



Public Health
England

Protecting and improving the nation's health

National End of Life Care Intelligence Network

What we know now 2014

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Public Health England

Wellington House

133-155 Waterloo Road

London SE1 8UG

Tel: 020 7654 8000

www.gov.uk/phe

Twitter: [@PHE_uk](https://twitter.com/PHE_uk)

Facebook: www.facebook.com/PublicHealthEngland

Prepared by: NEoLCIN

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The intelligence networks

Public Health England operates a number of intelligence networks, which work with partners to develop world-class population health intelligence to help improve local, national and international public health systems.

National End of Life Care Intelligence Network

The National End of Life Care Intelligence Network (NEoLCIN) aims to improve the collection and analysis of information related to the quality, volume and costs of care provided by the NHS, social services and the third sector to adults approaching the end of life. This intelligence will help drive improvements in the quality and productivity of services.

National Cancer Intelligence Network

The National Cancer Intelligence Network (NCIN) is a UK-wide initiative, working to drive improvements in standards of cancer care and clinical outcomes by improving and using the information collected about cancer patients for analysis, publication and research.

National Cardiovascular Intelligence Network

The National Cardiovascular Intelligence Network (NCVIN) analyses information and data and turns it into meaningful timely health intelligence for commissioners, policy makers, clinicians and health professionals to improve services and outcomes.

National Child and Maternal Health Intelligence Network

The National Child and Maternal Health Intelligence Network provides information and intelligence to improve decision-making for high-quality, cost-effective services. Its work supports policy makers, commissioners, managers, regulators, and other health stakeholders working on children's, young people's and maternal health.

National Mental Health Intelligence Network

The National Mental Health Intelligence Network (NMHIN) is a single shared network in partnership with key stakeholder organisations. The network will seek to put information and intelligence into the hands of decision makers to improve mental health and wellbeing.

Foreword

Since the National End of Life Care Intelligence Network (NEoLCIN) was established five years ago, our knowledge and understanding about the care received by people approaching the end of their lives, and those important to them.

This is the third 'What we know now' report. This illustrates the breadth of evaluation and research that is being carried out in a wide of topics, including public knowledge and attitudes, specialist palliative care services, primary care, end of life care in care homes and social care support for dying people. NEoLCIN aims to collate and report existing data and information on end of life care for adults in England to support the NHS and its partners to commission and deliver high quality end of life care, in a way that makes the most efficient use of resources and responds to the wishes of dying people and their families. Information is published on the NEoLCIN [website](#), in reports and in the scientific literature.

This report is a compilation of key findings and information that was produced by NEoLCIN and its partners during 2014. Although much of the research has been published previously, this is the first time it has been brought together in one place. We hope that this report will be useful to all those involved in palliative and end of life care, whether as care professionals, provider services, people using services, commissioners, researchers or policy makers and that it will help to inform and direct priorities for further investigation and quality improvement.

There remains a challenge to ensure that quality of care is as good as it can be, whatever the setting. The proportion of deaths that occur in hospital is continuing to fall but we must ensure that improving the experience of living and dying well wherever the person is, remains the central focus of our efforts. Much has been achieved. Much more need to be done.

Professor Bee Wee. National Clinical Director for End of Life Care. NHS England

Professor Julia Verne. Clinical Lead National End of Life Care Intelligence Network.
Public Health England

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Executive summary

This report is a compilation of key findings and information that was produced by NEOLCIN and its partners during 2014. Although much of the research has been published previously, this is the first time it has been brought together in one place. We hope that this report will be useful to all those involved in palliative and end of life care, whether as care professionals, provider services, people using services, commissioners, researchers or policy makers and that it will help to inform and direct priorities for further investigation and quality improvement.

We illustrate with this report the work being done to better recognise the needs of the dying and improve the quality of end of life care. Communication with both the dying and their carers together with effective planning and co-ordination of services are essential to that end. Surveys consistently report that most people would prefer not to die hospital and it is reassuring to see that the proportion of deaths that occur in hospital is continuing to fall. It is important, however, that the demands on community care to support the dying and their carers when they are at their most vulnerable 24 hours a day, seven days a week are recognised. There remains a challenge to ensure that quality of care is as good as it can be whatever the setting. Pain control for the dying is of particular importance to the dying person's loved ones and surveys indicate that pain management is not always managed well in a domestic setting.

What we know about need and trends in death

There were 473,552 deaths in England in 2013 and this number is projected to rise in the 2020s with increasing proportion of deaths in people aged over 85.

What we know about public attitudes

There is a growing understanding of what is most important to people approaching the end of life and a recognition that these priorities should direct quality improvement and quality measurement approaches.

What we know about place of death trends

Hospital remains the most common place of death in England, but the proportion of deaths that are in hospital is falling, and was less than half of all deaths in 2013. There is a better understanding of factors that impact on place of death such as marital status, underlying medical condition and access to palliative care services.

What we know about different disease groups

This section covers the knowledge about patterns of presentation, disease course and care provision for specific disease groups and shows the wide variation.

What we know about inequalities

Studies and data analysis shows that there are variations related to diagnosis, geography, age, ethnicity, culture, sexuality, place of death. For example people born in the south east of England have 14 more years living without disability than those from Liverpool or Manchester.

What we know about preferences for place of care and place of death

Meeting people's preferences for place of care and place of death is an important measure of the quality of end of life care. There is evidence that most people state that they prefer to die at home but there is variation in this and it should be recognised that people's preferences may change over time.

What we know about the costs of care

At present there is limited information about costs and comparable costs of care. To date most studies have focused on the costs of hospital care and the associated costs of shifting care to community settings and the indirect costs of informal end of life care have not been fully evaluated.

What we know about quality of care

The national VOICES survey provides information about bereaved carers' views on the quality of care given to their relatives in the last three months of life. The 3rd national survey in 2013 found that the overall quality of care as perceived by the bereaved has not changed significantly since the first national VOICES survey in 2011. Electronic palliative care co-ordination systems (EPaCCS) provide the facility to assess whether people's preferences for place of care are met. Real-time reporting of people's experiences of care can be a useful way to assess the quality of care.

What we know about health and wellbeing of people approaching the end of life and their carers

A holistic approach is required to take into account all dimensions of a person's wellbeing. This includes their physical, psychological, social, spiritual and cultural needs and those of their family and carers. There is growing recognition of the importance of community engagement in supporting people at the end of life and their families and that death, dying and bereavement is everyone's business.

What we know about hospital care in the last year of life

Around half of all deaths in England occur in hospital. Hospitals, therefore, have a core responsibility to deliver high-quality care for patients in their final days of life and to provide appropriate support to their families and carers. Research found that nearly

30% of current acute hospital in-patients die during the next 12 months and so hospital admission can be useful to support recognition of the last year of life.

What we know about specialist palliative care

A greater proportion of bereaved relatives rate quality of care and being shown dignity and respect highest in hospices than any other setting.

A high proportion of people receiving specialist palliative care services have a diagnosis of cancer. The proportion of people with conditions other than cancer being seen by specialist palliative care services is still low but continues to increase. The national audit of acute hospitals found only 21% of trusts provided access to face to face palliative care services seven days per week.

What we know about primary care and community services in the last year of life

The GP and the primary care team occupy a central role in the delivery of end of life care in the community. GPs have a key role in initiating discussions about end of life care but this is not happening often enough at present. Patients that are well supported at home are more likely to be able to die at home if that is their preference. The national survey of the bereaved (VOICES) suggests that the bereaved report significantly lower level pain management for patients at home compared to other settings.

What we know about care homes in the last year of life

There has been an increase in the proportion of deaths in care homes over recent years and this is an area where more insight is required. Approximately one third of people who die in care homes in England are temporary residents.

What we know about carers

Carers, those who provide unpaid support to a family member or friend, play an essential role in end of life care. They are not always receiving the support they need to cope with the overwhelming demands of caring for someone with a terminal illness.

What we know about care after death and bereavement

New guidance published this year includes guidance for families whose family member's death requires referral to the coroner from the Ministry of Justice, guidance on caring well for the deceased from the Human Tissue Association and new guidance on implantable cardiac defibrillator deactivation from the British Heart Foundation. A review of child deaths in England recommended that children are offered bereavement support following the death of a parent, carer or sibling.

What we know about end of life care education and training

Training about end of life care is important for all staff. The national audit of acute hospitals found that 82% of acute hospital trusts reported that they had provided some training on care of the dying but that it was only mandated for doctors in 19% of acute hospital trusts and for nurses in 28%.

Inclusion of death and dying in undergraduate training could help to change the current culture that considers death to be a medical failure.

What we know about co-ordination of care

Electronic palliative care co-ordination systems (EPaCCS) support patient choice, shared decision making, individual care planning and integration of care across sectors. A national survey carried out by PHE in 2013 found that about a third of clinical commissioning groups (CCGs) had operational EPaCCS, (30%, 64 CCGs). Early evaluation has found that people who have an EPaCCS record are more likely to die in their preferred place of death.

What we know about workforce

National surveys provide information about the specialist palliative care consultant workforce. The surveys report that much of the consultant workforce is female and work on a part time basis. The total number of consultants is continuing to increase year on year, although the rate of expansion is decreasing.

Introduction

Each year in England nearly half a million people die. Most of these people reach the end of their life after a period of increasing dependence on the care and support of others; friends, relatives, their wider community, health and social services. The duty to care well for those nearing the end of their life, respecting their wishes, treating them at all times with respect and ensuring their dignity is a significant responsibility for society.

The NEoLCIN works with partner organisations to collect, analyse and present end of life care intelligence, drawing together data and information from a range of sources. This report builds on 'What we know now 2013', published by the NEoLCIN in November 2013. It provides an update with new information and evidence about palliative and end of life care that has been produced by the network and our partners over the past year. We hope the information included in this report will help policy makers, commissioners, providers, researchers and others see the progress being made, identify the gaps and drive improvement.

We are always seeking to improve the information we deliver. You will find references to the original sources from which the key findings in this report are taken. All authors welcome queries, so please do get in touch. Please also send us feedback so we can continue to make our work as relevant and useful as possible – email neolcin@phe.gov.uk.

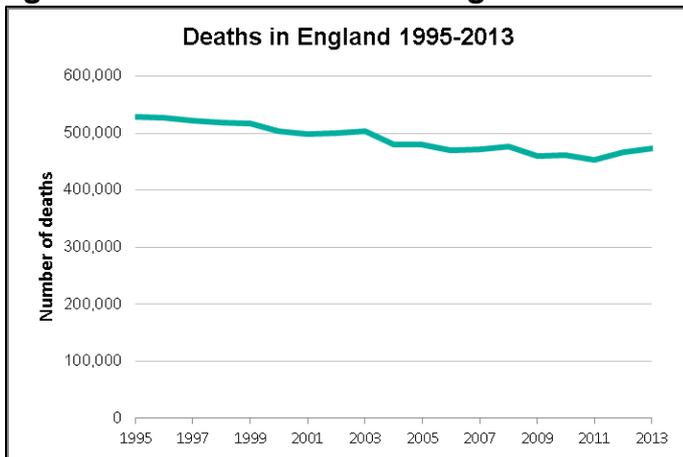
Death, dying and society

1 What we know about need and trends in death

Information about the numbers of deaths and future projections is important for those with responsibility for commissioning and planning palliative and end of life care services.

1.1 There were 473,552 deaths in England in 2013.

Figure 1: Trend in deaths in England



Source: Office of National Statistics (ONS)

1.2 Projections of the number of deaths in the future suggest that after a period of stability the number of deaths each year will be rising in the early 2020s.

Source: ONS 2012-based Subnational Population Projections for England

www.ons.gov.uk/ons/rel/snpp/sub-national-population-projections/2012-based-projections/rft-projected-coc.xls

1.3 In England and Wales 84% of deaths in 2013 were of people aged 65 or older and 39% were of people aged 85 or older. Almost half of women dying in England and Wales in 2013 (48%) were age 85 or older.

Source: ONS Death Registrations Summary Tables, England and Wales, 2013

www.ons.gov.uk/ons/publications/re-reference-tables.html?edition=tcn%3A77-317522

- 1.4 The number of people requiring palliative care each year in England has been estimated as 355,000 (Hughes-Hallett) and 63% of deaths (Murtagh) suggesting 294,000 in 2013.

Sources: Hughes-Hallett T, et al. Independent Palliative Care Funding Review.

www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_133105.pdf (accessed May 2012).

Murtagh FE, Bausewein C, Verne J, Groeneveld EI, Kaloki YE, Higginson IJ. How many people need palliative care? A study developing and comparing methods for population-based estimates. *Palliat Med.* 2014 Jan;28(1):49-58.

<http://pmj.sagepub.com/content/28/1/49.full.pdf+html>

- 1.5 The number of young adults (18 to 40) living with life-limiting conditions (LLC) in England is estimated to be 55,721, the prevalence of LLC in this age group per 10,000 has increased from 26.0 to 34.6 over ten years.

Source: Fraser Lorna, Miller Michael, Aldridge Jan, McKinney Patricia A, Parslow Roger C et al. (2013). Prevalence of life-limiting and life-threatening conditions in young adults in England 2000-2010: final report for Together for Short Lives. University of York.

www.togetherforshortlives.org.uk/assets/0000/6736/TFSLAdultReport2013Final.pdf

2 What we know about public attitudes

Understanding public perceptions, experiences and priorities is essential to inform end of life care services.

A reluctance to talk about death, dying and bereavement can impact on the way people experience a death. The **Dying Matters Coalition** was set up to help people talk more openly about dying, death and bereavement, and to make plans for the end of life. Talking about dying and planning for death makes it more likely that people die as they wish and also supports family and carers.

- 2.1 An international comparative study which explored people's priorities for treatment, care and information if faced with serious illness, has found most people would prioritise improving the quality of life for the time they have left. Common across all countries was the public's low priority for extending life regardless of health status.

Source: Higginson IJ, Gomes B, Calanzani N, Gao W, Bausewein C, Daveson BA, Deliens L, Ferreira PL, Toscani F, Gysels M, Ceulemans L, Simon ST, Cohen J, Harding R; Project PRISMA. Priorities for treatment, care and information if faced with serious illness: a comparative population-based survey in seven European countries. *Palliat Med.* 2014 Feb;28(2):101-10. doi: 10.1177/0269216313488989. Epub 2013 May 23.
www.ncbi.nlm.nih.gov/pubmed/23703237

- 2.2 In a similar study, when the public are asked to hypothetically consider their last year of life with cancer, they are not only concerned about medical problems, but also about being a burden to family and informal caregivers.

Source: Bausewein C, Calanzani N, Daveson BA, Simon ST, Ferreira PL, Higginson IJ, Bechinger-English D, Deliens L, Gysels M, Toscani F, Ceulemans L, Harding R, Gomes B; PRISMA. 'Burden to others' as a public concern in advanced cancer: a comparative survey in seven European countries. *BMC Cancer.* 2013 Mar 8;13:105. doi: 10.1186/1471-2407-13-105.
www.biomedcentral.com/1471-2407/13/105

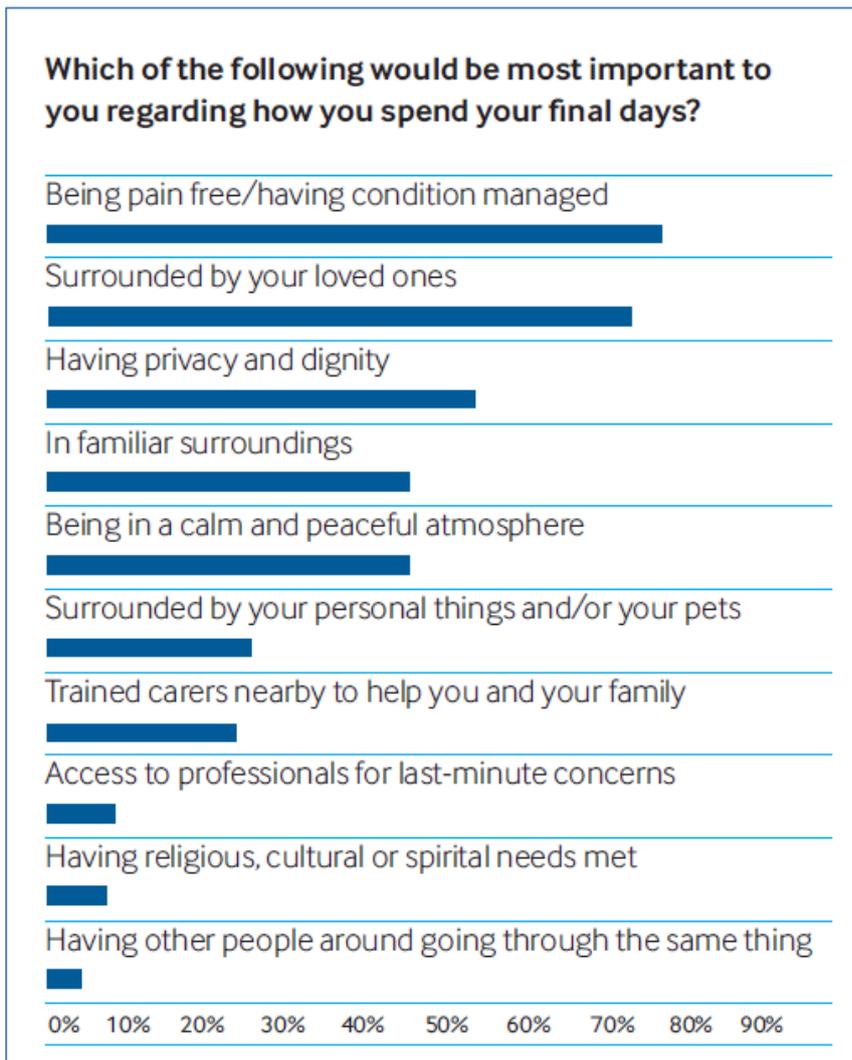
- 2.3 The quality of the patient experience of end of life care and factors that impact upon it were explored in a study carried out by Demos for Sue Ryder. It identified the following key messages:

- there are variations and ineffective use of best practice tools and processes for end of life care
- more people are dying with multiple, complex, non-cancer conditions
- the manner in which people enter the care system has a direct impact on the subsequent quality of their experience
- patient choice is not prevalent and consequently care is not personalised

Source: Paget, A & Wood, C (2013), Ways and Means
www.demos.co.uk/files/Ways_and_Means_-_web.pdf?1371658165

2.4 A second study carried out by Demos for Sue Ryder aimed to identify what was most important to people at the end of life. The top four priorities were found to be being pain free, surrounded by loved ones, having dignity and privacy and being in familiar surroundings.

Figure 2: Which of the following would be most important to you regarding how you spend your final days



Source: Sue Ryder, A time and a place: what people want at the end of life, July 2013.

People’s top priority – being pain free – is recognised as something home care cannot always deliver as well as other locations, but nonetheless, dying at home is the most popular choice. This suggests people are sacrificing the achievement of their top priority for the combined achievement of several of their other priorities. It is clear people feel that medical and practical forms of support are better in hospitals and care homes, while personal and environmental support are better in the home.

This same report explored perceptions of dying in different locations by comparing the opinions of people with and without first-hand experience of end of life care; it showed that:

- expectations of a more medical experience in care homes were proved wrong, while more personal and environmental factors were stronger than expected (although from a low base)
- in the absence of experience, peoples' expectations of hospital's ability to deliver the things that matter to them (with the important exception of pain relief) – the calm, dignified, loving death that people say they would like – are extremely low. These are confirmed with experience
- those who had experience of loved ones dying at home were slightly less positive about it than those who had not had that experience; in particular mentioning that dying at home creates complications and difficult experiences that no one anticipates
- there were very different perceptions about hospice care between those with and without previous experience of loved ones receiving hospice care, with some aspects more positive (calm, peaceful atmosphere surrounded by loved ones), and some more negative (availability of medical and professional support), than expected

Source: Sue Ryder, A time and a place: what people want at the end of life, July 2013.

www.sueryder.org/how-we-help/Policy-and-campaigns/Our-campaigns/Dying-isnt-working/A-time-and-a-place

2.5 A recent study suggests that although religious and spiritual beliefs might increase marginally as death approaches, they do not affect levels of anxiety or depression in patients with advanced cancer receiving palliative care.

Source: King et al (2013), Spiritual beliefs near the end of life: a prospective cohort study of people with cancer receiving palliative care. *Psychoncology* 2013 Nov 17; 22(11):2505-12. Epub 2013 Jun 17.

www.pubfacts.com/detail/23775823/Spiritual-beliefs-near-the-end-of-life:-a-prospective-cohort-study-of-people-with-cancer-receiving-p
2.6

2.6 The proportion of GPs reporting they had never initiated a conversation with a patient about their end of life wishes fell from more than a third (35%) in 2012 to a quarter (25%) in 2014, showing improvement.

More than half of the public (51%) who have a partner say they are unaware of their end of life wishes, which highlights the lack of open discussion even among family members.

Only 36% of British adults say they have written a will, just over a third (34%) that they have registered as an organ donor or have a donor card, 29% that they have let someone know their funeral wishes and just 6% that they have written down their wishes or preferences about their future care, should they be unable to make decisions for themselves.

Source: ComRes: NCPC Dying Matters Survey May 2014

[/www.comres.co.uk/polls/ncpc-dying-matters-survey](http://www.comres.co.uk/polls/ncpc-dying-matters-survey)

2.7 81% of the public think there should be a legal right to paid bereavement leave.

Source: ComRes polling of 4038 adults, November 2013.

www.dyingmatters.org/news/bereaved-workers-failed-employers

2.8 Almost a fifth of people surveyed in Northern Ireland had no understanding of the term palliative care. A repeated theme, borne out in this survey, was that having a close friend or relative accessing palliative care services was associated with increased awareness and familiarity with the concept and services.

Source: Sonja McIlfatrick, Felicity Hasson, Dorry McLaughlin, Gail Johnston, Audrey Roulston, Lesley Rutherford, Helen Noble, Sheila Kelly, Avril Craig and W George Kernohan BMC Palliative Care 2013, 12:34.
www.biomedcentral.com/1472-684X/12/34

2.9 Hospices are viewed very positively by the general public. More than two-thirds of people (69%) in a poll of 2036 adults carried out for Help the Hospices regard hospices as 'a place that offers compassionate care'.

Source: Populus. (2013) Attitudes to hospice care. [Fieldwork conducted 20 and 22 September 2013.]
www.populus.co.uk/Poll/Help-the-Hospices

3 What we know about place of death trends

3.1 Hospital remains the most common place of death in England, but the proportion of deaths that are in hospital is falling, and was less than half of all deaths in 2013.

Distribution of place of death in England, 2013 and 2004

	2013	2004
Hospital	48%	57%
Home	22%	18%
Care home	22%	16%
Hospice	6%	5%

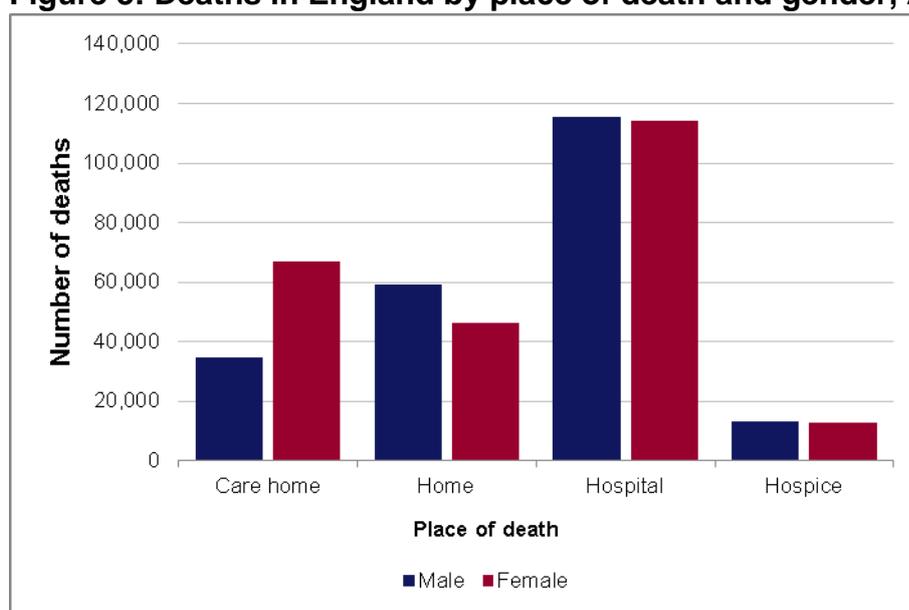
Source: NEoLCIN analysis of ONS Mortality data

3.2 Research has revealed that marital status is the second most important factor associated with place of death, after cancer type and therefore recommends that people who are single, widowed, or divorced should be a focus for end of life care improvement, along with known at risk groups such as haematological cancer, lung cancer, older age, and deprivation.

Source: Gao W, Ho YK, Verne J, Glickman M, Higginson IJ; GUIDE_Care project. Changing patterns in place of cancer death in England: a population-based study. www.plosmedicine.org/article/info%3Adoi%2F10.1371%2Fjournal.pmed.1001410

3.3 The gender balance within places of death varies. In particular home deaths are most likely to be male; care home deaths are predominately female.

Figure 3: Deaths in England by place of death and gender, 2013



Source: NEoLCIN analysis of ONS Mortality data

- 3.4 A population-based study that examined the relationship between place of death and underlying cause of death from neurological conditions found that those with Parkinson's disease are least likely to die at home and those with multiple sclerosis are most likely to die at home. People with Parkinson's disease or multiple sclerosis, with cancer as the underlying cause of death were more likely to die at home or in a hospice whilst people with neurological conditions with dementia as the underlying cause, were more likely to die in a care home.

Source: Sleeman KE, Ho YK, Verne J, Glickman M, Silber E, Gao W, Higginson IJ; GUIDE_Care Project. Place of death, and its relation with underlying cause of death, in Parkinson's disease, motor neurone disease, and multiple sclerosis: a population-based study.

<http://pmj.sagepub.com/content/27/9/840.full.pdf+html>

- 3.5 Two in five people with dementia die in hospital, indicating that the trend towards increasing hospital deaths for people living with dementia has reversed. A pattern of increasing hospital deaths for people with Dementia in England began to reverse in 2006. Less than 5% of dementia patients died at home or in hospice. Care home bed provision has been found to be the key to this trend reversal. Home/hospice death was more likely in affluent areas, for women, and for those with cancer as underlying cause of death, and less likely in the unmarried.

Source: Sleeman KE, Ho YK, Verne J, Gao W, Higginson IJ (2014) Reversal of English trend towards hospital death in dementia: a population-based study of place of death and associated individual and regional factors, 2001 to 2010

www.biomedcentral.com/content/pdf/1471-2377-14-59.pdf

- 3.6 The number of centenarians (people aged 100 years or more) deaths has increased by 56% in last ten years, between 2001 and 2010. Most died in a care home or in a hospital. 'old age' was stated on 75.6% of death certificates. Centenarians have a high risk of death in hospital from pneumonia.

Source: Evans CJ, Ho Y, Daveson BA, Hall S, Higginson IJ, Gao W (2014) Place and cause of death in centenarians: a population based observational study in England, 2001 to 2010.

www.plosmedicine.org/article/info%3Adoi%2F10.1371%2Fjournal.pmed.1001653

- 3.7 More people want to be in a hospice the closer they get to death – rising from 4% to 17% to 28% in the final year, months and days before death respectively. At the same time, fewer people want to be at home – from 91% to 75% to 63% over the same period. This shift is most dramatic for those with experience of hospice care:

- 11% of people with experience of hospice care say they would like their last year there, while 30% would want to spend their last weeks there
- at the very end (last days) of life, hospice becomes the preferred place to be for those with experience of hospices, 44% say they want their last days at home, and 55% in a hospice

Source: Sue Ryder, A time and a place: what people want at the end of life, July 2013.

www.sueryder.org/About-us/Policy-and-campaigns/Our-campaigns/Dying-isnt-working/A-time-and-a-place

3.8 The Gold Standards Framework (GSF) Centre analysis has found that organisations that become GSF accredited reduce their proportion of deaths in hospital and support more people to die in the place of their choosing for example:

- following GSF accreditation care homes have reduced hospital deaths by two thirds¹
- in primary care, GSF accredited practices the proportion of people dying in their preferred place of care increased from 43% to 72% and in some case studies hospital deaths have halved²

Source: 1. GSF CentreRound 10-13 2013-4 Accredited care homes evaluations.

Source: 2. GSF Accredited practices receiving Quality Hallmark award 2012-3 Key outcome ratios.

Available through: www.goldstandardsframework.org.uk/

3.9 A study that examined patterns in place of death among black and minority ethnic groups (BAME) in London found that country of birth impacts on place of death with BAME groups more likely to die in a hospital and less likely to die at home or in a hospice, however, it is not clear whether these differences result from patient-centred preferences, or other environment or service-related.

Source: Jonathan Koffman, Yuen King Ho, Joanna Davies, Wei Gao, and Irene J. Higginson. Mohammad Saleem, Editor (2014)

Does Ethnicity Affect Where People with Cancer Die? A Population-Based 10 Year Study PLoS One. 2014; 9(4): e95052.

Published online Apr 21, 2014. doi: 10.1371/journal.pone.0095052.

www.ncbi.nlm.nih.gov/pmc/articles/PMC3994011

4 What we know about different disease groups

- 4.1 An ONS study into leading causes of death in England and Wales 2012 reported:
- for women over 80, dementia and Alzheimer's disease was the leading cause of death in 2012, accounting for 16% of female deaths in that age group and 11.5% of all female deaths in 2012. Dementia and Alzheimer's disease was the second leading cause of death for men in this age group. Alzheimer's disease is the most common cause of dementia. Deaths from dementia and Alzheimer's disease are increasing as people live longer, with women on average living longer than men
 - for people aged 50 and over, the leading causes of death for both men and women are long-term diseases and conditions. Cancer of the trachea, bronchus and lung is the number one cause for women aged 50 to 64, accounting for 12% of deaths in this group in 2012. Breast cancer is the second leading cause of death for 50 to 64 year old women, accounting for 11% of deaths in this age group
 - heart diseases are the leading cause of death for men aged 50 and over, and for women aged 65 to 79 years. Heart disease was also the second leading cause of death for women over 80

Source Office of National Statistics

www.ons.gov.uk/ons/rel/vsob1/mortality-statistics--deaths-registered-in-england-and-wales--series-dr-/2012/sty-causes-of-death.html

- 4.2 Compared with a control group, people with dementia were less able to identify painful situations and used fewer categories to define their concept of pain - semantic memory for pain is diminished in dementia patients. This information is important for professionals considering pain management for people with dementia.

Source: When Pain Memories Are Lost: A Pilot Study of Semantic Knowledge of Pain in Dementia. Oosterman JM, Hendriks H, Scott S, Lord K, White N, Sampson EL. Pain Med. 2014 Jan 8. doi: 10.1111/pme.12336. [Epub ahead of print]. www.ncbi.nlm.nih.gov/pubmed/24401151

- 4.3 The impact of symptoms and psychosocial needs among people living with fibrotic interstitial lung disease and their family caregivers are profound, as found by a qualitative study. One of the major highlights was that supplemental oxygen requirement created angst for patients and informal caregivers, and prohibited patients and their carers from living the 'normal', carefree lives they desired.

Source: Bajwah S, Higginson I J, Ross J R, Wells A U, Riley J, Koffman J. The palliative care needs for fibrotic interstitial lung disease: a qualitative study of patients, informal caregivers and health professionals Palliative Medicine 2013;27:869-876. www.ncbi.nlm.nih.gov/pubmed/23885010

- 4.4 A Canadian cross-sectional interview-based survey found that knowledge and awareness of palliative care and related services among people with advanced chronic kidney failure is poor and if present often viewed negatively.

Source: Davison S, Jhangri G S, Koffman J. Knowledge of and attitudes towards palliative care and hospice services among patients with advanced chronic kidney disease. BMJ Supportive and Palliative Care 2014 (in press). <http://spcare.bmj.com/content/early/2014/06/10/bmjspcare-2013-000610.abstract>

- 4.5 There is evidence to support the benefits of systematic evidence-based approaches, such as Gold Standard Framework (GSF) to improve end of life care through earlier identification, more person-centred assessment and effective care planning for people with end stage renal disease, chronic heart failure and chronic obstructive disease.

Sources: Predicting palliative care needs and mortality in end stage renal disease: use of an at-risk register Kennedy Feyi, Sarah Klinger, Georgina Pharro, Liz McNally, Ajith James, Kate Gretton, Michael K Almond *BMJ Support Palliat Care* 2011;000165 Published Online First: 12 March 2013 doi:10.1136/bmjspcare-2011-000165

Beyond cancer. Identifying patients with chronic heart failure who may benefit from palliative care: a comparison of the Gold Standards Framework with a clinical prognostic model K K Haga, M A Denvir, J Reid, A Ness, M O'Donnell, D Yellowlees, S A Murray *BMJ Support Palliat Care* 2011;1:Suppl A8 doi:10.1136/bmjspcare-2011-00020.20

Predictors of survival in patients with chronic obstructive pulmonary disease receiving long-term oxygen therapy Sheonagh Law, Sara Boyd, James MacDonald, David Raeside, David Anderson *BMJ Support Palliat Care* 2014;4:2 140-145 Published Online First: 4 June 2013 doi:10.1136/bmjspcare-2012-000432

- 4.6 One in five men and one in six women will die within a year of diagnosis of head and/or neck cancer and that just over one in ten will die within six months. By implication, specialists making the diagnosis where prognosis is poor should consider early initiation of discussions with patients and their families about their views on end of life care and involvement of specialist palliative care. The NEoLCIN report also highlighted:

- the relatively young age at death and the impact that deprivation has on place of death with 44% of people from the most deprived areas of England dying in hospital compared with 38% from the least deprived
- conversely 21% of the most deprived die in hospices compared with 23% of the most affluent. This suggests geographical variations in the organisation and resources for end of life care that need to be addressed

Source: Head and neck cancers in England: who does from them and where do they die? National End of Life Care Intelligence Network, June 2014.

www.endoflifecare-intelligence.org.uk/resources/publications/head_and_neck

- 4.7 Only 20% of patients diagnosed with organ failure (heart, lung, liver or kidney) or dementia, either requested or were identified for palliative care before dying, compared to 75% of cancer patients.

Source: Zheng L, Finucane AM, Oxenham D, McLoughlin P, McCutcheon H, Murray SA. How good is primary care at identifying patients who need palliative care? A mixed-methods study. *European Journal of Palliative Care* 2013; 20: 216-222

www.palliativecarescotland.org.uk/content/publications/How-good-is-primary-care-at-identifying-patients-who-need-palliative-care--a-mixed-methods-study.pdf

5 What we know about inequalities

Studies and data analysis shows that there are variations related to diagnosis, geography, age, ethnicity, culture, sexuality, place of death.

- 5.1 There is geographical variation in disability-free life expectancy with people born in the south east of England having 14 more years living without disability than those from Liverpool or Manchester and people in Newham are expected to live nine more years with a disability than those in Richmond upon Thames.

Source: Sub-national health expectancies, Disability-Free Life Expectancy by Upper Tier Local Authority: England 2008-10. Released 1 May 2014 by Office for National Statistics.

www.ons.gov.uk/ons/rel/disability-and-health-measurement/sub-national-health-expectancies/disability-free-life-expectancy---subnational-estimates-for-england--2008-10/stb---disability-free-life-expectancy.html

- 5.2 Between 2012 and 2013, on average, 7% of new people accessing palliative care were described as non-white compared to 6.2% between 2011 and 2012. Although this represents an increase in the uptake of specialist palliative care services among the non-white population, it is still lower than would be expected given that a total of 14% of the population in England is reported as being of a non-white ethnicity.

Source: National Council for Palliative Care, National Survey of Patient Activity Data for Specialist Palliative Care Services, MDS Report for the year 2012-13. June 2014.

www.ncpc.org.uk/publication/MDS_Report_2012-13

- 5.3 Multiple Sclerosis disease progression is more aggressive among black Caribbean people compared to white British people. The former were also found to be more cognitively impaired and referred to feelings of extreme frustration and unresolved loss/confusion associated with their rapidly advancing disease compared to the latter.

Source: Koffman J, Gao W, Goddard C, Burman R, Jackson D, Shaw P, Barnes F, Silber E, Higginson I.J. Progression, symptoms and psychosocial concerns among those severely affected by Multiple Sclerosis: A mixed-methods cross-sectional study of Black Caribbean and White British people PLOS ONE 1 October 2013, Volume 8, Issue 10, e7543.

www.ncbi.nlm.nih.gov/pubmed/24098384

- 5.4 The quality and effectiveness of health and social care given to people with learning disabilities is deficient in a number of ways. People with learning disabilities are less likely to have access to specialist palliative care services, receive less opioid analgesia in their final illness and to have their deaths described as not being planned for, uncoordinated and poorly managed, as revealed by recent confidential inquiry.

Source: Confidential Inquiry into premature deaths of people with learning disabilities (CIPOLD). University of Bristol.

www.bris.ac.uk/cipold/reports/

- 5.5 Among people aged 100 years or more, dying in hospital is more likely to be associated with:

- pneumonia or heart disease than with dementia,
- having four or more contributing causes of death and;
- living in a deprived area (compared with those dying at ages 80 to 99)
- living in an area with a lower care-home bed capacity

Source: Evans CJ, Ho Y, Daveson BA, Hall S, Higginson IJ, Gao W, on behalf of GUIDE_Care project. Place and cause of death in centenarians: a population based observational study in England, 2001 to 2010. (IN PRESS) PLOS Med June 2014.

www.plosmedicine.org/article/info%3Adoi%2F10.1371%2Fjournal.pmed.1001653

Care Delivery

6 What we know about preferences for place of care and place of death

Meeting people's preferences for place of care and place of death is an important measure of the quality of end of life care. The end of life care strategy aims to support more people to die in their preferred place. Surveys and research indicate that home is the preferred place for many people.

6.1 The National Survey of Bereaved People (VOICES – Views of Informal Carers – Evaluation of Services) reveals that:

- only 32% of deceased people expressed a preference of where they would like to die. Of those who did, reported preferences for place of death were:

Home	79%
Hospice	8%
Care home	8%
Hospital	3%
Other	2%

- only half of the deceased who wanted to die at home actually died there
- about one-third who wanted to die at home, died in hospital

Source: National Survey of Bereaved People (VOICES), 2013. Published July 2014.
www.ons.gov.uk/ons/rel/subnational-health1/national-survey-of-bereaved-people--voices-/2013/stb---national-survey-of-bereaved-people--voices-.html

6.2 A systematic review exploring adult preferences for place of care at the end of life or place of death over 33 countries found evidence that most people prefer to die at home and that around four fifths of patients did not change preference as their illness progressed. The study also found indications that a preference for home may be less frequent amongst carers and older people and that sometimes although home is generally the ideal preference, circumstances may make this seem impossible. It should be noted that there was a substantial minority of patients and carers for whom home is not the first choice or who change their mind.

Source: Gomes et al. BMC Palliative Care 2013, 12:7 Heterogeneity and changes in preferences for dying at home: a systematic review
www.biomedcentral.com/1472-684X/12/7

- 6.3 People's preferences of place of care and place of death change can vary significantly over their final months with fewer people wanting to die at home – reducing from 91% to 75% to 63% in the final year, months and days before death respectively. Over the same periods more people want to die in a hospice the closer they get to death – rising from 4% to 17% to 28%.

Source: Sue Ryder, A time and a place: what people want at the end of life, July 2013.

www.sueryder.org/how-we-help/Policy-and-campaigns/Our-campaigns/Dying-isnt-working/A-time-and-a-place

- 6.4 Despite the preferences expressed in these surveys it should be recognised that hospitals are the preferred place of death for some people and not all hospital admissions at end of life should be viewed as negative.

Source: Boase S, Moran E, Barclay S (2014). The Community Care Pathways at the End of Life (CAPE) study – early findings. *BMJ Supportive and Palliative Care* 2014; 4 (Suppl 1); A26.

spcare.bmj.com/content/4/Suppl_1/A26.1.abstract

- 6.5 Understanding the preferences of health professionals who may have more insight into the experience of death may be useful. A survey of GPs, commissioned by National Council for Palliative Care (NCPC) was carried out this year and reported:

- 73% said given the choice they would want to die at home
- 19% said in a hospice
- 1% said in a nursing home/care home
- 1% said they would want to die in hospital
- 3% said in the home of a person close to them

Source: ComRes polling of 1003 GPs, April 2014.

www.comres.co.uk/polls/ncpc-dying-matters-survey/

The general public were also surveyed which confirmed earlier findings that the majority of people state that they would want to die at home:

- 72% of adults (general public) would want to die at home
- 10% in a hospice
- 2% in a nursing home or care home
- 6% in hospital
- 6% in the home of a person close to them

Source: ComRes polling of 2055 GB adults, April 2014.

www.comres.co.uk/polls/ncpc-dying-matters-survey/

- 6.6 A research project which looked retrospectively at the case notes of 1,127 patients who died under the care of the Marie Curie Hospice Edinburgh in 2009 and 2010 found that:

- three quarters (77%) of patients receiving specialist palliative care were willing to discuss their preferences for where they would like to die
- most people who had never spent time as an inpatient in the hospice wanted to die at home (79%), while the majority of those who had been a hospice inpatient – even if they had only been admitted once – wanted to die at the hospice (80%)

- researchers believe that this may be because patients in the hospice had more complex needs and/or less social support than those never admitted, or it may be because they were familiar with the hospice and the staff
- fewer than 1% of patients said that they wanted to die in hospital, but those who did not nominate a preferred place of death were nearly three times more likely to die there than those whose preferences were known
- of those who did express a preference, 85% died in the place of their choice

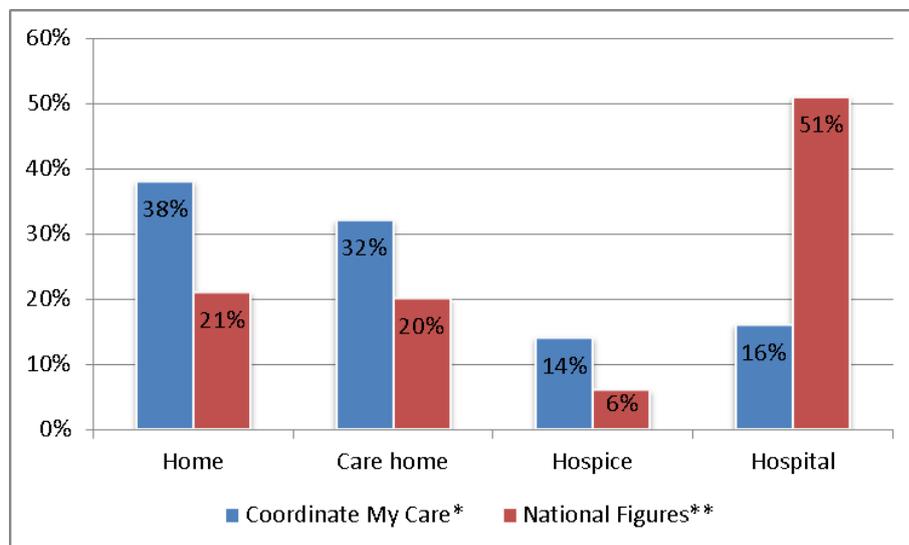
Source: Arnold E, Finucane AM and Oxenham D. Preferred place of death for patients referred to a specialist palliative care service. *BMJ Support Palliat Care*. Published online first 27 May 2013. doi:10.1136/bmjspcare-2012-000338 <http://spcare.bmj.com/content/early/2013/05/27/bmjspcare-2012-000338.full>

6.7 Patients receiving hospice at home services are likely to die in the place of their preference (88% achieved their preferred place of death).

Source: Richardson Heather. (2014) National organisations collaborate to learn more about the impact of hospice at home. *ehospice* April 14 [Reports on survey of care received by more than 4,800 patients across England and Wales conducted in 2013 by Help the Hospices and the National Association for Hospice at Home.] www.ehospice.com/uk/Default/tabid/10697/ArticleId/9882

6.8 This is also reflected in analysis of EPaCCS data for London’s Co-ordinate My Care - which found 82% of people that had both preferred and actual place of death recorded on their record, died in their preferred place.

Figure 4: Comparison of place of death for people with a record on London’s Coordinate My Care and national figures for England



* deaths recorded on Coordinate My Care 1 June 2012 to 31 May 2013

** annual average figures for England 2010 to 2012 (End of life care profile data NEoLCIN)

Source: Data to improve quality in end of life care: a new national information standard. Poster Presentation: Cancer Outcomes Conference. 2014. The Power of Information.

7 What we know about the costs of care

We face the demographic challenges of an ageing population, more complex health and care needs of an older, frailer population as people are living longer. It is essential that we understand the costs of care in order to deliver cost-effective services making best uses of resources. At present there is limited information about costs and comparable costs of care, however, we expect that the reports from the palliative care funding pilots' data collection will provide useful costing information.

- 7.1 A systematic review of the effectiveness of home palliative care services for adult patients with advanced illness and their family caregivers included appraisal of the current evidence on cost-effectiveness, identifying 16 studies that measured resource use. Of these, only six studies reported on total costs and there was inconclusive evidence on the cost-effectiveness of home palliative care compared to usual care. More work is needed to study cost-effectiveness especially for people with non-malignant conditions, assessing place of death and appropriate outcomes that are sensitive to change and valid in these populations, and to compare different models of home palliative care, in powered studies.

Source: Cochrane Review of Effectiveness and cost-effectiveness of home palliative care services for adults with advanced illness and their caregivers (Review). Gomes B, Calanzani N, Curiale V, McCrone P, Higginson IJ. Cochrane Collaboration 2014. <http://onlinelibrary.wiley.com/doi/10.1002/14651858.CD007760.pub2/abstract>

- 7.2 An observational retrospective study reviewed the case notes of 483 patients who died within one year of admission to two hospitals in England. The review found that 35 (7.2%) of these admissions were potentially avoidable, by direct admission to an alternative place of care, principally a nursing home. This would have better met patient preferences for place of death and would have reduced hospital costs by nearly £6 million per year. It also found that a 14% reduction in the length of stay of the same 483 patients could reduce hospital costs by nearly £50 million per year. It was acknowledged that reducing hospital costs would increase community care costs. This analysis was not carried out as accurate cost data were not available.

Sources: Palliat Med. 2013 Dec 23. [Epub ahead of print] Economic impact of hospitalisations among patients in the last year of life: An observational study <http://blogs.bmj.com/spcare/2014/04/25/shortcuts-29/> Gardiner C, Ward S, Gott M, Ingleton C

Palliat Med. 2014 May;28(5):422-9. doi: 10.1177/0269216313517284. Epub 2013 Dec 23. Economic impact of hospitalisations among patients in the last year of life: an observational study. Gardiner C1, Ward S, Gott M, Ingleton C. www.ncbi.nlm.nih.gov/pubmed/24367059

- 7.3 A literature review investigated the costs and cost-effectiveness of palliative care interventions over the period from 2002 to 2011, relative to some type of comparator or control. It found the main focus of these studies was on direct costs with little focus on informal care or out-of-pocket costs. Despite wide variation in study type, characteristic and study quality, it found consistent patterns in the results. Palliative care is most frequently found to be less costly relative to comparator groups, and in most cases, the difference in cost is statistically significant.

Source: Palliat Med. 2014 Feb;28(2):130-50. doi:10.1177/0269216313493466. Epub 2013 Jul 9. Evidence on the cost and cost-effectiveness of palliative care: a literature review. Smith S, Brick A, O'Hara S, Normand C. www.ncbi.nlm.nih.gov/pubmed/23838378

- 7.4 More than £90m in disability benefits is going unclaimed by people diagnosed with terminal cancer in the UK.

Source: Macmillan Cancer Support. Cancer patients lose out on millions of unclaimed benefits. www.macmillan.org.uk/Documents/AboutUs/Health_professionals/PCCL/primarycareupdates/RichPictureforPeopleattheEndofLife.pdf

- 7.5 Evaluation of Macmillan specialist palliative care services showed strong evidence that comprehensive end of life care can be provided at home with excellent outcomes for patients, carers and the health service. The results showed many more people able to receive care at home and to die in their preferred place; emergency admissions and patient stays in hospital reduced; and the total cost to the health and social care system of caring for people in the last year of life could be reduced by 20%. Further work is now underway to test the model in other contexts.

Sources: Noble B, King N, Woolmore A, Hughes P., Winslow M, Melvin J, Brooks J, Bravington A, Ingleton C. & Bath P A (2014) European Journal of Cancer Care. Can comprehensive specialised end of life care be provided at home? Lessons from a study of an innovative consultant-led community service in the UK. Article first published online: 15 April 2014 and full report. www.macmillan.org.uk/Documents/AboutUs/Research/Researchandevaluationreports/Midhurst-Final-overall-Report.pdf

- 7.6 An online survey of 1,504 UK adults responsible for planning a funeral and administering an estate within the last four years and 118 telephone interviews of funeral directors from across the ten UK regions was carried out by Sunlife UK. It found that the cost of dying for families and carers in 2014 has risen by 10.6% from 2013 and is now £8,427. The costs include funeral expenses - average cost £3,590, administration of the estate - average cost £3,004 and additional costs - average £1,833.

Source: Cost of Dying 2014. The 8th Annual Report. Sunlife www.sunlifedirect.co.uk/blogs-and-features/can-you-afford-to-die_-cost-of-dying-rises/

8 What we know about quality of care

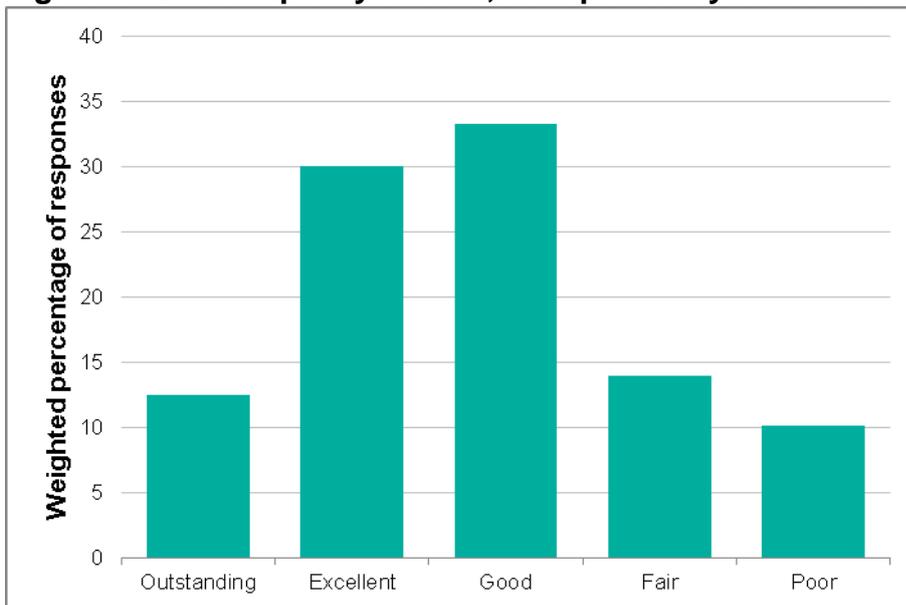
Improving the quality of end of life care in all settings, enabling people to live well and die in their preferred place are key national priorities.

8.1 The national VOICES survey provides valuable information about bereaved carers' views on the quality of care given to their relatives in the last three months of life. The survey has now been run for three years and was commissioned by the Department of Health in 2011 and 2012, and NHS England in 2013. It is administered by the Office for National Statistics (ONS).

The overall quality of care as perceived by the bereaved has not changed significantly since the first national VOICES survey in 2011 and that for 2013.

In 2013, ratings of the overall quality of care across all services in the last three months of life were reported by most respondents (96%). Of these 13% rated the care as outstanding, 30% as excellent, 33% as good, 14% as fair and 10% as poor.

Figure 5: Overall quality of care, as reported by bereaved relatives in 2013



Source: Office for National Statistics, Voices Survey 2013, Ratings of overall quality of care across all services in the last three months of life.

The key findings from the survey are:

- overall quality of care has not changed significantly between 2011, 2012 and 2013
- quality of care was rated significantly lower for people who died in a hospital, compared to people dying at home, in a hospice or care home
- for those dying at home, the quality of coordination of care was rated significantly lower in 2013 compared to 2012
- the dignity and respect for patients shown by hospital nurses and hospice nurses has increased between 2011 and 2013

- pain is relieved most effectively in the hospice setting (62%) and least effectively at home (18%)
- only half of people (50%) who express a preference to die at home, actually die at home

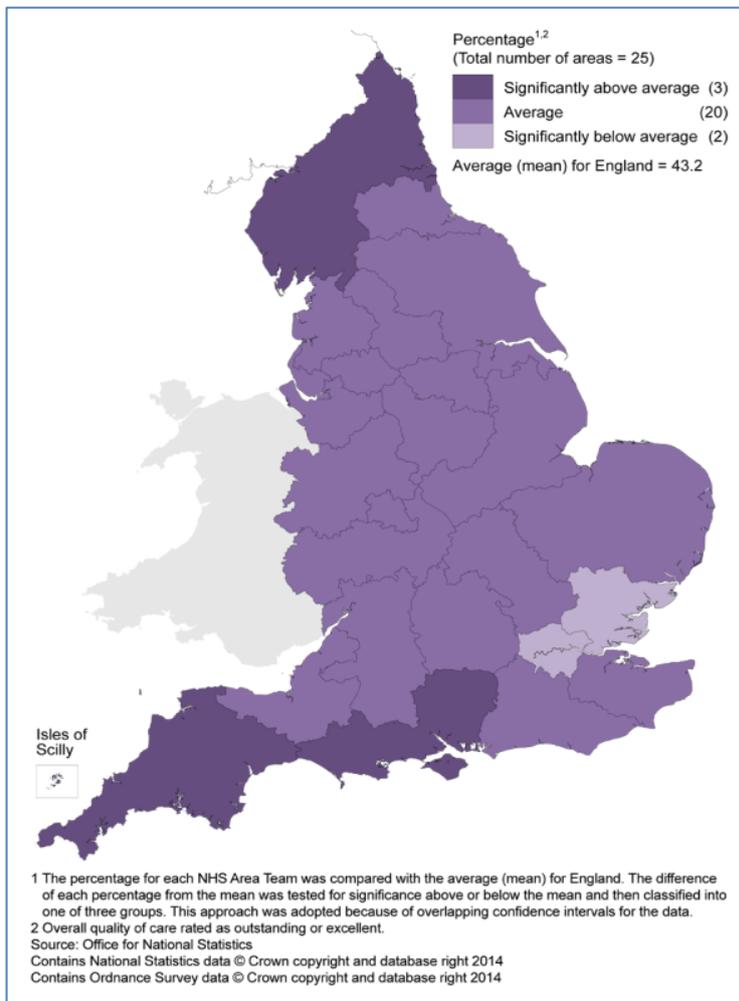
Source: Office of National Statistics VOICES Survey 2013

www.ons.gov.uk/ons/rel/subnational-health1/national-survey-of-bereaved-people--voices-/2013/index.html

8.2 Data from VOICES 2011 and 2012, has been combined to enable detailed analysis at NHS Area team level:

- overall, quality of care is consistent across the majority of NHS Area Teams in England, 43.7% on average rate quality of care as outstanding or excellent

Figure 6: Overall quality of care rated 'outstanding/excellent' , NHS Area Teams, 2011 to 2012



Source: Office for National Statistics

www.ons.gov.uk/ons/dcp171778_355031.pdf

- reports of 'always' being treated with dignity and respect are high across all medical professions, although numerous areas differ significantly from the national average
- relief of pain is managed least well at home and this is more geographically consistent than any other aspect of care assessed

- across NHS Area Teams, between 48% and 58% of people died in their preferred place of death, with the majority of NHS Area Teams showing no significant difference from the national average

Source: Office for National Statistics: National Survey of Bereaved People (VOICES) by NHS Area Team, 2011-2012
www.ons.gov.uk/ons/rel/subnational-health1/national-survey-of-bereaved-people--voices-/by-nhs-area-team--2011-2012/stb-national-survey-of-bereaved-people--voices-.html

- 8.3 Hospice care is rated the most positively for quality of care. 59% of people surveyed whose relatives died in a hospice rated their care as outstanding or excellent. Staff in hospices received the highest proportion of responses indicating the dying person was 'always' shown dignity and respect in the last three months of life (89% for hospice doctors and 86% for hospice nurses). Pain in the last 3 months of life is reported by relatives to be relieved most effectively in the hospice setting (62% completely all of the time) and least effectively at home (18% completely all of the time).

Being shown dignity and respect by staff is also highest in hospices (84% 'all the time' for hospice doctors and 82% for hospice nurses).

Source: Office for National Statistics. (2013) National bereavement survey (VOICES), 2012. Statistical Bulletin July 11
www.ons.gov.uk/ons/dcp171778_317495.pdf

- 8.4 The Leadership Alliance for the Care of Dying People have set out five priorities for care of a person when it is thought that they may die within the next few days or hours. As part of their work they produced a range of guidance and evidence to support health and care staff and commissioners and service providers. This includes:

- priorities of care for the dying person: duties and responsibilities of health and care staff
- report of rapid review on guidance of end of life care
- guidelines on intravenous fluids
- Cochrane reviews on the impact of morphine, fentanyl, oxycodone or codeine on patient consciousness, appetite and thirst when used to treat cancer pain, medically assisted nutrition for adult palliative care patients, medically assisted hydration for adult palliative care patients

Source: NHS Improving Quality website.
www.nhs.uk/improvement-programmes/long-term-conditions-and-integrated-care/end-of-life-care/care-in-the-last-days-of-life.aspx

- 8.5 There is evidence that electronic palliative care co-ordination systems (EPaCCS) are improving care. Since clinicians started using EPaCCS in Leeds there has been a significant increase in the numbers of patients identified with palliative care needs and who have an EPaCCS record. Clinicians report that GSF/palliative care meetings are now more streamlined and effective. EPaCCS has been found to benefit patients and clinicians in terms of more patients being identified and supported to realise their preferences for care and clinicians being more productive and proactive in their decisions making. There are added benefits that EPaCCS provides GP practices with evidence to support the QOF requirements of a palliative care register and similarly supports other healthcare organisations with their reporting requirements.

Source: The development of an electronic reporting mechanism to support the use of EPaCCS in clinical practice. Karen Henry, Suzanne Kite, Sarah McDermott, Naomi Penn, Westerman Paul. *BMJ Support Palliat Care* 2014;4:Suppl 1 A65-A66
doi:10.1136/bmjspcare-2014-000654.186.

- 8.6 People who receive hospice care value it enormously. Particular value is placed on the quality of the relationships that they have in this context, easy access to help and advice, the physical context for care (for inpatients) and support for families. There is a strong call from the public for greater access to hospice care and related information.

Source: Hospice UK Commission into the Future of Hospice Care. Learning more. London: Hospice UK, 2013
www.hospiceuk.org/what-we-offer/commission-into-the-future-of-hospice-care/commission-resources (select Future needs and preferences for hospice care: challenges and opportunities for hospices)

- 8.7 A real time reporting pilot project in Lincolnshire aimed to find more effective ways to collect, analyse and present data on the experience of people receiving care in their last year of life, as a basis for service improvement. The project provides evidence that the friends and family question (how likely are you to recommend this service to friends and family if they needed similar care or treatment?) is acceptable to people reflecting on care at the end of life.

The friends and family test gave an aggregate score of 75% of individuals who would recommend the service to their family and friends. Of the total number of participants, 96% of those receiving care responded to this question and 92% of the family/friend/carer of the person receiving care.

Source: Hospice UK, Listening differently to users: Assessing the feasibility and value of real-time reporting of the experience of people receiving care in the last year of life. April 2014.
www.hospiceuk.org/docs/default-source/default-document-library/listening-differently-to-users-report.pdf?sfvrsn=0

- 8.8 The validity and reliability of the post-bereavement questionnaire Evaluating care and health outcomes-for the dying (ECHO-D) was tested and found to be a valid and reliable instrument to assess quality of care for the dying and assess the effectiveness of interventions.

Source: Assessing the quality of care for dying patients from the bereaved relatives' perspective: the further validation of 'Evaluating Care and Health Outcomes – for the dying' (ECHO-D). Mayland CR, Williams EM, Addington-Hall J, Cox TF, Eilershaw JE. J Pain Symptom Manage. 2014 NaApr, 47(4): 687-96. Doi:10.1016/j.jpainsymman.2013.05.013. Epub 2013 Nov 5.
www.ncbi.nlm.nih.gov/pubmed/24210451

- 8.9 Surveys before and one year after implementation of the GSF in eight hospitals in England found an increase in the proportion of patients that were offered advance care planning discussions in hospitals supporting better quality of care aligned with patient preferences and improved communication with primary care teams.

Source: Improving advance care planning and end of life care in acute hospitals, using the Gold Standards Framework acute hospital programme. K Thomas, N Ahmad, F Battye, BMJ Support Palliat Care 2013;3:2 227-228 doi:10.1136/bmjspcare-2013-000491.9
spcare.bmj.com/content/3/2/227.3.abstract

9 What we know about health and wellbeing of people approaching the end of life and their carers

A holistic approach is required to take into account all dimensions of a person's wellbeing. This includes their physical, psychological, social, spiritual and cultural needs and those of their family and carers.

9.1 Loneliness can have profound health consequences for older people. There is evidence that feeling lonely increases risk of premature death by 14%.

Source: Social Relationships and Health: The Toxic Effects of Perceived Social Isolation, Prof. John Cacioppo, Social and Personality Psychology Compass Volume 8, Issue 2, pages 58–72, February 2014. University of Chicago.
<http://onlinelibrary.wiley.com/doi/10.1111/spc3.12087/abstract>

9.2 In its 'Commitment to Carers' NHS England has included support for bereaved carers and relatives.

Source: NHS England's Commitment to Carers. April 2014.
www.england.nhs.uk/wp-content/uploads/2014/05/commitment-to-carers-may14.pdf

9.3 Through provisions in the Children and Families Act the government has committed to extend the right to request flexible working to all employees after a 26 weeks qualifying period. This right came into effect 30 June 2014.

Source: Children and Families Act 2014
www.legislation.gov.uk/ukpga/2014/6/part/9

9.4 A small cross sectional audit (n=38) carried out in Shropshire looked at the benefits of encouraging compassionate communities to people near the end of their life. The introduction of volunteer visits to people at the end of life found the following reductions in service utilisation:

- reduced GP appointments 44%
- reduced A&E attendance 50% (8 to 4)
- reduced hospital admissions 35% (17 to 11)
- reduced home visits 30% (59 to 41)

Source: Paul Cronin, presentation, 3rd International Conference Public Health and Palliative Care, Limerick 2013.
www.publichealthpalliativecare.org/_literature_120215/Compassionate_Communities_in_Shropshire

9.5 A qualitative study was carried out using nine focus groups to explore the caring networks of people with a terminal illness who are being cared for at home. The results showed an increase in the size of the networks and that ties between the original members of the network strengthened. The qualitative data revealed the importance of both core and peripheral network members and the diverse contributions they make to care. The research supports the value of community development approaches to end of life care which can increase the supportive networks for people who are dying and

build social capital, rather than the normal trajectory of reduction in size of networks at end of life.

Source: Identifying changes in the support networks of end of life carers using social network analysis, Rosemary Leonard, Debbie Horsfall and Kerrie Noonan. *BMJ Support Palliat Care* doi:10.1136/bmjspcare-2012-000257. <http://spcare.bmj.com/content/early/2013/11/19/bmjspcare-2012-000257.full?rss=1>

- 9.6 An Australian population study aimed to define the people who actually provide care at the end of life found a substantial network of caregivers of all ages who are mainly invisible to the health team provide the majority of care. Extended family members (not first degree relatives) and friends accounted for more than half (n=1133/2028; 55.9%) of identified hands-on caregivers. These people came from the entire age range of the adult community. People with extended family or friends providing care, were much more likely to be supported to die at home compared to having a spousal carer.

Source: Uncovering an invisible network of direct caregivers at the end of life: A population study, Burns C, Abernethy A, Dal Grande E, Currow C. *Palliat Med* 2013 Jul;27(7):608-15. doi: 10.1177/0269216313483664. Epub 2013 Apr 15. www.ncbi.nlm.nih.gov/pubmed/23587738

- 9.7 There are many international examples of successful programmes of community development in end of life care.

Source: Salnow E, Kumar S, Kellehear A, eds. *International Perspectives on Public Health and Palliative Care* London: Routledge, 2012.

- 9.8 A study which explored what compromised difficult conversations with dying people and their families identified unmet needs which included:

- the absence of a road map or plan
- lack of a whole family approach
- lack of advice, navigation and signposting
- poor support with communication
- lack of practical support to enable people to remain in their usual place of residence
- a lack of 24/7 services
- poor access to emotional support at different stages of their journey

Source: Marie Curie Cancer Care, *Difficult conversations with dying people and their families*, March 2014. (Based on research by Oxford SM). www.mariecurie.org.uk/en-GB/Media/Media-resources/documents/Difficult-conversations-with-dying-people-and-their-families/

- 9.9 A mixed-methods study explored transition of care between settings for older people at the end of life. The study found deficiencies in care when people were transferred from one setting to another and identified a number of areas where intervention may enhance patient and family experiences. One of the key areas of concern was the organisation and way in which services were delivered which resulted in a reliance on family members to co-ordinate the input and fill the gaps between services.

Source: Barbara Hanratty, Elizabeth Lowson, et al. *Transitions at the end of life for older adults – patient, carer and professional perspectives: a mixed-methods study*. *Health Services and Delivery Research*. Volume 2 issue 17. National Institute for Health Research. June 2014. www.journalslibrary.nihr.ac.uk/__data/assets/pdf_file/0004/118642/ScientificSummary-hsdr02170.pdf

Care in different settings

10 What we know about hospital care in the last year of life

Around half of all deaths in England occur in hospital. Hospitals, therefore, have a core responsibility to deliver high-quality care for patients in their final days of life and to provide appropriate support to their families and carers.

10.1 Nearly 30% of current acute hospital in-patients will die during the next 12 months. A Scottish study following all in-patients in hospital on a single day in 2010 found:

- 2.9% had died by 7 days
- 8.9% by 30 days
- 16.0% by 3 months
- 21.2% by 6 months
- 25.5% by 9 months
- 28.8% by 12 months

Of the patients who died 32.3% died without leaving hospital ie 10% of current in-patients will leave hospital alive. Mortality rose steeply with age and was three times higher at one year for patients aged 85 years and over compared to those who were under 60 years (45.6% vs 13.1%; $p < 0.001$). The study followed 10,743 patients who were in-patients of an acute or teaching hospital on 31 March 2010.

Source: Imminence of death among hospital inpatients: Prevalent cohort study. David Clark, Matthew Armstrong, Ananda Allan, Fiona Graham, Andrew Carnon and Christopher Isles. published online 17 March 2014 Palliat Med. <http://pmj.sagepub.com/content/28/6/474>

10.2 Bereaved relatives reported that relief of pain 'completely, all of the time' was lower in hospitals (37%) than in care homes (45%) or hospices (63%), but higher than in own homes (18%).

Bereaved relatives reported variation in care provided by hospital doctors and nurses with 50% people always treated with respect from nurses and 58% people always treated with respect from doctors. Overall quality of care rated as excellent for 39% hospital doctors and 37% hospital nurses compared with 78% hospice care rated as excellent and 27% of out of hours care.

Source: Office for National Statistics: National Survey of Bereaved People (VOICES) by NHS Area Team, 2011-2012 www.ons.gov.uk/ons/rel/subnational-health1/national-survey-of-bereaved-people--voices-/by-nhs-area-team--2011-2012/index.html

10.3 A national audit of acute hospitals was carried out by the Royal College of Physicians in collaboration with the Marie Curie Palliative Care Institute Liverpool to explore the quality of care of people that died in hospital 2013 to 2014. The audit found:

- 87% of people dying in hospital had documented recognition that they were in last hours of days of life but communication of this to patients was undertaken in only 46% of those who were capable of participating in such discussions. Communication with family and friends occurred in 93% of cases
- an assessment of the need for clinically assisted (artificial) hydration was recorded for 59% of patients that died in hospital and discussed with the patient in only 17% of those who were considered capable of taking part in such discussions. Discussions with relatives and friends occurred in 36% of cases
- an assessment of the need for clinically assisted (artificial) nutrition was recorded for 45% of patients that died in hospital and discussed with the patient in only 17% of those who were considered capable of taking part in such discussions. Discussions with relatives and friends occurred in 29% of cases. Clinically assisted nutrition was in place in 7% of patients in hospital at the time of their death
- in keeping with national guidance, most patients that died in hospital (82%) were assessed five or more times in the final 24 hours of life
- 76% of bereaved relatives of people dying in hospital reported being very or fairly involved in decisions about care and treatment of their family member. 24% did not feel they were involved in decisions at all
- 63% of bereaved relatives of people that died in hospital reported that the overall level of emotional support given to them by the healthcare team was good or excellent
- only 47% of acute hospital trusts reported having a formal structured process in place to capture the views of bereaved relatives or friends

Source: National Care of the Dying Audit- Hospitals England 2013/14
www.rcplondon.ac.uk/resources/national-care-dying-audit-hospitals

10.4 A multi-site prospective study and consensus seeking exercise for people at risk of dying in the next 12 months found there are no sound metrics for measuring improvements in co-ordination, or for measuring the impact of such changes on patient outcomes. It recognised that many patients are cared for within general rather than specialist settings. Many generalists equate palliative care with the last few weeks of life. One of the key recommendations was that services should identify people near the end of their life to enable holistic assessments and care planning. Without identification it is not possible to assess needs and consequently plan care optimally with good co-ordination.

Source: Co-ordination of Care for People at Risk of Dying in the next 12 months: a multi-site prospective study and consensus seeking exercise. Final Report. NIHR SDO, HMSO, Southampton Mason B, Donaldson A, Epihianou E et al (2013).
www.nets.nihr.ac.uk/projects/hsdr/081813258

10.5 Care is poorly co-ordinated in generalist settings for patients in the last year of life, although those with cancer have better co-ordinated care than other patients. A model to improve co-ordination of care for all individuals approaching the end of life

must ensure that patients are identified in a timely way, so that they can be assessed and their care planned accordingly. This was a mixed methods study of three UK generalist clinical settings based on ethnographic observations followed by interviews of patients, their carers and a spectrum of clinicians and healthcare workers.

Source: Co-ordination of care for individuals with advanced progressive conditions: a multi-site ethnographic and serial interview study. Mason, Bruce, Epiphaniou, Eleni, Nanton, Veronica, Donaldson, Anne, Shipman, Cathy, Daveson, Barbara A, Harding, Richard, Higginson, Irene, Munday, Dan, Barclay, Stephen, Boyd, Kirsty, Dale, Jeremy, Kendall, Marilyn, Worth, Allison, Murray, Scott A.

The British journal of general practice: the journal of the Royal College of General Practitioners.

www.ncbi.nlm.nih.gov/pubmed/23972199

- 10.6 Testing use of the GSF prognostication tool in an acute hospital setting found that it can be used to support discharge planning. The tool was found to facilitate discussion and support patient needs being addressed and met in a timely manner. It facilitates communication and collaborative working with primary healthcare teams and so supports delivery of more seamless care across healthcare settings.

Sources: GSF Acute Hospitals Programme, Phase 2 and 3 Independent report by ICF GHK, Available from GSF Centre hospitals@gsfcentre.co.uk. Engagement with Prognostication. Incorporating the Gold Standards Framework into discharge planning.

Ann Griffiths, Alison Coackley, Agnes Noble, Susan Howarth, Heather Lee, Julian Hampton-Matthews, Margaret Foulkes
BMJ Support Palliat Care 2014;4:Suppl 1 A81 doi:10.1136/bmjspcare-2014-000654.230.

http://spcare.bmj.com/content/4/Suppl_1/A81.1.full.pdf

- 10.7 The national cancer patient experience survey (not limited to end of life) shows that of those patients who said it was necessary, only 54% said they had been given information about how to get financial help or benefits by hospital staff. Gaining such information can become a particularly pressing issue in end of life care.

Source: Department of Health. Cancer Patient Experience Survey 2013. Q27

www.quality-health.co.uk/resources/surveys/national-cancer-patient-experience-survey/2013-national-cancer-patient-experience-survey/2013-national-cancer-patient-experience-survey-reports

- 10.8 The learning from NHS Improving Quality's Transforming End of Life Care in Acute Hospitals Programme (Transform Programme) has informed new guidance on measurement of quality of care in the last days of life. This includes:

Factsheet 1: Sources of information for end of life care in acute hospitals

Factsheet 2: Clinical audit supporting quality improvement

Source: Considerations on assurance and quality improvement for care in the last days of life in acute hospitals. NHS Improving Quality. June 2014.

www.nhs.uk/media/2477322/consideration_on_quality_assurance.pdf

- 10.9 The positive impact for individuals and carers, staff and the wider system from hospital care quality programmes is demonstrated in a suite of case studies from the NHS Improving Quality Transform Programme.

Source: Case studies on NHS Improving Quality website.

www.nhs.uk/improvement-programmes/long-term-conditions-and-integrated-care/end-of-life-care/care-in-the-last-days-of-life.aspx

11 What we know about specialist palliative care

Specialist multidisciplinary palliative care teams include palliative medicine consultants, palliative care nurse specialists, and a range of expertise provided by physiotherapists, occupational therapists, dieticians, pharmacists, social workers and those who can give spiritual and psychological support.

- 11.1 A greater proportion of bereaved relatives rate quality of care in hospices as 'excellent' than any other setting. There is geographic variability between NHS Area Teams with the highest area rated as 'excellent' by 85% of people and lowest 68%.

A greater proportion of bereaved relatives report 'always' being shown dignity and respect from hospices than any other setting. There is geographic variability between NHS Area Teams with the highest scoring areas 'always' showing dignity and respect 91% of the time and lowest, 73%.

Source: Office for National Statistics: National Survey of Bereaved People (VOICES) by NHS Area Team, 2011-2012
www.ons.gov.uk/ons/rel/subnational-health1/national-survey-of-bereaved-people--voices-/by-nhs-area-team--2011-2012/index.html

- 11.2 The National Council for Palliative Care carried out an annual national survey of patient activity data for specialist palliative care services provided in 2012 to 2013. The key findings include: the national response rate (66%) is similar to recent years, but varied widely by country and strategic clinical network (from 89% in Cheshire and Merseyside Strategic Clinical Network down to just 33% in Northern England Strategic Clinical Network).

Approximately 29% of all deaths are from cancer. The proportion of people with conditions other than cancer being seen by specialist palliative care services is still low but continues to increase. This varies by care setting being highest in hospital support services where 27% of new patients seen had a non-cancer diagnosis and lowest in inpatients where only 12% of new patients had a non-cancer diagnosis.

The most common specifically recorded non-cancer diagnosis of people receiving care were:

- all specialist palliative care services; digestive cancers (ICD-10 C15-26)
- across all services except Outpatients; Chronic Respiratory disease (ICD-10 J40-70)
- outpatients; Other Heart and Circulatory conditions (ICD-10 I00-99 excl I50)
- the length of care for people with a condition other than cancer is shorter than for those with cancer. (12.6 days compared to 13.7)
- people aged under 75 have disproportionately higher access to specialist palliative care for the number dying (55.4%) than those aged over 85,

however, there has been an increase in the percentage of people over the age of 85 accessing services and, across all services, 14.9% were over 85 in 2013 compared to 8.8% in 2000

- the survey found large variation in the IT systems being used to record patient data across provider organisations, though three systems are used by 50% of respondents

Source: NCPC Minimum Dataset collection for 2012/13.

www.ncpc.org.uk/sites/default/files/MDS%20Full%20Report%202013_0.pdf

- 11.3 Research recommended the development of a continuous/rolling educational programme, incorporated into working practice for specialist palliative care teams to help them to better care for young adults with a terminal illness.

Source: Identifying the key elements of an education package to up-skill multidisciplinary adult specialist palliative care teams caring for young adults with life-limiting conditions: an online Delphi study. Stephanie Sivell, Victoria Lidstone, Mark Taubert, Catherine Thompson and Annmarie Nelson. *BMJ Support Palliat Care*. Online first 26 Mar 2014.

spcare.bmj.com/content/early/2014/03/26/bmjspcare-2013-000595.full

- 11.4 There is considerable variability in decision making between physicians about initiating/withholding and continuing/discontinuing certain medications in patients with end stage dementia (in Northern Ireland and the Republic of Ireland).

Source: Assessment of factors that influence physician decision making regarding medication use in patients with dementia at the end of life. Carole Parsons, Noleen McCorry, Kevin Murphy, Stephen Byrne, David O'Sullivan, Denis O'Mahony, Peter Passmore, Susan Patterson and Carmel Hughes. *International Journal of Geriatric Psychiatry*. Volume 29, Issue 3, pages 281–290, March 2014. Article first published online: 9 Jul 2013

<http://onlinelibrary.wiley.com/doi/10.1002/gps.v29.3/issuetoc>

- 11.5 A recent study recognised the value in having a seven-day-per-week palliative care service in an acute district general hospital.

Source: An evaluation of the activity of a 7-day, nurse-led specialist palliative care service in an acute district general hospital. *International Journal of Palliative Nursing* 2013 Mar; 19 (3): 148-51. Hall, Sally; Thompson, Jo; Davies, Andrew.

www.ncbi.nlm.nih.gov/pubmed/23665573

- 11.6 The national audit of acute hospitals found only 21% of trusts provided access to face to face palliative care services seven days per week. 73% provided face to face services on weekdays only.

Source: National Care of the Dying Audit- Hospitals England 2013/14

www.rcplondon.ac.uk/sites/default/files/ncdah_national_report.pdf

- 11.7 Joint working between specialist palliative care and breast medical oncology for patients with advancing metastatic breast cancer improves care in the last year of life, through a greater holistic approach to care, increased advanced care planning, fewer hospital admissions and greater community input leading to an increased quality of life.

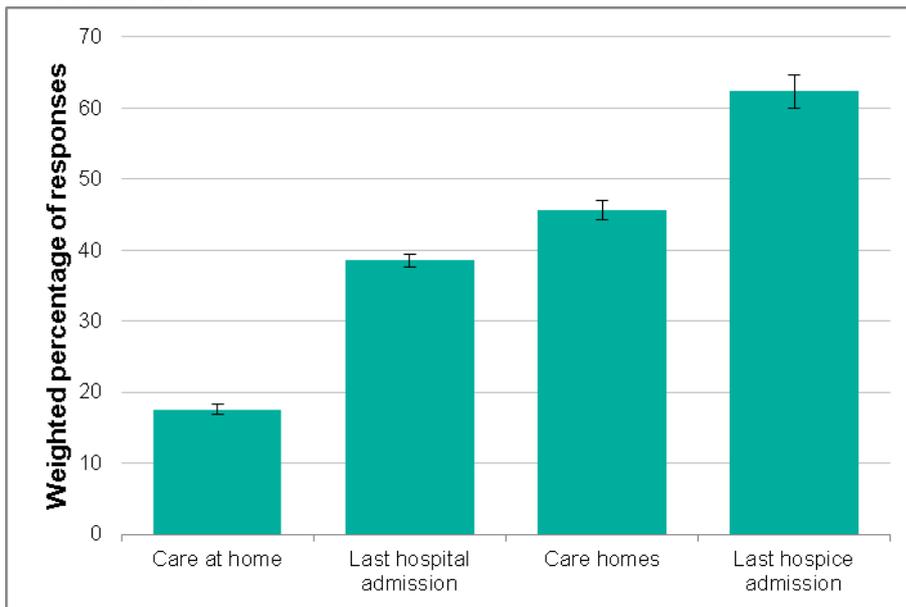
Source: *Oncology News*. Volume 8, Issue 6, Jan/Feb 2014 pg 189. Also won the Best Multidisciplinary Award, Nursing Network, Breast Cancer Care Organisation Nov 2013.

12 What we know about primary care and community services in the last year of life

Caring for people nearing the end of their lives and their families is part of the core business of General Practice and the GP and the primary care team occupy a central role in the delivery of end of life care in the community.

- 12.1 While majority of people would prefer to die at home, new evidence from the national survey of the bereaved (VOICES) suggests that the bereaved report significantly lower level pain management for patients at home compared to other settings.

Figure 7: During the last three months, how well was pain relieved – percentage of responses that report pain was relieved completely all of the time



Overall quality of care is least likely to be rated as excellent in out of hours services (25%) and GPs (33%) compared to other care settings.

Overall quality of care provided by district and community nurses is rated as excellent in 45% of cases, which is comparable to care homes (46%).

78% of district and community nurses and 71% of doctors always treat patients with dignity and respect.

Source: Office for National Statistics: National Survey of Bereaved People (VOICES) by NHS Area Team, 2013
www.ons.gov.uk/ons/rel/subnational-health1/national-survey-of-bereaved-people--voices-/2013/rft--table-1.xls

12.2 A systematic review and narrative synthesis have found that while a significant minority of frail older individuals find discussions on end of life unwelcome, the majority appreciate the chance to discuss them, however, most do not have this opportunity. Attitudes to the timing of these discussions were variable, but most perceived the risk of leaving them too late. Most doctors believed it was their professional responsibility to initiate discussions, but felt limited by time pressures and the absence of a precipitating event. A wide range of barriers were identified including the reluctance of family members to discuss end of life care, the passive expectation that someone else would decide on an individual's behalf, and significant uncertainty concerning future illness and decline.

Source: Sharp T, Moran E, Kuhn I, Barclay S. (2013) "Do the elderly have a voice? End of life care discussions with frail & elderly individuals: a systematic literature review & narrative synthesis. *British Journal of General Practice*: 63; 657 – 668. DOI: 10.3399/bjgp13X673667
www.ncbi.nlm.nih.gov/pubmed/24152480

12.3 A survey of volunteer support in specialist palliative care services in the UK provides an up-to-date picture of the role that volunteers play in supporting patients and their families:

- volunteers are often involved in hospice day care and bereavement services
- they may also provide some complementary therapy, beauty therapy, hairdressing and pastoral/faith-based care
- in 68% of services, volunteers were involved in counselling, in nearly half of organisations where volunteers were involved with inpatients, volunteers sat with patients in the last hours of life

Source: Burbeck R, Low J, Sampson L, Bravery R, Hill M, Ockenden N, Morris S, Payne J, Candy B. Volunteers in specialist palliative care: A survey of adult services in the UK. *Journal of Palliative Medicine*, Volume 17, Number X, 2014. Online at <http://online.liebertpub.com/doi/full/10.1089/jpm.2013.0157>.

12.4 The gap between diagnosis with a life-threatening illness and receiving palliative care is considerable and many patients receive this extra support on average only eight weeks before dying. This is often too late to fully benefit.

Source: Zheng L, Finucane AM, Oxenham D, McLoughlin P, McCutcheon H, Murray SA. How good is primary care at identifying patients who need palliative care? A mixed-methods study. *European Journal of Palliative Care* 2013; 20: 216–222
www.palliativecarescotland.org.uk/content/publications/How-good-is-primary-care-at-identifying-patients-who-need-palliative-care---a-mixed-methods-study.pdf

12.5 A recent Cochrane review has provided clear and reliable evidence that home palliative care increases the chance of dying at home and reduces symptom burden in particular for patients with cancer, without impacting on caregiver grief.

Source: Gomes B, Calanzani N, Curiale V, McCrone P, Higginson IJ. Effectiveness and cost-effectiveness of home palliative care services for adults with advanced illness and their caregivers. *Cochrane Database Syst Rev*. 2013 Jun 6;6:CD007760. doi: 10.1002/14651858.CD007760.pub2.
www.ncbi.nlm.nih.gov/pubmed/23744578

12.6 Patients receiving hospice at home services are most likely to die at home (76% of patients audited died at home).

Source: Richardson Heather. (2014) National organisations collaborate to learn more about the impact of hospice at home. ehospice April 15 [Reports on survey of care received by more than 4,800 patients across England and Wales conducted in 2013 by Help the Hospices (now Hospice UK) and the National Association for Hospice at Home.] www.ehospice.com/uk/Default/tabid/10697/ArticleId/9882

12.7 It is more than twice as likely that patients receiving hospice care will die at home with 60% fewer hospital deaths compared to those not referred to the hospice.

Source: Douglas Macmillan Hospice 2014, Quality Account: High Quality care for all. www.nhs.uk/aboutNHSChoices/professionals/healthandcareprofessionals/quality-accounts/Documents/2014/douglas-macmillan-hospice.pdf

12.8 Clinical decisions concerning starting or stopping artificial nutrition and hydration are challenging, particularly for patients who lack decision-making capacity. This systematic literature review found that increasing the patient's quality of life is the main decision-making factor, although the meaning of that term varied. Prolonging life was the second most cited factor; patient's wishes were influential but not determinative.

Source: Clarke G, Holland A, Barclay S. (2013) "How are treatment decisions made about artificial nutrition for individuals at risk of lacking capacity? A systematic review and qualitative synthesis". PLOS ONE: 8(4): e61475. doi:10.1371/journal.pone.0061475 <http://journals.plos.org/plosone/article?id=10.1371/journal.pone.0061475>

12.9 Prescribing behaviour, rather than patient factors, plays an important role in prescribing of opioids at the end of life; highlighting the need for training and education that goes beyond the well-recognised WHO approach for clinical practitioners.

Source: Gao W, Gulliford M, Bennett MI, Murtagh FE, Higginson IJ. Managing cancer pain at the end of life with multiple strong opioids: a population-based retrospective cohort study in primary care. PLoS One. 2014 Jan 27;9(1):e79266. doi: 10.1371/journal.pone.0079266. eCollection 2014. <http://journals.plos.org/plosone/article?id=10.1371/journal.pone.0079266>

12.10 A study highlighted the need for effective inter-professional working to deal with uncertainty and maintain co-ordinated care for in order to improve palliative care provision for non-cancer patients in the community.

Source: Oishi A, Murtagh FE. The challenges of uncertainty and interprofessional collaboration in palliative care for non-cancer patients in the community: A systematic review of views from patients, carers and health-care professionals. Palliat Med. 2014 May 12. [Epub 2014 May 12. <http://www.ncbi.nlm.nih.gov/pubmed/24821710>

12.11 Adoption and meeting the GSF has been shown to improve the quality of primary palliative care. Various studies show that where the GSF is adopted the benefits include:

- better support, collaboration and integration between primary care teams and the local specialist palliative care teams and improved continuity of care for hospices out of hours
- improved advanced care planning discussions
- improved carer support

Source: Marie Curie abstracts Posters: 10 Years on - has the Gold Standards Framework (GSF) influenced nursing care of patients with end of life care needs in the community? HC Meehan, D Munday BMJ Support Palliat Care 2014;4:1 120 doi:10.1136/bmjspcare-2014-000653.47

13 What we know about care homes in the last year of life

The national performance indicator 'percentage of deaths in usual place of residence' recognises that for many people, a care home is their usual residence. There has been an increase in the proportion of deaths in care homes over recent years and this is an area where more insight is required.

13.1 22% of deaths in England occur in a care home (2013).

Source : NEoLCIN analysis of ONS Mortality data.

13.2 Care homes are in some cases a temporary residence of people close to death:

- approximately one-third of people who die in care homes in England are temporary residents (the place of residence on their death certificate is not a care home)
- the proportion of long term care home residents who died in a care home increased from 61% in 2004 to 71% in 2013 (the place of residence on their death certificate is a care home)
- the proportion of temporary residents who died from cancer increased 24% (2004) to 33% (2013)

Source: NEoLCIN presentation to SCN workshops 2014 based on Office for National Statistics Mortality data.

13.3 The key findings of the second national survey of bereaved people asked about end of life care in the last three months of life. This has shown that overall quality of care across all services in the last three months of life was rated by 43% of respondents as outstanding or excellent compared to 23% of ratings as fair or poor.

Source: Office for National Statistics: National Survey of Bereaved People (VOICES) by NHS Area Team, 2011-2012
www.ons.gov.uk/ons/rel/subnational-health1/national-survey-of-bereaved-people--voices-/by-nhs-area-team--2011-2012/stb-national-survey-of-bereaved-people--voices-.html#tab-Quality-of-Care

13.4 An evaluation of the train-the-trainer education programme for end of life care in 17 care homes in East of England found:

- 79% of the residents who died, died in the care home, a finding that is consistent with the earlier evaluation of the ABC programme
- just over half of the randomly selected 274 residents had an advance care plan (ACP) in place and the majority (95%) did not have an unplanned admission during the time of data collection
- the review of decedents' notes found evidence of discussions relating to ACP for 111 residents (74%) and detailed discussions of symptom assessment and management
- most activity related to ACP and EoL Care was concentrated in the last week and days of life. Over a quarter of those who died had a DNACPR in place the week before death

- of 92 residents, 80 (87%) died in their preferred place of death, which included one person dying in hospital as specified, and one person where care was appropriate for their needs
- of the 118 residents whose death was expected 63% had anticipatory medication in place
- an unexpected finding was that of the 129 residents who had a recorded reason for admission, 23 (18%) had been admitted from hospital specifically with a diagnosis of dying and for end of life care. This would suggest that some of the care homes were being recognised for their expertise in EoL Care
- nearly two-thirds (65.7%) of residents had a diagnosis of dementia

Source: Goodman C, Mayrhofer A, Handley M, Smeeton N, Amador S, Davies S. (2014). Evaluation of the Train the Trainer (TTT) End of Life Care Education Model. (Version 2). Centre for Research in Primary and Community Care (CRIPACC), University of Hertfordshire. Hatfield: University of Hertfordshire.
www.herts.ac.uk/__data/assets/pdf_file/0014/60017/evaluation_endoflife_TTT_education_model2.pdf

- 13.5 A recent population-based observational study in England has found that areas with more care home beds per 1,000 population have fewer hospital deaths in people aged 100 or over (centenarians). The study also found that people in this age group are more likely to have causes of death certified as pneumonia and frailty and less likely to have causes of death of cancer or ischemic heart disease, compared with younger elderly patients.

Source: Evans CJ, Ho Y, Daveson BA, Hall S, Higginson IJ, Gao W, on behalf of GUIDE_Care project. Place and cause of death in centenarians: a population based observational study in England, 2001 to 2010. (IN PRESS) PLOS Med June 2014.
www.plosmedicine.org/article/info%3Adoi%2F10.1371%2Fjournal.pmed.1001653

- 13.6 A pilot cohort study in Singapore has found that use of UK GSF principles in care homes increases uptake of advance care planning discussions in patients with advanced medical conditions.

Source: Elderly care: Preliminary results of a formal advance care planning program in voluntary welfare nursing homes in Singapore C W Siew, Y Onn, M Koh, C M Gan, R Zainal, T W Ng, H IsmailBMJ Support Palliat Care 2011;1:1 91
doi:10.1136/bmjspcare-2011-000053.86
<http://spcare.bmj.com/content/1/1/91.2.abstract>

Support for carers and families

14 What we know about carers

Carers, those who provide unpaid support to a family member or friend, play an essential role in end of life care. With an ageing society and more people living with long-term conditions and frailty, there will be more people supporting family members through to the end of life. Death and dying affect both the individual and those around them. Poor management and inadequate support for individuals and their carers during the dying process and at the end of life creates additional burdens for the health and social care system and worse outcomes. The Carers Strategy (Department of Health 2010) recognises the importance of supporting carers of those at the end of life.

- 14.1 Families are not getting the support they need to cope with the overwhelming demands of caring for someone with a terminal illness because they may not recognise themselves as carers, the caring role increases over time and healthcare professionals tend to be more reactive than proactive which discourages carers for asking for support.

Source: Understanding the barriers to identifying carers of people with advanced illness in primary care : Triangulating three data sources. Emma Carduff, Anne Finucane, Marilyn Kendall, Alison Jarvis, Nadine Harrison, Jane Greenacre and Scott A Murray, BMC Family Practice 2014.
www.biomedcentral.com/1471-2296/15/48

- 14.2 Informal caring (from family and friends) in advanced chronic obstructive pulmonary disease often takes place over a prolonged period, yet carers identified unmet support needs and a lack of preparedness to care – particularly in relation to accessing services and information.

Source: Farquhar M, Ewing G, Moore C, Gardener AC, Holt Butcher H, White P, Grande G on behalf of the Living with Breathlessness study team. Preparedness to care in advanced COPD: how prepared are informal carers of patients with advanced COPD and what are their support needs? Baseline data from an ongoing longitudinal study (Palliative Care Congress abstract). BMJ Support Palliat Care 2014;4 (Suppl 1):A8.
<http://spcare.bmj.com/content/4/1/111.1.abstract>

- 14.3 There are a number of care situations where carers experience uncertainty and could seemingly benefit from greater information or instruction, as found by a qualitative study. Three main domains which could underpin an intervention which reflected carer experiences and needs in relation to potential information giving or education included:

- developing knowledge and competence
- facilitating preparedness
- supporting role recognition and confidence building

Source: "It's alright to ask for help" findings from a qualitative study exploring the information and support needs of family carers at the end of life, Emily Harrop, Anthony Byrne and Annemarie Nelson, BMC Palliative Care 2014, 13:22.
www.biomedcentral.com/1472-684X/13/22

15 What we know about care after death and bereavement

Good end of life care does not stop at the point of death. If a person's wishes are not respected, the bereaved not well supported and the impact of the death not acknowledged, there can be long lasting impact on how people grieve, their health and their memories of the person who has died.

Grieving is a natural process but, even when expected, the death of a close family member or friend is likely to be emotionally distressing. If the bereaved are not well supported there can be long lasting impact on how they grieve, their health and their memories of the person who has died. Bereavement is a trigger factor associated with increased risk of persistent physical and mental health problems.

- 15.1 Provision of information is important in supporting carers. The Ministry of Justice has published new guidance for families whose family member's death requires referral to the coroner. Guide to Coroner Services' booklet and an accompanying leaflet, 'Coroner investigations – a short guide'. The guidance explains what people can expect from the coroner's investigation and sets out the standards of service that they should receive and what they can do if they are not satisfied.

Source: Guide to Coroner Services. Ministry of Justice 2014.

www.gov.uk/government/uploads/system/uploads/attachment_data/file/363879/guide-to-coroner-service.pdf
www.gov.uk/government/publications/guide-to-coroner-services-and-coroner-investigations-a-short-guide

- 15.2 A review of child deaths in England between April 2012 and March 2013 was carried out and reported by the Local Safeguarding Children Boards. The review explored the circumstances of the fatality, identified any modifiable factors and lessons to be learned to reduce future child deaths. The Board identified a number of issues which continue to be a concern. This included the need for bereavement support to be offered to children following the death of a parent, carer or sibling.

Source: The Department of Education Statistical Release. Child death reviews: year ending 31 March 2013. Published July 2013.

www.gov.uk/government/statistics/child-death-reviews-year-ending-31-march-2013

- 15.3 The Human Tissue Association have taken the learning from clinical incidents and published clear guidance on caring well for the deceased. This includes caring for those who have bariatric needs, processes for the release of the deceased to funeral directors, identification of the deceased, security measures for mortuaries, and procedures for back up power supply for mortuary fridges.

Source: Sharing Lessons. Lessons learned from HTA reportable incidents in the post mortem sector, 2012/13. Human Tissue Authority (HTA).

www.hta.gov.uk/sites/default/files/HTARI_Review_2012-13.pdf

- 15.4 A study of the experiences of families who consented to organ and tissue donation made 14 recommendations – the most significant being the need to myth bust in public education about organ and tissue donation; to reduce the time from consent to donation; to review the support available for families whilst they wait for donation; and for high quality facilities and comprehensive visiting policies for families involved in end of life care.

Source: Sque M. Walker W. Long-Sutehall T. Morgan M. Randhawa G. and Warrens A. Bereaved families' experiences of organ and tissue donation, and perceived influences on their decision making. University of Wolverhampton, Final report of a study funded by the Department of Health, June, 2013. Please contact Magi Sque m.sque@wlv.ac.uk for copies of the report. www.sciencedirect.com/science/article/pii/S0041134504013284

- 15.5 New guidance for implantable cardiac defibrillator deactivation has been published by the British Heart Foundation. It is clearly recommended that ICD deactivation should be part of the pre-implantation process consent and counselling process. It also gives advice for post mortem device deactivation.

Source: ICD Deactivation at the end of life. Principles and Practice. British Heart Foundation. 2013, author Dr James Beattie, Consultant Cardiologist, Heart of England NHS Foundation Trust, Birmingham. www.bhf.org.uk/publications/living-with-a-heart-condition/icd-deactivation-at-the-end-life

The end of life care workforce

16 What we know about end of life care education and training

Caring for and supporting people approaching the end of their life is considered among the most challenging work any health and social care worker faces. It can also be the most rewarding - if they have the right knowledge, skills and attitude to provide the care and support they need.

- 16.1 Classroom-based education and training is useful for enhancing professionals' skills and perceived preparedness for delivering end of life care but should be reinforced by actual practice experience.

Source: Classroom-based and distance learning education and training courses in end of life care for health and social care staff: A systematic review. *Palliative Medicine* 2013 March; Vol. 27 (3), pp. 221-35. Pulsford, David; Jackson, Georgina; O'Brien, Terri; Yates, Sue; Duxbury, Joy
www.ncbi.nlm.nih.gov/pubmed/22126845

- 16.2 Many obstacles hinder a patient's wishes about dying, including how nurses perceive their role in end of life care situations and knowing how to intervene on behalf of the patient. Nursing education needs to create meaningful and relevant learning experiences to enable future nurses to effectively care for the dying patient. Nurse educators have a responsibility to increase students' knowledge about end of life care so that patients' preferences can be realised.

Source: Integrating professional apprentices into an end of life course. *Journal of Nursing Education*, Feb 2014, vol. 53, no. 2, p. 112-115, 0148-4834 (February 2014). Hold, Judith L; Ward, Elizabeth N; Blake, Barbara J.
www.healio.com/nursing/journals/jne/2014-2-53-2/%7B9721948d-26d5-4626-8284-f710ae7ee3d9%7D/integrating-professional-apprentices-into-an-end-of-life-course

- 16.3 Specific training in end of life care in cardiology remains a neglected part of the curriculum. The level of confidence in delivering end of life care in advanced heart failure and discussing prognosis in patients with an implantable cardiac device is poor.

Source: Training in cardiology: Is end of life care being addressed? *Heart*, May 2013, vol./is. 99/(A11), 1355-6037 (May 2013). Ismail Y; Shorthose K; Nightingale A.K.
heart.bmj.com/content/99/suppl_2/A11.2.abstract

- 16.4 The national audit of acute hospitals found that training in care of the dying was mandated for doctors in 19% of acute hospital trusts and for nurses in 28%.

Source: National Care of the Dying Audit- Hospitals England 2013/14
www.rcplondon.ac.uk/sites/default/files/ncdah_national_report.pdf

- 16.5 The same audit found that 82% of acute hospital trusts reported that they had provided some training on care of the dying in the previous year. This training included a communications element for doctors in 61% of trusts and 69% for nurses. 18% of acute trusts reported that they had not provided any formal training in care of the dying in the previous year.

Source: National care of the dying audit for hospitals. National Report. May 2014. Royal College of Physicians and Marie Curie Cancer Care.

www.rcplondon.ac.uk/sites/default/files/ncdah_national_report.pdf

- 16.6 Current recommendations about what medical undergraduates ought to be taught about ageing are not consistently achieved. Teaching innovations might close the gap between aspiration and current practice, for example, new technologies, inter-professional education, patients' involvement in teaching and education to improve attitudes towards care of older patients.

There is strong evidence to suggest that medical schools are not delivering enough teaching about ageing and geriatric medicine. This is not unique to the UK but the UK is no better than other countries.

The study, included a major poll of British medical schools, revealed that some medical undergraduates received as little as 55 hours of specialist training in the area of elderly care over their five-year courses.

'If we are to prepare our workforce for the future we need to devote more time to teaching medical students about how to manage older people with frailty.'

Source: Rachel Oakley, Joanne Pattinson, Sarah Goldberg et al. New Horizons: Equipping Tomorrow's Doctors for the Patients of Today published on Monday, 23 June 2014, in Age and Ageing, the research journal of the British Geriatrics Society.

www.bgs.org.uk/index.php/press/3015-new-horizons-tomorrows-doctors

- 16.7 Older people with lung and colorectal cancer want high quality written information on complementary therapy services to enable choice, improve their knowledge, and promote wider access. Increased physician education may facilitate provision of such information.

Source: Audrey Roulston, Pauline Wilkinson, Tommy Haynes, Jim Campbell. Complementary Therapy: perceptions of older people with lung or colorectal cancer. International Journal of palliative Nursing, 2013, Vol 19, No 7.

www.ncbi.nlm.nih.gov/pubmed/24273810

- 16.8 Greater understanding of how decision aids impact on the decision-making process is needed if we are to design improved interventions that are effective on the core aspects of decision-making.

Source: Theory based analysis of the effects of decision aids for surgery in breast cancer: a systematic review. Stephanie Sivell, Adrian Edwards, Antony SR Manstead, Ben Carter, Natalie Joseph-Williams, Lisa JM Caldon, Alison Clements, Karen Collins, Anne Donald, Malcolm WR Reed, Glyn Elwyn (on behalf of the BresDex Group) European Journal of Person Centered Healthcare.

<http://ubplj.org/index.php/ejpc/article/view/649>

- 16.9 Medical students often view patients receiving palliative and/or end of life care as being in 'denial' about their condition, and approach denial as if it were a disease that they can, and should, diagnose and treat. Patients who do not behave in the way expected, such as those displaying what is labelled as denial, can ultimately block what student doctors consider to be good treatment, care and death. For some students such a dynamic can lead to feelings of personal failure. For patients this may affect their relationship with doctors and the timing and content of the communication that does – or does not – take place.

Source: Borgstrom E, Barclay S, Cohn S. (2013) 'Constructing denial as a disease object: accounts by medical students meeting dying patients'. *Sociology of Health and Illness* 35(3):391-404.
www.ncbi.nlm.nih.gov/pubmed/22882704

17 What we know about co-ordination of care

People approaching the end of their lives need a combination of health and social care services often provided by a wide range of professional and staff groups. **Statement 8 of the NICE Quality Standard for end of life care for adults** requires that people approaching the end of life receive consistent care that is co-ordinated effectively across all relevant settings and services at any time of day or night, and delivered by practitioners who are aware of the person's current medical condition, care plan and preferences.

17.1 Electronic palliative care co-ordination systems (EPaCCS) support patient choice, shared decision making, individual care planning and integration of care across sectors. They are expected to play a significant role in supporting the care integration agenda, including the Integrated Care and Support Pioneers Programme.

A national survey of clinical commissioning groups (CCGs) was carried out in 2013 to determine the status of EPaCCS implementation across England. Key findings:

- as of August 2013, the majority of CCGs (83%) are working in partnership with each other and with other agencies to implement EPaCCS. About a third (30%, 64 CCGs) had operational EPaCCS, and just over half (53%, 111 CCGs) had started planning for EPaCCS implementation, and of the latter group, 40 were expecting to have operational systems by January 2014 and an additional 17 by January 2015
- there was much positive feedback from areas where EPaCCS have been implemented. The greatest benefits were identified as improvements in communication and information sharing between healthcare professionals and support for making appropriate decisions about patients' care

Of those CCGs with operational systems, only a few of these are able to report on EPaCCS data in this survey, but that data suggests that the use of EPaCCS:

- helps people to die in their preferred place of death
- decreases the percentage of hospital deaths
- increases the percentage of deaths at home and in hospices
- developmental aspirations, it is still early days for EPaCCS implementation

Future work is needed to:

- determine which stakeholders are best able to provide this kind of information
- build a better database of EPaCCS leads across the CCGs
- increase the number of systems to which social care services have access

- improve CCG access to EPaCCS data
- better understand and resolve technical issues for EPaCCS management
- EPaCCS is a complex project that aims to support end of life care co-ordination across a multitude of different agencies. Successful implementation requires the appropriate configuration of systems, services and infrastructure. For many CCGs this has raised a number of issues, such as system interoperability, stakeholder engagement, data ownership, costs, information support and funding, which need to be resolved to ease implementation

Source: Electronic Palliative Care Co-ordination systems (EPaCCS) Survey of CCGs. April 2014. NEoLCIN and NHS Improving Quality.

www.endoflifecare-intelligence.org.uk/resources/publications/epaccs_in_england

17.2 82% of people who had their preferred place of death recorded on London's Co-ordinate My Care electronic system died in their preferred place (based on those who were recorded as having died between June 2012 and May 2013).

Of all those recorded on the system with an EPaCCS record, dying between June 2012 and May 2013, during this period; 38% died at home, 32% in a care home, 14% in a hospice and 17% in hospital.

Source: EPaCCS survey data submitted by Coordinate My Care December 2013.

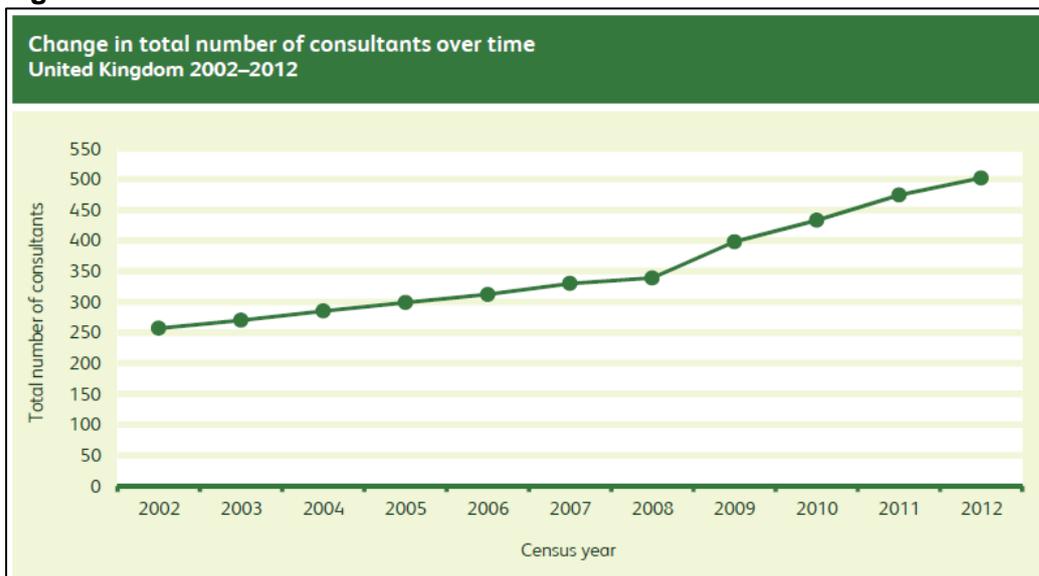
18 What we know about workforce

18.1 The national census carried out by the Royal College of Physicians in 2012 identified 502 consultants in palliative medicine across the UK (414 consultant posts in England, 28 in Wales, 43 in Scotland and 16 in Northern Ireland).

- 48% of consultants in palliative medicine were working less than full time
- there are more female than male consultants in palliative medicine with 359 (71.5%) females and 143 (28.5%) males responding to the survey
- the annual UK expansion of palliative care consultant numbers showed a decrease from 9.5% in 2011 to 5.9% in 2012. This compares to an overall fall in expansion rates for medical specialties from 10.2% in 2009 to 3.5% in 2012
- the average retirement age of consultants in palliative medicine was reported as 60.8 years

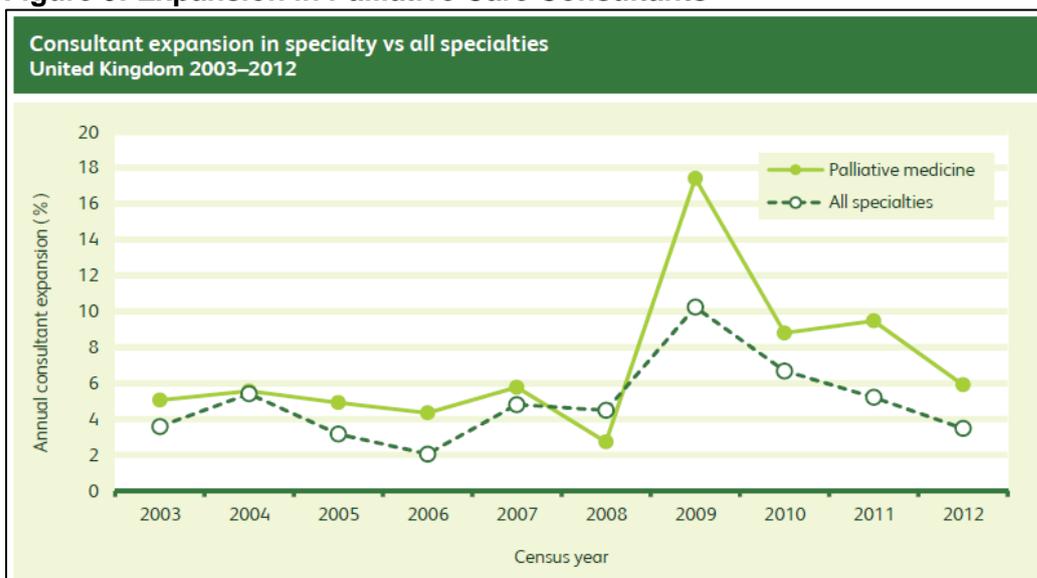
Source: Census of consultant physicians and medical registrars in the UK 2012. The Royal College of Physicians.2014. www.rcplondon.ac.uk/sites/default/files/2012_full_text_census_of_consultant_physicians_and_medical_registrars.pdf

Figure 8: Palliative Care Consultants*



Source: Reproduced from: Federation of the Royal Colleges of Physicians of the UK. Census of consultant physicians and medical registrars in the UK, 2012: data and commentary. London: Royal College of Physicians, 2014. www.rcplondon.ac.uk/sites/default/files/2012_full_text_census_of_consultant_physicians_and_medical_registrars.pdf

Figure 9: Expansion in Palliative Care Consultants



Source: Reproduced from: Federation of the Royal Colleges of Physicians of the UK. Census of consultant physicians and medical registrars in the UK, 2012: data and commentary. London: Royal College of Physicians, 2014. www.rcplondon.ac.uk/sites/default/files/2012_full_text_census_of_consultant_physicians_and_medical_registrars.pdf

18.2 The Association of Palliative Medicine for Great Britain and Ireland (APM) carried out a workforce survey from 28 August 2012 to 27 May 2013. The response rate was 70% and, therefore, there is under-reporting of the workforce numbers.

Gender	England
Female WTE posts	154.4
Male WTE posts	75.9
Total WTE posts	230.3
Total number of consultant posts	284
Substantive headcount	265

Estimated consultant retirements per year in England:

Year	2012	2013	2014	2015	2016	2017	2018	2019	2020	2021
Posts (FTE)	2 (2.8)	10 (7.9)	5 (5.0)	9 (8.1)	5 (4.7)	3 (2.8)	5 (4.4)	5 (5.1)	11 (11.9)	11 (10.4)

FTE: full time equivalent

- the estimated workforce requirements are two FTE consultants for a population of 250,000 representing 497 FTE working across the UK
- overall there is the potential risk in the next five years that there will be an over production of CCT holders in regard to available consultant posts. One of the consequences of this may be the facilitation of recruitment of consultants to regions that are currently under supplied
- there is a high proportion of women trainees (greater than 80%)
- a high percentage of doctors work less-than-whole-time (44% for consultants, 76.5% for non-consultant doctors and 38% for trainees)

Source: The Association of Palliative Medicine for Great Britain and Ireland Workforce Survey 2012 (draft report).

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Kings College London

Local Government Action

Macmillan Cancer Support

Marie Curie Cancer Care

National Council for Palliative Care

National Nurse Consultant Group

NHS Improving Quality

Office for National Statistics

Public Health England, Health and Wellbeing Team

University of Cambridge

Weston Area Health Trust & Weston Hospice care