New report captures the latest information on end of life care in England – the good and the bad

A report published today by the National End of Life Care Intelligence Network marks a significant moment in the progress of the Department of Health’s 2008 End of Life Care Strategy, which made clear the need to know more about the care people receive in their last year or months of life.

‘What do we know now that we didn’t know a year ago? New intelligence on end of life care in England’ pulls together facts and figures from a wide range of recent studies and surveys that provide an important insight into the pattern of death and dying in England.

The report highlights areas where improvements have been made as well as where further action is needed to improve care for people who are dying. The publication is divided into 16 categories ranging from place of care and death to latest trends in different settings, different disease types, costs, quality of care, workforce and public attitudes.

It highlights one of the continuing concerns about end of life care – that the majority of people would prefer to die in their usual place of residence, whether home or care home, or in a hospice. Yet over half still die in hospital.

But there are encouraging signs that things are changing. At the beginning of the 20th century almost everybody died at home, but by the end it was down to about 20%. It is only in the last few years that trends have started to reverse; the number of people dying in their home or care home is increasing while the number of people dying in hospital dropped from 58.3% in 2005 to 53.3% in 2010.

It is hoped that commissioners and providers of end of life care across both health and social care will use the knowledge contained within the report not only to take stock of what has been achieved but to plan and identify future priorities.

For example, the report highlights that on average people have two emergency hospital admissions in their last year of life, but that there is an important sub-group of people who are admitted on multiple occasions in their last year - sometimes 10 times or more. Now that this information is available, it is apparent that more needs to be done to help this group of people.

It is also clear from the section on costs within the report that further improvements in end of life care will not only benefit people who are dying and their families; it will also lead to significant savings for the NHS. A reduction in the number of emergency hospital admissions for example would not only improve people’s quality and experience of care, it would result in more cost effective care when there isn’t a clinical need for the person to be in hospital.
In addition, the report shows that most people who benefit from specialist end of life care services have a cancer diagnosis, which presents an inequality when considering that more than 70% of deaths are not from cancer. This is not surprising given that cancer tends to be more predictable in its trajectory than most other conditions, however, it does mean that more work needs to be done to identify all people who are likely to be in their last year of life, so that end of life care plans can be put in place in line with their preferences.

Claire Henry, director of the National End of Life Care Programme, said: “One thing that shines through in this report is that there are numerous factors which make a person more or less likely to receive high quality end of life care. For example, we know that those who are identified as being at the end of life at an early stage and are placed on an electronic palliative care co-ordination system are likely to get significantly better care.

“We must use this information as a lever for change to help identify and prioritise where to channel our efforts most effectively in order to significantly improve end of life care for all.”

Dr Julia Verne, clinical lead for the National End of Life Care Intelligence Network, said: “In the two years since the National End of Life Care Intelligence Network was created, we have made enormous progress. We now know much more about the factors that influence differences in where people die, for example age, socioeconomic factors and cause of death.

“We want professionals to be able to take our findings on board and use them to improve services for people who are dying. This is all about ensuring people at the end of life and their carers can have the care they really want, which will make such an important difference to people’s lives.”

ENDS

Notes to Editors:

1) For further information and to arrange interviews please contact Communications Lead Kate Henry on 07795 684 897 or kate.henry@eolc.nhs.uk.

2) The report, What do we know now that we didn’t know a year ago? New intelligence on end of life care in England, will be available to download from 8th May 2012 at: www.endoflifecare-intelligence.org.uk/resources/publications/default.aspx

3) The National End of Life Care Intelligence Network was set up in 2010 to collate and analyse data and information on end of life care in England, addressing previous limitations of lack of information. Further information can be found at: www.endoflifecare-intelligence.org.uk

4) The National End of Life Care Programme is an NHS organisation working across health and social care to improve end of life care for adults by implementing the Department of Health’s End of Life Care Strategy. Further information can be found at: www.endoflifecareforadults.nhs.uk.