



## Plans for a new specialist palliative care data collection in England: what this means for provider services, commissioners, clinicians, patients and the public

25 September 2015

Public Health England (PHE) and NHS England are progressing plans to improve specialist palliative care outcomes and support commissioning through a new national data collection from April 2017. This follows a [joint statement](#) announcing the data collection in September 2014.

We are working closely with the [Health and Social Care Information Centre \(HSCIC\)](#), the [National Council for Palliative Care \(NCPC\)](#), [Hospice UK](#) and the [Cicely Saunders Institute](#) and others to develop this data collection.

### What has happened so far

We have consulted on, developed and are now testing a data set to collect demographic information about individual patients, service activity data, and outcomes as measured by a validated set of patient and carer questions.

We have recruited [11 pilot sites](#) to test the data collection. These include hospices and specialist palliative care services in acute and community settings. We are expecting the first data to be submitted in September 2015. An evaluation of the pilot will be published in 2016. [Advance notification](#) of the national information standard to support the data collection was published by the Standardisation Committee for Care Information on 9 September 2015.

### What this means for specialist palliative care provider services

#### Planning for data collection and submission

Electronic clinical data collection and submission from all specialist palliative care provider services in England will be rolled out from April 2017. Providers need to consider this plan and the timescales for implementation. Services that already have electronic clinical systems

in place should review these systems to determine whether they have the capacity to collect and submit patient-level data. Those services which do not have the required IT capacity, should develop plans for implementation. The data collection will include clinical outcomes data and services will need to consider staff training implications.

### **Maintaining the Minimum Data Set**

The **Minimum Data Set (MDS)** run by the National Council for Palliative Care will continue to run for the foreseeable future. We strongly recommend that organisations providing specialist palliative care continue submitting data to NCPC in order to keep this resource as comprehensive as possible.

### **What this means for commissioners**

The data will be a rich source of information for commissioners providing:

- comparative data across clinical commissioning group areas
- information about service complexity and quality improvement over time
- consistently recorded values grouped by currency units to inform commissioning discussions with providers

It will enable the effectiveness of quality improvement incentive programmes to be measured, identifying and leveraging service integration and co-operation across care settings.

Commissioners should start thinking about building a change programme into incentives and contracts from April 2016 onwards. This will allow smaller service providers time to embed the collection of outcome data in clinical practice, develop their IT systems and train staff. It may also be helpful for commissioners to facilitate IT developments and connectivity, particularly to support smaller service providers.

Commissioners encouraging providers to adopt and adapt local clinical assessment processes during 2016/17 will greatly speed up the national roll out and ensure early accuracy and consistency of data recording and collection.

### **What this means for clinicians**

Specialist palliative care clinicians should be aware of the plans for this data collection and consider the impact on their current way of recording clinical information. The proposed data set standardises the clinical outcomes information that is required for national collection. This may require a change from current practice. It should be noted that the data standard will only specify the data required for national collection and any additional data which the services wish to collect can be held in the clinical record.

## What this means for patients, carers and their families

The proposed data collection includes information from patients and their carers about the difference that care is making for them. This will be collected in a consistent way in all specialist palliative care provider services. We expect that this information will support clinicians in planning care and so improve care for individual patients and their families. In addition, national reporting of the outcomes of care may be useful to patients and their carers when making choices about their care.

## Next steps

The timescales for next steps may change and we will communicate any changes via the [National End of Life Care Intelligence Network](#) website:

- evaluation of the pilot data collection to inform decisions on the data collection – April 2016
- decision made to confirm approach – April 2016
- national information standard to be published – June 2016
- data collection to start – from July 2016 with full conformance by April 2017

## Further information

Further information about the proposed new data collection and the new information standard is available from [PHE's National End of Life Care Intelligence Network](#) website or by emailing [neolcin@phe.gov.uk](mailto:neolcin@phe.gov.uk).

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