, it is important to remember that the policy context has shifted considerably.

The policy context will have as much an impact on the development of a new funding system as the political context.
The current state funding of hospice care in England

As a sector, we knew and experienced the variation that the palliative care funding review highlighted in the statutory funding or spend on hospice and palliative care.

Help the Hospices has long used the average statutory funding hospices receive as a proportion of costs (excluding fundraising) to highlight two important issues. The first is the disparity in funding between NHS and voluntary sector provided hospice and palliative care. The second is the financial support that the sector enjoys from the public. The average does obscure the significant variation that exists in the statutory funding that different hospices receive.

The graphs below are taken from the ‘Hospice Accounts’ which are compiled by Help the Hospices, and clearly demonstrate the differences in levels of statutory of funding among hospices.
Mechanisms

Prior to the Health and Social Care Act there were only two models of funding hospices in England:

1. **Grant funding** – the majority of hospices received their funding from the NHS in the form of a grant. At the same time the use of grant funding by the NHS had been in decline outside of the hospice sector. Grants were and continue to be considered a contribution towards the costs of hospice care services, rather than an attempt to fully fund the care provided on behalf of the NHS.

2. **Local tariffs** – a number of members had experience of this type of funding after some PCTs developed local tariffs for the hospices services they
commissioned. Local tariffs can be seen as an attempt to emulate the ‘payment by results’ system, a national payment system that has gradually been introduced across the NHS since 2003.

Help the Hospices survey of members in early 2013 highlighted the emergence of a new approach to hospice and palliative care service funding in response to the Health and Social Care Act:

3. **Any Qualified Provider** – a number of hospices have successfully bid for the provision of palliative care services put out for tender by CCGs. Providers with a licence from the Care Quality Commission and Monitor are able to bid for tenders under any qualified provider (AQP). There is an expectation that the use of AQP by commissioners will increase over time.

**Agreements**

Similarly, prior to the Act there were three principle types of agreement used to deliver either the grant or local tariff funding to hospices:

1. **NHS Community Contract** – the ‘standard’ NHS Community Contract were widely used by PCTs, which were keen to move hospices from grant funding to a formal contract. While the contract should have specified the services and volumes being commissioned this was rarely done, which added to the uncertainty over the hospice services that the NHS was directly funding.

2. **Service Level Agreements** – service level agreements (SLAs) were also popular with PCTs. The agreements had varying levels of detail about the services being commissioned, ranging from high-level service objectives to full service specifications and indicators.

3. **Joint funding agreements** – some hospices negotiated a joint commissioning or joint funding agreement with local PCTs, which recognised that the hospices and the PCT jointly funded palliative care services, and that they held shared and separate objectives.

Help the Hospices survey of members highlighted the increasing use of a new NHS Standard Contract by CCGs. Serious concerns exist about the appropriateness and proportionality of the contract for use by commissioners with hospices.

We have raised the concerns of the sector with the Department of Health and NHS England over the past year. Clear guidance was published in December 2013 clearly stating that NHS commissioners do not have to use the NHS Standard Contract if they do not feel that it is appropriate.
Emerging trends

The increased number of ways hospices are funded by the NHS is a key trend but it is also important to note that they are not mutually exclusive. Some hospices, as they have in the past, receive funding in a number of ways.

For example, some services that a hospice provides may be funded with a contract while others might be grant funded. Grant funding continues to be the most common way in which hospices receive NHS funding despite commissioners attempts to disguise such payment as either SLA or an NHS Standard Contract.

Moving forward the complexity of statutory funding for hospices is likely to increase.

- CCGs are may develop more detailed services and volumes specifications, which would be supported by a tariff being established.

- Personal health budget use is expected to increase in palliative care and may ‘cut out’ traditional commissioners leading to the ‘purchase’ of hospice services by their users.

- Local authorities’ role in meeting people’s end of life care needs is growing and may lead to them commissioning more hospice services.
Palliative care funding programme and pilot sites

The palliative care funding programme is working to develop a currency based on data collected by eight pilot sites across England. The data collection exercise includes; phase of illness (Stable, unstable, deteriorating, dying), age, functional status and provider type and setting (Acute and community).

What is a currency?
A healthcare currency is a defined unit of output, activity or healthcare, which is paid for by commissioners. This relies on the ability to accurately define and count the unit of healthcare.

Eight pilot sites were established in 2012 to collect the data. Unfortunately, being called ‘pilots’ has led to the belief that the sites are piloting a new funding system – this has not been the case.

Palliative care funding programme pilot sites
Adult sites are being led by:
- NHS North Yorkshire and York
- St Christopher’s Hospice, London
- University of Sheffield
- University Hospital Southampton NHS Foundation Trust
- The Heart of Kent Hospice
- Poole Hospital NHS Foundation Trust
- Royal Wolverhampton Hospitals NHS Trust

Children’s Consortia site being led by:
- East of England Child Health and Wellbeing Team
- West Midlands Paediatric Palliative Care Network
- Great Ormond Street Hospital, London
- Northwest Children and Young Peoples Palliative Care Network

The work of the PCFP and the pilots is unprecedented. While Australia developed a palliative care tariff for adult services, the PCFP is attempting to develop a palliative care funding system for both adults and children’s services.

Aims

Overall, the three explicit aims of the PCFP and the pilots have been:

1. A case-mix classification system – data capture is essential for developing an understanding of the criteria that best predict the needs of people with palliative care needs and drive costs based on ‘phases of illness’ that occur in a ‘spell of care’. 
2. **National picture** – data capture to better understand the need for palliative care services, resource use and their associated costs.

3. **Fully integrated care at the end of life** – health and social care data capture to inform the proposals for a ‘national choice offer’ and free social care (Originally only health care data was to be collected by the pilots but this was extended to social care data).

The aim is for the pilots to collect 7,000 adult spells and 2,000 children spells across in-patient and community settings by April 2014. The data that will be collected will help the PCFP to develop an NHS currency, which will likely effect voluntary and commercial providers if commissioners adopt the currency.

### What are ‘phases’ and ‘spells’?

A ‘phase of illness’ is a clinical assessment of a person’s condition. The phases of illness of illness include stable, unstable, deteriorating and dying.

A ‘spell of care’ is the period of contact between a provider and a person using its palliative care service in one setting.

A person with palliative care needs may have multiple phases and spells. The data being collected by the pilots will enable the PCFP to understand and compare people’s care journeys.

### Progress

The PCFP and the pilots have made significant progress in meeting their aims since 2012. As of November 2013 the data collection targets for palliative care spells had been fulfilled (See the table below).

<table>
<thead>
<tr>
<th></th>
<th>Inpatient</th>
<th>Community</th>
<th>Total</th>
<th>Target</th>
<th>%</th>
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<tbody>
<tr>
<td>Adult</td>
<td>3,373</td>
<td>3,569</td>
<td>6,942</td>
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<td>99%</td>
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<tr>
<td>Children</td>
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<td>1,123</td>
<td>2,026</td>
<td>2,000</td>
<td>101%</td>
</tr>
<tr>
<td>Total</td>
<td>4,276</td>
<td>4,692</td>
<td>8,968</td>
<td>9,000</td>
<td>100%</td>
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</table>

### Number of palliative care spells (All data provisional and subject to change)

<table>
<thead>
<tr>
<th></th>
<th>Inpatient</th>
<th>Community</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Adult</td>
<td>5412</td>
<td>5431</td>
<td>10843</td>
</tr>
<tr>
<td>Children</td>
<td>1331</td>
<td>1594</td>
<td>2925</td>
</tr>
<tr>
<td>Total</td>
<td>6743</td>
<td>7025</td>
<td>13768</td>
</tr>
</tbody>
</table>

### Number of palliative care phases (All data provisional and subject to change)
The future

Over the coming months the PCFP and pilots will continue to work together to ensure that the data is fit for purpose.

Linking adult social care data with health care data has been a challenge. While some sites have been able to link this data the PCFP will retrospectively link available social care data with other data, wherever possible over coming months.

The PCFP will also be working to validate the data that it has received from the pilots. The validated data will be used to establish a final case-mix classification system or currency, and inform the PCFP’s final report expected in summer of 2014.

NHSE and Monitor are expected to examine and sign-off on proposals. These will lead to a new currency system being established in April 2015, ahead of the General Election.

Timescale

**Nov 2013 - Mar 2014:** Data collection and validation  
**Nov 2013 onwards:** Engagement strategy on PCFP progress and next steps  
**End March 2014:** Pilots finish data collection  
**April-June 2014:** Establish case-mix classification (currency)  
**Summer 2014:** Final data analysis report  
**Autumn 2014:** Monitor/NHS England sign-off currency proposals and policy  
**April 2015:** Establish new currency system  
**April 2015 onwards:** On-going development of currency and pricing

Next steps

The workshops that we held with Together for Short Lives and NHS England highlighted that the sector has many questions that require answering to support readiness for a new funding system. The PCFP and NHSE are working to provide answer to some of these questions and we will update members in due course.

Some of the questions require answers that are dependent upon political decisions for example, whether there will be an increase in the financial envelope for the funding of hospice and palliative care. In turn a larger envelope would determine whether the sector will receive greater statutory funding. Help the Hospices and Together for Short Lives will continue to engage closely with all political parties on this issue.
We also need to recognise that the health and social care system is much more local following the Health and Social Care Act. Commissioners now have greater freedom in how they secure and fund NHS services, and may impact on uptake of what was intended to as a ‘national’ currency or tariff. Again, Help the Hospices and Together for Short Lives will continue to engage with the Government and the NHSE to raise the issue of equitable and sustainable funding for the sector.