JOINT STATEMENT ON THE MINIMUM DATA SET FOR SPECIALIST PALLIATIVE CARE SERVICES

Public Health England (PHE), the National Council for Palliative Care (NCPC) and Hospice UK regret to announce that the National Minimum Data Set collection for Specialist Palliative Care Services (MDS) will no longer be collected with effect from 31 March 2017.

The reasons are partly financial, but perhaps more importantly, in order to remain relevant, the MDS would need extensive review and change. As it currently stands, it is not giving us the information we need at the right level.

We know that this may come as disappointing news to many people working or interested in specialist palliative care. The purpose of this joint statement is to explain these reasons in more detail and what follows from it.

About the MDS and the decision to stop the collection

NCPC set the MDS up in the mid 1990’s and has collected, analysed and published it every year since then. It has been the only national data collection for specialist palliative care. It covers both statutory and voluntary sector services. It collects aggregated demographic and diagnostic data about adults who access specialist palliative care providers and the various services they receive. It covers England, Wales & Northern Ireland. It is a voluntary collection, and the response rate has been about 66% for the last few years.

Over the years the MDS has been an invaluable source of data about specialist palliative care, and has been useful to many people, including provider organisations, commissioners, researchers, clinicians and policymakers. It has been an important foundation for collecting evidence and data about specialist palliative care, particularly in terms of key trends such as non-cancer activity, death rates in inpatient beds, and demographic patterns of who accesses different services.

However, the MDS was set up 20 years ago in a very different health and care system, and specialist palliative care services have also developed and changed significantly. If the MDS were to continue, it would need complete review and overhaul. We need data that informs us about individual outcomes as well as aggregated activity. Because it is aggregated, the MDS doesn't give us basic data on the total numbers accessing specialist palliative care, as individuals can be double-counted between services. Diagnostic categories need changing.
Some of what is collected is no longer relevant to future service planning, whilst important data about current services is not collected.

It has been funded through a variety of sources during its history. However, as we are all aware, the financial climate is very tight and unfortunately no funds have been identified either to develop the MDS into a more useful tool, or collect further data beyond the end of the current financial year. There is therefore no option but to end the MDS collection in its current format. We hope that a way is found to fund a relevant approach that is simple, meaningful and sustainable in the future.

**Future data collection for specialist palliative care**

All of our organisations believe that collecting and using good data intelligently is absolutely essential to the future of specialist palliative care, as well as to end of life care more broadly. We welcome the emphasis on this in the National Commitment for end of life care and the Ambitions framework for palliative and end of life care. There are now other initiatives which will enable data to be collected, and there is a need to maintain momentum and support for these. We hope that ways can be found to create a robust national survey that gives insight into quality and individual outcomes.

In December 2016 PHE published with NHS England the Palliative Care Clinical Data Set (PCCDS) Guidance and Definitions, and Evaluation report. NCPC and Hospice UK have worked closely with PHE and NHS England to help inform the development of the PCCDS. The PCCDS includes some of the data that would have been collected for the MDS. Although the PCCDS will not be collected nationally, which is a disappointment, we strongly encourage commissioners and providers at local level to use this individual data set to enable better informed discussions about local provision and outcomes.

Hospice UK is developing a specific data collection for hospices. There will be a further update on this in due course.

**What does this decision mean for the current MDS collection?**

The MDS is fully funded for the current year. This means that we have been able to collect data for service activity in the year ending 31 March 2016. Individual data providers have already received their own reports. Analysis is under way and a national report will be published in Spring 2017. We have also carried out an additional survey on support provided by specialist palliative care services to care homes. This will also be published in the Spring.

However, we will not be carrying out any further MDS surveys or collect data after 1 April 2017. This means that we will not be collecting data for specialist palliative care activity that took place during the current year 2016-17.

We know that many organisations will have been collecting data during 2016-17, in anticipation of making an MDS return after the year end, in April 2017. We are sorry not to be collecting your data and reporting back to you. However, we would expect that the data
you have collected will still be essential to you to inform your organisational reporting and business-planning as well as discussions with local commissioners.

Enquires and further information

Please e-mail mds@ncpc.org.uk if you have any enquiries or need further information about this.

Finally, but most importantly, we are extremely grateful to all organisations and individuals who have supported the MDS over the years and provided data to it, and would like to thank you for all the work and effort you have put in. Your support for the MDS has made an invaluable contribution to developing specialist palliative care in England Wales and Northern Ireland. We look forward to working with you on future data initiatives, as we consider how best to approach and work for a new national data collection.

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