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

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Publications Gateway Reference:	**02399**
Document Purpose	Guidance
Document Name	Developing a new approach to palliative care funding: A first draft for discussion
Author	NHS England/Finance/Strategic Finance/Pricing Team
Publication Date	23 October 2014
Target Audience	CCG Clinical Leads, CCG Accountable Officers, Medical Directors, Directors of Nursing, Directors of Finance, Directors of Children's Services, palliative care clinicians, hospice Finance staff, hospice informatics staff, commissioners of palliative care
Additional Circulation List	
Description	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.
Cross Reference	
Superseded Docs (if applicable)	
Action Required	Please send comments on this document to england.pcf@nhs.net
Timing / Deadlines (if applicable)	**Responses should be made to england.pcf@nhs.net by 22/11/14**
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Document Status

Palliative care currency guidance

Version number: 1

First published: 23rd October 2014

Prepared by: Pricing Team

Contents

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 – this document
- **23 October - 22 November**: Engage sector through written feedback, engagement events and discussing with groups of commissioners and providers.
- **December**: Second draft published
- **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 the document* – please send comments to england.pcf@nhs.net Comments received by 22 November will be fed into the December 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

In late October and November NHS England will be running several engagement events to introduce the currency and discuss with the palliative care sector. At each event we will be holding parallel sessions on children's and adults' services. These events are now all fully subscribed.

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.

1.2 Purpose of guidance

This document introduces the 2015/16 palliative care development currency and outlines how organisations can use the currency in support of commissioning palliative care services in 2015/16.

The final aim of this document is 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)[1] 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.

To support the development of the currency this project is advised 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.

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[1] https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/215107/dh_133105.pdf

3 Healthcare 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.

Palliative care has different challenges to much of acute care, so an approach based on procedures is not appropriate. The palliative care currency presented in this document is based on the needs of the patient rather than the procedures performed.

3.1.2 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. When a national price is placed upon a currency, this is referred to as a tariff. The development currency available for 2015/16 will have no national prices associated with it.

For example, in 2014/15 the tariff for a tonsillectomy carried out on an adult patient was £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 the market forces factor which reflects those costs that a provider has which relate to its particular geography[2].

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 look to design services to ensure that the money spent provides best value for the patient population and reimburses providers fairly for the work they do.

3.1.3 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 commissioners generally purchase servicers via a block contract. The lack of transparency makes evidence-based discussions on how best to deliver services

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[2] https://www.gov.uk/government/publications/guide-to-the-market-forces-factor-201415

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. It gives:

- **Patients** a clearer view of what services are available to them, the quality of those services and greater equity in provision.
- **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 development currency for the palliative care sector will not impact on the proportion of palliative care funding which is generated from charitable donations.

4 The palliative care development currency

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.

4.1.2 Defining currency units

The funding pilots collected detailed data on casemix and the cost of care for each 'phase of illness'. These phases are described in Table 1. 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[3] of palliative care. 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.

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.

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

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

Currency unit	Phase	Other
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 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
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 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+

4.1.4 Data items

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 a patient’s condition against the criteria outlined in Table 1.

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.[4] Table 1 below contains the updated versions of the definitions from this study, these differ very slightly from the definitions used in the pilot data collection.

Table 1 - Phase of illness criteria

Start of phase	End of phase		For example
Stable: Patient problems and symptoms are adequately controlled by established plan of care and • Further interventions planned to maintain symptom control and quality of life **and** • Family/carer situation is relatively stable and no new issues are apparent	**Stable:** • 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)		Symptoms and other concerns are well controlled and stable. Family carers are aware of how to access support in the event of change.
Unstable: An urgent change in the plan of care or emergency treatment is required **<u>because</u>** • 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** • Family/ carers’ experience changes which impact on patient care	**Unstable:** • 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 care (ie the patient is now stable or deteriorating) **and/or** • Death is likely within days (ie patient is now terminal)		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.

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[4] 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

Deteriorating: The care plan is addressing anticipated needs but requires periodic review **because** - 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	**Deteriorating:** - 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
Dying: Death is likely within days	**Dying:** - 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 Karnofsky Scale to functional status as used during currency development

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 of his personal needs.
	50%	Requires considerable assistance and frequent medical care.
	40%	Disabled; requires special care and assistance.
LOW	30%	Severely disabled; hospital admission is indicated although death not imminent.
	20%	Very sick; hospital admission necessary; active supportive treatment necessary.
	10%	Moribund; fatal processes progressing rapidly.
	0%	Dead

4.1.5 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

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.

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. Discussions on the state's funding responsibility for palliative care will need to include the Department of Health and will take place if national prices are developed.

5 Future development of the currency

5.1 Using the currency for commissioning 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 across the country. 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 local prices are unlikely to be available for 2015/16. We suggest that economies 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.

In order to make use of the currency, will be necessary to collect some activity data. A national data collection is being developed, 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.

Local data systems can also be used.

5.2 Developing the currency for 2015/16 and beyond

In autumn of 2014 the NHS England Pricing Team will be hosting 5 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 represent the beginning of the next stage of development of the currency.

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 refining the initial 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.

During 2015/16 the NHS England will further test the currency both analytically and as a usable, clinically meaningful, commissioning tool.

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. 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.

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.

Exactly how this is carried out is something we do not want to be prescriptive about. 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.

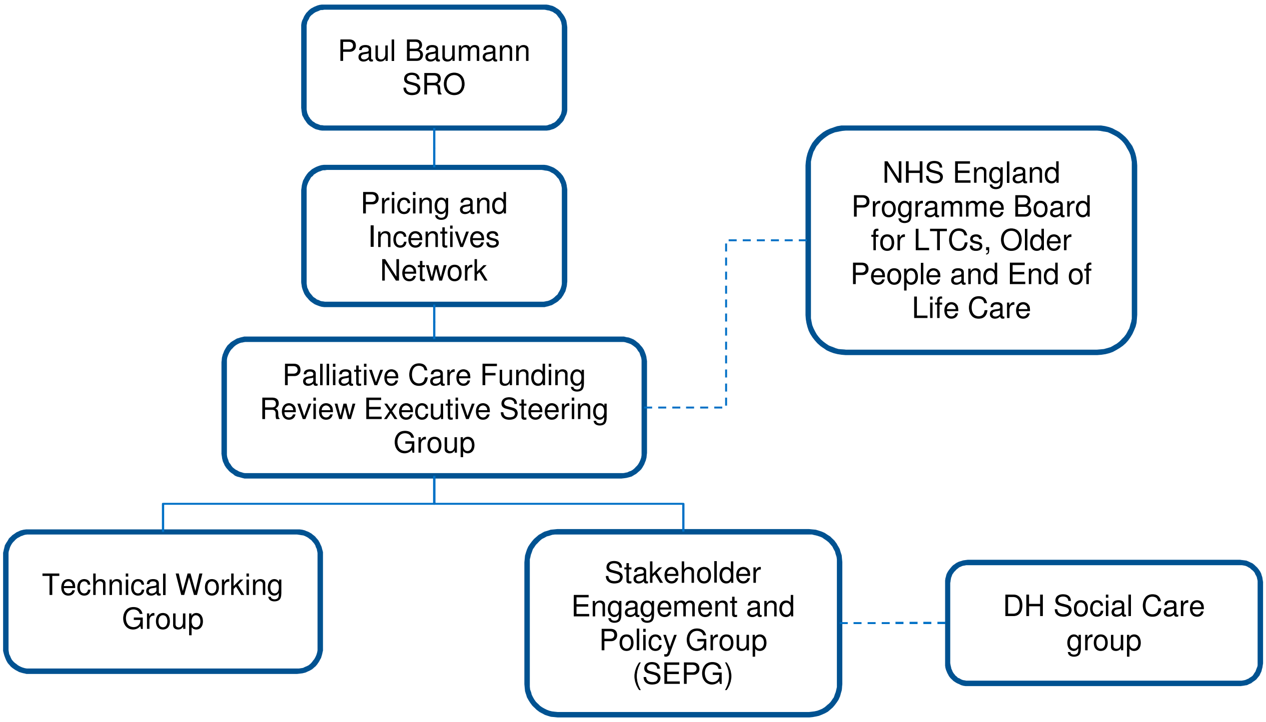
The main focus of this group is to ensure the delivery of a currency and payment system for palliative care supporting a needs-based, per-patient funding system for those who need it through effective decision making and ensuring appropriate top-level engagement.

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 the 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 classification[5] (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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[5] 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 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, however as the patient is cared for by a single provider only a single spell of care is generated.

Patient A

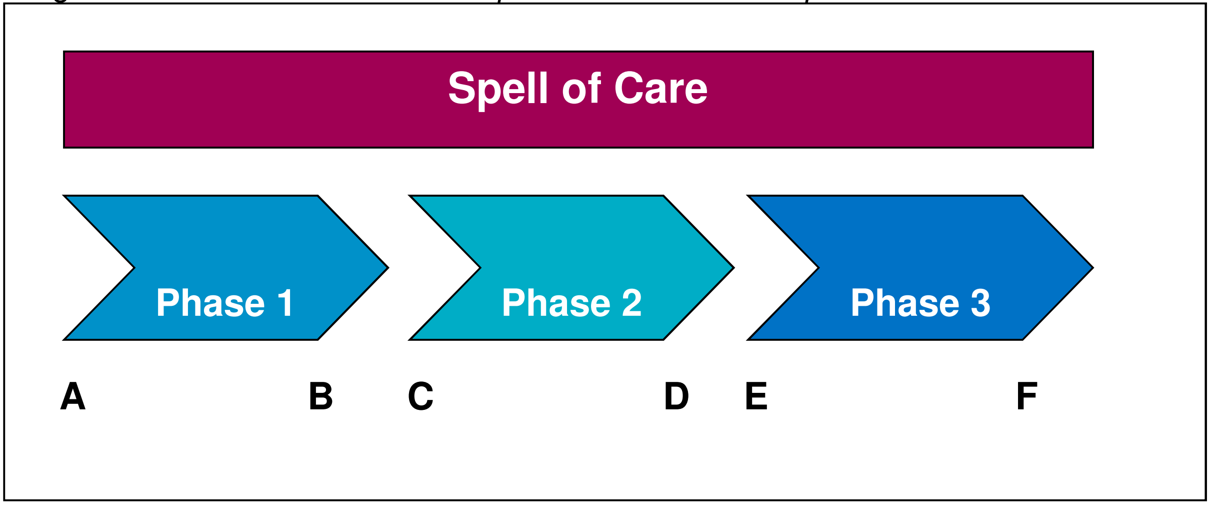
Phase Start	Phase End	Phase Identifier	Provider	Spell
Stable	Unstable	1	Hospice A	A1
Unstable	Stable	2	Hospice A	A1
Stable	Deteriorating	3	Hospice A	A1
Deteriorating	Dying	4	Hospice A	A1

For patient B a number of phases are triggered by change to the patient's condition, in this example there are a changes to the care setting in phases 2, 3 and 4 new spells are generated. 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.

NCPC 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.