

Developing a new approach to Palliative Care Funding- Final Report 2015/16 Testing



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Developing a new approach to Palliative Care Funding: Final Report

A Qualitative and Quantitative Assessment of the Palliative Care Development Currency

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- 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

In September 2014 we shared a set of specialist palliative care currencies for adults and children and young people with the sector, following an extensive period of data collection and analysis. We undertook extensive stakeholder engagement on the currencies during Autumn 2014 and early 2015. As a result of the engagement, we decided to test the currencies further during 2015/16, to check their validity, and in consideration of other developments in the sector since the start of the project. This new round of testing was undertaken by service providers and local CCG commissioners who volunteered to participate in the process. The testing was designed to review whether the four key criteria of a good currency were met:

1. That it is analytically robust
2. That it makes clinical sense
3. That it is useful to the commissioning process
4. That it is practical to implement

In addition to testing these areas, a number of clinically validated outcome measures had become available for adults. We wanted to check that these did not necessitate changes being made to the currency units. We also wanted to explore whether we could simplify the currency model by combining some of the individual currencies, and to look at the impact of transition for young people moving into adult services.

Our testing had two strands, quantitative testing and qualitative testing. Quantitative testing was primarily focused on the analytical robustness of the currency and whether it made clinical sense. Qualitative testing was primarily focused on how the currency could be used in the commissioning process, and how practical it was to implement, although much was learnt from the quantitative test sites on this latter point. Qualitative testing required participation from commissioners as well as their providers to look at how the currency could be used alongside existing contracting arrangements.

Alongside our own testing programme for 2015/16 a project was funded by NHS England, and led by PHE to develop a clinical data set for specialist palliative care for adults. The dataset included items that would support the currency. A technical feasibility pilot covering all the data items took place with 11 sites.

Quantitative Testing Results

From the 34 organisations that originally registered to take part in the quantitative testing, 21 adult and 5 children and young people's specialist palliative care providers submitted data for analysis about the care they had provided. We received information about 17,487 completed phases of illness for adults and 1570 phases of illness for children and young people. Our analysis supported the case mix classification element of the development currency that was launched in September 2014.

In addition to ensuring that currency units are clinically meaningful, we wanted to test them from a funding perspective by revisiting the cost weights we had identified through the initial Palliative Care Funding pilots.

Data was received which allowed us to cost 29% of phases for adults and 31% for children and young people. However, 87% of all the information on costed phases came from four providers (BA, BC, AM and AB),¹ and the individual sample sizes for each of the currency units were generally too small for meaningful analysis, with the exception of adult acute hospital in-patients.

We applied the currency units to the data we had collected and compared this with the original Palliative Care Funding Pilots (PCFP) to see the degree of correlation between the two. There was significant variation between the two pilots in the reported percentages of two categories of hospital in-patient currency units: '1 diagnosis with unstable phase' and 'deteriorating phase with 1 diagnosis'. The variation between the two virtually balances out and we believe that in the 2015/16 testing round, the criteria for a 'deteriorating' phase has been applied more consistently. This may reflect greater maturity in the use of phase of illness in clinical assessment.

Overall the data showed that adult outcome measures had a high degree of correlation with the results of the original pilot data, and enhanced rather than altered the evidence supporting the currency settings and units from a casemix perspective. Age and gender distributions were as expected and broadly in line with the PCF Pilot data. Data shows that cancer still predominates as the primary diagnosis for adult patients although there appears to be significantly more patients with non-cancer diagnoses being included.

Variation was seen in phase distribution, but we believe that this was in part due to the nature of the test group. The original PCF pilot had been structured around linked data from local economies, whereas our 2015/16 test group were individual organisations. A small number of individual providers submitted a significant proportion of the total data received, giving a bias to their models of care. As there was insufficient data submitted on resource usage to make a comprehensive review of the currencies across all settings, this limited our scope for considering combining units and reviewing cost relativities. We therefore decided that since casemix suggested the units were robust and made clinical sense, we would keep to the original currency set, and review them in the future when more data is available.

We had hoped to look at the impact of transition for young people to adult services but the amount of data received was too small, and in the main lacked resource activity data to make a meaningful assessment. We will continue to monitor and review when more data is available.

Qualitative Testing Results

Feedback from the qualitative assessment was limited. Of 12 commissioner-provider pairings who applied to take part 3 dropped out before the process fully began. Of the remaining 9, only 3 sites completed the process of working together with their

¹ Each registered provider was given a two-letter identification code known only to the provider and the NHS England Palliative Care funding Team, no provider will be referenced by name in relation to the data they submitted at any point in this document in order to maintain client data confidentiality

commissioners so that both took part in the site visit and in-depth interviews carried out by the review team. Of the three providers involved in the joint interviews;

- 1 site completed qualitative testing, submitted data as part of quantitative testing, and was part of the PHE palliative care clinical dataset pilot.
- 1 site completed qualitative testing and submitted data as part of quantitative testing
- 1 site complete qualitative testing but was not engaged in either quantitative testing or the pilot for the data set.

Of the remaining 6 commissioner / provider pairings no commissioners were available for interview, 2 providers gave in-depth site visit interviews; 1 provider gave an in-depth telephone interview, 1 completed an online survey and 2 providers gave no response, although one of these had submitted quantitative data.

Lines of investigation considered through the qualitative research

Is the currency practical to implement?

- Concerns were raised about the transition costs to modify or establish IT systems that would collect data at the patient level. The support of clinical staff was essential to the success of data collection. This point was echoed by the expert reference group for the palliative care clinical data set.

Is the currency useful to the commissioning process?

- Some sites reported that they struggled to report on the data to make it meaningful to commissioners. It should be noted that most specialist palliative care providers have little or no prior exposure to working with currencies and would therefore need support from their commissioners who do have such experience, a point raised in interview. Commissioners said they wanted the data to tell them a story and did not feel what they received from their providers did that echoing the comments of the providers struggle to make the data meaningful.
- Several sites felt that because they were relatively new to the currency they were some time away from being able to say how useful the currency is as a commissioning tool and how it supports decisions on the complexity of care alongside service planning
- One provider felt very strongly that the data collected about their service had considerable potential to be valuable in conversations with commissioners, a point echoed by others.
- A lack of resources and skills to interpret the data meant that no conversation of this kind with commissioners had yet been possible.

While 3 provider-commissioner groups had discussions about the data none had used it alongside existing arrangements as part of a commissioning discussion. Several reasons were given for not being able to maintain the commissioner-provider dialogue:

- Two sites reported that their commissioner who had signed up to support the testing process had changed employment or been reassigned.
- Sites perceived commissioners to be too busy to get involved or take much interest.

- Local commissioning environments were too complex, this was especially apparent with the providers of children and young people's services.

Commissioners were commissioning multiple services with limited resources and did not want to add a test to their workload. Although discussions did not go as far as we would have liked to see a number of providers were keen to highlight that even initial, rudimentary discussions with commissioners has been beneficial. There was a feeling that issues could be overcome if the data set became a requirement and sites made appropriate investment.

Conclusions

Following the 2015/16 testing a decision has been taken to publish the currency in the 2017/19 Tariff. This means that it is available for use if providers and commissioners wish to do so. A reference cost collection pilot based on currencies will be undertaken with NHS providers, during 2017/18, with the aim of incorporating into reference costs in 2018/19.

Separate guidance documents have been prepared for adults and for children's and young people's services on how to use the currencies. It is planned to review the currency again in 2018/19 in light of further feedback from the sector and further data analysis.

2 Introduction

NHS England worked with providers and commissioners to test the development currency for Specialist Palliative Care Providers during 2015/16. A currency is a way of grouping the healthcare interventions that patients receive into units that are clinically similar and have broadly similar resource needs and costs. A currency model allows commissioners and providers to have an evidence-based discussion about the patients for whom a service is provided and the financial implications of delivering that care.

2.1 The context of this document

This document is a report on the qualitative and quantitative testing of Specialist Palliative Care Currencies for Adults and Children. We highlight the feedback that we have received from providers that have used the currency in the provision of Palliative Care Services. We are making the currencies available for the sector to use from April 2017 and so we have also produced two guidance documents which should help organisations who wish to use the currencies to support commissioning of Specialist Palliative care services.

2.2 Purpose of Report

This document introduces the 2015/16 palliative care development currency and describes the Quantitative and Qualitative Testing of the Currency during 2015/16.

The document also outlines the next steps for future development, including plans to engage organisations to continue using the non-mandatory currency.

3 Healthcare currencies

3.1 What is a currency?

In relation to health the word currency is used to describe a consistent unit of healthcare, 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. A currency should be clinically meaningful, and on average the care delivered in relation to each individual currency should cost roughly the same.

3.1.1 The currency must be clinically meaningful

A currency must group the care provided in a way that makes sense to clinicians delivering the care. Is the grouping of patients or service users accepted by clinicians? For the adult palliative care currency groups, the language that underpins the currency is the same that underpins the clinically validated OACC² IPOS³ Outcome Measures.

² The OACC project is led by the Cicely Saunders Institute. It is funded by the Guy's and St Thomas' Charity. OACC is working in collaboration with the NIHR Collaboration for Leadership in Applied Health Research and Care (CLAHRC) Palliative End of Life Care Theme. The Collaboration for

3.1.2 The currency should be analytically robust

When using the currency, individuals within a proposed currency group should require a similar type and amount of resource. This should take into account variables of patient need, plus resource usage and individual packages of care. This ensures that costs associated with a unit of currency are broadly similar within the defined boundaries of the currency unit, and that the units are sufficiently distinct from each other to validate the data collected.

3.1.3 The currency should be useful for commissioning

Currencies can be used to support a variety of payment mechanisms. These can vary from block contracts to per patient payment by results (PbR). They provide a common language to describe the services being delivered for the funds that are provided.

3.1.4 The currency should be practical for use

For a currency to be practical to use there needs to be a good balance between granularity of data collected, and the burden of collecting that data. So when we develop a currency try to develop units that group people together in a way that reflects the care provided and that best predicts cost. Many currencies draw their data from clinical assessment and management information that is routinely collected and are therefore not an additional burden as the data is required to treat and monitor the patient. During the design phase the information required may be quite detailed and include a large number of variables. In our original pilot 139 items of data for each phase of illness for each patient was collected. The development process helps to identify which data items underpin the currency and which are not required once the currency is established. 2015-16 testing was about testing the currency and so required the collection of 68 data items per patient, 10 items to identify the patient are collected once, 8 items to identify the spell of care are, collected once for each spell of care and 58 data items collected against each phase of illness. Of these 58 items 12 are mandatory to complete, the remaining 38 data items will depend on staff activity and major equipment use.

3.2 Why use a currency

Palliative Care is currently commissioned through a mixture of block contracts, local tariffs and spot purchasing. A currency model provides an essential foundation for creating a more transparent way of purchasing health services:

Leadership in Applied Health Research and Care (CLAHRC) South London is part of the National Institute for Health Research (NIHR), and is a partnership between King's Health Partners, St George's University London, and St George's Healthcare NHS Trust. Hospice UK is working in partnership with the Cicely Saunders Institute to support the OACC Project.

³ The Integrated Palliative care Outcome Scale (IPOS) is copyright. IPOS – including terms of use – are available to download from www.pos-pal.org. In this document IPOS is reproduced with the permission of Kings College London as the Intellectual Property owners of IPOS.

- **Providers** have greater clarity on the services required and confidence in the level of anticipated funding in future years, allowing better planning, innovation and workforce development. Providing transparency between providers.
- **Commissioners** have an evidence-based framework for commissioning, supporting them to drive quality and efficiency. Whilst also providing a transparent platform for them to compare against and engage with other commissioners.
- **Patients** improved quality of life for patients and their families and carers, high quality services and greater equity in provision of care.

3.3 How are currencies used?

The currency model makes use of widely accepted standards and clinically validated outcome measures that are used in palliative care. It may require some organisations to modify their clinical and assessment processes to embed these standards but many providers are already be working in this way. Evidence from this and other projects suggests that for those who need to change the way they work to implement the currency model it will take 12-18 months to fully embed the language and process.

4 The Palliative Care Currency

The Palliative Care Currency model describes differences in the complexity of an adult's or a child's palliative care needs, and likely differences in the associated costs of providing that care. It is a casemix classification that provides a building block by which palliative care activity and resource use can be collected, measured and compared locally, regionally and nationally. The following illustrates the currency model tested in 2015-16:

There are two separate currency models one for adult specialist palliative care and one for children and young people's specialist palliative care. Each currency model covers three settings, Acute In-patients, Hospice in-patients and non-in-patient community care. Within each setting there are a number of currency units determined by the best predictors of cost. Against each of these currency units the relative costs of delivering care have been calculated, based on the average cost of treatment across all currencies in that setting.

4.1 Adult specialist palliative care currency model

Acute In-Patient

Currency Unit	Phase	Other	Relative Costs
AW_1	Stable	1 diag	0.37
AW_2	Stable	1 diag <75	1.42
AW_3	Stable	1 diag >75	1.06
AW_4	Unstable	1 diag	1.18
AW_5	Unstable	1+ diag	0.96
AW_6	Deteriorating	1 diag	0.45
AW_7	Deteriorating	1+diag <75	1.58
AW_8	Deteriorating	1+diag >75	1.27
AW_9	Dying	1 diag	0.46
AW_10	Dying	1+diag	1.04

Hospice In-Patient

Currency Unit	Phase	Other	Relative Costs
AH_1	Stable	Low Function	1.36
AH_2	Stable	Med/High Function	1.04
AH_3	Unstable	Low Function	1.07
AH_4	Unstable	Med/High Function	1.25
AH_5	Deteriorating	Low Function	0.98
AH_6	Deteriorating	Med/High Function	1.36
AH_7	Dying	Low Function	0.50
AH_8	Dying	Med/High Function	1.00

Non-In-Patient / Community

Currency Unit	Phase	Other	Relative Costs
AC_1	Stable	Low Function	1.60
AC_2	Stable	Medium Function	0.96
AC_3	Stable	High Function	0.50
AC_4	Unstable	Low Function	1.31
AC_5	Unstable	Medium Function	0.68
AC_6	Unstable	High Function	0.39
AC_7	Deteriorating	Low Function	1.31
AC_8	Deteriorating	Medium Function	0.95
AC_9	Deteriorating	High Function	0.57
AC_10	Dying		1.87

4.2 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

4.3 Aim

The aim of the Palliative Care Funding Project was to develop a palliative care currency model for adults and children. This meant we needed to identify those criteria which best predict patient needs and drive costs. When the project started very little evidence existed on the value of palliative care services, and there was very little transparency on how services were delivered.

It was also expected that we would be looking at the potential for a per patient payment system. However, since then a range of new payment approaches are being used in the NHS. The currency model that we have developed and tested can be used to support a variety of payment and care models. It allows commissioners and providers to have an evidence-based discussion about the care provided to palliative care patients, and the funding requirements.

The palliative care currency model describes differences in the complexity of an adult's or a child's palliative care needs, and the associated costs of providing that care. In effect, the currency is a casemix classification that provides a building block through which palliative care activity and resource use can be collected and measured.

5 Engagement events and testing the currency 2015/16

The 2015/16 testing project has included both qualitative and quantitative testing. We recruited organisations to take part advertising through Hospice UK, Together for Short Lives, our bulletin list and engagement events held in March. Volunteer organisations were asked to complete a registration form. We accepted all applicants for quantitative testing as we wanted the widest possible reach and were particularly interested in organisations that had not previously been involved in the palliative care funding pilot data collections. For Qualitative testing we used a similar process of gathering expressions of interest followed by site visits and interviews as we were looking for a smaller group that would be representative of national models of care.

Qualitative testing called for local pairings of commissioners and providers to work together and use the currency alongside existing arrangements to answer questions about the role of the currencies in commissioning and the practicalities of collecting the data. We originally planned for working with 6 areas, but signed up 12 anticipating that some would not be able to complete the process.

Site visits were made to each of the 12 areas and initial conversations were held with the Palliative Care Funding Team at NHS England. A third-party research organisation was commissioned to develop a set of survey questions and define the interview processes. Each of the registered participants was then contacted to discuss completing the on-line survey, or to arrange for in-depth interviews to be held on site.

The quantitative testing called for each provider to collect data against a reduced data set of pseudonymised patient level data, using a data collection tool provided by NHS England. 36 palliative care providers registered to take part, and 26 provided data. Of these 21 were adult sites and 5 were providing services to children and young people. Data was collected throughout the testing period with a monthly report sent to NHS England.

The quantitative testing process started with workshops in London and Leeds. Sites were then given telephone and e-mail supported by the Palliative Care Funding Team at NHS England.

During the data collection period an interim analysis report was provided. Each site was given a code which enabled them to identify their results but none of the other organisations submitting data.

The quantitative testing process was supported by an advisory group with provider and commissioner representatives as well as academics, senior clinicians, and national representative bodies Hospice UK and Together for Short Lives.

At the end of the testing process roundtable discussions were held to discuss how a range of payment mechanisms could be supported by the currencies.

5.1 Qualitative Testing

12 commissioner-provider pairings initially registered to participate in the qualitative testing of the currency, 9 of them gave us feedback on the currency through face to face interviews, telephone interviews and online questionnaires. Five of the provider sites that participated also took part in the quantitative testing of the currency.

Evidence from the qualitative assessment was somewhat limited, of the original 12 commissioner provider pairings 3 dropped out before the process fully began. 1 provided quantitative data but did not complete the qualitative testing and 1 did not complete the testing process.

Of the remaining 7 pairs 3 completed the process and both provider and commissioner were part of the site visit and participated in in-depth interviews. Of the providers in the three pairings;

- 1 provider site completed the qualitative process, submitted data as part of quantitative testing, and was also part of the PHE palliative care clinical dataset pilot⁴.
- 1 provider site completed the qualitative process and submitted data as part of quantitative testing
- 1 provider site completed the qualitative process but was not engaged in either quantitative testing or the data set pilot.

Of the remaining 4 commissioner / provider pairings no commissioners were available for interview, 2 providers took part in in-depth site visit interviews; 1 provider gave an in-depth telephone interview, and 1 completed an online survey,. Engagement varied due to several factors:

- How effectively the provider found they could collect the data required.
- Their ability to produce meaningful analysis for internal use and to inform conversations with commissioners.

⁴ The Palliative care clinical data set project was funded by NHS England and led by Public Health England specifically for Adult Specialist Palliative Care see www.endoflifecare-intelligence.org.uk/resources/publications/pccdseval and www.endoflifecare-intelligence.org.uk/resources/publications/pccdsguide

- The extent to which providers had initially believed the currency was a tariff or would lead to a tariff.
- The extent to which they believed the appetite for a national currency in the current policy climate was waning

Key findings are as follows:

5.1.1 The testing undertaken

Sites became involved in qualitative testing for several key reasons. In many cases involvement was encouraged by the presence of a 'data champion', and the hope that by collecting more data they would be able to further evidence the value of the service they offered.

For some sites commitment was affected by difficulties with data collection, loss of a key member of staff or a perception that the need for a national currency was diminishing.

5.1.2 Is the currency practicable?

Those who participated in the testing of the currency raised a number of detailed points that needed to be taken into consideration for a currency (and supporting data requirements) to be more practicable. These included:

- The need to address the administrative burden (through funding, IT infrastructure, appropriate staffing).
- The need to embed data collection within the culture of the organisation and evidence to clinicians the impact that better data collection could have for the service.

5.1.3 Is the currency useful and meaningful?

Whilst there are some practical issues to overcome the currency has proved very valuable in increasing providers' understanding of their service and the needs and make-up of the patients they serve, and their ability to articulate that internally and with commissioners.

5.1.4 Detailed feedback on the currency and wider data

In terms of the elements that currently comprise the currency, phase of illness was the subject of much of the feedback from participants. Providers perceive there to be potential for inconsistency of interpretation and a high degree of subjectivity with regard to the phases. The categories in the middle of the phase of illness scale (unstable and deteriorating) were those that caused the greatest difficulty and potential for inconsistency.

A number of providers also made comments and suggestions around the current age groupings for children and young people. Comments made in this regard were not always consistent and appear to depend on the specific nature of the provider's patient case mix

5.1.5 The currency as a commissioning tool

One of the key objectives of the qualitative testing was to explore how the currency works when used as part of the commissioning process. The evaluation reveals that whilst some sites had initiated conversations with commissioners none had used the data to inform discussions about the actual commissioning of services. There was a sense amongst all those that we spoke to that these conversations could only take place when sites were more confident in the data being collected. Although discussions did not go as far as we would have liked, several providers were keen to highlight that even initial, rudimentary discussions with commissioners have been beneficial. There was a feeling that several issues could be overcome if the palliative care data set became a mandatory requirement and sites made appropriate investment.

5.2 Provider Perspectives

5.2.1 Phase of illness

In terms of the elements that currently comprise the currency the phase of illness data is the subject of much of the feedback from participants. Providers perceive there to be potential for inconsistency of interpretation and a high degree of subjectivity with regard to the phases. During the quantitative data analysis process we found that there was consistency in the application of phase of illness both within and across organisations despite some provider perception. The categories in the middle of the phase of illness scale (unstable and deteriorating) were those that caused the greatest difficulty and perceived potential for inconsistency, this was not observed in the data received.

5.2.2 Complexity of Care

Some providers that have used the currency model felt they were a long way from having detailed discussions about how useful the currency is as a commissioning tool and how it can support decisions on the complexity of care and service planning. The currency had not been used alongside existing commissioning processes. It is important to note that where the providers consistently applied IPOS and Karnofsky scores there was a significant and direct benefit to care planning and service provision throughout the different phases of care.

5.2.3 Efficiencies

One provider, who has invested in IT infrastructure to facilitate data collection has reported that they have streamlined their MDT meetings, and it has enabled all staff members present at the weekly meeting to articulate clearly the different packages of care that each patient in the hospice has received. This in turn has resulted in better use of staff time and reduced their meeting by hours. Providers who have used the currency have identified that there is a cost involved with data collection (even more significant for those involved in quantitative and qualitative testing) and they felt that any move to a mandated currency would need to be accompanied by investment since data collection will be difficult to absorb into existing budgets. Sites explicitly referred to the cost of acquiring an adequate IT system and the cost of employing

more staff to record and collate the data, but the example above is evidence that over time the cost of investing in IT infrastructure becomes worthwhile.

5.2.4 Issues in the wider sector

A number of broader issues and questions were raised by many of those who have been involved in the qualitative testing process, including:

- How the Palliative Care Currency links to funding. The ultimate motivation for many of those involved in the testing is to increase their access to funding. Whilst most of those testing the currency understood that it does not relate to a tariff, some sites raised questions about the value of the exercise if this is not to be the ultimate aim.
- Some of the providers who have participated in the testing process have little faith that the project will continue to develop. There was a strong perception that support for the project is waning at a political level and that little is likely to change in the sector as a result of the work that has been undertaken thus far. Not all sites felt like this several have found participation a positive experience that has led to material change in their organisation.

5.3 Commissioners Perspectives

5.3.1 Currency in relation to pricing models

Only three commissioners gave feedback on the palliative care currency. Those who did feedback recognised that the data collected and currency gave them insight into the complexity of cases dealt with by each provider. However, they were uncertain about whether, and how, the currency (and any eventual associated tariff) would enable more effective commissioning of services. They also highlighted the wider financial challenges within CCGs.

"The messages at the moment very strongly are that we have huge financial challenges that the system has got to address and across the board that seems to be the big focus." (Commissioner)

5.3.2 Lack of richness in the data

Although the three commissioners could see some benefit in the data collected they did not feel that it translated to a narrative that could ultimately inform a business case for commissioning. This we believe highlights an issue with the reporting of the data rather than the data itself. One commissioner explained that it did not provide insight into the effectiveness of services and where money would be best spent.

"It's not yet telling a story, that's the point. And for a commissioner that's what you need it to do, you need it to tell you a story." (Commissioner)

"No, I think my knowledge of the kids behind it helped me but just if I looked at it, if or say my colleagues looked at it. Say I've taken a

business case in and I just use those figures, I'm not sure that I would particularly be able to take it anywhere. I didn't feel the data was rich enough." (Commissioner)

"And then being able to use that in a constructive way to say we are spending the right money in the right place, or actually we should be allocating more of this to this particular activity. Because I guess that's the bit at the moment that doesn't feel clear." (Commissioner)

5.3.3 The feasibility of commissioning different specialist palliative care services in different ways

One commissioner indicated that it was very unlikely they would adopt different commissioning approaches for different hospices, as this would significantly increase the workload for commissioning organisations and have associated costs. They went on to suggest that the feasibility of using the currency was reliant on it becoming a mandated and associated with a national tariff.

"You can put it in the contract but, nevertheless, if this was going to work it's got to be done at a national level. I think the playing field is so uneven across the country so the only way you're ever going to get any kind of sensible comparative would be to do it as a national tariff." (Commissioner)

5.3.4 The niche nature of children's palliative care

One commissioner highlighted that not only was children's palliative care uniquely different to adult palliative care but that the numbers involved in the commissioning of children's palliative care were too small to derive meaningful or helpful data.

5.3.5 Changes within the wider commissioning environment

Clearly, since the original review of funding in palliative care took place in 2011 the health commissioning structure and environment has changed considerably with the creation of CCGs and the transfer of public health responsibilities to local authorities. A key issue was raised that the creation of a national currency and the desire for greater equity in the funding of palliative care across the country, appears to be at odds with the current move towards more localised commissioning.

"Of course, these things change, how does localism work with equity? All these kind of issues just need to be worked through."

Agendas have moved on and current developments in commissioning appear somewhat at odds with the national currency idea. A commissioner raised the point about the move towards **localism and block contracts**. A further point about the currency was raised in terms of where it sits in relation changes to commissioning processes with regard to the **integration of health and social care** commissioning and other development such as personal budgets:

"This model does not allow for integrated commissioning between health and social care."

"Of all the different ways that people can be funded through health and social care, how does this mechanism fit in? So it's all that kind of continuity, so it still has a personal budget, how does that work. Just how does it all fit?"

One commissioner for an adult hospice was concerned that that palliative care would be unaffordable using any potential tariff based on the currency; a point which was echoed by the Chief Executive of the same hospice.

"I think my main concern would be that it becomes unaffordable. That would be my main concern, yes." (Commissioner)

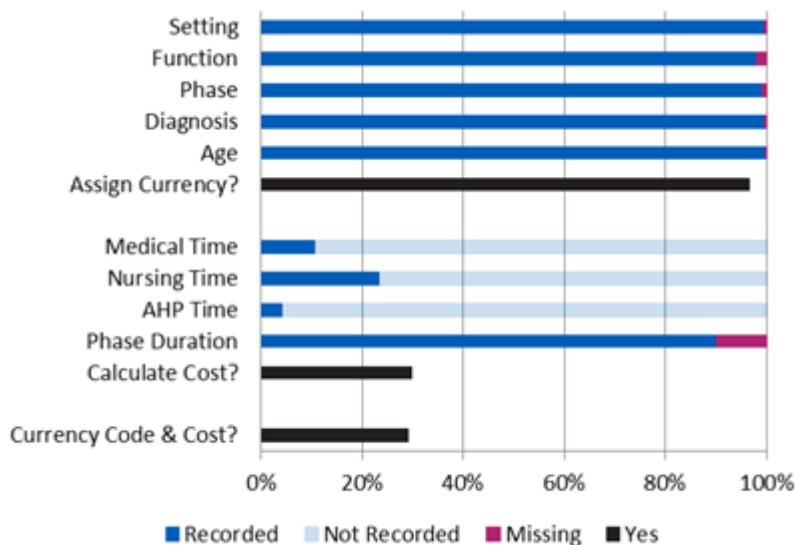
5.4 Quantitative testing

This work stream was focused on validating the analytical robustness of the currency and testing possible adaptations. Providers were asked to return data on current service provision and the associated resource usage. Most of the organisations that took part in testing the currency were encouraged to do so by a data champion. Each registered provider received a data collection guidance document, data collection template and tools.

5.4.1 Data Completeness

Data were in the end collected from 21 providers for adult specialist palliative care and 5 providers of specialist palliative care for children and young people.

Data were provided for 17,487 phases for 8,699 adult patients and 1570 phases for 588 children and young people. Data completeness is very high for, setting, phase,



function⁵, diagnosis⁶, and age⁷ enabling a currency to be assigned to 16,881 phases, 97% of adult phases and 95% of children and young people phases.

Data completeness on medical time, nursing time, AHP time, resource time and equipment for the duration of the phase was low. A cost could

⁵ Not required for hospital in-patient or community/outpatients where Phase = Dying

⁶ Only required for hospital in-patients.

only be calculated for 30% of adult phases (5220) for adults. and 32% of children and young people phase (508).

9 of the 21 providers for adult care provided data that could be used to cost the phases. for six of these more than two-thirds of their phases could be costed, and 87% of all costed phases were from four providers.

A robust analysis of the costs of each phase requires a sufficient sample size providing the costs associated with each currency unit. This was only the case for adult acute inpatient care, but not for non-inpatient and hospices. It was also not the case for any setting for children and young people.

The sample size for adult acute in-patients was sufficient for an analysis of cost and comparison with the palliative care funding pilot data.

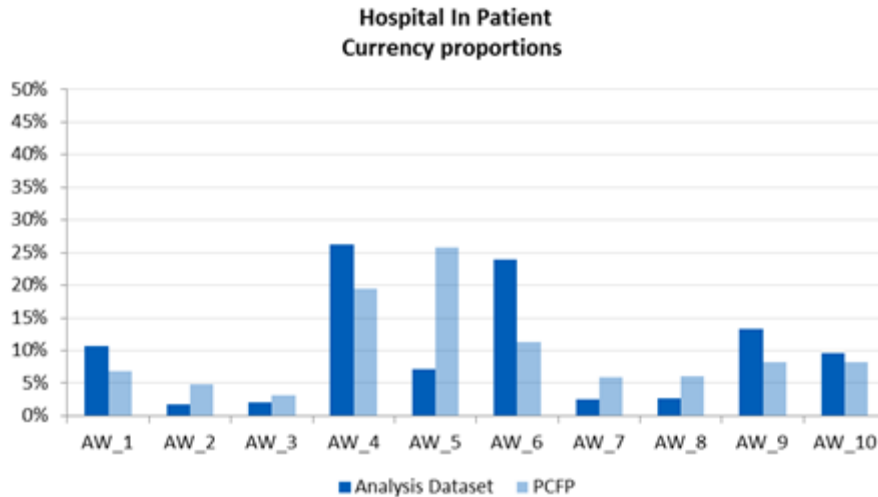
Adult hospice in-patient s In contrast presented a small number of phases with cost data for each currency unit. This presented a significant risk that any analysis of costs could be skewed by a small number of patients with atypical costs. For this reason, an analysis of costs was not undertaken.

Similarly, the data needed to test our cost assumptions for non-bed and community services currencies were available for just 15% of phases. The small number of phases for many of the currency units carries the same risks outlined for adult hospice in-patients and therefore, no analysis of costs was undertaken.

For the three settings of care for children and young people, data were available for 136 phases of acute hospital in-patients, 117 phases for hospice in-patients, and 238 phases for non-bed based and community services. The number of currency units with costs was too low for meaningful analysis as they were not likely to be representative of typical costs for example 67% of phases for non-bed based and community services were for one currency unit.

5.4.2 Comparison with palliative care funding pilot data – adult acute in-patients

The percentage of phases with cost by currency unit between the adult acute in-patient testing data and the same setting in the palliative care funding pilot data was compared.



■ 2015-16 Testing data ■ Palliative Care Funding Pilot data (PCFP)

There are large differences (>10 percentage points) in the proportion of phases assigned to two of the currency codes compared with the original PCFP work. These are unstable 1+ diagnoses (AW_5), where there are fewer in the analysis dataset and deteriorating 1 diagnosis (AW_6) where the opposite is the case, with more in the analysis dataset.

The 4,369 costed phases were all submitted by 5 of the participants. One of these participants (AM) also took part in the PCFP. AM submitted over a third of the costed phases in the most recent collection and 12% of the 3,651 phases in the PCFP.

Provider	Patient s	Spells	Phase s	Spells /Patient	Phase s/Spel l	Average Phase Duration	% of Phases
AB	202	249	651	1.2	2.6	3.6	15%
AM	1,064	1,234	1,517	1.2	1.2	8.9	35%
AY	228	229	326	1.0	1.4	7.7	7%
BA	446	484	702	1.1	1.5	6.8	16%
BC	792	883	1173	1.1	1.3	5.8	27%
Total	2,732	3,079	4,369	1.1	1.4	6.9	100.0 %

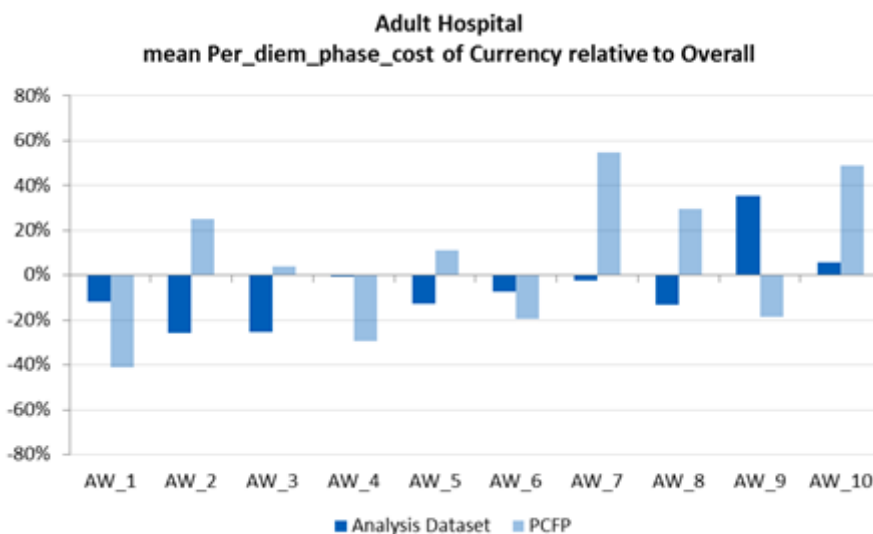
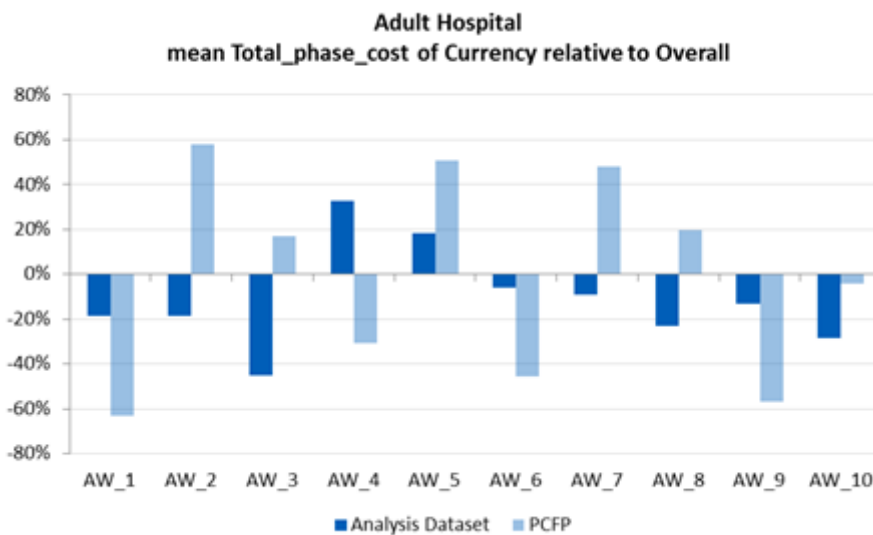
The different shares of all costed phases from provider AM between the analysis dataset and PCFP (35% and 12% respectively) needs to be borne in mind in the following section comparing the costs of the phases. In the analysis data set, overall costs will be influenced far more by provider AM than in the PCFP data set.

The costs identified for each currency unit were significantly lower than PCFP, but differ less between currency units than the PCFP data, and have a wider variation within each unit than the PCFP data.

Per diem costs were also lower than for the PCFP, and had wider variation within each unit and differed less between units.

There are several possible reasons for the differences as observed, including different data collection methods. The PCFP collected linked data across local health economies, the 2015-16 testing collected data from individual volunteer providers. Also, the use of staff activity as a proxy for total resource use in the 2015/16 testing may have contributed to lower costs being recorded.

The mean cost for each currency was compared with the mean cost of all currencies. This was done for both total phase costs and per diem phase costs. In both cases, the 'cost relativities' were found to be markedly different from those for the PCFP data. This confirms that the costs have a different pattern and ranking across the currency units between the analysis data set and PCFP.



The 'cost relativity' comparison was repeated using Currency AW_1 (Phase = Stable, Diagnosis = 1, Aged <75/75+) as the index cost. Once again, they were found to be markedly different from those for the PCFP data.

Undertaking the same investigations for provider AM, common to both the analysis and PCFP data sets, also showed marked differences between the two data collections. Cost are lower, have a wider variation and a different ranking between currency units). Currencies with small phase counts (<40) were excluded).

The differences between the cost data for the two data collections do not permit any safe conclusions to be drawn at this stage, with regard to the validity or otherwise of the cost weightings assigned to the currencies developed in the PCFP.

It has been suggested that 'secondary diagnoses' should be removed from the currency definitions. The secondary diagnoses data item adds information in the definition of currency codes for:

- Stable, 75+
- Unstable
- Dying

Using total phase costs, a comparison of the means and 95% confidence intervals for currency units with and without a secondary diagnosis shows including this data item produces currencies that are significantly different for some phases for adult acute hospital inpatients

The costs of AM_9 (dying 1 diagnoses) are statistically significantly different from the costs of AW_10 (dying, 1+ diagnoses) as the mean total phase costs for AW_9 falls outside the 95% confidence Intervals for AW_10, and vice versa. The costs are also significantly different between AW_4 and AW_5.

The costs are not statistically significantly different between AW_1.1 and AW_2, between AW_1.2 and AW_3, between AW_6.1 and AW_7, and between 6.2 and 8.

This analysis would suggest that removal of the secondary diagnoses data item from currency code definition should only be considered for phases in the deteriorating phase (AW_6, AW_7, AW_8).

Further factors affecting relative costs between currency units has not been undertaken using the latest data collection because of the limited sample sizes and unexplained differences with PCFP.

There was insufficient data submitted to consider the impact of transition for young people to adult services within the currency model. The currency model will be introduced as is further analysis of data collected and submitted between April 2017 and March 2019 will be used to consider these issues again.

6 Local and National Data flows

6.1 Palliative care clinical data set

In tandem with the work that was done by NHS England in developing the palliative care currency, Public Health England developed a Palliative care clinical dataset for Adults funded by NHS England. An evaluation of the pilot and guidance for dataset have been published and are available through www.endoflifecare-intelligence.org.uk/resources/publications/pccdseval and www.endoflifecare-intelligence.org.uk/resources/publications/pccdseval

The evaluation contains a useful review conducted by the technical pilots sites of how easy it was to collect and record the different items of data covered by the data set.

NHS England together with Public Health England and NHS Digital are looking at ways in which the work done of the palliative care clinical data set can be incorporated into or used to inform the development of nationally mandated clinical data sets within the Five Year Forward View development framework. This will include ensuring key outcome measures are incorporated in SNOMED to simplify coding and data entry.

7 Conclusions

Quantitative data testing confirmed the currency as analytically robust. There were some differences in distribution against currency units with each setting when compared with the palliative care funding pilot data. A number of factors may have been at play:

1. Individual organisations rather than linked data across local health economies were submitted.
2. Small sample sizes of phases against each currency unit
3. The dominance of a small number of organisations in particular settings

Cost analysis was only possible for adult acute in-patient settings the outcome of which was in-conclusive. Because of the potential risk that the small number of providers who submitted cost data were not truly representative of the sector as a whole.

We were unable to draw an conclusion regarding the need for a separate currency for transition of young people to adults as there was insufficient data submitted or identified.

Qualitative Testing had three questions to answer, is the currency clinically meaningful? Is it practical? Is it useful to the commissioning of services?

Feedbacks from the palliative care funding pilots, engagement events, from the palliative care clinical data set technical pilots and from our testing in 2015-16 suggest that the currency is clinically meaningful. Although concerns were expressed about the potential for inconsistency of interpretation of phase of illness across organisations was raised, analysis of the data suggests a reasonable level of

consistency was achieved even by those organisations relatively new to the language of the currencies.

Concerns about the administrative burden in relation to funding for appropriate IT infrastructure and staff and the need to embed data collection within the culture of the organisation, suggest the degree to which an organisation felt the currency was practical to implement depended on their ability to adapt. Data collection burden in terms of the maximum number of data items collected has been halved from the pilot to 2015-16 testing

From the feedback we received it was generally felt that it was too early to tell how useful the currency would be in the commissioning process, providers needed to develop their own understanding of its benefits in order to be able to express and illustrate a narrative to commissioners that meet their needs.

Based on all the evidence we have available to us the decision was taken to publish the currencies as they stand without variation with the 2017-19 Tariff. Providers and commissioners may if they choose use the currencies from April 2017.