

Developing a new approach to palliative care funding: A revised draft for discussion



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Developing a new approach to palliative care funding: A revised draft for discussion

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1 Introduction

1.1 The context of this document

This document sets out the draft palliative care development currency and provides supporting guidance. It has been published to support NHS England's engagement with the palliative care sector, including clinicians, commissioners and providers.

The currency and guidance will continue to be developed until a final draft is published in February.

- **23 October:** First draft published.
- **23 October - 22 November:** Engage sector through written feedback, engagement events and discussions with groups of commissioners and providers.
- **16 December:** Revised draft published – this document.
- **December - January:** Receive written comments on updated draft
- **February:** Publish final development currency

The development currency published in February will not be mandatory and will continue to be tested during 2015/16.

There are two main ways of helping to shape this work:

- *Comment on this document* – please send comments to england.pcf@nhs.net
Comments received by 23rd January 2015 will be fed into the February publication.

As well as comments from individuals and organisations, feedback also is sought from groups of commissioners and providers who already work together. Annex 1 provides more information on this.

- *Express an interest in testing the currency in 2015/16.* After the 2015/16 development currency is finalised further testing will take place, there are different levels of involvement possible.

If you are interested in being part of this testing please email england.pcf@nhs.net

Later in the year, the *2015/16 National Tariff Payment System* will be published for statutory consultation. The palliative care development will not be covered by this package of materials.

This document is in-line with the NHS England and Monitor jointly branded *Reforming the payment system for NHS services: supporting the Five Year Forward View*¹

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https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/381637/ReformingPaymentSystem_NHSEMonitor.pdf

1.2 Purpose

This document reflects comments made by the palliative care sector following the initial publication of the 2015/16 palliative care development currency during our stakeholder engagement. The aim of this document is fourfold:

- To restate the proposed currency model;
- to identify and address some of the main issues raised during our consultation and to outline the areas we will investigate further prior to the February 2015 publication of final draft of the palliative care currency for piloting in 2015/16;
- to outline how organisations can use the currency in support of commissioning palliative care services in 2015/16; and
- To outline the next steps for future development, including plans to engage organisations for further data collection to validate and refine the currency in 2015/16.

2 Project background

Following the publication of the independent Palliative Care Funding Review (PCFR)² in July 2011, a pilot data collection was undertaken to address the lack of robust cost and activity data within the sector. As recommended by the PCFR, the data collected was based upon *phase of illness*. The findings from our pilot data collection supported those made in a similar programme in Australia, further details of which can be found in Annex 2 of this document alongside further project background.

The data collection was undertaken to gather a better understanding of the resources utilised in the provision of palliative care services. 11 pilots gathered detailed palliative care data from 59 provider organisations, gathering over 100 data fields for each phase of a patient's care – the phase being the central characteristic defined within the PCFR. Further details on the pilot data collection and phases of illness can be found at Annex 3 of this document.

In October 2014 the NHS England Pricing Team published the first draft of the palliative care currency for discussion. An open consultation was held via the NHS England website. Seven regional events and two webinars were also held with the palliative care sector to seek views on our initial proposals, to understand other issues that stakeholders felt we might need to consider or test, and to seek the further involvement of the sector with the ongoing development of the currency.

The currency development project is also advised and supported on an on-going basis by a Technical Working Group and a Stakeholder Engagement and Policy Group. The members of these groups come from a wide range of organisations within the palliative care sector and represent different fields of interest within this work; clinical, finance, informatics, policy and academia.

The Pricing Team will be working alongside the National End of Life Care Intelligence Network in the development of a national Palliative Care dataset. This project, led by Public Health England (PHE) will pilot the dataset with palliative care organisations around the country throughout 2015/16. It may therefore be possible for organisations to participate in both exercises. Efforts will be made to align these two workstreams to reduce the burden for participants.

Throughout the continued development of the palliative care currency, work will be undertaken to align the palliative care currency work with wider payment strategy, government policy, and palliative care sector developments.

²https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/215107/dh_133105.pdf

3 Healthcare currencies

3.1 Understanding Currencies

3.1.1 What is a currency?

In the context of healthcare a currency is made up of consistently identified units of care that can be used as the basis for payment between commissioners and providers. Currencies can take different forms; for example they can be based upon a specific procedure having taken place, the time period over which a patient would be treated for a condition, or an appointment during which a patient receives treatment for an illness or diagnostic tests are carried out.

In a care intervention such as a tonsillectomy, the resources used (staff, equipment, location and consumables such as dressings and drugs) are similar, so a tonsillectomy can be defined within a unit of currency which will differ from other units of currency, such as a coronary artery bypass graft.

Each unit of currency is a defined grouping of healthcare provision with broadly similar resource usage. This requires that they are evidence based and analytically identifiable, but also it is imperative that the units are clinically meaningful – that they are rooted to the care the patient receives and are therefore reasonable and practical to implement. For the palliative care currency the driving principle was that the units of currency reflect patient need.

Palliative care has different challenges to much of acute care, so an approach based on procedures is not appropriate. It is more akin to some of the pathway currencies that we have implemented elsewhere, such as the 21 mental health care clusters. Clinicians identify the needs of people coming into mental health services using a tool based on HoNOS³ and through using the tool people are allocated to the cluster that best meets their needs. Each cluster has a maximum review period within which a person must be reassessed.

The palliative care currency presented in this document is based on the needs of the patient rather than the procedures performed. The evidence base underlying the development of the currencies is a rich dataset collected during the pilot data collection.

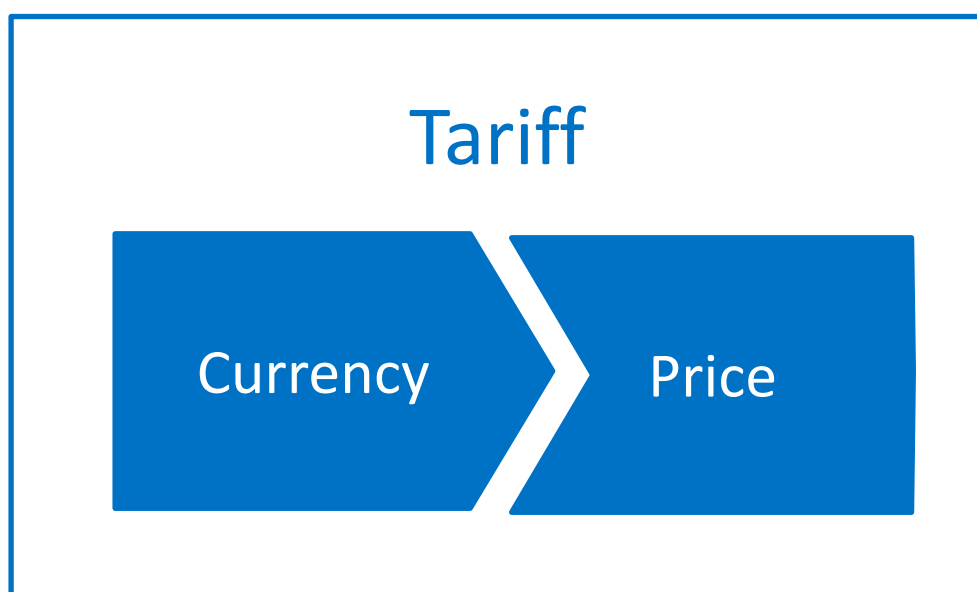
3.1.2 What a currency is not

The word currency is often confused with the word tariff, however these two terms are not interchangeable. A tariff can only be developed once there is a consistently recognisable and identifiable currency in place. When a currency is consistently utilised by the sector, and robust information collected on the basis of the currency, then a price can be attached.

³ Health of the Nation Outcomes Scores (HoNOS)

Where a price is agreed upon for a currency between a commissioner and provider in a local health economy, this is known as a local price. Where a currency and price are published by NHS England and Monitor within the National Tariff Document, this is a national tariff.

An example of a national tariff is for a, tonsillectomy carried out on an adult patient. For 2014-15 the national tariff is £1071. This is the basic payment made by the commissioner for tonsillectomies undertaken within the financial year, subject to agreements on expected levels of activity, and the application of a market forces factor which reflects those costs over which a provider does not have full control and which relate to its particular geography⁴.



3.2 Use of Currency

3.2.1 How are currencies used?

Currencies provide a consistent and transparent vocabulary for commissioners and providers to use when commissioning activity. When a currency unit is assigned a price they can be used to calculate funding for providers for delivering any particular service. When a national price is placed upon a currency, this is referred to as a tariff. The development currency available for 2015/16 has no national prices associated with it, as we are still testing the model.

As well as providing a standard basis for payment, the use of currencies can result in a better understanding of the patient populations that providers serve and can be a path towards better understanding of the costs incurred in treating patients.

For providers and commissioners, the use of currency and the resultant information can be used to ensure that the service provided matches the needs of patients in a local health economy, and to design services to ensure that the money spent

⁴ <https://www.gov.uk/government/publications/guide-to-the-market-forces-factor-201415>

provides best value for the patient population and reimburses providers fairly for the work they do.

3.2.2 Why use a currency?

The PCFR found that the lack of transparency in the current palliative care payment system meant that providers were not incentivised to care for more patients as services were purchased via a block contract regardless of the level of activity. The lack of transparency makes evidence-based discussions on how best to deliver services difficult, and has led to wide variations in the level of funding and access to palliative care services.

The palliative care currency aims to support a fair and transparent discussion between commissioners and providers about the funding requirements for these patients. This is particularly useful where service transformation is being considered, as it allows open, evidence-based, discussions on appropriate changes to funding as services adapt. This allows providers to be fairly reimbursed where they take on extra responsibility and commissioners to ensure that the services they are purchasing are cost-effective.

A currency provides the essential foundation for creating a more transparent system. The palliative care currency is intended to provide (but is not limited to) the following benefits:

- **Providers** greater clarity on the services required and confidence in the level of anticipated funding in future years, allowing better planning, innovation and workforce development
- **Commissioners** an evidence-based framework for commissioning, supporting them to drive quality and efficiency the quality of the services commissioned and greater equity in provision

The development currency for the palliative care sector will not impact on the proportion of palliative care funding which is generated from charitable donations.

For organisations who want to work with us and test using the currency during 2015-16, the benefits are likely to reflect those reported to us by those organisations who participated in the original pilot data collection. They reported that using the currency provided an evidence base upon which to make decisions about service provision and for discussions with service commissioners. Sites also reported that continued use of terms such as phase of illness has aided in predicting patient need and co-ordination of care.

4 The palliative care development currency

4.1 Analysis and currency derivation

4.1.1 Aim

The palliative care development currency is a first attempt to create a set of currency units that are suitable for use across all organisations providing palliative care in England, whether to adults or children. The currency units have been defined using data collected through the Palliative Care Funding Pilots (PCFP) and aim to describe differences in the complexity of a person's palliative care need and the associated costs of providing care. In effect, the currency is a casemix classification that provides the building blocks by which palliative care activity and resource use can be measured.

4.1.2 Defining currency units

The funding pilots collected detailed data on casemix and the cost of delivering care for different 'phases of illness'. These phases are described in Table 1. Data were collected from acute, hospice and community settings. For inpatient settings, care was provided by specialist palliative care teams. For community settings, all patients identified as having a palliative need were included in the data collection and all palliative care provided to that patient was recorded. This included palliative care provided by district nurses, who often lead the provision of care in community settings. However, care delivered or led by GPs was not included.

The palliative care development currency was developed by identifying the casemix variables and patient attributes in the PCFP dataset that were associated with variations in the direct cost⁵ of palliative care (for the inpatient category overhead costs⁶ such as bed costs and laundry costs incurred during the patient stay – known as hotel costs – were also collected). Descriptive statistics were used to assess consistency of interpretation of casemix variables, most notably phase of illness, across pilot sites and different types of provider.

Variables identified as a 'cost driver' were then used to group the data in such a way that phases of care within each group had a similar direct cost. These groupings were further refined to form currency units that were defined by variables that were measurable and clinically meaningful. Analysis was undertaken separately for adults and children.

As decisions regarding funding mechanisms are yet to be finalised, resource use associated with each currency unit was analysed on both a per diem and phase basis, giving the option to use either payment approach, or a combined 'blended' model, for funding palliative care services.

⁵ *Direct costs* are those that relate directly to the delivery of patient care, for example nursing time, medical time, etc.

⁶ *Overhead costs* are the running costs of an organisation which cannot be linked to an individual patient, such as the costs of cleaning staff. Overhead costs are apportioned across patients at an aggregate level.

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The process of identifying potential currency units was guided by the following 'design rules':

- As far as possible, currency units reflected variations in the complexity of palliative care need, rather than provider type
- The currency *minimised* direct cost variation *within* each unit and maximised direct cost variation between units
- Variables used to define each currency unit needed to be measurable, clearly defined and clinically meaningful
- The set of variables used to derive currency units was as consistent as possible across different types of provider to facilitate the development of a single minimum dataset for palliative care
- Within each provider category (e.g. adult acute inpatient or adult community), the variation in cost ratios for currency units was similar across providers, irrespective of differences in service models, overall funding and ways of working

Although the currency units, as far as possible, describe differences in a person's palliative care need, the large variety of organisations providing palliative care, and the wide range of settings in which care is delivered, has meant that we have provided currency units separately for acute inpatients, hospice inpatients and 'community' settings (a broad category encapsulating a range of non-inpatient services).

To facilitate the development of a single minimum dataset for palliative care the set of variables used to derive currency units is as consistent as possible across different types of provider.

For adults, 'phase of illness' was a cost driver across all types of palliative care provider. In an acute inpatient setting, differences were also observed between patients with a single diagnosis and multiple diagnoses and where a patient was aged 74 and under, or 75 and over. For hospice inpatient and community settings, functional status (grouped into high, medium and low) was also associated with variations in direct costs.

For children, age was a key driver of variations in direct costs. 'Phase of illness' was also associated with direct costs, as was 'physical severity' (grouped into high, medium and low). Diagnosis had a complex relationship with cost variations but has not been included as a variable in the development currency for children at this stage.

4.1.3 Palliative care development currency units

A total of 28 development currency units are identified for adults and 28 units for children. Currencies are grouped into three ‘provider categories’: acute inpatients, hospice inpatients and community providers. See figure 4A.

Figure 4A: Palliative Care Development Currency (version 1.0)

ADULTS			CHILDREN		
Currency unit	Phase	Other	Currency unit	Phase	Age group /other
Adult Acute Inpatient			Children Acute Inpatient		
AW_1	Stable	1 diag	CW_1		<1
AW_2	Stable	1+ diag <75yrs	CW_2		1-4
AW_3	Stable	1+ diag 75+yrs	CW_3	Stable	5-9
AW_4	Unstable	1 diag	CW_4	Unstable	5-9
AW_5	Unstable	1+ diag	CW_5	Det/dying	5-9
AW_6	Deteriorating	1 diag	CW_6	Stable	10+
AW_7	Deteriorating	1+ diag, <75 yrs	CW_7	Unstable	10+
AW_8	Deteriorating	1+ diag, 75+ yrs	CW_8	Det/dying	10+
AW_9	Dying	1 diag			
AW_10	Dying	1+ diag			
Adult Hospice Inpatient			Children Hospice Inpatient		
AH_1	Stable	Low function	CH_1		<1
AH_2	Stable	Med/high function	CH_2		1-4
AH_3	Unstable	Low function	CH_3	Stable	5-9
AH_4	Unstable	Med/high function	CH_4	Unstable	5-9
AH_5	Deteriorating	Low function	CH_5	Det/dying	5-9
AH_6	Deteriorating	Med/high function	CH_6	Stable	10+
AH_7	Dying	Low function	CH_7	Unstable	10+
AH_8	Dying	Med/high function	CH_8	Det/dying	10+
Adult Community			Children Community		
AC_1	Stable	Low function	CC_1	Stable	Low phy severity
AC_2	Stable	Med function	CC_2	Stable	Med/high phy severity
AC_3	Stable	High function	CC_3	Unstable	<1
AC_4	Unstable	Low function	CC_4	Unstable	1-4
AC_5	Unstable	Med function	CC_5	Unstable	5-9
AC_6	Unstable	High function	CC_6	Unstable	10+
AC_7	Deteriorating	Low function	CC_7	Deteriorating	<1
AC_8	Deteriorating	Med function	CC_8	Deteriorating	1-4
AC_9	Deteriorating	High function	CC_9	Deteriorating	5-9
AC_10	Dying		CC_10	Deteriorating	10+
			CC_11	Dying	0-9
			CC_12	Dying	10+

4.2 Data items

4.2.1 Initial currency design

Definitions for the data items used to construct the palliative care currency units (version 1) are outlined below.

Phase of illness: Phase of illness was predicative of resource usage across all provider types for both adults and children. Phase of illness is based upon the clinical assessment of both a patient's condition *and* family/carer circumstances against the criteria outlined in Table 1. It is important to note that the patient and family/carer circumstances are treated as a single unit of care. A significant change impacting the family/carers of the patient could, by itself, trigger a change in the patient's phase of illness.

A patient may have numerous phases of care within a spell of care (each period of contact between a patient and a palliative care service provider or team of providers that occurs in one setting). One phase ends and another begins when a clinical decision is made that the patient has moved between one of the four phases of illness – Stable, Unstable, Deteriorating, Dying.

Phase of illness was developed as a clinical measure in Australia and has recently been validated as a reliable and acceptable measure that can be used for palliative care planning, quality improvement and funding purposes.⁷

Table 1 below contains the updated versions of the definitions from this study; the definitions differ very slightly from those used in the pilot data collection..

Table 1 - Phase of illness criteria

Start of phase	End of phase	For example
<p>Stable: Patient problems and symptoms are adequately controlled by established plan of care and</p> <ul style="list-style-type: none"> Further interventions planned to maintain symptom control and quality of life and Family/carer situation is relatively stable and no new issues are apparent 	<p>Stable:</p> <ul style="list-style-type: none"> The needs of the patient and or family/carer increase, requiring changes to the existing care plan (ie the patient is now unstable, deteriorating or terminal) 	<p>Symptoms and other concerns are well controlled and stable. Family carers are aware of how to access support in the event of change.</p>
<p>Unstable: An urgent change in the plan of care or emergency treatment is required because</p> <ul style="list-style-type: none"> Patient experiences a new problem that was not anticipated in the existing plan of care, and/or Patient experiences a rapid increase in the severity of a current problem; and/or 	<p>Unstable:</p> <ul style="list-style-type: none"> The new care plan is in place, it has been reviewed and no further changes to the care plan are required. This does not necessarily mean that the symptom/crisis has fully resolved but there is a clear diagnosis and plan of 	<p>Symptoms and overall condition need regular review because they are unpredictable and at risk of worsening quickly. Informal carers need additional support as condition is unpredictable.</p>

⁷ Masso et al (2014) 'Palliative Care Phase: Inter-rater reliability and acceptability in a national study', *Palliative Medicine*, <http://pmj.sagepub.com/content/early/2014/09/22/0269216314551814>

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<ul style="list-style-type: none"> Family/ carers' experience changes which impact on patient care 	care (ie the patient is now stable or deteriorating) and/or <ul style="list-style-type: none"> Death is likely within days (ie patient is now terminal) 	
<p>Deteriorating: The care plan is addressing anticipated needs but requires periodic review because</p> <ul style="list-style-type: none"> Patient's overall function is declining and Patient experiences an anticipated and gradual worsening of existing problem and/or Patient experiences a new but anticipated problem and/or Family/carers experience gradual worsening distress that is anticipated but impacts on the patient care 	<p>Deteriorating:</p> <ul style="list-style-type: none"> Patient condition plateaus (ie patient is now stable) or An urgent change in the care plan or emergency treatment is required and/or Family/ carers experience a sudden change in their situation that impacts on patient care, and requires urgent intervention (ie patient is now unstable) or Death is likely within days (ie patient is now terminal) 	Symptoms and overall condition are gradually worsening, but in an anticipated way. Informal carers may need pre-emptive support to facilitate on-going care
<p>Dying: Death is likely within days</p>	<p>Dying:</p> <ul style="list-style-type: none"> Patient dies or Patient condition changes and death is no longer likely within days (ie patient is now stable, or deteriorating) 	Prognosis is assessed to be hours or days Review and re-assessment is frequent (daily or more than daily contact)

Physical severity: It is recognised that palliative care providers may use different measures of pain and problem severity, but for the purposes of the development currency a 0-3 point scale for 'pain' and 'other physical problem severity' should be used respectively: 0 (Absent); 1 (Mild); 2 (Moderate); 3 (Severe). The PCFP dataset included variables on 'pain severity' and 'other physical problem severity'.

From the PCFP data, a combined physical severity score was derived by adding the scores of each variable (giving a severity scale ranging from 0-6) which, when grouped into three categories of low (0-2), medium (3-4) and high (5-6), was predictive of direct costs for some palliative care phases for children.

Number of diagnoses: The number of diagnosed conditions a patient has presented with should be recorded. In the adult dataset there was significant variance in costs between patient phases where multiple diagnoses had been recorded, and those patients with a single diagnosis.

Age: For the development currency, five age groups are used for children (<1, 1-4, 5-9, 10-14 and 15-19 years). For adult acute inpatient settings, age groups (under 75 years and 75 years and above) have been identified. Age was a strong predictor of direct palliative care costs for children and for some phases of illness in adults.

For both children and adults, it would be preferable if age was reported by year rather than by age group to permit further testing of the most appropriate age groups to use for a palliative care currency.

Functional status: As the pilot data collection was informed by the PCFR the modified Karnofsky scale was utilised. It is recognised that different scales are used across the country; therefore a global low-medium-high functionality scale has been employed for the currency. This scale should allow for interaction between any functional status stratifying tool used locally and the new currency. Table 2 below illustrates the mapping between the Karnofsky scale and the global scale used for currency development, it is expected that similar mappings would be possible for other locally used tools.

For the palliative development currency, functional status is grouped into three categories of low (0-30%), medium (40-60%) and high (70-100%) functional status.

Table 2 – Mapping from Modified Karnofsky Scale to functional status as used during currency development process

Mapping	Status Score	Descriptor
HIGH	100%	Normal no complaints; no evidence of disease.
	90%	Able to carry on normal activity; minor signs or symptoms of disease.
	80%	Normal activity with effort; some signs or symptoms of disease.
	70%	Cares for self; unable to carry on normal activity or to do active work.
MEDIUM	60%	Requires occasional assistance, but is able to care for most personal needs.
	50%	Requires considerable assistance and frequent medical care.
	40%	In bed more than 50% of the time.
LOW	30%	Almost completely bedfast
	20%	Totally bedfast and requiring extensive nursing care by professionals and/or family
	10%	Comatose or barely arousable
	0%	Dead

4.2.2 Refining the currency units

The palliative care development currency reflects our initial grouping of casemix and patient variables that were found to be most strongly associated with variations in direct palliative care costs. We will be looking at further refinement following the piloting of the development currency in 2015/16. Stakeholders have raised a number of issues with us that we would like to explore through the piloting process.

For example:

- For children, 'diagnosis' and 'physical severity' also had some predictive power and there may be advantages in collecting these data items during the piloting of the 'development currency'
- For adults in an acute inpatient setting, there may be more appropriate measures for capturing complexity of need than distinguishing between patients with a single diagnosis and those with multiple diagnoses.
- A need for further understanding in the most appropriate categorisation of providers

See section 5 for our proposals on testing the currency during 2015/16.

4.3 Scope of care covered

4.3.1 The currency model

The initial design of the currency reflects the elements of care recommended for inclusion by the PCFR:

Everybody

- Assessment
- Coordination of care
- Clinical care to include all medical care, nursing care and rehabilitation support
- Pre-bereavement assessment

Children and young people only

Short breaks for clinical monitoring or adjustments to care

The report recommended that drugs and pharmacy services should not be included in the palliative care currency, and that they should continue to be funded as they currently are. Where drugs are already separately funded whether using the National Tariff Payment System or local arrangements, we would expect these to continue. Any drugs that are currently within block or activity based local arrangements for palliative care should also be considered for separate funding, to ensure the total cost of these drugs is recovered.

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Within hospitals, other treatment costs will continue to be funded as they currently are; the palliative care currency will just provide a top-up to cover specialist palliative care needs.

The decision on what was included in the analysis to create the currency is not a decision on what should and should not be funded by the state. Decisions on the state's responsibility for funding palliative care will need to take place and will include the Department of Health.

5 Future development of the currency

5.1 Using the currency for commissioning 2015/16

5.1.1 Establishing the evidence base in 2015/16

The 2015/16 development currency for palliative care is the first attempt to create a currency for palliative care that is suitable for use in England. The currency is not mandatory; it is for commissioners and both NHS and non-NHS palliative care providers to decide whether and how to use the currency during 2015/16.

The model used when there is a national currency, without national prices, involves commissioners and providers setting local prices for each currency unit. Providers are then reimbursed for their activity based on these prices. The National Tariff Document contains a set of rules which must be used in setting local prices. Adherence to the rules can be enforced by Monitor.

In reality most economies will not have developed local prices for 2015/16. We suggest that organisations wanting to test out the currencies in 2015/16 use 2015/16 as a baseline year, paying for palliative care as previously, but monitoring how much care was provided by each provider with whom they have a contract, and how the care was split by unit of currency. This could make it possible to introduce local prices in 2016-17. If not, it may at least allow discussions to be had on whether the relative payments made to different providers are reasonable and whether the value of a block contract should be amended if activity changes.

5.1.2 The need for further data

In order to make use of the currency, it will be necessary to collect some activity data. The Pricing Team proposes working with organisations to collect data to support the wider development of the currency. This will help to validate and refine the currency units, but help us to test the potential data gaps which were identified through the engagement process.

A national dataset is also being developed by Public Health England, more information can be found in Annex 4. Those wishing to pilot the currency are likely to be able to also take part in the pilot data collection for the new dataset.

Specific issues we want to investigate further

Comorbidity + Acuity

A patient's co-morbidity is a reflection of other conditions which may impact upon their health and wellbeing. During the analysis of the data collected and during the development of the currency there was statistical significance within the variance of costs and resource usage between patients reported as having no comorbidities and those reported as having multiple diagnosed illnesses.

Feedback from the engagement events suggested that the severity of illness and the compounded complexity of multiple diagnoses may have an effect on the cost profile for a specific patient. The problem severity data collected during the initial data

collection were not a significant driver of cost in most cases. Further data collected on severity will be key to investigating this further.

Transition

Throughout the regional events there were discussions about the handling of service users transitioning between child and adult services. As the data gathered on this area during the original pilot data collection was not of sufficient size to ensure significant analytical results we are looking to the ongoing work to provide greater data in this area.

Several topics relating to transition have been identified through the engagement events and in 2015/16 the Pricing Team will look to ensure the requisite data is collected to support further development in this area. Additional data will be key to understanding the issues and challenges in this area, however this is likely to support wider work ongoing in this area.

Day hospice

In the initial draft model, day hospice and hospice outpatients services were included within the Community currencies. Following feedback from service providers, consideration will be given to alternative models as appropriate.

5.2 Developing the currency for 2015/16 and beyond

5.2.1 Engagement process following previous publication

In autumn of 2014 the NHS England Pricing Team held seven regional engagements events to introduce the currency to the palliative care sector and to ask for continued participation through use of the development currency. These events began the next stage of development of the currency.

A vast amount of feedback was provided by those who attended the events or participated in the webinars. This feedback will be analysed and taken into consideration for the finalised draft currency for use in 2015/16.

5.2.2 Ongoing development work

To build upon the work already undertaken, and to continue the dialogue between the Pricing Team and the sector in developing the currency, organisations will be asked to contribute to further refinement of the currency model over the next couple of months to ensure its clinical relevance and feasibility, and to finalise a model which can be piloted by organisations during 2015/16. The results of this continued engagement will be the publication of this finalised model in February 2015.

If you are interested in helping us test the currency in 2015/16 please contact us on england.pcf@nhs.net. Several different levels of involvement are possible.

Annex 1: Feedback from groups of organisations

As part of testing the palliative care development currency we are interested in the views of commissioners and providers who are already work together to improve the provision of palliative care. Ultimately a currency is meant to support the commissioning discussion, so we think it would be particularly valuable to get this shared perspective on our currency development. It will provide a view that it is not possible to get from comparing separate commissioner and provider feedback. We would like commissioners and providers who work together to read the document and discuss their views before feeding back to NHS England.

We do not want to be prescriptive about exactly how this is carried out. Some areas are looking at discussing the guidance at regular network meetings, some are meeting specifically to discuss the document and email discussions have been suggested.

Joint feedback can be sent in writing. If it easier to provide feedback over the phone, or you would like one of our team to listen to the discussion please contact us on england.pcf@nhs.net

Annex 2 - Project background

Per patient funding for palliative care

In summer 2010, the Secretary of State for Health commissioned the independent Palliative Care Funding Review (PCFR) to investigate the existing palliative care provision in England. The review was asked to make recommendations for a new funding system for palliative care, which would be fair to all providers, encourage more community-based care and support choice by care users of provider and location. The review published their final report in 2011.

The report recommended that a number of pilots were set up to gather the data and information needed to take the work forward. This data collection has now closed after running for two years and work is beginning to construct a currency upon which to base a new funding system.

Project Governance

In order to support the development of a currency and funding system, the project is overseen by an Executive Steering Group (ESG). The ESG provides the decision making to enable the NHS England Pricing team to develop a new funding system for palliative care.

The main focus of this group is to ensure the delivery of a currency and payment system for palliative care supporting a needs-based, per-patient funding system for those who need it through effective decision making and ensuring appropriate top-level engagement.

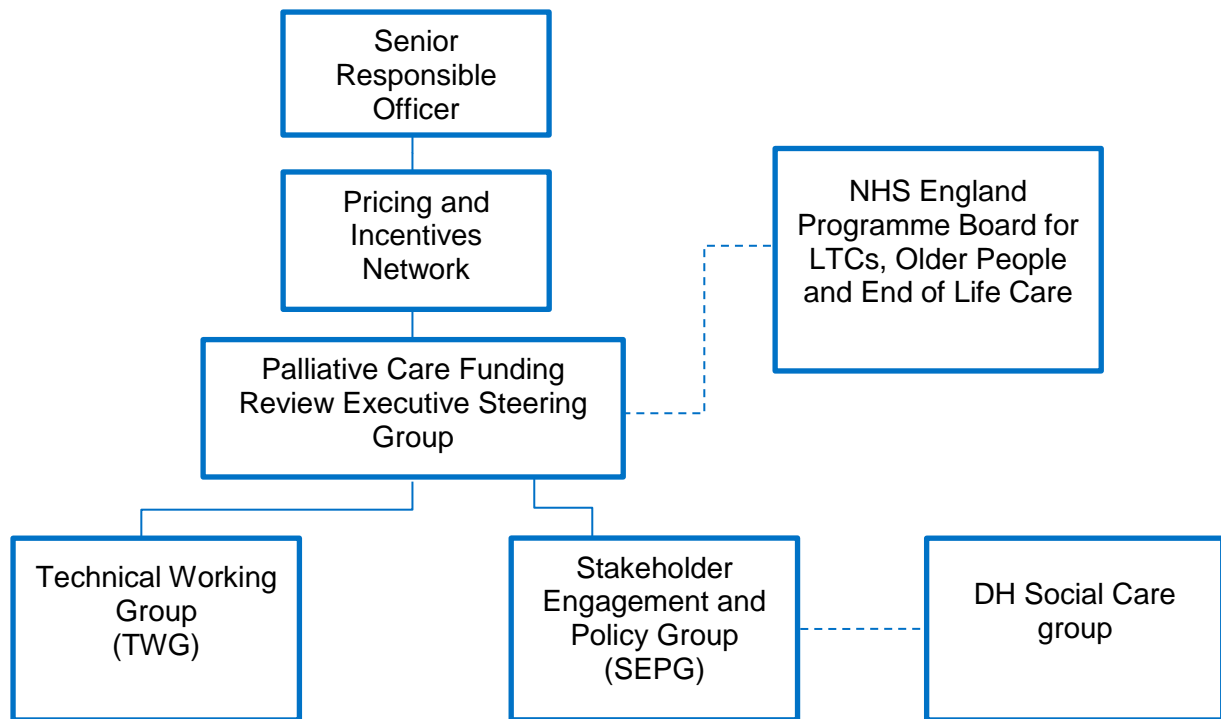
The core membership of the ESG is comprised of:

The National Clinical Lead for End of Life Care (Dr Bee Wee); Head of the NHS England Pricing Team (Martin Campbell); Department of Health's Assistant Director for Social Care (Sebastian Habibi); Pricing Development Manager at Monitor (Sadaf Dhalabhoy); Chair of the SEPG (Dr Teresa Tate); Chair of the TWG (Dilwyn Sheers), with analytical and administrative support from the Palliative Care Funding Team within the NHS England Pricing Team.

The group is advised by the Technical Working Group (TWG) and Stakeholder Engagement and Policy Group (SEPG). Both groups are comprised of memberships from across the palliative care sector with representatives from NHS organisations, data pilot organisations, hospices and hospice charities, Monitor, the National Casemix Office, the National Council for Palliative Care, research organisations. These individuals contribute invaluable advice and guidance on the work being undertaken by the NHS England Pricing team across clinical, informatics, finance and academic perspectives on behalf of the wider palliative care sector.

Diagram 2A below illustrates the governance structure.

Diagram 2A – Project Governance Structure



Independent Review of Palliative Care

The PCFR published its final report in July 2011, this set out a series of significant proposals and recommendations designed to create a fair and transparent funding system for palliative care.

The review identified some major issues for any funding system:

- It is estimated that in excess of 90,000 people have unmet palliative care needs;
- The significant challenges facing any undertaking to develop a palliative care currency which covered both adults and children, , as no such system is in use for children’s palliative care anywhere in the world and
- There was a lack of quality data surrounding the cost of palliative care at a national level.

The PCFR also stated that the introduction and implementation of a funding system should be cost neutral to the sector.

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

From the Palliative Care Funding Review

To introduce a tariff for a service requires a consistent and agreed unit upon which to base the tariff.

A currency is the unit of health care upon which a tariff is based. In 2011 the Secretary of State for Health agreed with the recommendation for a pilot collection of more detailed data about the services delivered as part of palliative care and the costs of those services.

The Australian Model

The recommendations around developing a currency model based on phase of illness came from looking at the model utilised in Australia under the Australian National Sub-Acute and Non-Acute Patient classification⁸ (AN-SNAP). The PCFR identified the similarities between British and Australian palliative care need. The ANSNAP model identified the key cost drivers for palliative care to be phase of illness, age, functional status and severity of problem. From these variables a classification system comprised of 11 in-patient classes and 22 classes for non-admitted patients was developed, and these classifications form the basis of per-patient funding.

⁸ http://ahsri.uow.edu.au/Publications/pre2001_pubs/snapstudy1997.pdf

Annex 3 - Currency Development

Pilot data collection for palliative care

Background to the pilot collection

The PCFR published its final report in July 2011. It set out a series of significant proposals and recommendations designed to create a fair and transparent funding system for palliative care. The report recommended that a pilot data collection was set up to gather the data and information needed to take the work forward. This data collection was undertaken by the Department of Health in 2012 and was transferred to NHS England prior to completion in May 2014. NHS England has begun the analysis on the collected data.

Alongside the aim of gathering the data required to better understand the national picture for palliative care need, the pilot aimed to achieve further goals, primarily the development of an understanding of the criteria which best defined patient need and the associated cost drivers.

The scope of the pilots covered all activity and the associated costs in the delivery of specialist and generalist palliative care provided in acute and community settings based upon the definition for palliative care that is set out on the National Council for Palliative Care (NCPC) website.

Palliative care is provided by two distinct categories of health and social care professionals:

- Those providing the day-to-day care to patients and carers in their homes and in hospitals
- Those who specialise in palliative care (consultants in palliative medicine and clinical nurse specialists in palliative care, for example)

Those providing day-to-day care should be able to:

- Assess the care needs of each patient and their families across the domains of physical, psychological, social spiritual and information needs
- Meet those needs within the limits of their knowledge, skills, competence in palliative care
- Know when to seek advice from or refer to specialist palliative care service.

From the National Council for Palliative Care website <http://www.ncpc.org.uk/palliative-care-explained>

As an initial collection of data intended to collect as comprehensive a picture of palliative care as possible over 100 data fields were identified. This information was grouped into 13 sections within the collection template including information on the provider, the patient, activity undertaken, tests and imaging alongside the details of

the patient's condition, primarily the severity of their condition and their phase of illness.

A major focus of the pilot data collection was to capture the activity and associated costs of all palliative care provision within a pilot area, provided in both acute and community settings and for both adults and children by NHS and non-NHS providers. Through this collection NHS England was able to gather the required data to test the recommendations of the Palliative Care Funding Review and enable the development of a per-patient palliative care funding system.

Pilot locations

The pilots covered a population of around 5.4 million people, distributed across six different regions in England: Yorkshire and the Humber, South East, London, South Central, South East Coast, South West and the West Midlands.

Each of the seven adult pilot areas were led by staff at lead organisations:

- 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 NHS Trust

The seven adult pilot areas involved a total of 54 organisations, including 19 hospitals, 13 voluntary sector providers, 11 CCGs, five Local Authorities, two nursing home providers, two community health trusts, one university and one health and social care partnership trust.

The pilot area for children's palliative care services was a consortium being led by the following organisations:

- East of England Child Health and Wellbeing Team
- West Midlands Paediatric Palliative Care Network
- Great Ormond Street Hospital
- Northwest Children and Young Peoples Palliative Care Network

The children's pilot, involved 39 organisations, including hospitals, voluntary sector providers, commissioners, community health trusts, a university and children's palliative care networks.

The basis for the collection

The pilot sites were issued with a collection template in Microsoft Excel format to input data on the basis of *phases of care* which can be aggregated into *spells of care*.

Phases of illness are based upon the assessment of the patient's condition against the criteria outlined in table 3. As the patient moves between two criteria a new phase of care is recorded. Over 100 data fields were available against each phase of

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care allowing the recording of comprehensive resource use/cost information utilised in the care of a patient at any point during their care.

A *spell of care* is built from one or more phases of care which are given to the patient by a provider in a single setting, whether this be the patient's home, a hospital or hospice.

The examples below illustrate how spells and phases interact. For patient A, the number of phases is triggered by the change in the patient's condition or that of family/carers, however as the patient is cared for by a single provider, only a single spell of care is generated.

Patient A

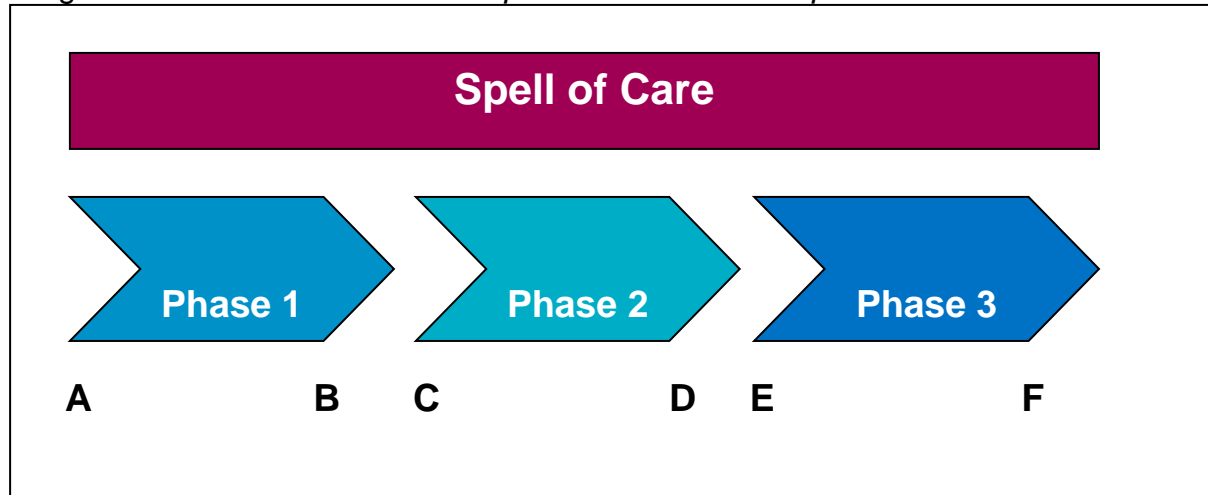
Phase Start	Phase End	Phase Identifier	Provider	Spell
Stable	Unstable	1	Hospice A	A1
Unstable	Stable	2	Hospice A	A1
Stable	Deteriorating	3	Hospice A	A1
Deteriorating	Dying	4	Hospice A	A1

For patient B a number of phases are triggered by change in the patient's condition or that of family/carers, in this example, as there are changes to the care setting in phases 2, 3 and 4, new spells are generated at the end of each phase. As phases 4 and 5 occur in the same setting they occur within 1 spell of care.

Patient B

Phase Start	Phase End	Phase Identifier	Provider	Spell
Stable	Stable	1	Hospital A	B1
Stable	Deteriorating	2	Hospice B	B2
Deteriorating	Stable	3	Hospital A	B3
Stable	Deteriorating	4	Hospice B	B4
Deteriorating	Dying	5	Hospice B	B4

Diagram 3A – Interaction between *phase of illness* and *spell of care*



In Diagram 3A, point A could represent the initial contact between patient and provider at which point the patient is assessed as in a stable phase of illness, which concludes at point B. Point C identifies that the patient has begun to deteriorate, this phase of care concludes at point D. At point E the patient has begun the dying phase of illness which concludes at point F.

These three phases all take place within a single provider and are therefore a single spell of care.

The collected data

A target of 9000 spells of care was set for the pilot data collection. Table 7A shows the spells collected against target and table 7B shows the phases of illness collected against provider type.

Table 7A – Spells submitted by provider type against target

	Total	Target
Adult Providers	10380	7000
Child Providers	2123	2000
Total	12503	9000

Table 7B – Phase of illness by provider type

	Total
Adult Providers	16021
Child Providers	3557
Total	19578

This data has been used to inform the development and refinement of a classification system categorising palliative care patients based on the level of patient need, the phase of their illness, resource usage and costs of the service provision.

The inclusion of social care data in the collection

In 2013 the decision was taken to append the collection of social care data to the health data being submitted by pilot organisations. This was to support a better understanding of the whole picture of costs across health and social care with regards to palliative care and as a horizon scan for the future aims of linking health and social care into a single funding mechanism and providing free social care at the end of life. While the pilot data collection was utilised to provide this data it remains a separate workstream from the development of a new payment system for palliative care.

The work to investigate the costs of free social care at the end of life is the responsibility of the Department of Health and is not a component of the currency development work being undertaken by the NHS England Pricing Team.

Annex 4 - Palliative care data

Sources of palliative care data

A national dataset for palliative care

Currently a standard national dataset for palliative care does not exist. Public Health England (PHE) and NHS England are working together to develop such a dataset. This will develop in parallel with the work on the new payment system – they are separate but closely related workstreams.

The Pricing Team will be working alongside the National End of Life Care Intelligence Network, part of PHE as they define a national palliative care dataset. This will include the minimum data items which currently define the currency.

It is likely that further refinement is possible using the variables currently proposed for defining currency units.

NCPD Minimum Dataset

The National Council for Palliative Care collects the Minimum Data Set (MDS) for Specialist Palliative Care Services annually, providing the only data available nationally which covers patient activity in specialist services in the voluntary sector and the NHS in England. The data are also collected from Wales and Northern Ireland.

While this is a rich source of data, the granularity required for the development of a new currency and payment system for palliative care is not available.

Annex 5 - Summary of Changes

Chapter	Section	Subsection	Update	Page
1 Introduction	1.1 Context of this document	-	Updated to reflect the work of the engagement process	5
	1.2 Purpose of guidance	-	Updated to reflect the revision of the document	6
2 Project Background	-	-	Updated to reflect the work undertaken since the previous publication	7
3 Healthcare Currencies	3.1 Defining a currency	3.1.1 What is a currency	Updated to reflect feedback from the engagement process	8
		3.1.2 What a currency is not	Additional information to reflect feedback from the engagement process	8 + 9
	3.2 Use of currency	3.2.2 Why use a currency	Updated with additional information to reflect feedback from the engagement process	10
4 The palliative care development currency	4.1 Analysis and currency derivation	4.1.2 Defining currency units	Additional information to reflect feedback from the engagement process	11
		4.1.3 Palliative care development currency units	Additional information on the analysis	13
	4.2 Construction	4.2.1 Data Items	Additional information	14

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	of the currency		around the interaction between phases of illness and carers	
		4.2.2 Refining the currency units	Additional information on identification of secondary variables	17
5 Future development of the currency	5.1 Using the currency for commissioning 2015/16	5.1.2 The need for further data	Updated to reflect issues identified by the engagement process	19
	Developing the currency for 2015/16 and beyond	5.2.1 Engagement process following previous publication	Updated to reflect issues identified by the engagement process	20
		5.2.2 Ongoing development work	Updated to reflect issues identified by the engagement process	20