

Guidance for using the Children's Palliative Care Currency



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Developing a new approach to Palliative Care Funding

Guidance for using the Children's Palliative Care Currency

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- Given due regard to the need to eliminate discrimination, harassment and victimisation, to advance equality of opportunity, and to foster good relations between people who share a relevant protected characteristic (as cited under the Equality Act 2010) and those who do not share it; and
- Given regard to the need to reduce inequalities between patients in access to, and outcomes from healthcare services and to ensure services are provided in an integrated way where this might reduce health inequalities

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1 Executive Summary

The Children and Young People's Specialist Palliative Care (SPC) Currency Guidance Document is written for both commissioners and specialist palliative care providers to support the use of a new currency model Specialist for palliative care which has been introduced in the National Tariff for 2017/19

We know that Commissioners will be familiar with the concept of currencies and their use, but recognise that most specialist palliative care providers will have little or no prior experience of currency models and their use in commissioning and paying for health services. This guidance document seeks to give a clear explanation of what the currency model is and how it can be used. It will also explain several technical terms which are used elsewhere in relation to currencies and payment, but maybe unfamiliar to specialist palliative care providers. There is a separate guidance document for Adult's specialist palliative care.

The commissioning of children and young people's specialist palliative care is the responsibility of CCG's. The government's 'Our commitment to you for end of life care'¹ states that; "To support high quality personalised care for children and young people, commissioners and providers of services must prioritise children's palliative care in their strategic planning so that services can work together seamlessly and advance care planning can be shared and acted upon". NHS England Specialised Commissioning, pays for tertiary centre services it does commission hospice care. NHS England makes an annual grant to 36 hospice organisations that provide care to children and young people with life limiting complex care needs in support of local commissioning, this currency is meant to assist CCG's in understanding and paying for these services locally. Further information can be found in the NICE guideline: End of life care for infants, children and young people: planning and management².

What are currencies?

Currency is the word that is given to a consistent unit of healthcare which can form the basis of payment for that service. Simple examples would be a hip replacement or an appendectomy. These are routine procedures which on average cost the same to perform. Our system in England is slightly more nuanced as providers will be paid more for a patient who is more complex and who on average will require a more intensive package of care. Not all currencies have a national tariff associated with them, but are none the less used in commissioning and in planning services.

¹ www.gov.uk/government/uploads/system/uploads/.../choice-response.pdf

² www.nice.org.uk/guidance/ng61

Underpinning all currencies is a requirement for robust data. That was not readily available when the project to develop currencies for specialist palliative care was started.

Why did the project start?

The project started with the Palliative Care Funding Review which published a report in 2011. The review presented 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 were to be achieved by developing:

- A funding system based on need
- A funding system which incentivise good outcomes for patients irrespective of both time and setting
- The commissioning of integrated care packages which stimulate community services.

It was also widely recognised that there was a general lack of good data about the sector. In order to achieve these aims it was agreed that we needed to collect data from the sector so that we could develop some currencies for specialist palliative care. A pilot was designed for this purpose, with a target to collect information about 2000 spells of care. The pilot ran from 2012 and data collection was completed in May 2014.

We then ran some comprehensive analysis on the data and that led to the design of a development currency. From October 2014 to February 2015 we ran an engagement programme with the sector to explain the proposed model and gather their feedback. This led to the publication of “A New Approach to Palliative Care Funding” in March 2015. This set out the proposed development currencies for both adult and children and young people’s specialist palliative care.

The Currency Model

In order to be useful to the sector a good currency must meet four key criteria:

1. It must be **meaningful to the clinicians** working in the area, so that the data that underpins the currency is a direct consequence of the casemix arising from the clinical assessment and management systems they work with.
2. It must be **analytically robust**, which means that each of the units of currency are distinct one from another but costs and services within a unit are reasonably homogenous.
3. It must be **useful to the process of commissioning** services, in that it facilitates a common understanding between providers and commissioners of what services are being commissioned without ambiguity and with the potential to compare with other providers of similar services locally, regionally and nationally.
4. It must be **practical to implement**, a currency that is difficult or costly to apply is unlikely to be used widely and accurately devaluing its purpose.

So, following the engagement programme it was decided to test the development currency against these criteria during 2015/16.

The currency presented in this guidance is based on the detailed analysis of 1394 patients with a collective 3452 spells of care involving 5056 phases of illness. As such the currency is based on the best evidence ever compiled for specialist palliative care services in England. For each currency unit, the key drivers of cost are identified, but these were not the only factors considered in the original pilots. Some 139 items of data were collected against each phase of illness in the original data collections exercise. This was reduced in the subsequent 2015/16 testing. The template used for 2015/16 testing is detailed in this document and forms the basis of the data collection template you will need to use the currency. The template excel spreadsheet will be available to CCG's and Providers on request via England.pcf@nhs.net.

The currency model consists of 28 units split across three care settings;

1. **Acute In-Patients** This setting recognises the advisory role of palliative medicine in acute hospitals, supporting the work of admitting specialties, and recognises the evidence supporting early intervention of specialist palliative care to improve the quality of life of patients. The currency is designed to be used for a top-up payment reflecting only those costs associated with the intervention of the palliative care team in the hospital. It does not substitute but complements the admitting specialty currencies that will apply. There are 8 units of currency for this setting. A spell of care ends when a patient is moved to another care setting. Within one spell of care there could be several consecutive phases of illness.
2. **Hospice In-Patients** This setting has 8 units of currency and reflects the costs associated with an in-patient stay in a hospice whether provided by the NHS or independent / charitable sector. The currency units reflect the full cost of care although only the key drivers of cost are identified in the descriptions of the units. Several units of currency may apply against a spell of care for a single patient, reflecting the complexity of their condition as they move between phases of illness. As with acute hospital in-patient a spell ends when the patient is no longer an in-patient. Within one spell of care there may be several consecutive phases of illness.
3. **Community / non-in-patient bed based services**; this setting has 12 units of currency and reflects all services provided to patients who are not in-patients. This could be care provided to a patient in their own home or in a nursing home. Where more than one provider is supporting a patient simultaneously there will be the possibility of concurrent spells of care, each of which should mirror the several phases of illness that may occur.

Using the Currency

A currency consists of two elements, casemix³ and resources needed to deliver that case mix. A service provider should be able to derive the casemix data from their normal clinical assessment and management practices assuming you are already working with spells of care, phase of illness and severity scores⁴. Evidence from our

³ Casemix is explained in the Glossary

⁴ These terms are explained in the Glossary and their use is described in Annex 3,4,5 and 6

pilot sites suggests that where providers are not using this approach it may take 12 to 18 months to fully embed it into working clinical practise. The benefits of doing so are illustrated in the case study to be found in Annex 1. For many providers collecting information about the resources associated with activities can be more challenging, and will depend to some extent on whether your accounting practices allow you to collect costs at a patient level. The data collection templates discussed in the section entitled, “How to Use the Currency - a Practical Guide” is supported by further detail in Annex 2 and will help you to formulate an approach appropriate to your organisations circumstances. We have not provided benchmark costs because of the wide variation of models in operation. For those who do not wish, or find it difficult to collect resource activity, provided that it is possible to arrive at an average cost per phase for either acute hospital in-patients, or hospice in-patients; and an average daily cost for community settings, it is possible to arrive at a cost for each unit of currency by multiplying the average cost by the ratio provided in the right-hand column of the currency table in section 3.1 Children and Young People’s specialist palliative care currency model.

The currency is not a tariff, nor at this stage is it mandatory to use the currency. CCG’s may choose to use this when working with providers to establish a framework for understanding specialist palliative care service need locally, as such providing data about the currencies may become a local data collection requirement within the scope of a service level agreement or local contract. Providers may find the currency model useful as a tool for demonstrating the increasing complexity of care provision and as a reference point for service transformation.

To help providers who find themselves in unfamiliar territory and trying to make sense of where currencies fit with payment we have also provided a section on payment types and how they could work with the currency. When the palliative care funding pilot began, there was an expectation of a per-patient pricing mechanism. However, there are now many alternatives payment approaches being used, and NHS England is no longer committed to a per-patient pricing strategy for all services.

A glossary is provided to give further explanation of terms used.

Questions about the use of the currency, or seeking clarification of points raised in this guidance document may be directed to NHS England via england.pcf@nhs.net We will maintain and publish an FAQ and will update this as required.

Further development of the currency is dependent on the commissioners and providers actively using the currency and collecting the data required. We plan to engage the sector about the use of the currency towards the end of 17/18 through a survey of providers and commissioners, followed by roundtable discussions.

2 Purpose

This guidance gives organisations providing specialist palliative care and their commissioners the information and tools to use the palliative care currency model that was developed with the assistance of the sector from 2012-2016. There are several other documents that NHS England has published which explain in detail the work that has been undertaken to develop the model.⁵

The palliative care currency model describes differences in the complexity of a child's palliative care needs, and the likely differences in the associated costs of providing that care. In effect, the currency is a casemix classification that provides a building block by which palliative care activity and resource use can be collected and measured. This guidance describes the data that providers will need to collect to use the model, and how this can be shared with commissioners to support how services are paid for.

This guidance covers the children and young people's palliative care currencies. There is separate guidance on adult's palliative care currencies.

Specifically, this guidance provides information on:

- The details of the currency model and how it supports local payment
- The data required to use the currency model
- A Microsoft Excel data collection template
- Tools to support data collection and validation
- Sharing information with commissioners

In carrying out the work to develop the currency we have been very well supported and advised by palliative care sector, providers and commissioners who worked directly with us, and by the representative bodies of the sector, Together for Short Lives and the National Council for Palliative Care.

⁵ Please see Annex 10 Glossary where these terms are described

3 The currency model and how it can support local payment

In relation to health the word currency is used to describe a consistent unit of health care, which may also be used as the basis for payment. Currencies are a way of categorising the many types of interventions that are carried out in a health care setting and the complexity of the patients that are using that care into consistent units of care. They need to be clinically meaningful and on average the care delivered in relation to each individual currency unit should cost roughly the same.

The process to develop this currency involved NHS England in two phases of collecting and analysing a detailed set of data from a range of providers of Children and young people’s specialist palliative care that agreed to work with us, 40 organisations in total. In analysing that data what we were seeking to identify those factors that were likely to be key predictors of the resources required to care for any patient. Although we had an example of a currency model which is already used for palliative care in Australia, we were not specifically seeking to confirm the validity of that model. The data we collected enabled us to carry out some complex analysis of many different factors. The purpose of this was to understand those factors that most consistently explained differences in the resources required for a patient’s care, and which could be used to develop the currencies. Through that analysis, we developed the currency model set out below.

3.1 Children and young people’s specialist palliative care currency model

Acute In-Patient

Currency Unit	Phase	Other	Relative Costs
CW_1		<1	1.34
CW_2		1-4	1.04
CW_3	Stable	5-9	0.34
CW_4	Unstable	5-9	1.10
CW_5	Deteriorating/Dying	5-9	1.27
CW_6	Stable	10+	0.48
CW_7	Unstable	10+	0.82
CW_8	Deteriorating/Dying	10+	0.83

Hospice In-Patient

Currency Unit	Phase	Other	Relative Costs
CH_1		<1	1.28
CH_2		1-4	1.17
CH_3	Stable	5-9	0.72
CH_4	Unstable	5-9	0.67
CH_5	Deteriorating/Dying	5-9	1.41
CH_6	Stable	10+	1.12
CH_7	Unstable	10+	1.09
CH_8	Deteriorating/Dying	10+	0.81

Non-In-Patient / Community

Currency Unit	Phase	Other	Relative Costs
CC_1	Stable	Low phy severity	0.61
CC_2	Stable	Med/high phy severity	1.28
CC_3	Unstable	<1	1.62
CC_4	Unstable	1-4	1.08
CC_5	Unstable	5-9	0.62
CC_6	Unstable	10+	1.52
CC_7	Deteriorating	<1	1.85
CC_8	Deteriorating	1-4	1.29
CC_9	Deteriorating	5-9	0.82
CC_10	Deteriorating	10+	1.39
CC_11	Dying	0-9	1.22
CC_12	Dying	10+	1.73

As you can see there are different units for different care settings. This guidance document is specifically for those people commissioning and delivering specialist palliative care for children and young people. Analysis of the data collected identified phase of illness as a consistent factor in most settings, along with age. Phase of illness was not seen as significant for both acute hospital and hospice in-patient setting for children below 1 year and up to 4 years where the age of the patient was the most significant factor. You will also note that for patients who have a stable phase of illness in community settings age was not significant but physical severity was.

We have not reported benchmark costs against each unit because the cost structures of different types of specialist palliative care providers, and even different providers of a similar type is very different, and a benchmark cost could not take this into account.

We have however, identified the relative cost ratios of each of the currency units, and these are set out in the right-hand column. We found that the relative costs of delivering care for each of the currency units for in-patient hospice services for both NHS and non-NHS hospices was very similar, although their cost structures are very different. This also applied to community care whether provided by the NHS or not.

The relative cost ratios provided for in-patient acute settings and in-patient hospice settings are based on mean cost per phase of illness.

The relative cost ratios provided for non-bed based / community settings are based on mean cost per diem.

These ratios can be used to establish a local pricing system that reflects the complexity of care provided, volume of patients that receive care, and the outcomes of that care as measured by the indicators that support the currency or any combination of these factors. If for example the mean cost per phase for a hospice in-patient was determined to be £1000 this would be equivalent to 1.00. The cost of delivering care for someone in any phase might be expected to be £1000 X the specific relativity.

Currencies may or may not have a national price associated with them. In the early years of their use they do not. There are some currencies which have been in use for many years, and for which there are no plans to introduce a set of national prices, but which are in use for the purposes of commissioning and paying for services. We are now at the stage of introducing the currency model for specialist palliative care. The currencies are not mandatory, but we think they provide a useful tool for both providers and commissioners. At this stage, there will not be national tariffs attached to the specialist palliative care currencies.

The advantages of using a currency model to inform commissioning and payment include:

- The ability for commissioners to make comparisons between providers through a consistent approach to describing case-mix and resource use. This can also support service re-design and inform service specification
- Improved service planning – participating organisations in the original palliative care pilots reported that using consistent casemix measures aided predicting patient need and co-ordination of care
- Facilitating evidence-based discussions between providers and commissioners to describe activity and casemix
- Providing the evidence base to support discussions on payment

3.2 Payment Methods

The health and social care landscape has changed significantly since the Palliative Care Funding review was first published in 2011. Following the Health and Social Care Act CCGs have been established as local commissioners, and commissioning decisions are increasingly taken at a local level. The currencies will assist local discussions about the funding and provision of services for children and young people with complex and life limiting conditions, alongside other tools and local intelligence. Several payment approaches are used in the delivery of NHS Services. These range from **Block contracts** which are more bundled to **Fee-for-Service** which are the least bundled and pay for each individual item of service.

Block Contracts

Block contracts are typically defined as a periodic lump sum for a defined range of services often independent of the volume of services provided or the complexity of care delivered.

The risk of a block contract to the commissioner is they are unsure what they are getting for the funding invested. The risk for the provider is that the payment does not increase as volume and complexity of care increases.

When a currency is used to support a block contract, the values of the currency units evidence the volume and complexity of care provided. This gives the commissioner confidence that the contract is meeting the aims and objectives of the CCG, while providing value for money. It would give the provider the opportunity to demonstrate

increasing complexity of care and the impact of changing demographics to support changes to the funding arrangement.

Capitation

Capitation may be defined as a periodic lump sum for a range of services per the number of patients which can be weighted / risk adjusted. This means that risk inherent in a block contract is shared between the Commissioner and Providers. There are numerous ways in which capitation can be achieved. Whole population budgets can be based on a defined area population or specific group within an area population.

In roundtable discussions with Providers and Commissioners a type of capitation model known as a three-part payment was felt to be a good fit for specialist palliative care. The three parts include a core payment that represents the required capacity of the service; a volume based payment that reflects the actual activity and an outcomes and performance payment based on an agreed set of metrics.

Personal Budgets

Personal budgets are payments linked to an individual patient for care services that are coordinated by the patient. They require any provider to the patient to understand the cost of their services at a patient level, and to be able to demonstrate that the care provided is directly comparable to other similar services.

Year of Care

Year of care payments are generally annual payments for the care of patients with a chronic long term condition. This is unlikely to be a suitable vehicle for specialist palliative care funding as it is focused on payment for a package of care that help people to live with their condition.

Bundled Payments

Bundled payments are payments for all services involved in a defined pathway or episode of care for a patient. The currency units are driven by phase of illness within a spell of care and therefore could be aggregated to provide a cost structure to support bundled payments based either on a spell of care or individual phases of illness.

Fee-for-Service

Fee-for-Service payments involve a payment for each individual item of service for each patient. An itemised billing process would not lend itself well to work with the currency model.

4 How to use the currency model in practice

4.1 Overview for Commissioners

In order to use the currency effectively Commissioners will need access to a consistent regularly updated flow of data from contacted specialist palliative care service providers. The data will need to include those variables required to allocate patients to the currency units.

Data items to be collected are split into four broad sections:

- *Patient information* – collected when a patient is first identified to the service
- *Spell information* – collected when a patient starts and ends a spell of care
- *Phase information* – collected at each change in a patient's phase of illness
- *Functional status* – data collected regularly and recorded for each phase

Data can be entered onto an Excel spreadsheet; NHS England can provide an Excel template, for which an outline can be found in Annex 2, contact england.pcf@nhs.net to request a copy of the template.

We recommend that Commissioners consider making this data collection an explicit requirement including all of its relevant data requirements in all contracts for specialist palliative care services (i.e. Schedule 6 of the NHS Contract).

Where arrangements similar to lead provider models⁶ are in operation the commissioner may wish to consider organising local data sharing agreements that allow patient data to be linked across specialist palliative care providers in order to map service provision and inform longer term strategies.

NHS England Information Governance has produced an information sharing agreement template which is available via the NHS England intranet.

When commissioning services using the currency model you will need to consider the impact of any transitional requirements for each local service provider. Some may have already begun using elements of the currency others will be new to this work and the concepts underpinning it, and therefore require a longer lead time to report against the currencies, and potentially assistance with implementation costs. Some providers will be highly IT capable while others remain paper based impacting on the ability to work effectively with other providers in the locality and transfer data in a useful format. The way in which data is shared will also need to be considered given that most specialist palliative care providers are non-NHS organisations who may struggle with N3 connections. There are IT organisations that will act as N3 hubs reducing the cost and time taken to establish such a connection. That may need to be explored as part of an overall IT solution. The exact nature of

⁶ The Term Lead Provider is defined in the Glossary

requirements will be dictated by local circumstances and cannot be dealt with in detail in this guidance document. Further information to support commissioning of specialist palliative care can be found in the Specialist-level palliative care; information for commissioner's document produced by NHS England, a link is provided in section 6: Support available.

4.2 Overview for Providers

The Palliative Care currencies make use of widely accepted standards for patient assessment, and clinically validated outcome measures. Some organisations may need to modify their clinical assessment and management processes to embed these standards, but many organisations will already be working in this way. Evidence suggests that for those who need to make a major change to the way they work it will take 12-18 months to fully embed the language and processes.

In using the currency model, you will have to be able to consistently and routinely collect and present information about the patients that use your services. Much of the data that you as a provider organisation will need to use the currencies should flow from that which is collected as part of normal clinical activity; it should not be an additional data collection burden. An example of this can be seen in the Case Study in Annex 1.

Once collected, patient data can be grouped according to the currency design which is set out in section 3, to inform commissioning negotiations, service planning and agreed payment mechanisms. You may also want to refer to the Specialist-level palliative care information for commissioners document referenced in Section 6.

Commissioners may make data submission to support the currency and payment model a requirement of any future service level agreement or contract. It is therefore important that consideration is given to how effectively this can be achieved within your organisation and any other benefits you may gain, the case studies in Annex 1 may help with this. You may also find it helpful to review the work being done by the Ambitions partnership that is set out in the Ambitions Framework, this document will aid your understanding of where all the various streams of development are linked and how they work together; a link to the document is provided in Section 6; Support available.

4.3 Scope of data to be collected

To use the currency model providers will need to collect data on those variables required to allocate patients to the currency units.

Data items to be collected are split into four broad sections:

- *Patient information* – collected when a patient first identified to the service
- *Spell information* – collected when a patient starts and ends a spell of care
- *Phase information* – collected at each change in a patient's phase of illness
- *Severity Scores* – data collected regularly and recorded for each phase

Data can be entered onto an Excel spreadsheet; NHS England can provide an Excel template, for which an outline can be found in Annex 2, contact england.pcf@nhs.net to request a copy of the template. Tools to support data collection can be found in the following;

Annex 3: Phase of Illness Definition provides a useful table that sets out the phase of illness map, organisations that took part in the pilot and testing often printed and laminated this chart and made it widely available to staff.

Annex 4: Tools Supporting Data Entry sets out Severity Scores based on IPOS⁷ used by the currency model for adults in the absence of an agreed clinically validated standard specific to children and young people which we would be happy to adopt in a future release when available.

Annex 5: Activity Tracker gives a template for recording staff resource usage required to support the casemix.

Annex 6: Phase Assessment Tool provides a template for clinical assessment at phase level and provides a template for data recording.

The following sections provide further details on how data should be entered and the data items to be collected.

4.4 Phases and Spells

Organisations who wish to use the currency will need to collect the data items by *phases of illness* which occur within a *spell* of care. **Annex 9: Palliative Care Currency Patient Case Study**, illustrates the relationship between spells of care and phases of illness

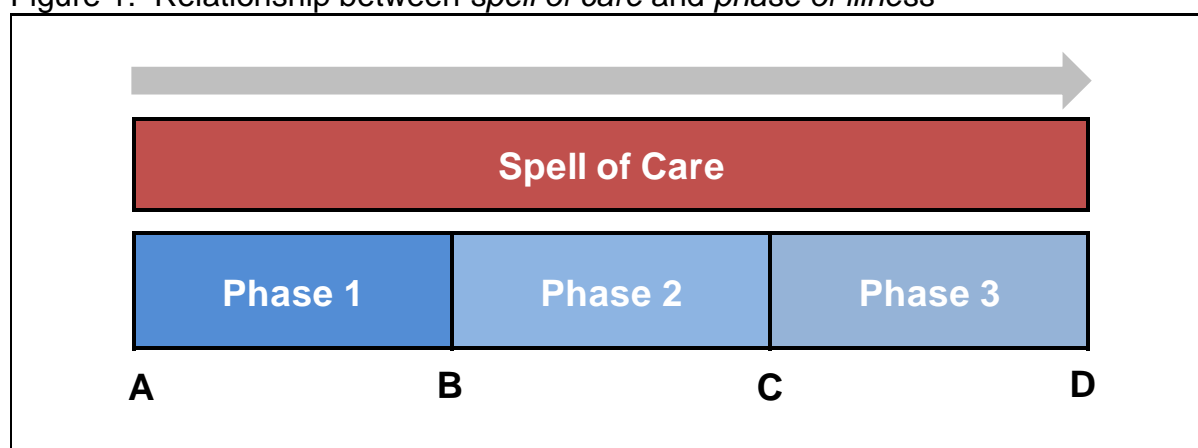
4.4.1 Spell of care

A spell of care is defined as each period of contact between a patient and a palliative care provider or team of providers that occurs in one setting. This may be a stay in a hospital or a hospice, or a period of care by a community provider in the patient's own home or care home. Whenever the patient moves to a different location, a new spell of care is initiated, even if it is the same organisation that provides the service in the new location. For example, if a community patient has an admission to an inpatient setting, and stays overnight (i.e. past the midnight bed count), then they have started a new spell.

A spell of care commences at the start of palliative care involvement with a patient and finishes when the patient moves to a different location or is discharged from palliative care. Within each *spell of care* a patient may have numerous *phases of illness* - each triggered by a change in the patient's condition and/or a change in family/carer's circumstances. Phase level information is recorded at the start of each phase and at the end of the last phase in a spell (points A, B, C and D in figure 1).

⁷ IPOS is defined in the Glossary

Figure 1: Relationship between *spell of care* and *phase of illness*



Note: Phase assessment data are collected at points A, B, C and D

Timing of clinical assessments

Data needs to be recorded against each phase of illness. A change in a patient's phase of illness should trigger a new data entry in the Excel spreadsheet. To ensure phase changes are identified promptly, a patient's phase of illness needs to be assessed on a regular basis – ideally as part of routine clinical assessment. An example of a 'phase assessment tool' is provided in annex 6.

Experience from the Palliative Care Funding Pilots suggests assessment of a patient's phase of illness should happen at least daily in an inpatient setting and at every patient contact for patients in a non-inpatient/community setting.

Although 'phase of illness' should be assessed on a regular basis, clinical assessment data will only be added to the Excel data collection template in the following instances:

- At first patient contact
- At the start of each new spell
- At the start of each new phase of illness
- At the end of the last phase of illness in a spell

4.4.2 Phase of illness

Phase of illness is based upon the assessment of the patient's condition using a casemix classification for palliative care describing four distinct phases: *stable*, *unstable*, *deteriorating* and *dying*⁸. The definition for each phase includes both the patient's condition and family/carer circumstances; these can be found in Annex 3.

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 - triggered by a change in the patient's condition.

⁸ Masso M *et al.* Palliative Care Phase: Inter-rater reliability and acceptability in a national study. *Palliative Medicine* Sept 2014

4.5 The Excel data collection template

Throughout the Pilot data collection and 2015/16 Testing data was entered into a excel spreadsheet provided by NHS England. This template is available for you to use from england.pcf@nhs.net.

Data entry is organised around three worksheets: 'Patient details'; 'Spell data' and 'Phase data'. Data entry is split across these three worksheets to minimise data entry requirements by avoiding duplicate data entry. For example, patient details will only need to be entered once. The broad categories of each worksheet are shown in table 2 for a detailed outline see Annex 2.

It is likely that data for individual patients will be entered on separate occasions during their period of care from a provider. For example, patient, spell and phase data will be entered at first contact with the patient, and then subsequently updated with new phase of illness and spell data as appropriate. The Excel template will therefore be 'refreshed' with the latest data for as long as a patient receives palliative care from a provider.

Table 2: Excel template worksheets

Worksheet	Notes
Patient Details	<ul style="list-style-type: none">• Information entered for all new patients• Data for each patient is captured on a single row and entered only once• Each new patient is allocated a unique patient ID
Spell Data	<ul style="list-style-type: none">• Each spell is entered on a single row• Each spell is allocated a unique spell ID• Data entered at the start and end of each spell of care for a patient
Phase Data	<ul style="list-style-type: none">• Each phase of illness is captured on a single row• Each phase of illness is allocated a unique phase ID• Clinical and administrative data entered at the start of each phase of illness for a patient• Clinical and administrative data entered at the end of the last phase in a spell <hr/> <ul style="list-style-type: none">• Staff activity data and equipment use entered at the end of each phase* (data collected on a regular basis and aggregated at phase end)

Each worksheet can be opened by clicking on the appropriate tab at the bottom of the screen (see figure 3).

Figure 3: Worksheet tabs for data entry in the Excel spreadsheet

**The Palliative Care Currency:
Children data collection template**
Version 3.1a

**NHS
England**

Provider ID: **ZZ** Provider name: **Sample**

Data Entry
Data entry is organised around three worksheets (*Patient Details*, *Spell Data* and *Phase Data*) to minimise the need for duplicate data entry. For example, patient details will only need to be entered once. Details on data that need to be entered on each worksheet are shown below:

Worksheet	Notes
Patient Details	<ul style="list-style-type: none"> - Information entered for all new patients - Data for each patient is captured on a single row and entered only once - Each new patient is allocated a unique patient ID (<i>when the provider code is entered in the first cell on a new row</i>)
Spell Data	<ul style="list-style-type: none"> - Each spell is entered on a single row - Each spell is allocated a unique spell ID (<i>when the relevant patient ID is selected from the drop-down list</i>) - Data entered at the start and end of each spell of care for a patient
Phase Data	<ul style="list-style-type: none"> - Each phase of illness is captured on a single row - Each phase of illness is allocated a unique phase ID (<i>when the relevant spell ID is selected from the drop-down list</i>) - Clinical and administrative data entered at the start of each phase of illness for a patient - Clinical and administrative data entered at the end of the last phase in a spell - Staff activity data and equipment use entered at the end of each phase* (data collected on a regular basis and aggregated at phase end)

*if included in data collection

For detailed guidance, including data definitions and tools to support data entry, please see:
[Guidance for using the Children's Palliative Care Currency](#)

Please send any queries or comments by email to: england.pcf@nhs.net

Worksheets for data entry

Notes Patient Details **Spell Data** Phase Data

Providers may also wish to collect staff activity data associated with the care of each patient. There is scope for doing this in the Excel spread sheets we are providing. Staff activity allocated to a patient's phase would be collected by Agenda for Change (AfC) bands, split into three main sections: *Medical*, *Nursing* and *AHP/Therapies/Psychological*. The staff activity data is collected in minutes rounded to the nearest five. If providers intend to look at their own cost relativities against the currency groups they may wish to collect this data, as an alternative to the relative cost ratios we have provided in section 3.1.

Providers may also wish to record and highlight the use of major items of equipment per phase of illness specific to the patient's need. Annex 8 provides a sample list of commonly used and relatively expensive equipment you may choose to agree others with your Commissioners and enter these on the spreadsheet too.

5 Sharing the information with commissioners

This section is intended as a guide to help you when considering what actions you need to take to ensure appropriate data governance practices are in place to guarantee the safety of the data collected that you have agreed to share with your CCG and other local providers of palliative care services.

The NHS Standard Contract provides guidance and requirements in relation to Information Governance, specifically Schedule 6. Further information can be found [here](#) with particular reference to General Conditions 21 (GC21). This also includes the importance of ensuring relevant compliance with the Information Governance Toolkit (IG Toolkit) or its successor framework managed through NHS Digital. Further information to the IG Toolkit is available online [here](#).

5.1.1 Legislation and Codes of Practice

- The Data Protection Act (DPA) 1998 is the current key statutory requirement for compliance with information security. The Act regulates the processing of data on identifiable living people. The General Data Protection Regulations (GDPR) comes into force May 2018 and will replace the DPA. This has specific requirements for organisations to demonstrate explicit compliance with data protection including information security.
- The NHS Code of Practice: Information Security Management has been published as a guide to the standards of practice relevant to all those accessing or processing NHS information (i.e. patient health records). All organisations that are part of the PCF Pilots need to be familiar with the NHS Code of Practice.

6 Support available

Supporting documentation providing additional information on the development, scope and implementation of the palliative care development currency:

- NHS England ‘Developing a new approach to palliative care funding’, 5 March 2015 <http://www.england.nhs.uk/2015/03/05/palliative-care-funding/>
- FAQ document – provides answers to questions raised during the pilot data collection and engagement process. Available from England.pcf@nhs.net
- Excel data collection template with integrated validation tool Available from england.pcf@nhs.net
- Table of Phases in Annex 4
- “Our commitment to you for end of life care”
www.gov.uk/government/uploads/system/uploads/attachment_data/file/438190/choice-response.pdf
- NICE Guideline: End of life care for infants, children and young people: planning and management. www.nice.org.uk/guidance/ng61
- Together for Short Lives: Jointly commissioning palliative care for children and young people aged 0-25.
www.togetherforshortlives.org.uk/professionals/resources/8558_jointly_commissioning_palliative_care_for_children_and_young_people
- Kings College IPOS tool -[Palliative care Outcome Scale \(POS\) - Home](http://www.kingscollegehospital.nhs.uk/our-services/palliative-care/outcome-scale-pos)
- Specialist level palliative care: information for commissioners -
<https://www.england.nhs.uk/wp-content/uploads/2015/04/specialist-palliative-care-commissioning-guid.pdf>
- Ambitions Framework: <http://endoflifecareambitions.org.uk/wp-content/uploads/2015/09/Ambitions-for-Palliative-and-End-of-Life-Care.pdf>
- Severity Scores in Annex 4

6.1 Contact

To contact the Palliative Care Funding Team at NHS England please email:

england.pcf@nhs.net

Annex 1: Case Studies

KEECH Children's and Adults Hospice

National Palliative Care Funding Pilot & IT Capital Grant Funding Background:

This case study outlines the background of the National Palliative Care Funding Pilot and the IT Capital Grant, and how these have supported implementation of outcomes measurement across Keech Hospice Care.

Keech Hospice Care provides specialist palliative care to adults from Luton and South Bedfordshire and children from all of Bedfordshire, Hertfordshire and Milton Keynes. We are one of only a few children's and adults hospice, based on a single site.

The organisations key purpose is to care for patients and to support their families and friends. Keech aims, "to give the most appropriate and efficient treatment and care to patients; to assist in the relief of their physical and emotional suffering and to help them to lead an acceptable, purposeful and fulfilling life in their home or in the hospice".

Importantly measuring impact, outcomes and effectiveness is central to enabling the team to provide the highest possible quality of care, optimising the use of resources across the organisation and achieving best value for money. Keech strategy 2015 identified the need to implement a systematic approach to outcome measurement and Keech Hospice expressed an interest to NHS England to take part in the National Palliative Care Funding Pilot (second phase testing 2015-2016), and subsequently applied for IT Capital Funding to support this.

National Palliative Care Funding Pilot:

The National PCF Pilot set out a core dataset for collection during the second phase testing and provided guidance for pilot sites on both definition of data items and also methodology/ tools for data collection. The following key data items were collected:

- Spell start /end dates
- Phase – Stable , Unstable, Deteriorating, Dying
- Patient Experience-Integrated Palliative Care Outcomes Score and Children’s Global Problem Severity Score
- Modified Karnofsky Performance Status

NHS England set out the objectives for data collection from providers participating in currency testing as follows:

- Collect sufficient data to validate the currency across all types of palliative care provider
- Inform the future development of the currency units
- Further understand how case-mix and costs vary across providers
- Understand how palliative care activity will populate currency units
- Understand the education/training requirements to ensure consistent data collection

In September 2015 resources were identified to take the work forward across the Hospice and initial meetings were planned to consider project requirements and implementation approach.

Implementation approach

A project team was identified with: executive support; project management; implementation support; clinical leads; and data intelligence/analysis. The team discussed the ambitions and best approach adopting learning from the Kings College London “Outcome Assessment and Complexity Collaborative Suite” (OACCS) to develop a project implementation plan. It was agreed that whilst the initial priority was to support the National Palliative Care Funding Pilot the longer term ambition was to embed outcome measurement into practice across all service units in the Hospice. Due to the short lead in time to deliver the pilot phase testing data, the decision was taken to invest time in education/training and supporting clinical teams across the hospice and to focus on effective implementation, knowing that this may take longer to facilitate/implement but would deliver sustainable benefits in the long term. The learning from the literature relating to outcome measurement identifies the following critical success factors:

- Tailored implementation, addressing local context
- Educational Intervention, using standardised approach
- Timely feedback to clinical teams
- Use of a facilitator working alongside the clinical teams

These elements were considered by the project team and strategies identified to ensure that clinical champions were identified across all service units at the outset. The project Implementation Lead planned one to one meetings with each of the unit

leads to discuss the project requirements and to plan the educational input for teams so that education and training was tailored to need. During early October, 15 education sessions introducing the outcome measurement tools and project data requirements were undertaken across all of the units with excellent staff attendance and engagement. The sessions provided an opportunity to consider the use of the OACCS palliative care outcome measures, what would be implemented initially across the service units, practical implementation strategies, use of tools and resources to support.

Unit resource folders were devised for areas including the specific measurement tools, literature, evidence base and presentations, filmed supporting materials and case studies. As part of the Pilot, the Hospice purchased a learning resources pack from the Cicely Saunders Unit, Kings College Hospital and shared opportunities for the unit staff to take part in monthly learn and share webinars. The slide sets and notes were circulated post calls and also saved on the Hospice shared drive for staff to access if not able to join the calls.

However, the vision for Keech was real time data collection, onto i-pads immediately within the patient room. The IT Capital Grant was to be the funding source, which would enable us to achieve this.

The IT Capital Grant:

The aim of our application for an IT Capital Grant was to make i-pads available to the clinical staff, working within both of the adult and children's inpatient units, children's community teams and adult outpatient setting, to allow real time information to be captured into the spreadsheet provided by the NHS as part of the palliative care currency data collection requirements.

As a result of this funding, Keech Hospice has installed an iPad in every patient room, plus allocated others to our outpatient setting (Keech Palliative Care Centre) and in the children's community team.

Each of these i-pads are fixed to the wall to ensure security and safety, whilst also meeting requirements for infection control, in that they will only be used by nursing staff when caring for a single patient. Having these located in the patient rooms would enable convenience and minimise clinical disruption around data entry and reduce the risk of staff putting off the work required by the study until later, thus preventing poorly captured data or falling behind with data entry.

We chose i-pads over android devices, because of their flexibility; robustness; lightness (especially for community and outpatient staff); screen size, given staff will need to complete sizeable excel spreadsheets; and their ability to integrate with Microsoft Office 365 also for this reason. This fits with our longer term strategy.

We also required devices, for our qualified nursing staff to enter data in a timely fashion, within the children's community team; day support; and adult outpatients

nursing staff who would also enter IPOS assessment data at the point of assessment.

Our Experience:

The importance of outcome measures was supported, all members of the group chose to continue their use after the final data submission to NHS England on 7th January 2016.

The teams identified a range of factors which are important within the Hospice environment and able to feed this back to the national PCF team e.g:

- Additional items of high cost equipment
- Importance of respite breaks
- Allied health professionals activity
- Health care assistants activity
- Psychological assessment
- Patients 'at peace' question (IPOS score)

In general the feedback from data captured to date is that it is reflective of current practice, complexity and resources, but that we need to capture data for a longer period to begin to see trends and opportunities for change over time. Importantly the data captured to date also demonstrates patients experience and satisfaction with the current service, acknowledging for the senior team that the model of care and staff attitude/communication are of a high quality throughout the service.

However, the language, although appropriate within the adult setting, was a barrier within the children's environment. Our Paediatric Doctor commented that she didn't really feel that the IPOS questions, suited the children's services, especially when scoring how families are feeling. Even if hospice staff are doing everything they can, having a palliative child tends to leave the family feeling 'overwhelmed'. The scoring therefore in the questions, is not reflected in data collected. With IPOS and OACCS having an adult focus, the children's unit await a suite of outcomes, specifically designed for children and young people. To support this, Keech has been involved in work with Together for Short Lives, Cicely Saunders and more recently a group of children's hospices to support this development.

With SystMone compatibility on i-pads impending, (this was anticipated originally for July 2016, but now more likely to be in the next financial year) our starting point for capturing real-time data was to use an excel spreadsheet on the i-pads.

Feedback to date has been mixed. Initially for the PCF pilot it was very positive with the staff feeling encouraged by the opportunity to quantify outcomes and impact for patient and family benefit. The staff embraced the training and education sessions and actively engaged in implementing the project across all of the service units. I-pads were installed in: each of the patient bedrooms (adult and children); and allocated to the outpatients department (KPCC); Day therapy and children's

community. Assessing spells and phases took a while to understand, but once it was there appeared to be evidence supporting staff assessments being very similar.

For the i-pads, staff in KPCC found them easy to use once it was clear what they would be used for. However, there were reservations around access and the number of staff being able to amend and update the one spreadsheet. If anyone made a mistake or accidentally deleted something, it could affect everyone.

Within the adult inpatient unit it was reported that staff found it difficult at first. ID numbers had to be entered manually and were not automatically populated from the previous tab (as when you do it on the computer). To begin with staff felt it could be easier to write on paper and then transfer to the computer, but with some degree of perseverance found entering the data straight onto the i-pad okay. The IT skillset of the nursing staff can vary enormously and this has to be taken into consideration in training, not all staff are familiar with Apple technology and those with a lower level of IT literacy could find the technology 'fiddly'.

Updating data in real-time onto the i-pad, in the patient room, was more challenging for the adult staff. One nurse said "when relatives are in the room with their loved ones, you want to do your checks and update the system with as little interruption as possible, especially if the patient is in a dying phase. I felt having the i-pad in the room was insensitive to the patient's family." Another comment was "having completed my nursing tasks, when I started entering the data onto the i-pad, in the patients room, I felt like the family saw me as an administrator, rather than a nurse to provide patient care and emotional support etc. I feel this changes the relationship I have with the family"

However, within the children's inpatient unit, updating patient records has always taken place in the child's bedroom, even when manually writing paper patient notes etc. In the event sensitivities, such as a patient being later in the dying phase, nursing staff would be sensitive of this.

Our Learning:

1. There's not a one size fits all – The language is appropriate to adults, but less so for children's. A child's trajectory is likely to be very different, even in 2 children with the same condition. However, specialist palliative care, adult oncology patients' journeys can be very similar (and almost textbook).
2. This will require a change in the way we work – There are different cultures in adult and children's nursing. Children's nurses often look to parents for information about the patient and are therefore used to having notes in front of them when they 'special a child' or have 1:1s in front of parents/ carers. However, adult nurses would tend to have conversations with the patient directly, rather than the families. Therefore adult nurses are less familiar with sitting writing up notes in front of their patients. They are more likely to feel

writing up notes in the room create a barrier in the relationship between them and the patient. This will therefore require a change in-house, potential with training and support for these nurses.

3. Always have the 'auto save' setting turned on. This is full assurance, in the event of being called away in an emergency.
4. Use of sensitivity for patient's family's especially in the dying phase - If needs be collect data and enter onto the system elsewhere.

Conclusion:

Providing resource packs and placing a high focus on training and skilling up of the nursing staff at the start of this project was invaluable.

The language worked well within an adult setting, but not in children's – it was just too far from their normal baseline. Also a child's phase could change more rapidly than within adults and change either way. More work is required nationally around the use of IPOS for children with specialist palliative care needs.

Despite all departments across the Hospice having captured and provided data for the PCF pilot, and learnt from this process, there is still a great deal to learn and further development to take place to enable the IPOS and OACCS to be embedded in the day to day work of the Hospice, especially on the children's side.

Keech Palliative Care Centre has IPOS embedded in all clinical assessments and the IPOS questionnaire for each patient is included within the patients SystMone record. The adult inpatient unit staff wanted to continue to collect this data over a longer period, although without a continual push, data is not always collected. We need to stay on top of this to maintain data collection of this nature. Currently this has not really impacted MDTs yet, partly because of the external teams involved the language often reverted away from spells and phases back to condition/deterioration.

Embedding this is not only a way of capturing and recording data, but a change in working practice for all clinical staff. This is something which will take time and a need to realise the full benefits of this way of working will help drive the agenda forward. To keep driving this forward Keech are willing to be involved in national work around the development of appropriate outcomes for children, and will monitor progress within adults on a regular basis.

At this stage we have had early discussions with our commissioners, but this is likely to be impacted by national direction rather than locally.

For the i-pads, as we use the SystMone patient data system, it is not feasible to continue entering spells and phases onto an excel spreadsheet, due to staffing restraints for transposing the information across. Instead we need to focus the Hospice on being system ready when SystMone is available for i-pads, at which time

spells and phases will be coded within SystMone and entered directly onto the iPads in real-time.

Keech Hospice Care is extremely grateful for the funding which has enabled us to learn ahead on implementation and support us in being system ready for real-time SystMone

Annex 2: Data Collection Template Guide

○ Patient Details

No.	Variable name	Description/comments
1	Provider ID	Unique identifier for each provider. Format: a two letter and two digit code issued by NHS England (e.g. AA00)
2	Patient ID	Unique identifier for each patient. Format: 'Provider ID' followed by '/' and a four digit number unique to each patient (e.g. AA00/1234)
3	Age	Patient's age in years at start of first spell
4	Gender	Options: <ul style="list-style-type: none"> • Male • Female • Other • Unknown
5	Primary Palliative Care/ End of Life Care Diagnosis	Primary reason for patient's palliative care. <i>Options shown in annex 7</i>
6a	Secondary Diagnosis 1	Any secondary conditions / co-morbidities the patient has. This is to ascertain if multiple conditions are a cost driver. <i>Options shown in annex 7</i>
6b	Secondary Diagnosis 2	
6c	Secondary Diagnosis 3	
7	Carer Availability	Assessment of whether the patient has a caregiver available at the start of the spell <ul style="list-style-type: none"> • Caregiver available and involved in the home • Caregiver available and involved outside the home • No caregiver • Unknown
8	Living Circumstances	Assessment of patients living circumstances at the start of the spell <ul style="list-style-type: none"> • Patient lives alone • Patient does not live alone • Unknown

9	Transition Flag	<p>Is the patient currently in the transition process from child & young people services to adult services?</p> <ul style="list-style-type: none"> • Yes • No • <i>Unknown</i> <p>The timely preparation and move at a developmentally appropriate time of a young person from child centred to adult delivered services.</p>
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○ **Spell Data**

No.	Variable name	Description/comments
10	Patient ID	Provider ID followed by '/' and a four digit number unique to each patient (e.g. AA00/1234)
11	Spell ID	Unique identifier for each spell. Format: 'Patient ID' followed by '_' and a three digit number (e.g. AA00/1234_001)
12	Care Setting	<p>The location in which a patient is receiving the service. Options are:</p> <ul style="list-style-type: none"> • <i>Hospital - inpatient</i> • <i>Hospital - outpatient</i> • <i>Hospice - inpatient</i> • <i>Hospice - outpatient</i> • <i>Hospice - Day service</i> • <i>Community – Nursing/residential home</i> • <i>Community - Patient's/ carer's own home</i> • <i>Other (please state in 'additional information' field)</i>
13	Provision Lead	<p>The lead provider of palliative care for this spell</p> <ul style="list-style-type: none"> • <i>Consultant led specialist palliative care team</i> • <i>Non-consultant led specialist palliative care team</i> • <i>Non-specialist palliative care team</i> • <i>Other</i>
14	Referral Source	<p>Please detail the service in which the patient has been referred from.</p> <ul style="list-style-type: none"> • <i>Hospital - NHS</i> • <i>Hospital - Outpatient</i> • <i>Hospice - Inpatient</i> • <i>Hospice - Day Services</i> • <i>Hospice - Outpatient</i> • <i>Community - GP</i> • <i>Community - Hospice at Home</i> • <i>Community - Out of Hours Services</i> • <i>Self-referral / Family-referral</i> • <i>Other (Please state)</i>
15	Spell Start Date	<p>The date delivery of care to the patient starts in a setting</p> <p>Format: dd/mm/yy</p>
16	Spell End Date	<p>The date delivery of care to the patient ends in a setting</p> <p>Format: dd/mm/yy</p>

17	Discharge / Outcome	Please provide the location to which the patient was discharged. If the outcome is that the patient has died, please select 'Died' <ul style="list-style-type: none"> • <i>Discharged to own home (or Relative's/Carer's Home)</i> • <i>Discharged to nursing/residential home</i> • <i>Discharged to hospital</i> • <i>Discharged to NHS Hospice</i> • <i>Discharged to Non-NHS Hospice</i> • <i>Died</i> • <i>Unknown</i>
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○ **Phase Data**

No.	Variable name	Description/comments
18	Phase ID	Unique identifier for each phase. Format: 'Spell ID' followed by '_' and a three digit number (e.g. AA00/1234_001_001)
19	Phase Start Date	The date when a patient begins a phase of illness within a spell of care Format: dd/mm/yy
20	Phase of Illness (start)	The patient's phase of illness, assessed at the start of the phase <ul style="list-style-type: none"> • <i>Stable</i> • <i>Unstable</i> • <i>Deteriorating</i> • <i>Dying</i> • <i>Unknown</i> See annex 2 for phase definitions
21	Functional Status (adults only)	An adult's functional status assessed at the start of the phase. Measured using a modified Karnofsky scale ranging from 0-100% in 10% increments, (where 100% is fully functioning and 10% is unrousable). See annex 4 for scale
22	Pain severity	Assessed at the start of the phase (See annex 4) <i>0- Not at all</i> <i>1- Slight</i> <i>2- Moderate</i> <i>3- Severe</i> <i>4- Overwhelming</i> <i>Cannot assess (e.g. unconscious)</i>
23	<i>Adults:</i> Breathlessness <i>Children:</i> Other Physical Severity	Assessed at the start of the phase (See annex 4) <i>0- Not at all</i> <i>1- Slight</i> <i>2- Moderate</i> <i>3- Severe</i> <i>4- Overwhelming</i> <i>Cannot assess (e.g. unconscious)</i>

24	<p><i>Adults:</i> Anxiety/distress</p> <p><i>Children:</i> Family/carer Concerns</p>	<p>Assessed at the start of the phase (See annex 4)</p> <p>0- <i>Not at all</i> 1- <i>Slight</i> 2- <i>Moderate</i> 3- <i>Severe</i> 4- <i>Overwhelming</i> <i>Cannot assess (e.g. unconscious)</i></p>
25	<p><i>Adults:</i> At Peace</p> <p><i>Children:</i> Psycho-social Severity</p>	<p>Assessed at the start of the phase (See annex 4)</p> <p>0- <i>Not at all</i> 1- <i>Occasionally</i> 2- <i>Sometimes</i> 3- <i>Most of the time</i> 4- <i>Always</i> <i>Cannot assess (e.g. unconscious)</i></p>
No.	Variable name	Description/comments
26	<p><i>Adults:</i> Information needs</p>	<p>Assessed at the start of the phase (See annex 4)</p> <p>0- <i>Not at all</i> 1- <i>Occasionally</i> 2- <i>Sometimes</i> 3- <i>Most of the time</i> 4- <i>Always</i> <i>Cannot assess (e.g. unconscious)</i></p>
27	Phase End Date	<p>The date when a patient's phase of illness changes or the end of the last phase in a spell</p> <p>Format: dd/mm/yy</p>
28	Phase of Illness at end of last phase in a spell	<p>The patient's phase of illness, assessed at the end of the phase for the last phase in a spell</p> <ul style="list-style-type: none"> • <i>Stable</i> • <i>Unstable</i> • <i>Deteriorating</i> • <i>Dying</i> • <i>Died</i> • <i>Not last phase</i> • <i>Unknown</i> <p>See annex 2 for phase definitions</p>
29	Duration of Phase	Automatic field recording length of phase of illness in days (calculated by deducting Phase Start Date from Phase End Date)
Staff Activity / Equipment use		
30 (a-g)	Total Medical activity (minutes)	<p>Total medical activity recorded in minutes for each Agenda for Change (AfC) band for the phase of illness</p> <p>See annex 5 for activity tracker tool</p> <p>See annex 3 to map non-AfC staff to AfC bandings</p>

31 (a-j)	Total Nursing activity (minutes)	Total nursing activity recorded in minutes for each AfC band for the phase of illness See annex 5 for activity tracker tool See annex 3 to map non-AfC staff to AfC bandings
32 (a-j)	Total Allied Health Professional / Therapies / Psychological activity (minutes)	Total medical activity recorded in minutes for each AfC band for the phase of illness See annex 5 for activity tracker tool See annex 3 to map non-AfC staff to AfC bandings
33 (a-e)	Equipment use	Equipment used for patient's care during the phase of illness See annex 8 for a suggested list of equipment to be recorded if used
34	Additional information	Only used if extra information will help with interpreting data entered for a phase

Annex 3: Phase of illness definitions

Start of phase	End of phase
<p>Stable: Patient problems and symptoms are adequately controlled by established plan of care and</p> <ul style="list-style-type: none"> • Further interventions planned to maintain symptom control and quality of life and • Family/carer situation is relatively stable and no new issues are apparent 	<p>Stable:</p> <ul style="list-style-type: none"> • The needs of the patient and or family/carer increase, requiring changes to the existing care plan (ie the patient is now unstable, deteriorating or terminal)
<p>Unstable: An urgent change in the plan of care or emergency treatment is required because</p> <ul style="list-style-type: none"> • Patient experiences a new problem that was not anticipated in the existing plan of care, and/or • Patient experiences a rapid increase in the severity of a current problem; and/or • Family/ carers' experience changes which impact on patient care 	<p>Unstable:</p> <ul style="list-style-type: none"> • The new care plan is in place, it has been reviewed and no further changes to the care plan are required. This does not necessarily mean that the symptom/crisis has fully resolved but there is a clear diagnosis and plan of care (ie the patient is now stable or deteriorating) and/or • Death is likely within days (ie patient is now terminal)
<p>Deteriorating: The care plan is addressing anticipated needs but requires periodic review because</p> <ul style="list-style-type: none"> • Patient's overall function is declining and • Patient experiences an anticipated and gradual worsening of existing problem and/or • Patient experiences a new but anticipated problem and/or • Family/carers experience gradual worsening distress that is anticipated but impacts on the patient care 	<p>Deteriorating:</p> <ul style="list-style-type: none"> • Patient condition plateaus (ie patient is now stable) or • An urgent change in the care plan or emergency treatment is required and/or • Family/ carers experience a sudden change in their situation that impacts on patient care, and requires urgent intervention (ie patient is now unstable) or • Death is likely within days (ie patient is now terminal)
<p>Dying: Death is likely within days</p>	<p>Dying:</p> <ul style="list-style-type: none"> • Patient dies or • Patient condition changes and death is no longer likely within days (ie patient is now stable, or deteriorating)

Annex 4: Tools supporting data entry

Problem severity - Children

For children, given the absence of a single measure for problem severity that is widely used across England, we are re-questing that a global score across four different domains is reported. This approach is consistent with that used by children providers in the original data collection for the Palliative Care funding Pilots.

The four domains are shown below, each with a possible score from 0-4:

Domain	<i>Includes, for instance:</i>	Scoring
Pain		0- Not at all 1- Slight 2- Moderate 3- Severe 4- Overwhelming - Cannot assess (e.g. unconscious)
Other physical symptoms	<ul style="list-style-type: none"> • <i>Shortness of breath</i> • <i>Weakness</i> • <i>Nausea</i> • <i>Vomiting</i> • <i>Poor appetite</i> • <i>Constipation</i> • <i>Mouth problems</i> • <i>Drowsiness</i> 	0- Not at all 1- Slight 2- Moderate 3- Severe 4- Overwhelming - Cannot assess (e.g. unconscious)
Psychological/ spiritual problems	<ul style="list-style-type: none"> • <i>Feeling anxious</i> • <i>Feeling depressed</i> • <i>Feeling good about him/herself</i> • <i>Level of communication</i> • <i>Ability of patient to share feelings</i> 	0- Not at all 1- Occasionally 2- Sometimes 3- Most of the time 4- Always - Cannot assess (e.g. unconscious)
Family/carer concerns	<ul style="list-style-type: none"> • <i>Overall carer burden</i> • <i>Family anxiety</i> • <i>Practical concerns of the family</i> 	0- Not at all 1- Slight 2- Moderate 3- Severe 4- Overwhelming - Cannot assess (e.g. unconscious)

Annex 5: Activity tracker tool

The tools below may be used to collect information on the quantity of staffing resource used to provide care to a patient (in minutes). This information will be used to understand variations in resource use across different case-mix groups and currency units.

It is recognised that for some services, for example children’s hospice services, all activity is palliative care related, but for others services, such as CCN services, activity will include some palliative care activity within their other patient activity. For the purposes of this project palliative care activity collected should include:

- Symptom management
- Communication (breaking bad news/ dealing with collusion)
- Advance care planning
- Emergency healthcare planning
- Clinical ethics
- Co-ordination of care/ key working
- Discharge planning including rapid discharge to facilitate end of life care in the setting of choice
- Education (of patient/ family)
- Psychological support (for the patient, or family including siblings)
- Non-drug symptom management techniques such as guided imagery, massage
- Pre-bereavement assessment (for child and family including siblings)
- Short break clinical care
- End of life care (care in the last hours and days of life) including provision of 24 hours a day 7 days a week on call service
- Transition between children and adult services

The following table is an example of a time tracker tool which could be used to aggregate staff activity data by staff grade/band and type of activity for each phase of illness.

Patient, phase & staff details			Time (recorded to the nearest 5 minutes)					
Patient ID	Phase ID	Staff grade/band	Patient contact	Family/carer contact	Professional contact*	Admin time	Co-ordination of discharge**	Travel time

*Professional contact: includes communication between professionals both within and external to an organisation

**Co-ordination of discharge: relates to any activity which specifically relates to planning and actioning the discharge of a patient from the care of a provider

The following table is an example of a time tracker tool which could be used by each staff member providing care, with the intention of capturing the approximate time spent by type of activity delivered.

Staff member:	
Grade/Band:	

Patient & phase details				Time (recorded to the nearest 5 minutes)					
Date	Patient name	Patient ID	Phase ID	Patient contact	Family/carer contact	Professional contact*	Admin time	Co-ordination of discharge**	Travel time

*Professional contact: includes communication between professionals both within and external to an organisation
 **Co-ordination of discharge: relates to any activity which specifically relates to planning and actioning the discharge of a patient from the care of a provider

Annex 6: Phase assessment tool

Children phase assessment tool

Patient Information			
Patient First Name		NHS Number	
Patient Last Name		Local Patient ID	
		Age	
Primary diagnosis		Gender	
Secondary diag. 1		Carer Availability	
Secondary diag. 2		Living Circumstances	
Secondary diag. 3		Transition Flag	

Spell Information						
Spell ID	Start date	End date	Referral source	Care setting	Provision Lead	Discharge Outcome

Phase Information							
Phase assessments			<i>Data to record if phase of illness changes</i>				
Assessed by:	Assessment date	Phase of illness	Problem severity(0-4 score for each domain)				High cost equipment use during phase
			<i>Pain</i>	<i>Other physical symptoms</i>	<i>Psychological/spiritual problems</i>	<i>Family/carer concerns</i>	

Annex 7: Diagnostic Groups

Children Diagnosis Groups

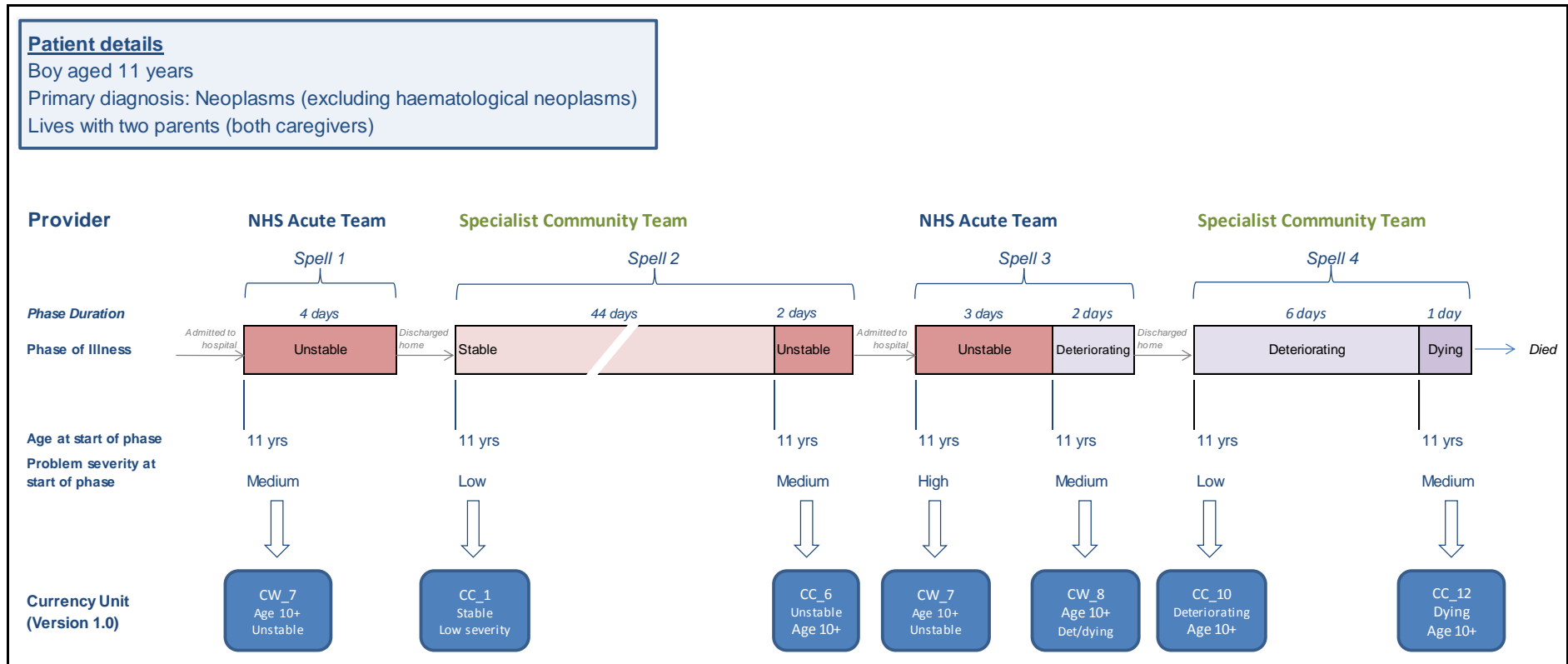
Diagnostic Group	ICD-10 codes
Congenital & Chromosomal disorders	Q00-Q07, Q20-Q28, Q30-Q34, Q38-Q45, Q60-Q62, Q64, Q77-Q81, Q85-Q87, Q89-Q93
Nervous system disorders (including muscular dystrophy, epilepsy)	G10-G13, G20-G26, G31-G32, G35-G37, G41, G45-G46, G60-G64, G70-G73, G80-G83, G90-G91, G93-G96, G98-G99
Conditions originating in the perinatal period (including birth asphyxia, cerebral palsy)	P00-P03, P07-P08, P10-P11, P20-P29, P35-P37, P39, P52-P54, P57, P77, P90-P91
Neoplasms, excluding haematological neoplasms	C00-C26, C30-C34, C37-C41, C43-C58, C60-C85, C88, C90-C97, D17-D48
Diseases of the blood and blood forming organs, including haematological neoplasms	D55-D61, D63-D64, D66-D77, D81-D84, D86, D89
Circulatory disorders	I11-I13, I15, I20-I25, I27-I28, I31, I34-I37, I42, I50-I51, I69-I70, I77, I85, I89
Respiratory disorders (including cystic fibrosis)	J43-J44, J47, J82, J84, J96.1
Endocrine, nutritional and metabolic disorders	E22-E25 (excluding E24.4), E31-E32, E34-E35, E70-E72, E74-E80, E83-E85, E88, E90
Musculoskeletal and connective tissue disorders	M07-M08, M30-M32, M35, M40-M41, M43, M85, M95
Infections and immune disorders	B20-B25, B44, B90-B92, B94
Genito-urinary disorders	N07, N11-N13, N15-N16, N18-N19, N25-N29, N31-N33
Digestive disorders	K72-K77
Other "Please detail"	
Unknown	

Annex 8: List of Equipment to record if used

Equipment
PEG, RIG or NG feeding
Assisted ventilation (e.g. NIV)
Syringe driver
Sleep system
Suction equipment
Nebuliser
Bariatric equipment
Customised seating
<i>Other: please state</i>

Annex 9: Palliative Care Currency Case Studies

Children



Annex 10: Glossary of Terms Used

Casemix

Casemix is the system classification used by NHS England to describe healthcare activity. These classifications underpin payment systems from costing through to payment, and support local commissioning and performance management.

Currency

In the context of health care a currency is a consistently identified unit used as the basis for payment between provider and commissioners. A currency is a balance of casemix and the resources required to deliver it.

Currencies can take different forms; for example, they can be based upon a specific procedure having taken place, the period over which a patient would be treated for a condition or an appointment during which a patient receives treatment for an illness. A straight forward example of a currently used currency is removal of tonsils. In general, for a tonsillectomy, the resources used (staff, equipment, location and consumables such as dressings and drugs) are similar, so a tonsillectomy can be defined as a unit of currency.

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.

Tariff

A tariff is where a currency and pricing mechanism are brought together to establish a set of prices. A tariff can be set locally or nationally.

Relative Cost

A relative cost is the cost of a service in terms of another; this could be the ratio of one or more costs. A relative cost may be expressed in terms of a ratio between costs or the ratio between the cost of providing one service and a weighted average of all other services available

Spell of Care

A spell of care is determined by the care provided to a patient by a single provider. This may be a continuous stay of a patient using a hospital or hospice bed on premises controlled by a single service provider. Or where the patient is at home and receives care from a single provider at a clinic or in their home. For in-patient stays it is unlikely that there will be concurrent spells of care, in community settings it is possible for complementary packages of care to be delivered by different providers concurrently and therefore it is possible to have concurrent spells of care. A single provider will have only one open spell of care for each patient at any given time.

Phase of Illness

The palliative care phase of illness used by the currency are based on the Australian model, we use four stages, Stable, Unstable, Deteriorating and Dying. Detailed descriptions of each phase at the start and end of phase are set out in Annex 3. Each phase looks at the patient and the environment in which care is given and include family and carer issues. These definitions are also intrinsic to IPOS.

Analysis of data collected has shown phase of illness to be a key predictor of cost. A spell of care will consist of multiple phases of illness.

IPOS – Integrated Palliative Care Outcome Scale

Developed by Cicely Saunders Institute at Kings College London IPOS is a clinically validated for adults palliative care outcome scale that captures important concerns in relation to symptoms, information needs, practical concerns, anxiety or low mood, family anxieties and overall feeling of being at peace. The elements of IPOS used by the currency are illustrated in Annex 4 and cover five areas; Pain, Breathlessness; Anxiety/Distress; At Peace; Information Needs.

Lead Provider Model

The lead provider or accountable lead provider model is a model of contracting where a single provider assumes responsibility generally through a contract for delivering an integrated pathway of services for a commissioner.

Annex 11: Frequently asked questions

PCF review

1. **Why are you not introducing a national tariff?**

The health and social care landscape has changed significantly since the Palliative Care Funding review was first published in 2011. New models of commissioning are emerging that reduce the prominence of national tariffs, whereas a currency can be used to underpin any commissioning and payment model.

2. **The PCF review considered a wide range of issues, including who should pay for bereavement services. When will these questions be answered?**

Following the Health and Social Care Act CCGs have been established as local commissioners, and commissioning decisions are increasingly taken at a local level. The currencies will assist local discussions about the funding and provision of services for people approaching the end of life, alongside other tools and local intelligence. Bereavement counselling does not form part of the currency model, but commissioners should think about the excellent value that these services provide, especially in terms of impacts on the wider health system, in thinking about the way they commission services.

Implementation

3. **If I am an NHS trust or hospice, do I need to adopt the currencies?**

The currencies are not mandated nationally. However, if your commissioner has asked that you collect and submit the data that underpins the currency as part of your local contract or grant agreement, then you will need to comply accordingly.

4. **If I want to adopt the currencies, what support is available and where can I get help?**

Guidance has been provided to support implementation of the currencies. This FAQ is being prepared and will be updated in response stakeholder feedback. Further help can be sought by contacting the NHS England Palliative Care Funding team on england.pcf@nhs.net

5. **How long does it take to implement the currencies?**

The best evidence we have from the organisations that were involved in both the pilot data collection and 15/16 testing is that it takes about 12 to 18 months to fully embed the language and tools into clinical assessment and management practice. Case studies are included in the guidance document from organisations that have been through this process.

6. **How much resource will it take to implement the currencies?**

The extent to which temporary additional resource will be required depends on several factors. These include the extent to which you are already using elements of the language that is inherent in the currency design and the degree to which your organisation uses information technology in support of your daily clinical operational activity. Implementation requires commitment at all levels within the organisation from Trustees and senior management team to consultants and the nursing and clinical team, IT and administrative support.

7. As a provider, what are the benefits of implementing the currencies?

The currencies are not just a technical exercise that may lead to additional funding, some of the benefits that others have found in using currency is that they have been able to better plan care for their patients; they have improved the efficiency of MDT's; they provide a short form language that can be shared between organisations that describe the patient's condition reducing lengthy transfer reports. The currency, also provides the means to improve quality reporting and allows providers to compare and contrast performance in a consistent directly comparable manner, locally, regionally and nationally. Use of the currency aids the formation and articulation of a national voice.

8. I've adopted the currencies but I'm still struggling to engage with my commissioners – what else can I do?

There are a number of ways to engage with commissioners. Sharing information and data about the services you provide and outcomes achieved are a central way of doing this. Other tactics are to understand and utilise some of the tools they use and to articulate how the work you do can support make improvements in the areas they are focussed on.

9. I'm considering adopting the currencies – what top tips would you give me before starting out?

Talk to others that have already done it, plan out your approach, be realistic in your goals, use IT as an integrated part of your plan, review the guidance and FAQ documents and tools available from NHS England, contact NHS England on england.pcf@nhs.net if you cannot find the answers you are looking for.

10. When will SNOMED codes be made available for IPOS?

The standards committee responsible for the addition or revision of SNOMED CT generally has two releases each year, the next release is not scheduled until March 2017 and this is the earliest possible date that IPOS or any other clinically validated set of values could be added to SNOMED. The addition of IPOS will be timed to coincide with the ability to add palliative care data into a nationally mandated data set. No specific times has been set for this at present but we are working towards early adoption against wider National Information Board data set development priorities.

The currencies

11. Is there a link between the currencies and cost of the services provided?

There is a relationship. Although cost structures vary considerably between different types of organisation and therefore the actual cost of providing that care, we found that there was good consistency in the relative costs of providing care for each of the different currencies. So if someone is being seen in the community, whether by a hospice, community provider or acute outreach a stable patient with low function will have the same relative cost compared to other currency units.

12. How robust are the currencies?

We found that a number of factors related to patients were consistently predictors of the costs of care for groups of patients. These factors form the basis of the

information needed to assign someone to a particular currency. Inevitably the resource inputs associated with any currency are an average and there will always be examples where someone who is assigned to a particular currency will cost more than other patients.

13. What age are the children's currencies for?

The standard answer to this question is up until the day before their 19th birthday, however the currencies should continue to be used for any young person that continues beyond this date with the agreement of all involved in providing and their care.

14. How do the currencies work for children and young people at transition?

We had intended to look at this issue in 2015-16 testing however we received limited data and were unable to consider options to create a separate transition currency. In many instances, it is recognised that a young person's care may best be suited to continuing with the children and young people's services where this is the case then the currency units that apply for C&YP should continue irrespective of age.

Commissioning

15. As a commissioner, what are the benefits of implementing the currencies?

The currencies provide a common way of describing patients receiving care from Specialist Palliative Care services. If you receive the data that underpins the currencies from each Specialist Palliative Care provider who you have a contract with, you will be able to see the level of case complexity each provider is dealing with and likely costs of delivering care.

16. What is the relationship between the currencies and the Specialised commissioning aspect of children's Specialist Palliative Care?

There is no relationship between the currencies and specialised commissioning, as specialised commissioning fund tertiary level care in specialist hospitals for children and young people they do not specifically commission palliative care.

Future developments

17. How will the currencies be reviewed to check they are fit for purpose?

Questionnaire towards the end of 17/18 sent to all providers and commissioners, voluntary data submission and roundtable discussion. We will look toward the reference cost data and voluntary submissions across 16/17 and 17/18 to review the currencies in operation. The currencies being launched in 16/17 are based on the best evidence available to us at this point detailed analysis of that data suggests that they are fit for purpose we will therefore be looking to ensure they continue to be fit for purpose as changes in models of care are implemented and payment systems incentivise innovation and outcome centred approaches.

18. If non NHS hospices are not contributing to this exercise (as they don't have to do references costs), how will you know if they are working for this important part of the sector?

We hope that non-NHS hospices will find it to their advantage to collect and submit as a minimum casemix data based on the language used by the currency

and that Commissioners work on transitional approaches to making this data submission a requirement of their contracts.

19. Will the currencies be mandated in the future?

The option remains open to mandate this will in part depend of future strategic policy with regard to mandating in general and the extent to which the currency is found to be useful in the sector.

20. What does 'mandating' the currencies mean? As a commissioner, will I have to provide more financially towards SPC provision? As a provider, will I have to implement it?

Mandating a currency only means that it should form the basis of whatever payment mechanism is agreed either locally or nationally and that commissioners should deal fairly with all providers of similar services.