



Joint statement from NHS England and Public Health England: update on development of the Palliative Care Clinical Data Set and Palliative Care Currencies

Palliative care clinical data set

In September 2014, we published a joint statement about our plans to work together to explore the feasibility, options and costs of collecting individual-level adult palliative care data nationally. Since then, we have worked with an Expert Reference Group consisting of clinicians, researchers, data experts, commissioners and people with personal experience, and colleagues from 11 pilot sites to develop and test such a data set.

The data set consists of:

- demographic details
- information about the complexity of the patient's condition
- activity information
- patient and carer outcomes

It includes data that supports the implementation of palliative care currencies (ie case-mix) for adults.

Our vision is for a single data set that captures activity, complexity and outcomes from adult hospices and specialist palliative care providers across a range of settings including inpatient hospice/hospital, and community. Our goal is to minimise the burden of data collection by identifying key data items that will make the most difference, incorporating data held in routine clinical and care records wherever possible.

This feasibility project is coming to a conclusion soon. We have learnt a great deal and early indications from the pilots are that this work has been worthwhile, and has shown benefits in improving both the process and outcomes of care.

Our next steps are to make the list of recommended data items available, along with accompanying guidance later in 2016. We will also publish an evaluation of the pilot, which will include lessons learned and recommendations for how to use the data for clinical, commissioning and business intelligence purposes.

As part of the feasibility work, we did explore the potential for a centrally managed national data collection and the development of a national information standard, but resource constraints mean that it is not possible to pursue this option at this time. Instead, local commissioners and providers will be able to adopt the dataset locally to support local commissioning and service improvement, if they choose to do so. Over the longer term we will also be looking to see how the palliative care clinical dataset can be incorporated into the development of other national datasets.

Palliative care currencies

In 2015, NHS England published a set of developmental currencies for palliative care for both children and adults. Over the past year, further testing of these currencies has taken place, with the team on this project working very closely with that of the Palliative Care Clinical Data Set (PCCDS) project. Later this year, NHS England will publish a definitive set of palliative care currencies – to help categorise people receiving palliative care according to level of complexity and resource need – which will be available for use from April 2017.

Data items relevant to the adult palliative care currencies are also contained within the PCCDS, so some providers and commissioners may wish to adopt the list of data items recommended by PCCDS as part of their plans to support collection and use of the currencies.

However, it has become clear that a ‘per-patient tariff’, which was the original model proposed by the Palliative Care Funding Review of 2011, may not be the only, or most suitable, funding model for palliative care. Over the next months, we will be engaging with our stakeholders to review and consider a range of approaches to palliative care funding for children and adults, all of which will require the use of the palliative care currencies as the ‘building blocks’ for any funding model.

Minimum Data Set (MDS) currently collected by NCP

It is very important that specialist palliative care providers and hospices continue to submit aggregate MDS data to the National Council for Palliative Care, which is commissioned by Public Health England and Hospice UK to conduct this data collection and analysis on their behalf. We would strongly urge those who have not hitherto engaged in this process to do so. This aggregated data continues to be a crucial part of the data and evidence for specialist palliative care services, which is essential for service development and commissioning.

In the meantime, Hospice UK and Cicely Saunders Institute will continue to work together to support the adult palliative care sector to use patient-centred outcome measures to improve care. The Cicely Saunders Institute is also studying whether and how implementing outcome measures has benefit for patients and families, to underpin the work with robust evidence.

All these organisations are working closely together to ensure the data collected is consistent and aligned as far as possible to serve different purposes.

What does this mean for providers of specialist palliative care services for adults?

We recommend that services collect the PCCDS to improve and more effectively measure outcomes and the quality of care, supported by the guidance to be published by PHE later this year. We also recommend that specialist palliative care services continue to collect the Minimum Data Set.

Guidance covering collection of currency data, including the use of PCCDS for this purpose, will be published in due course by NHS England.

What does this mean for commissioners?

Commissioners can expect to receive guidance later in 2016 detailing the currencies that can be adopted for use from April 2017 for both children and adults. They should be prepared to have discussions with their local palliative care providers about how and when to introduce these currencies as part of local commissioning arrangements. Commissioners should also consider adopting the wider data set, the PCCDS, as part of these commissioning arrangements.

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Further information

For further information about the palliative care clinical data set, contact Public Health England: neolcin@phe.gov.uk

For information about the palliative care currencies, contact NHS England: england.pcf@nhs.net

For information about the MDS, contact NCPC: mds@ncpc.org.uk

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