



Joint statement from NHS England and Public Health England on plans for improving palliative care data

Working with National Council for Palliative Care, Help the Hospices and Cicely Saunders Institute

September 2014

Proposal for the national collection of individual level data

There is a recognition that data in the specialist palliative care sector needs to be more robust and comprehensive. There are a number of work programmes that record and use individual level palliative care data but there is currently no mechanism for bringing this data together across sectors to provide a full picture of the care provided to patients. We therefore have significant gaps in our understanding of end of life care provision and a lack of evidence on what is 'good' end of life care.

NHS England and Public Health England are working together to explore the feasibility, options and costs of collecting individual level palliative care data nationally. In this way we can better support clinicians, service providers and commissioners in improving quality of care and achieving better outcomes for individuals and their families.

Our vision is for a single data set that captures activity and outcomes from hospices and specialist palliative care services. Our goal is to minimise the burden of data collection by identifying the key data that will make the most difference and incorporating data held in routine clinical and care records wherever possible.

The data set will include demographic details, activity information and patient outcomes. It will have the potential to make a real difference to end of life care, providing clear information on the amount of palliative care activity, filling the gaps in available data and making it possible to link with other national data sets to get a more complete picture of care and to measure the impact of care delivery.

The purposes of the data collection will be to:

- improve care for individual patients and their families through reporting of patient centred outcomes
- inform patient choice and better support their preferences
- enable providers to streamline team working and better implement local, regional and national audit and quality improvement initiatives
- provide a more complete picture of palliative and end of life care provision nationally
- enable comparisons across services and benchmarking (with appropriate case-mix adjustment)
- facilitate more effective commissioning of palliative care services and support new funding models
- demonstrate effectiveness and cost-effectiveness of care
- underpin and inform future research

Current activity

Public Health England is leading the project to develop a core national data set and test its collection. Consultation on the data set has begun. Public Health England is working closely with NHS England, the Health and Social Care Information Centre (HSCIC), the National Council for Palliative Care (NCPC), Help the Hospices and the Cicely Saunders Institute. Public Health England aims to start testing data collection this financial year and, if successful, will work with NHS England to consider implementation of a national system. To avoid duplication, this data set would be fully aligned with the data collection requirements of the new palliative care funding system.

NHS England's review of data collection by specialist palliative, community and social care services will be used to inform the continued development of the palliative care funding system. The information gathering process for this project is now complete and analysis is underway. Development currencies will be introduced in 2015 as a first step in the process of introducing a future palliative care funding system. It is expected that this new system will require the national collection of individual level data. E-mail enquiries to England.PCF@NHS.Net

Public Health England, NCPC and Help the Hospices are also working closely to review the current minimum data set (MDS) for specialist palliative care. This is aggregated data compiled through an annual survey of specialist palliative care providers carried out by NCPC and commissioned by Public Health England. It is expected that the MDS will continue in the medium term and collection of this data will be improved. It is important that providers submit MDS data in order to strengthen the data and evidence for specialist palliative care services and to support the case for individual-level data collection.

Help the Hospices and Cicely Saunders Institute are working together to support the sector to use patient-centred outcome measures to improve care. The Cicely Saunders Institute is also studying whether and how outcome measures have benefit for patients and families, to underpin the work with robust evidence.

All of these organisations are working closely together to ensure the data collections are coordinated and do not place an undue burden on services.

What does this mean for services?

There are no immediate implications for service providers. As outlined in this statement, we are working towards having more robust data available in the future and this will mean changes to current reporting. However, nothing has been finalised yet and we will communicate further about the plans for a national individual level data set and changes to the MDS for next year.

If you would like to comment on our current activity or future plans or offer to participate in our work on data collection, please contact:

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