

# Developing a new approach to palliative care funding



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## 1 Introduction

### 1.1 The context of this document

This document presents the 2015/16 palliative care development currency.

The currency is a first attempt to group specialist palliative care into packages of care that are similar in terms of resource need and clinical input. The currency is not mandatory and will be further tested and refined during 2015/16. The aim is that it will provide a meaningful tool to support service planning and commissioning.

Section 2 provides some background to the project. Section 3 is an overview of what a currency is and how they are used, while section 4 explains the currency and how it was developed. Section 5 outlines briefly plans for developing the currency in 2015/16.

## 2 Project background

Following the publication of the independent Palliative Care Funding Review (PCFR)<sup>1</sup> 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 1 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. In total, 11 pilots gathered detailed palliative care data from 93 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 2 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, as well as 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. A second draft of the palliative care currency was published in December 2014 for further written comment. This document is the final draft of the 2015/16 development currency and will be tested further during 2015/16.

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 including 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 palliative care national clinical dataset. This project, led by Public Health England (PHE) will pilot the technical aspects of the dataset with a small number of palliative care organisations around the country in 2015/16. Although the purpose of testing differs between the two projects in 2015/16, the aim is to align, wider implementation of the dataset data collection and the use of the currency from 2016/17.

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.

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<sup>1</sup>[https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/215107/dh\\_133105.pdf](https://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?

A currency is a way of grouping patients' healthcare needs into units that are clinically similar and have broadly similar resource needs and costs. Each unit of currency must be evidence based and analytically identifiable, but most importantly it must be clinically meaningful. The currency must be rooted to the care the patient receives and be practical to implement.

Currencies can take different forms, for example they can be based on a specific activity, or the time period over which a patient would be treated for a condition.

One example of an activity based currency is an appendectomy performed on a patient 19 years or over, without any major complications or comorbidities. The resources used (staff, equipment, location and consumables such as dressings and drugs) are similar, so this type of appendectomy can be defined as a unit of currency that will differ from other activity based units of currency, such as a coronary artery bypass graft.

An example of currencies based on a longer time period are those for Mental Health services or HIV, which are care pathways that have regular reviews built into the currency model. The mental health currency is based on 21 mental health care clusters. Clinicians identify the needs of people coming into mental health services using a standard tool based on HoNOS<sup>2</sup> 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. Palliative care has different challenges to much of acute care, so an approach based on procedural activity is not appropriate. 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 currency refers to a grouping of healthcare into units of similar resource and clinical need, a tariff is a currency with prices assigned to the units of currency. 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.

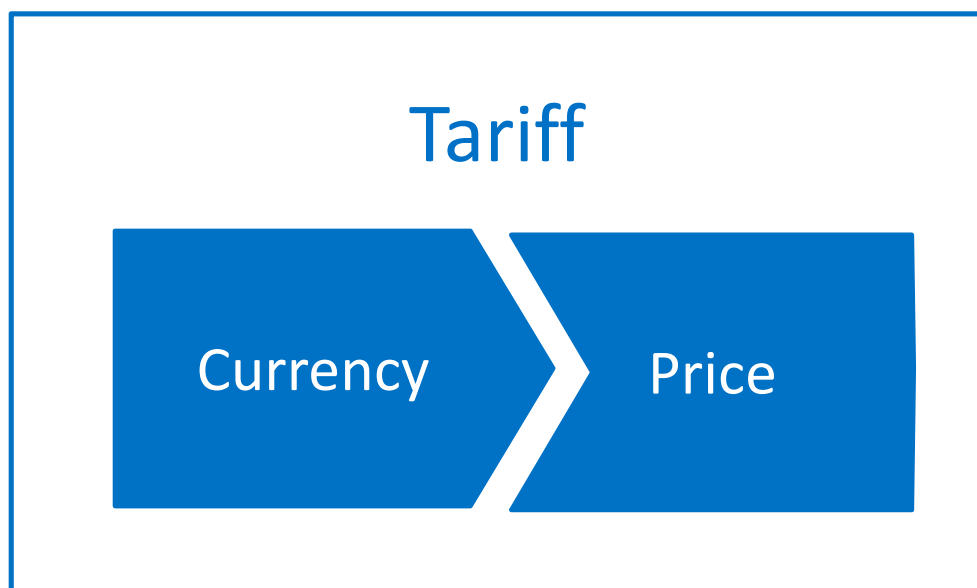
Where a price is agreed upon for a currency between a commissioner and provider in a local health economy, this is known as a local price. Where a currency and price

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<sup>2</sup> Health of the Nation Outcomes Scores (HoNOS)

are published by NHS England and Monitor within the National Tariff Document, this is a national tariff.

For example there is a currency unit in the national tariff for an appendectomy carried out on an adult patient without major complications or comorbidities. For 2014/15, the associated price for this procedure is £1,579. This is the basic payment made by the commissioner for this type of appendectomy 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 geography<sup>3</sup>.



## 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 then 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 testing in 2015/16 will not have any prices associated with it at either local or national level. The aim of testing in 2015/16 is to establish how the currency will work in a variety of local care delivery models. The currency is not mandatory, for those who do wish to use it, we recommend using it alongside existing local payment arrangements. This approach is usually used when new currency models are developed so that they can be safely tested, and any unintended consequences identified.

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.

<sup>3</sup> <https://www.gov.uk/government/publications/guide-to-the-market-forces-factor-201415>



For providers and commissioners, the use of a currency and the resultant information can be used to ensure that the service provided matches the needs of patients in a local health economy. Currencies can also inform service development and re-design to ensure that the money spent 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 often purchased via a block contract that reimbursed providers at the same level the level of activity. This 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
- **Patients** high quality services and greater equity in provision

The palliative care currency introduces a common language between providers and commissioners. Local data collected against each of the currency units will inform conversations about the needs of patients in each CCG locality and the associated costs. As such the currency's introduction without local prices will not impact the proportion of palliative care funding which is generated from charitable donations. The currency could influence the development of local pricing. Any potential impacts on fundraising may well be a part of local discussions between commissioners and providers. If a decision was made in the future to develop a national pricing model based on the currency, part of that process requires Monitor to conduct a full impact assessment of the proposed prices. This would include looking at any impacts a tariff might have on the sector's ability to raise 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 data collection pilots. They reported that using the data provided an evidence base upon which to make decisions about service provision

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and for discussions with service commissioners. Sites also reported that consistent casemix measures aided 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. However, as the currency units are defined by those variables that are the strongest predictors of the costs of care they do not necessarily describe the full detail of a patient's palliative need and are not intended to replace clinical assessment data or the patient record.

#### 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 figure 2. 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. 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 cost<sup>4</sup> of palliative care (for the inpatient category overhead costs<sup>5</sup> 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.

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<sup>4</sup> *Direct costs* are those that relate directly to the delivery of patient care, for example nursing time, medical time, etc.

<sup>5</sup> *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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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.

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 for non-inpatient/community settings (a broad category encapsulating a range of community, outpatient and daycare services).

The grouping of providers was also partly driven by the sample size of the PCFP dataset. The relatively small number of phases in a daycare or outpatient setting meant it was not possible to robustly assess if costs and cost drivers differed markedly in these settings compared with community settings to warrant separate provider categories for the currency units.

Inevitably, the process of defining currency units is a trade-off between describing the full detail of variations in casemix, and designing a pragmatic grouping that summarises casemix and resource use in a way that supports commissioning and a new funding mechanism. The number and choice of variables used to define the currency units was led by the results of statistical analysis to identify the strongest predictors of costs. Through testing the currency units in 2015/16 we will assess the validity of this variable selection by collecting data on a wider set of variables than those required to define the first version of the currency units.

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 non-inpatient/community settings. See figure 1.

The acute inpatients currency applies to phases of care for admitted patients in an acute setting. This currency covers only the care carried out by specialist palliative care teams as, other costs, such as treatment of the underlying condition are covered by existing payment mechanisms, often national tariffs.

The hospice inpatients currency applies to phases of care for patients admitted to a hospice.

The non-inpatient/community currency applies to all other settings, including outpatients, day care and people being cared for in their own place of residence.

For each currency unit an indicative cost weight was calculated as the relative cost of a currency unit compared to the average cost for a provider category (e.g. adult hospice inpatient). These costs weights reflect if a currency unit has higher or lower costs compared to the average cost of a phase within a provider category. Cost weights for each currency unit and further details are provided in annex 3.

Adults and children are defined not by their age, but by the services they are accessing. So services provided to a 25 year old person who was continuing to receive care in children's services would be recorded in the children's currency.

Figure 1: Palliative Care Development Currency (version 1.0)

**ADULTS**

Currency unit	Phase	Other
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**Adult Acute Inpatient**

AW_1	Stable	1 diag
AW_2	Stable	1+ diag <75yrs
AW_3	Stable	1+ diag 75+yrs
AW_4	Unstable	1 diag
AW_5	Unstable	1+ diag
AW_6	Deteriorating	1 diag
AW_7	Deteriorating	1+ diag, <75 yrs
AW_8	Deteriorating	1+ diag, 75+ yrs
AW_9	Dying	1 diag
AW_10	Dying	1+ diag

**Adult Hospice Inpatient**

AH_1	Stable	Low function
AH_2	Stable	Med/high function
AH_3	Unstable	Low function
AH_4	Unstable	Med/high function
AH_5	Deteriorating	Low function
AH_6	Deteriorating	Med/high function
AH_7	Dying	Low function
AH_8	Dying	Med/high function

**Adult Non-Inpatient/Community**

AC_1	Stable	Low function
AC_2	Stable	Med function
AC_3	Stable	High function
AC_4	Unstable	Low function
AC_5	Unstable	Med function
AC_6	Unstable	High function
AC_7	Deteriorating	Low function
AC_8	Deteriorating	Med function
AC_9	Deteriorating	High function
AC_10	Dying	

**CHILDREN**

Currency unit	Phase	Age group /other
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**Children Acute Inpatient**

CW_1		<1
CW_2		1-4
CW_3	Stable	5-9
CW_4	Unstable	5-9
CW_5	Det/dying	5-9
CW_6	Stable	10+
CW_7	Unstable	10+
CW_8	Det/dying	10+

**Children Hospice Inpatient**

CH_1		<1
CH_2		1-4
CH_3	Stable	5-9
CH_4	Unstable	5-9
CH_5	Det/dying	5-9
CH_6	Stable	10+
CH_7	Unstable	10+
CH_8	Det/dying	10+

**Children Non-Inpatient/Community**

CC_1	Stable	Low phy severity
CC_2	Stable	Med/high phy severity
CC_3	Unstable	<1
CC_4	Unstable	1-4
CC_5	Unstable	5-9
CC_6	Unstable	10+
CC_7	Deteriorating	<1
CC_8	Deteriorating	1-4
CC_9	Deteriorating	5-9
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 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 figure 2. 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, and 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.<sup>6</sup>

Figure 2 below contains the updated versions of the definitions from this study; the definitions differ very slightly from those used in the pilot data collection.

Figure 2 - Phase of illness criteria

Start of phase	End of phase	For example
<p><b>Stable:</b> Patient problems and symptoms are adequately controlled by established plan of care and</p> <ul style="list-style-type: none"> <li>• Further interventions planned to maintain symptom control and quality of life <b>and</b></li> <li>• Family/carer situation is relatively stable and no new issues are apparent</li> </ul>	<p><b>Stable:</b></p> <ul style="list-style-type: none"> <li>• The needs of the patient and or family/carer increase, requiring changes to the existing care plan (i.e. the patient is now unstable, deteriorating or terminal)</li> </ul>	<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><b>Unstable:</b> An urgent change in the plan of care or emergency treatment is required <b>because</b></p> <ul style="list-style-type: none"> <li>• Patient experiences a new problem that was not anticipated in the existing plan of care, <b>and/or</b></li> <li>• Patient experiences a rapid increase in the severity of a current problem; <b>and/or</b></li> </ul>	<p><b>Unstable:</b></p> <ul style="list-style-type: none"> <li>• 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</li> </ul>	<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>

<sup>6</sup> 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"> <li>Family/ carers' experience changes which impact on patient care</li> </ul>	care (i.e. the patient is now stable or deteriorating) <b>and/or</b> <ul style="list-style-type: none"> <li>Death is likely within days (i.e. patient is now terminal)</li> </ul>	
<p><b>Deteriorating:</b> The care plan is addressing anticipated needs but requires periodic review <b>because</b></p> <ul style="list-style-type: none"> <li>Patient's overall function is declining <b>and</b></li> <li>Patient experiences an anticipated and gradual worsening of existing problem <b>and/or</b></li> <li>Patient experiences a new but anticipated problem <b>and/or</b></li> <li>Family/carers experience gradual worsening distress that is anticipated but impacts on the patient care</li> </ul>	<p><b>Deteriorating:</b></p> <ul style="list-style-type: none"> <li>Patient condition plateaus (i.e. patient is now stable) <b>or</b></li> <li>An urgent change in the care plan or emergency treatment is required <b>and/or</b></li> <li>Family/ carers experience a sudden change in their situation that impacts on patient care, and requires urgent intervention (i.e. patient is now unstable) <b>or</b></li> <li>Death is likely within days (i.e. patient is now terminal)</li> </ul>	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><b>Dying:</b> Death is likely within days</p>	<p><b>Dying:</b></p> <ul style="list-style-type: none"> <li>Patient dies <b>or</b></li> <li>Patient condition changes and death is no longer likely within days (i.e. patient is now stable, or deteriorating)</li> </ul>	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.

*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. Figure 3 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.

Figure 3 – 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

### 4.3 Scope of care covered

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

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.

#### 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.

## 5 Future development of the currency

### 5.1 Testing the currency in 2015/16

The 2015/16 development currency for palliative care is the first attempt to create a currency for palliative care 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.

We will continue testing and refining the currency during 2015/16. The aim is by April 2017 to have a final currency based on routine data collection that is clinically meaningful and a robust measure of case mix and resource use across all types of palliative care provider.

Testing for 2015/16 falls into two streams:

- **Qualitative testing** – focussed on exploring how the currency works when used as part of the commissioning process.
- **Quantitative testing** – focussed on validating the analytical robustness of the currency and testing possible adaptations.

As part of the quantitative testing we will be asking providers to return data on current service provision and associated resource usage.

Qualitative testing will require groups of commissioners and providers to begin using the currency model as part of their commissioning process, and report back to us on its utility. We will gather feedback using qualitative methods such as semi-structured interviews with people involved in the commissioning process.

### 5.2 Specific issues we want to investigate further

#### *Interaction between the currency and the wider system*

Palliative care is a complex area with multiple funding streams and multiple approaches to delivering and commissioning care. There are also a number of ongoing policy developments, both within and palliative care and more broadly with the health sector. As part of qualitative testing we will explore the interaction between the currency and these other factors.

#### *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 important for 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. We also hope to recruit a site for the qualitative work that will be able to help us explore how the currency can be used as people transition.

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 important for 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.

## Annex 1 - 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: National Clinical Director 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.

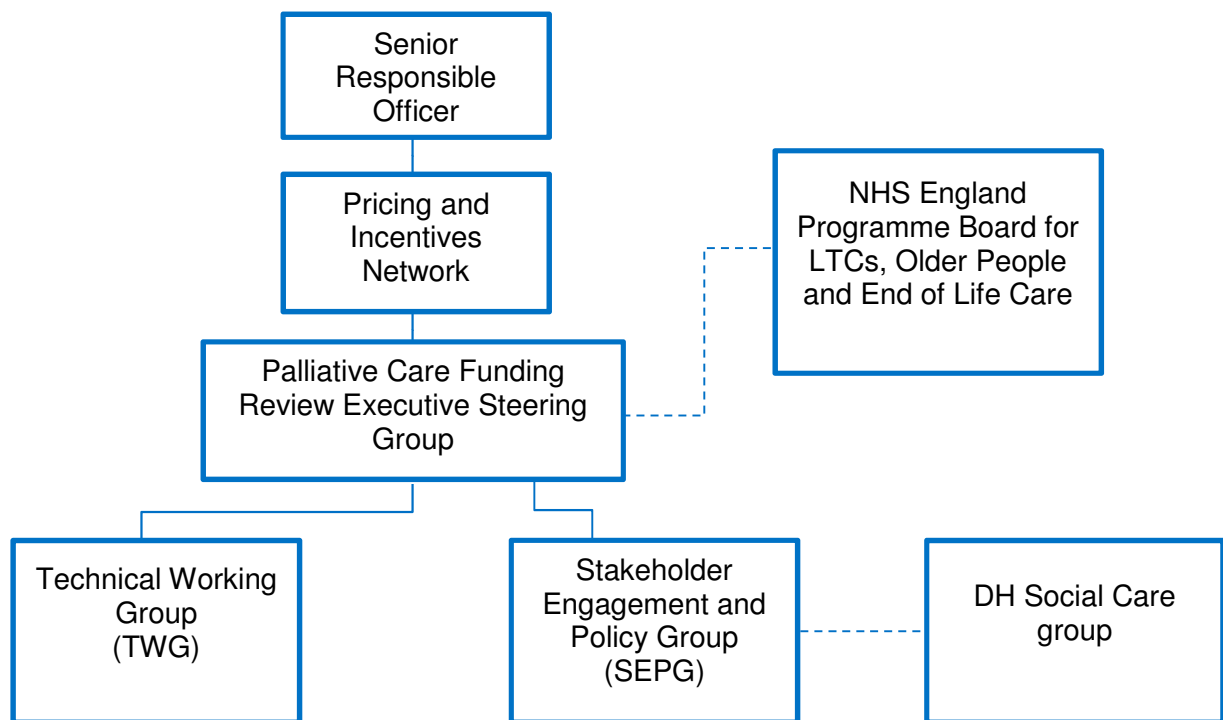
The group is advised by the Technical Working Group (TWG) and Stakeholder Engagement and Policy Group (SEPG). Both groups are comprised of memberships from across the palliative care sector with representatives from NHS organisations, data pilot organisations, hospices and hospice charities, Monitor, 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. Figure 4 below illustrates the governance structure.

The TWG membership was: Dilwyn Sheers (NHS England (Chair)), Jeff Featherstone (NHS England), Katrina McNamara (Together for Short Lives), Fliss Murtagh (Kings College London), Fiona Boyle (NHS Southampton), Dave Allen (Health and Social Care Information Centre), Jayne Harding (Health and Social Care

Information Centre), Saj Kahrod (The Royal Wolverhampton NHS Trust), Malcolm Roxburgh (Public Health England), Nigel Sykes (St Christopher's Hospice), Michael Cooke (Marie Curie), Gary Stinson (NHS England),

The SEPG membership was: Teresa Tate (Chair), Bee Wee (National Clinical Director for End of Life Care), Martin Campbell (Palliative care funding review team), Sadaf Dhalabhoy (Monitor), Bruce Pollington (Kent Community Health Trust), Inge Shepherd (Bristol CCG), Jacqueline Cornish (NHS England), Jonathan Ellis (Hospice UK), Andrew Fletcher (Together for Short Lives), Jocelyn Hinds (National Council for Palliative Care), Chris Ward (National Nurse Consultant Group (Palliative Care)), Susi Lund (National Nurse Consultant Group (Palliative Care)), Alan Craft (Author of the Funding Review), Tom Hughes-Hallett (Author of the Funding Review), Pat Carragher (Association for Paediatric Palliative Medicine), Rob George (Association of Palliative Medicine), Sue Nowak (NHS England), Barry James (NHS England), Adam Millican-Slater (NHS England),

Figure 4 – 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 classification<sup>7</sup> (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.

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<sup>7</sup> [http://ahsri.uow.edu.au/Publications/pre2001\\_pubs/snapstudy1997.pdf](http://ahsri.uow.edu.au/Publications/pre2001_pubs/snapstudy1997.pdf)

## Annex 2 - 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 was 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 figure 2. 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

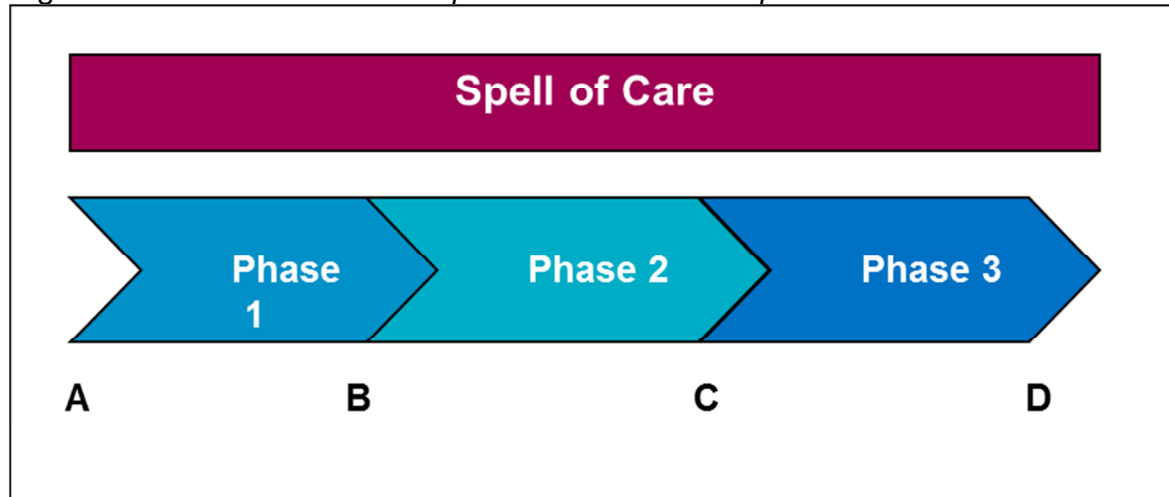
Phase Start	Phase End	Phase Identifier	Provider	Spell
Stable	Unstable	1	Hospice A	A1
Unstable	Stable	2	Hospice A	A1
Stable	Deteriorating	3	Hospice A	A1
Deteriorating	Dying	4	Hospice A	A1

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

Figure 5 – Interaction between *phase of illness* and *spell of care*



In figure 5, 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, where the patient has begun to deteriorate. This deteriorating phase of care concludes at point C, where the patient has begun the dying phase of illness which concludes at point D.

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. Figure 6 shows the spells collected against target and figure 7 shows the phases of illness collected against provider type.

Figure 6 – Spells submitted by provider type against target

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

Figure 7 – 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 a 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 for someone in receipt of palliative care and as a horizon scan for the future aim of linking health and social care into a single funding mechanism, and potentially providing free social care to every patient at the end of life. While the pilot data collection was extended to collect this data, the possibility of providing free social care at the end of life is a separate work stream from the development of a new payment system for palliative care.

### **Annex 3 - Indicative cost weights by currency unit**

For each currency unit an indicative cost weight has been calculated (as the relative cost of a currency unit compared to the average cost for a provider category). For example, in an adult hospice inpatient setting the average direct cost for a phase was calculated from data submitted by hospices participating in the palliative care funding pilots. The cost for each hospice inpatient currency unit was then compared with this average cost to identify how much higher or lower costs were for a currency unit compared to the average hospice inpatient phase cost. A currency unit with a cost weight of 0.5 costs 50% less than average, whereas a cost ratio of 1.2 would equate to a cost 20% above average. Cost weights for each currency unit are shown in figure 8.

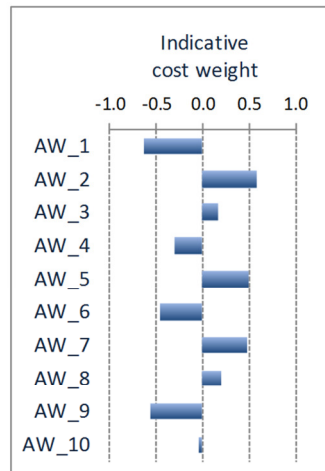
Currency unit cost weights, rather than actual reported costs, were used due to variations in the costs submitted by individual providers in the palliative care funding pilots. In large part, the differences in reported costs are likely to reflect differences in models of care and shared care arrangements. To limit the confounding effect of different service models, cost weights allow the relative difference in costs between currency units to be compared between services reporting different absolute costs.

For example, for adult hospice services, direct costs differed between NHS and Non-NHS hospices. However, cost ratios (i.e. the relative difference in costs between currency units) were broadly similar, suggesting that the currency units operated in a similar manner across NHS and Non-NHS hospices despite differences in reported direct costs, see figure 9.

Figure 8: Currency unit cost weights

Adult acute inpatients

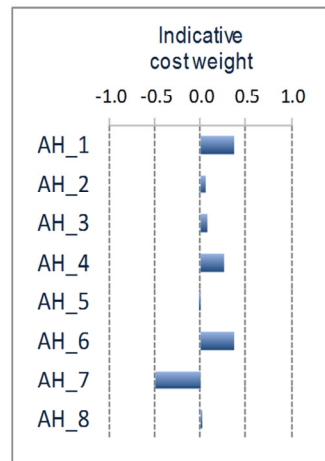
Currency unit	Phase	No. of diagnoses	Age group
AW_1	Stable	1	
AW_2	Stable	2+	<75 years
AW_3	Stable	2+	75+ years
AW_4	Unstable	1	
AW_5	Unstable	2+	
AW_6	Deteriorating	1	
AW_7	Deteriorating	2+	<75 years
AW_8	Deteriorating	2+	75+ years
AW_9	Dying	1	
AW_10	Dying	2+	



Note: *Per phase* cost weights

Adult hospice inpatients

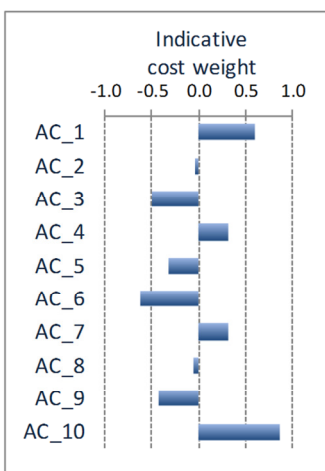
Currency unit	Phase	Functional status
AH_1	Stable	Low function
AH_2	Stable	Med/high function
AH_3	Unstable	Low function
AH_4	Unstable	Med/high function
AH_5	Deter'ing	Low function
AH_6	Deter'ing	Med/high function
AH_7	Dying	Low function
AH_8	Dying	Med/high function



Note: *Per phase* cost weights

Adult non-inpatient/community

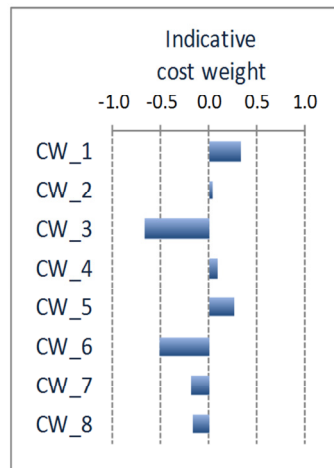
Currency unit	Phase	Functional status
AC_1	Stable	Low function
AC_2	Stable	Med function
AC_3	Stable	High function
AC_4	Unstable	Low function
AC_5	Unstable	Med function
AC_6	Unstable	High function
AC_7	Deter'ing	Low function
AC_8	Deter'ing	Med function
AC_9	Deter'ing	High function
AC_10	Dying	



Note: *Per Diem* cost weights

### Children acute inpatients

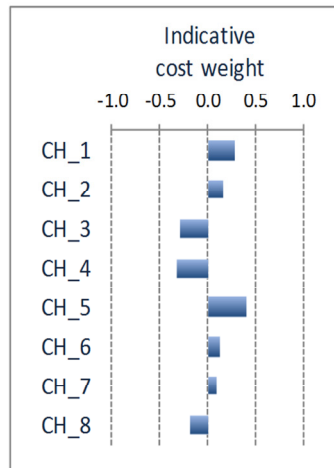
Currency unit	Age group	Phase
CW_1	<1	
CW_2	1-4	
CW_3	5-9	Stable
CW_4	5-9	Unstable
CW_5	5-9	Det/dying
CW_6	10+	Stable
CW_7	10+	Unstable
CW_8	10+	Det/dying



Note: *Per phase* cost weights

### Children hospice inpatients

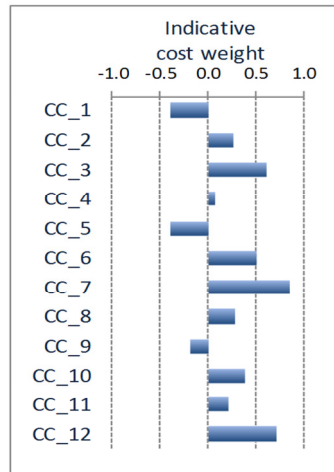
Currency unit	Age group	Phase
CH_1	<1	
CH_2	1-4	
CH_3	5-9	Stable
CH_4	5-9	Unstable
CH_5	5-9	Det/dying
CH_6	10+	Stable
CH_7	10+	Unstable
CH_8	10+	Det/dying



Note: *Per phase* cost weights

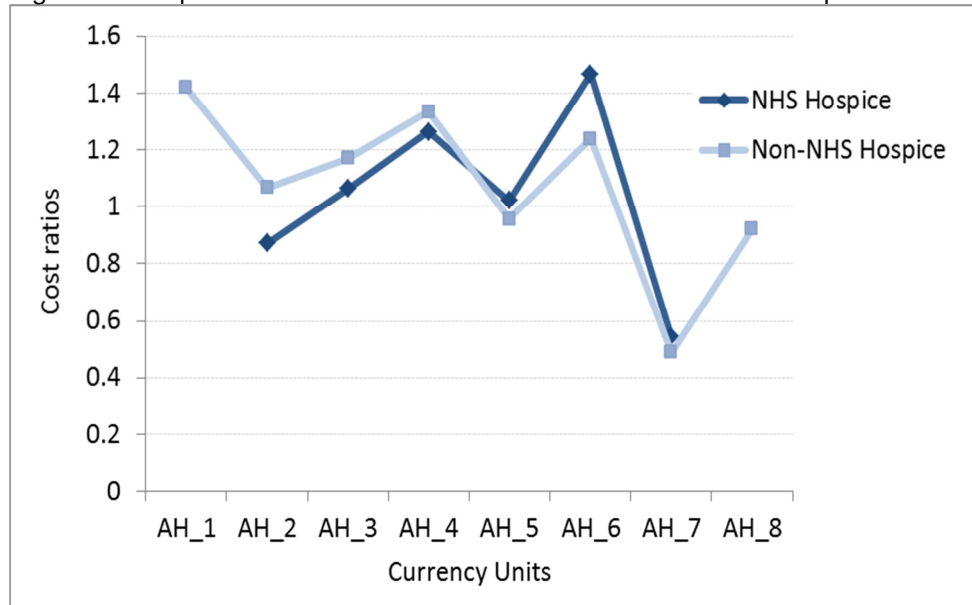
### Children non-inpatient/community

Currency unit	Phase	Age group/other
CC_1	Stable	Low phy severity
CC_2	Stable	Med/high phy severity
CC_3	Unstable	<1
CC_4	Unstable	1-4
CC_5	Unstable	5-9
CC_6	Unstable	10+
CC_7	Deter'ting	<1
CC_8	Deter'ting	1-4
CC_9	Deter'ting	5-9
CC_10	Deter'ting	10+
CC_11	Dying	0-9
CC_12	Dying	10+



Note: *Per Diem* cost weights

Figure 9: Comparison of cost ratios for NHS and Non-NHS Adult Hospices



Note: NHS hospice data for AH\_1 & AH\_8 not shown due to small numbers

## **Annex 4 - Palliative care data**

### **A national clinical data-set for palliative care**

Currently a national individual-level clinical data collection from specialist palliative care does not exist. Public Health England and NHS England are working together to develop such a data-set. This will develop in parallel with the work on the new payment system – they are separate but closely related work streams.

This data set, which includes outcomes, will be supported by a national information standard. It is anticipated that, once the standard is approved, the data-set will be embedded within routine clinical record keeping systems in all specialist palliative care provider services, and this mechanism will be used to provide the data required to support a roll out of the currencies in 2017. This alignment means that there will be a single data collection for outcomes and currencies which will minimise the data burden for provider services.

### **NPC minimum dataset**

The National Council for Palliative Care collects the Minimum Data Set 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 from first to second draft

Chapter	Section	Subsection	Update
1 Introduction	1.1 Context of this document	-	Updated to reflect the work of the engagement process
	1.2 Purpose of guidance	-	Updated to reflect the revision of the document
2 Project Background	-	-	Updated to reflect the work undertaken since the previous publication
3 Healthcare Currencies	3.1 Defining a currency	3.1.1 What is a currency	Updated to reflect feedback from the engagement process
		3.1.2 What a currency is not	Additional information to reflect feedback from the engagement process
	3.2 Use of currency	3.2.2 Why use a currency	Updated with additional information to reflect feedback from the engagement process
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
		4.1.3 Palliative care development currency units	Additional information on the analysis
	4.2 Construction of the currency	4.2.1 Data Items	Additional information around the interaction between phases of illness and carers
		4.2.2 Refining the	Additional

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		currency units	information on identification of secondary variables
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
	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
		5.2.2 Ongoing development work	Updated to reflect issues identified by the engagement process

## Annex 6 - Summary of changes from second draft

Chapter	Section	Subsection	Update
3 Healthcare currencies	3.2 Use of currency	3.2.2 Why use a currency?	Updated to reflect comments
4 The palliative care development currency		4.1. 2 Defining currency units	Expanded on methodology including addition of discussion on cost weights and change of a provider category name from 'community' to 'non-inpatient/community'
4 The palliative care development currency		4.1.3 Palliative care development currency units	Included description of when the adults' and children's acute inpatient currency should be applied.
5 Future development of the currency			Updated to reflect development of testing design
Annex 3			Added currency unit cost weightings