



National end of life care  
INTELLIGENCE NETWORK

*National End of Life  
Care Programme*

Improving end of life care

**What do we know now that  
we didn't know a year ago?**

New intelligence on end of life care in England

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## Foreword

Published four years ago, the End of Life Care Strategy made clear the need to know more about the care people receive in their last year or months of life. With the creation of the National End of Life Care Intelligence Network in 2010, we began to address previous limitations of lack of information.

We now combine Hospital Episode Statistics (HES) and Office for National Statistics (ONS) data on end of life care, and are working to link this with local authority data on the social care people receive at the end of life. This is giving us a clearer understanding than ever before of end of life care across the country. Reassuringly, we now know where our efforts are making a real difference; however we also now know where we need to do a lot more to make substantial improvements.

The publication of this report marks a significant moment in the progress of the strategy. The knowledge contained within it will enable commissioners and providers not only to take stock of what has been achieved but to plan and identify future priorities.

For example, we now know that the average number of emergency hospital admissions in the last year of life is around two, but that the data highlights an important sub-group of people who are admitted on multiple occasions in their last year, sometimes 10 times or more. Now that we know this, it is apparent that we are not helping this group of people as much as we could and that urgent action is needed. As well as improving the quality of care for people in the last year of life, which is our main priority, a reduction in the number of admissions would also lead to cost savings.

Nevertheless, there are encouraging signs that improvements are being made. The number of people dying at home is increasing, which is where we know most people would prefer to die. In addition, we have seen a sustained rise in number of deaths in care homes over the past four years. We must continue to build upon these improvements and ensure that they are consistent across all regions and socio-economic groups so that everyone at the end of life receives high quality care in their preferred place.

The information contained within this report provides a great opportunity and lever for change and should be used to help identify where to channel our efforts most effectively over the coming years.



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## Introduction

The National End of Life Care Intelligence Network (NEoLCIN) was established in May 2010. Its work is overseen by a stakeholder group which comprises of representatives from the various key holders and users of data and information relating to end of life care. This includes:

- South West Public Health Observatory (SWPHO)
- Office for National Statistics (ONS)
- The Information Centre
- National charities
- Researchers in end of life care.

The network aims to bring all the diverse strands of nationally available data on end of life care together, transform it into intelligence and make this information available in forms which are useful for commissioners, service providers and the public.

This publication identifies the new intelligence that has been made available during 2011/12, submitted by stakeholder group members.

The aim is to use this compiled data to help inform the priorities of the National End of Life Care Intelligence Network for 2012/13. It will also be made available online to inform all who are interested or working in end of life care: [www.endoflifecare-intelligence.org.uk](http://www.endoflifecare-intelligence.org.uk)

This publication will be updated at regular intervals to incorporate new end of life care intelligence that becomes available.

## Disclaimer

This is a working document that will be regularly revised to incorporate new end of life care intelligence as it becomes available. It therefore may not be comprehensive and the National End of Life Care Intelligence Network welcomes contributions of additional data: [information@neolcin.nhs.uk](mailto:information@neolcin.nhs.uk).

Whilst every effort has been made to provide accurate data, we cannot guarantee its correctness and completeness. We do not accept responsibility for any loss, damage or expense resulting from the use of this information.

## 1. What we know about preferences of place of care and place of death

### As reported by those approaching the end of life:

1.1 Preferred place of death of people with Electronic Palliative Care Co-ordination System (EPaCCS) record:

■ Home	<b>47%</b>
■ Care home	<b>29%</b>
■ Hospice	<b>33%</b>
■ Hospital	<b>1%</b>

EPaCCS are electronic systems, linking care providers across a locality, which hold key information for individuals who have been identified as approaching the end of life.

1.2 Proportion of people on EPaCCS that died in preferred place of death: **76%**

1.3 Proportion of people on EPaCCS that did not die in preferred place of care: **21%**

1.4 Proportion of people on EPaCCS that died in hospital: **8%**

*(Source: EPaCCS data report North Somerset, 2011)*

### PRISMA telephone survey of the general population aged 16 and over, and comparison with ONS mortality data:

1.5 Home is the first preferred place of death in England and hospice the second preference. Home and hospices together accounted for the preferences of at least 89% of participants in every region in England.

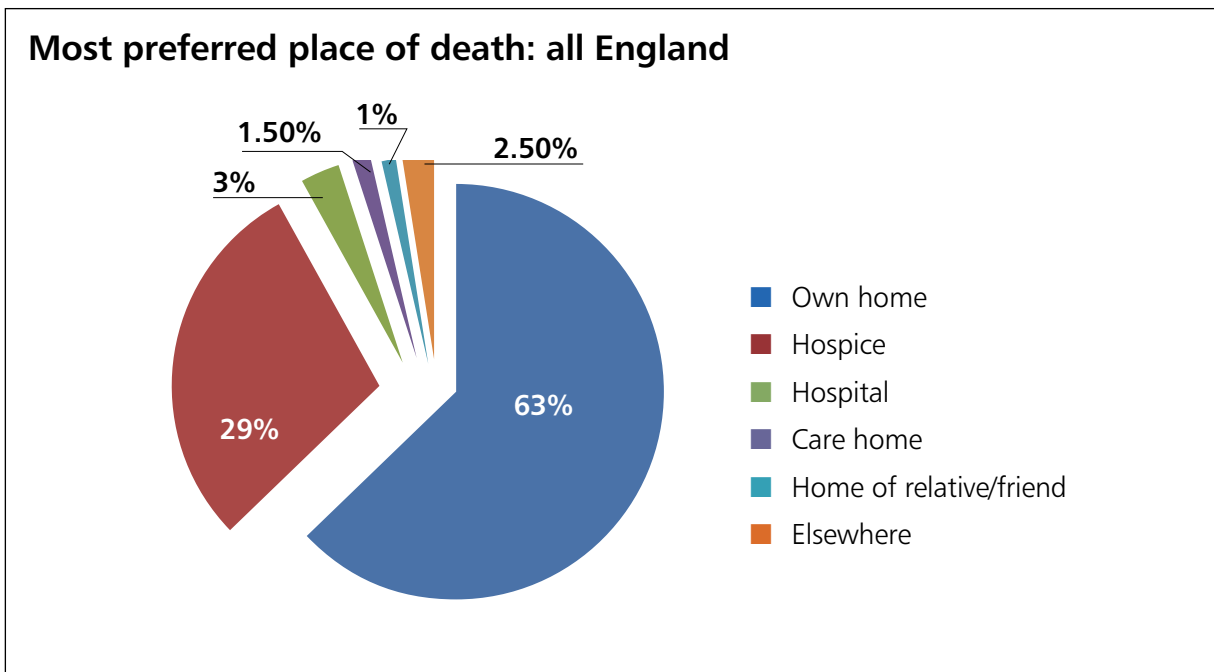


Figure 1: Most preferred place of death: all England

*(Source: PRISMA survey 2010)*

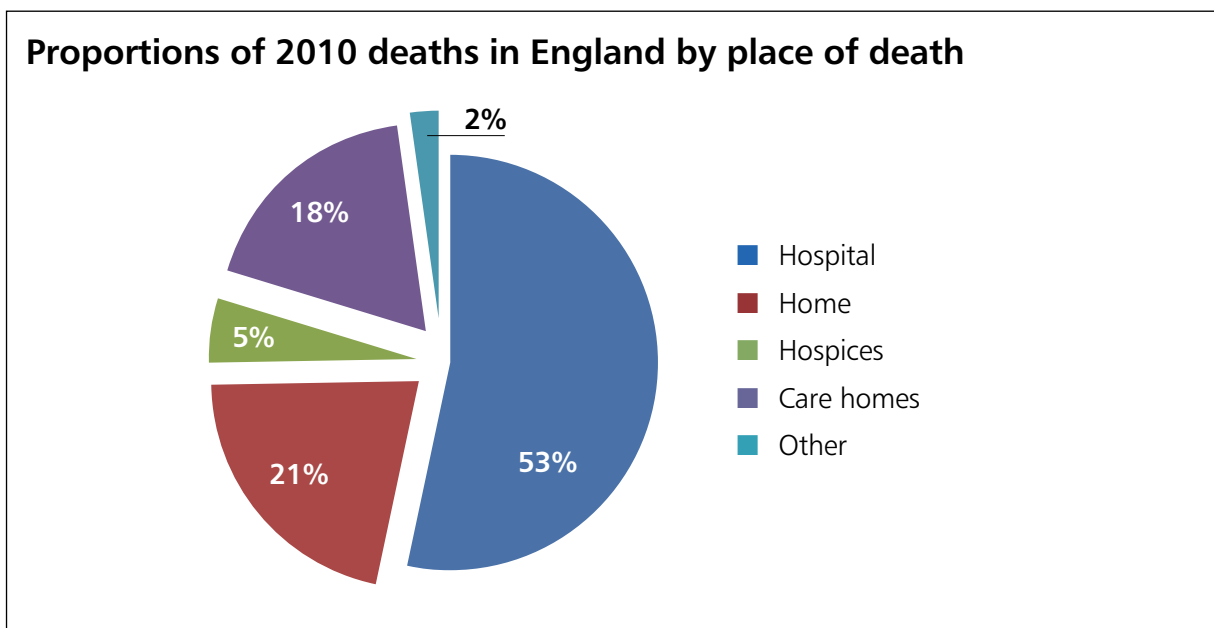
1.6 As age increased, a preference to die at home decreased while a preference to die in a hospice increased (except for the group aged 55-64). Preferences for home death ranged from 45% (for those aged 75+) to 75% (for those aged 25-34).

- 1.7 When compared with 2003 data, a preference to die at home and in a hospice has increased in most regions.
- 1.8 Hospital was the least preferred place of death in all regions except for the North East, where care homes are the least preferred.
- 1.9 People think that dying in the preferred place of death is an important priority. Across the country, ranking 'Dying in preferred place' as the number one care-related priority' varied by region from 29% to 43%.
- 1.10 There is variation between people's preferred place of death and actual place of death. The gap between a preference for a hospice death and actual deaths in a hospice is highest for older people.

*(Source: Local preferences and place of death in regions within England 2010, Barbara Gomes, Natalia Calanzani, Irene J Higginson, August 2011)*

## 2. What we know about place of death trends

- 2.1 In 2010, 53.3% of people died in hospital, showing a year on year decrease from high of 58.3% in 2005.



**Figure 2: Proportions of 2010 deaths in England by place of death**

*(Source: End of Life Care Profiles 2008-2010, NEoLCIN)*

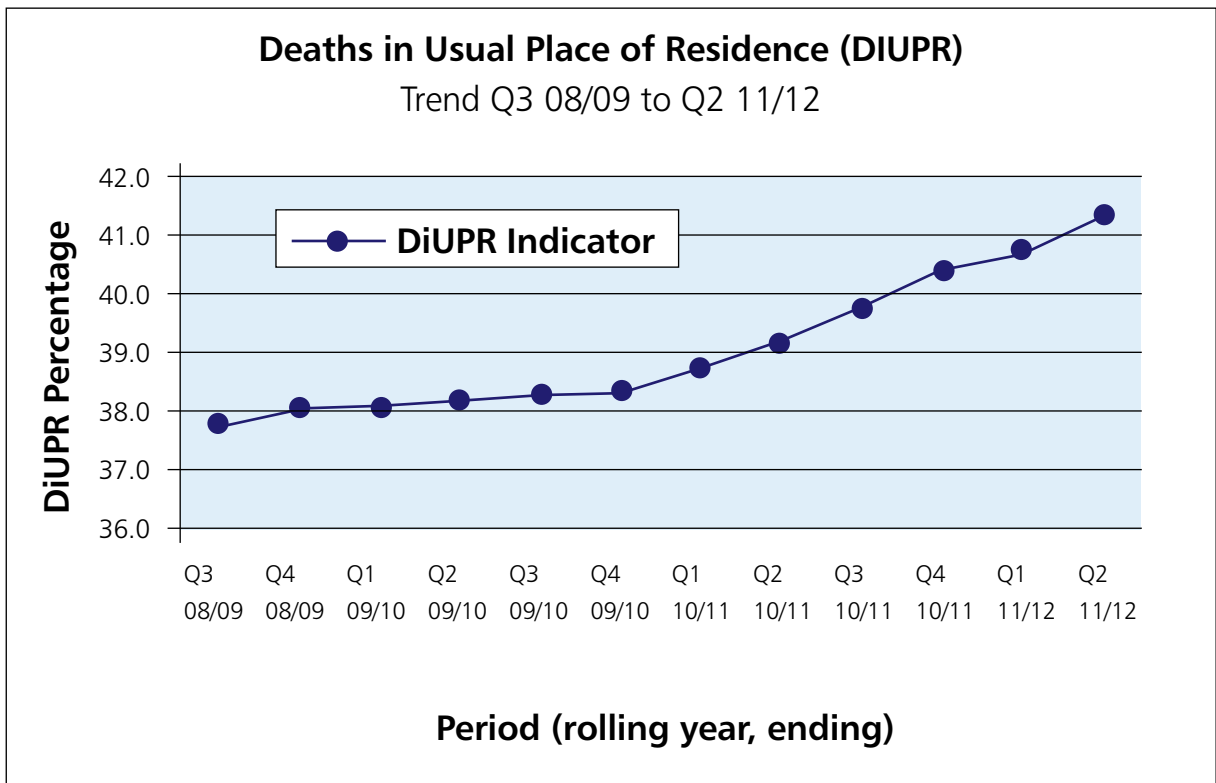


Figure 3: Deaths in usual place of residence (DIUPR) trends

(Source: SWPHO analysis of ONS mortality data)

2.2 Older people are more likely to die in hospital, except in very old age. In 2010, 54% of those aged 75 and over died in hospital, 57% of those aged 75-79 and 48% of those aged 90 and over.

2.3 Men are more likely to die in hospital than women. For example in 2010, 58% of men aged 75 and over died in hospital compared to 52% of women aged 75 and over. Across all ages, the figures for proportions of hospital deaths are men 55% and women 52%.

(Source: ONS data analysis by SWPHO, *End of Life Care Profiles and Deaths in Older Adults in England*, NEoLCIN, 2010)

2.4 People from most deprived quintiles are more likely to die in hospital. 61% of people in most deprived quintile die in hospital compared with 54% of people in least deprived quintile (2007-2009).

(Source: *Deprivation and death: variations in place and cause of death*, NEoLCIN, 2012)

2.5 Proportion of deaths in hospital 2008-10:

Local authorities with the lowest proportion of deaths in hospital:		
12UB	Cambridge	39.0%
40UE	Taunton Deane	39.8%
36UB	Craven	41.7%
00HH	Torbay	42.2%
45UG	Mid Sussex	42.8%

Local authorities with the highest proportion of deaths in hospital:		
00AJ	Ealing	65.6%
00AK	Enfield	66.8%
00BC	Redbridge	67.0%
00BB	Newham	67.7%
00BH	Waltham Forest	70.2%

(Source: *End of Life Care Profiles 2008-10, NEoLCIN*)



### 3. What we know about inpatient hospital care in the last year of life

#### Palliative Care Funding Review:

3.1 An analysis of hospital use in England in the last year of life for people with conditions that may indicate a need for palliative care<sup>1</sup> shows that almost a third (32.6%) of all hospital admissions in last year of life occur in the last 30 days before death.

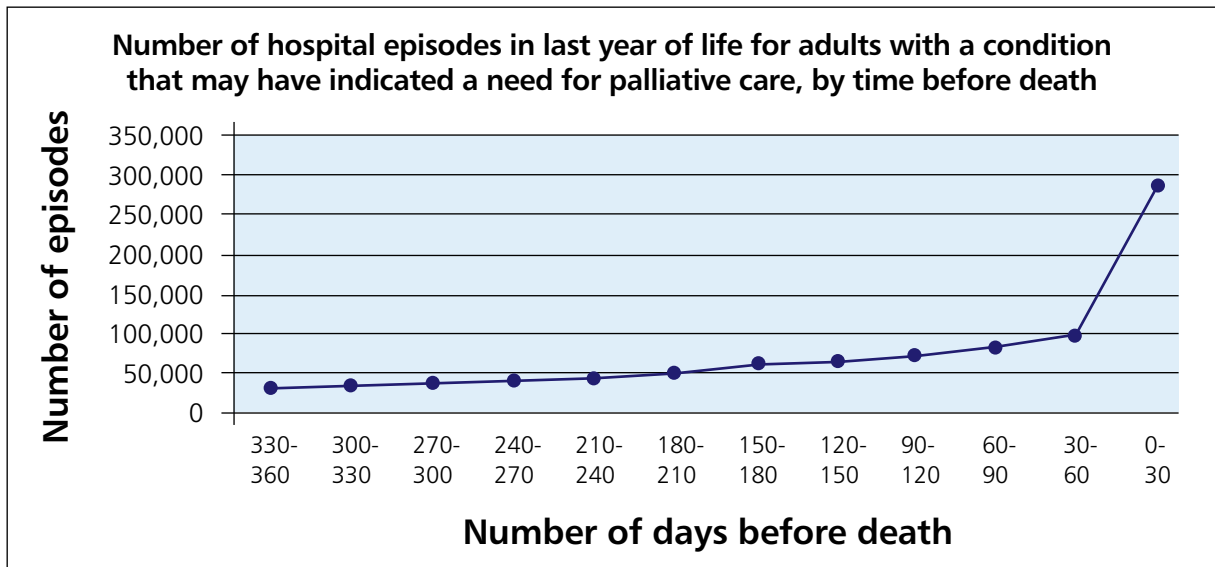


Figure 4: Number of hospital episodes in the last year of life for adults with a condition that may have indicated a need for palliative care, by time before death

(Source: Analysis by the Department of Health of ONS mortality data from 2009 linked with HES data)

3.2 Hospital admissions, days spent in hospital ('bed days') and deaths in hospital were significantly higher than average for some 'non-white' ethnic groups. These differences were not large, but persisted even after adjusting for several factors such as age, gender, socioeconomic deprivation and illness type.

3.3 Across England people average around 2.1 hospital admissions in the last 12 months of life accounting for on average 30 bed days. Admission rates are highest in young age groups.

3.4 Comparing data (2005-2007) from 159 hospitals in England and 2892 in the US (2001-2005), rates of hospital admission were slightly lower in the last two years of life in England compared to the US, but rates of days spent in hospital were approximately 88% higher (43.8 days compared with 23.3 days). Variation between hospitals was lower in England compared to the US. This needs further investigation.

(Source: John Billings Nuffield report – to be published)

3.5 Approximately 78% of people will be admitted to hospital at least once in their last year of life.

(Source: HES data – Deaths 2004-2008)

<sup>1</sup> This analysis constitutes an update of Cochrane et al (2007). The original analysis covered children only. The updated version, undertaken by the Department of Health, refreshes this, and extends the methodology to adults using a different list of conditions, derived from Rosenwax et al (2005). The data used for this analysis are derived from a linked dataset of ONS mortality data from 2009 and The Information Centre for health and social care Hospital Episode Statistics data from 2008 and 2009.

- 3.6 89% of those who die in hospital do so following an emergency admission. 32% of these people die after a stay of 0-3 days, 18% after a stay of 4-7 days and 50% after a stay of 8 days or longer.

*(Source: HES data – Deaths in hospital 2010)*

- 3.7 12% of those who die in hospital will have been admitted from a care home.

*(Source: ONS data – Deaths in hospital 2010)*

**QIPP analysis using 2004-2008 data provided by South West Public Health Observatory:**

Quality Innovation Productivity Prevention (QIPP) is an NHS transformation change programme. End of life care has been identified as a work stream for the QIPP agenda, with data analysis being carried out to support it.

- 3.8 346,000 people have an emergency admission in the last year of life.
- 3.9 Around 9.4 million bed days are occupied by people in the last year of life who have emergency admissions.
- 3.10 On average, people who have emergency admissions in the last year of life have two or fewer admissions.
- 3.11 Twenty per cent of those that die will have had three or more emergency admissions in the last year of life. These are spread evenly by cause of death (e.g. cancer, stroke, cardiac, respiratory, other).
- 3.12 Just over 200,000 emergency admissions end in death per annum. This compares with 24,000 planned admissions which end in death.
- 3.13 The 24,000 planned admissions ending in death account for around 500,000 bed days. The length of stay for most of these individuals is 8+ days.
- 3.14 86% of all admissions in the last year of life (106,000) are emergency admissions with an average length of stay of 27 days (cancer 24 days, stroke 30 days) and account for 2.8 million bed days.
- 3.15 Cancer accounts for around 25% of emergency admissions lasting 8+ days and ending in death. (Cardiovascular 17%, stroke 12%, respiratory 17%, other 28%).
- 3.16 The vast majority of these deaths (over 90%) are thought to be in acute rather than community hospitals).
- 3.17 The number of 8+ day emergency admissions ending in death is sufficiently large (average 800 per PCT) to allow robust and valid statistical monitoring of progress at PCT level.
- 3.18 Crude and age standardised rates vary substantially between PCTs (at least in the South West) suggesting scope for improvement.

*(Sources: QIPP Indicator for End of Life Care. Proposal of a new indicator, NEOLCIN, unpublished QIPP End of Life Care. Hospital admissions in the last year of life, NEOLCIN, unpublished)*

### National Care of the Dying Audit Hospitals (NCDHAH) Round 3:

Audit of clinical data from over 7,000 individuals (from 127 NHS Trusts) whose care was supported by the Liverpool Care Pathway for the Dying Patient (LCP), and organisational data regarding provision of care for people in the last hours or days of life from 131 NHS Trusts in England.

#### Organisational audit:

3.19 Participation increased by 13% for both Trust and individual hospital participation between NCDHAH Round 2 and Round 3:

	Round 2	Round 3
Number of trusts	115	127
Number of hospitals	155	178

3.20 20% of Trusts provide a seven day face to face specialist palliative care service.

3.21 Education and training in care of the dying appears to have increased between NCDHAH Round 2 and NCDHAH Round 3, however the majority of programmes are still not mandatory:

- 90% of Trusts provide some education and training in care for the dying for medical staff (Round 2: 74%), however this was mandatory in only 29% of hospital Trusts
- 87% of Trusts provide some education and training in care for the dying for qualified nursing staff (Round 2: 84%), however this was mandatory in only 21% of hospital Trusts
- 74% of Trusts provide education and training programmes in care of the dying for non-qualified staff (Round 2: 58%), however this was mandatory in only 12% of hospital Trusts.

3.22 53% of Trusts have a formal multidisciplinary process for diagnosing dying.

#### Clinical Audit:

3.23 The proportion of people with a diagnosis other than cancer has increased to 69% (Round 1: 55%, Round 2: 61%).

3.24 Where data was available, 91% of people had anticipatory prescribing of medications for five key symptoms that may occur in last hours or days of life (pain, agitation, respiratory tract secretions, nausea and vomiting and breathing difficulties).

3.25 Communication appears more challenging with people at the end of life, with a relatively high proportion variance recorded for goals relating to explaining the plan of care, awareness of dying, and spiritual/religious/cultural needs and wants of the person at this time. Encouragingly, where documented, these results indicate that where it was not possible to enter into discussion with the person (and variance has been documented), these issues have been addressed with the relatives or carers:

- 94% of relatives/carers were given a full explanation of the care plan (LCP); healthcare professionals were able to discuss this with 56% of people at the end of life
- 97% of relatives/carers were aware that the person was dying; healthcare professionals were able to discuss this with 58% of people at the end of life
- 90% of relatives/carers were given the opportunity to discuss any spiritual/religious/cultural requirements at this time; healthcare professionals were able to discuss this with 61% of people at the end of life.

- 3.26 Results show that people with a diagnosis other than cancer were more likely to have a higher recording of variance for goals relating to communication than those with a diagnosis of cancer.
- 3.27 Routine on-going assessment (four hourly assessments), where documented, showed that the majority of individuals were documented as 'comfortable' across the board for those goals relating to symptom control (93 – 99%).
- 3.28 Compliance with completion of the documentation shows room for improvement, however where a hospital Trust has an LCP facilitator in post, this audit illustrated improved compliance with the clinical documentation of care (LCP generic version 12).

*(Source: National Care of the Dying Audit Hospitals (NCDAH) Round 3 Benchmark Report. 2011)*

#### **Dementia and mental health:**

- 3.29 As one in three adults over the age of 65 years will die with dementia (Brayne et al. 2006), it is important to consider available information about dementia and end of life care provision. Of people aged over 70, admitted to an acute hospital:

- 27% have previously diagnosed dementia
- 50% have cognitive impairment
- 27% have delirium
- 24% have possible major depression
- 8% have definite major depression

*(Sources: The prevalence of mental health problems among older people admitted as an emergency to a general hospital. Sarah E. Goldberg et al. Age and Ageing 2012; 41: 80-86, 2012*

*Dignity in the Care of Older People. Jackie Morris. BMJ 2012;314:e533 doi:10.1136/bmj.e533, 2012)*

## **4. What we know about social care in the last year of life**

- 4.1 Approximately 30% of people use some form of local authority funded social care in the last year of life.
- 4.2 Though hospital use climbs steeply in the last few months of life, social care use shows a only steady increase in the last 12 months.
- 4.3 There is some evidence across all age groups that higher social care costs at the end of life tend to be associated with lower inpatient costs. While a direct causal link between high social care use and lower hospital use cannot be confirmed, it does suggest that any reductions in the availability of local authority-funded social care might increase demand on hospital services.
- 4.4 The use of social care also differed according to the presence of certain long-term conditions. For example people with mental health problems, falls and injury, stroke, diabetes and asthma tended to use more; those with cancer appeared to use relatively less local authority-funded social care.

*(Source: Social care and hospital use at the end of life. M Bardsley, T Georghiou, J Dixon. The Nuffield Trust. 2010)*

## 5. What we know about specialist palliative care

- 5.1 Although only 4% of deaths take place in hospices, specialist palliative care support is provided to many more people, which enables them to die at home.

*(Source: National Council for Palliative Care (NCPC) data on hospice services)*

- 5.2 73.7% of the palliative medicine consultant workforce are women; 42% of the palliative medicine consultant workforce work less than full time.

*(Source: 2010 Census of consultant physicians and medical registrars in the UK. Data and commentary. Royal College of Physicians)*

- 5.3 Full time consultants work an average of 47.5 hours a week. 14.1% consultants work more than 48 hours per week.

*(Source: Royal College of Physicians (RCP) Consultant physicians working with patients, 5th edition, 2011)*

- 5.4 Of people receiving hospice care that have engaged in advance care planning (ACP), 10% die in hospital compared to 26% of those who have not engaged in ACP.

- 5.5 Home death rates for people receiving hospice care with ACP is 40% compared to 23% for those who have not engaged in ACP.

*(Source: NHS South West review of 960 records in last 2.5 years)*

### **Minimum Data Set report on specialist palliative care service provision:**

- 5.6 The proportion of people diagnosed with conditions other than cancer increased in all specialist palliative care settings. Outpatient services had the highest percentage at 24%.

- 5.7 Almost a third (33%) of new individuals seen in inpatient settings were aged under 65.

- 5.8 The ethnicity of 77% of new inpatients were recorded as White British (ethnicity not recorded for 16%).

- 5.9 For inpatient stays – 69% people are admitted from their own home and only 2% from a care home.

- 5.10 The mean length of an inpatient stay is 14 days.

- 5.11 55% of inpatient admissions end in death.

- 5.12 The average length of time people were under the care of a day centre was around 6 months. 58% attended for 90 days or fewer and 24% attended for more than 180 days.

- 5.13 Compared to previous year's data, there has been an increase in the number of people receiving community care who died at home or in care homes while numbers of deaths in other settings has decreased.

- 5.14 Over 115,000 people were seen by specialist palliative care community teams with an average of 4.2 visits per person. 71,222 people were seen by Home Care teams, 10,661 were seen by Hospice at Home teams and 27,324 were seen by Combined Homecare and Hospice at Home teams.

*(Source: National Survey of Patient Activity Data for Specialist Palliative Care Services. MDS Full Report for the year 2009-2010. NCPC and NCoLCIN, 2011)*

## 6. What we know about primary care in the last year of life

### Quality and Outcome Framework (QOF):

QOF achievement for 2010/11 is presented for 8,245 general practices in England. There are two indicators for palliative care in the clinical domain:

- PC 2: The practice has regular (at least three monthly) multidisciplinary case review meetings where all patients on the palliative care register are discussed
- PC 3: The practice has a complete register available of all patients in need of palliative care/support irrespective of age.

6.1 In 2010/11 the QOF raw prevalence rate for palliative care register (based on all ages) was 0.2 (In 2009/10 the rate was 0.1) where raw prevalence = (number on clinical register / number on practice list) \* 100.

6.2 In 2010/11 the average practice score was 91.4 percentage points for palliative care (89.3% in 2009/10).

*(Source: Quality and Outcomes Framework 2010/2011, Information Centre)*

### Gold Standards Framework after death analysis:

6.3 People on the register get better care at the end of life than those not on the register:

- Among participating practices, 27% of all deaths were included on the palliative care register. A further 15% were thought by practices to have been predictable but were not put on the register
- 78% of people on the register were discussed at a team meeting in their final three months
- 58% of those on a register were offered a discussion about their preferences and wishes
- 65% of people on a palliative care register dying at home or in a care home received anticipatory prescribing
- 56% of those on the register had a preferred place of care recorded. Of those on the register who had a preferred place recorded, practices said 42% had died in their preferred place of care
- Practices said that for 50% of those on the palliative care register there had been some assessment of the carer's needs. (20% of all deaths).

6.4 There is more work to do to get people on the register – those with cancer are more likely to be on the register than others:

- 71% of people on a register had cancer yet just 28% of people dying had a primary diagnosis of cancer.

6.5 There is more work to do to improve end of life care, including supporting people with their preferred place of care and providing bereavement support:

- In assessing all deaths, including sudden deaths, 32% of families were offered bereavement support.

*(Source: GSF National Primary Care Audit in end of life care, 2009)*

- 6.6 The average GP cares for around 20 people who die each year with the following proportions:

Frailty/Comorbidity/Dementia	8
Cancer	5
Organ failure	5-6
Sudden unexpected death	1-2

*(Source: Prognostic Indicator Guidance 4th Edition Sept 2011 - © The Gold Standards Framework Centre In End of Life Care CIC, Thomas.K et al)*

- 6.7 A review of the literature reveals both GPs and community nurses view bereavement care as an important and satisfying part of their work, although one for which they have received little training. They are anxious not to 'medicalise' normal grief. Home visits, telephone consultations and condolence letters are all used.

*(Source: Bereavement care in primary care: a systematic literature review and narrative synthesis. Shobhana Nagraj and Stephen Barclay. Br J Gen Pract, January 2011)*

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

- 7.1 For people registered on an EPaCCS and would prefer to die in a care home, 98% achieve their preferred place of death.

*(Source: Weston Hospicecare review of 960 hospice records in last 2.5 years)*

- 7.2 A study of over 1200 people who died in two Local Authorities indicated that around 15-20% of people used a care home in the last 12 months of life. Yet the figure for a third area was much lower around 5%, indicating the scale of differences in social care provision.

*(Source: Social care and hospital use at the end of life. M Bardsley, T Georghiou, J Dixon. The Nuffield Trust. 2010)*

- 7.3 Benefits of the Gold Standard Framework were symptom control and communication but barriers were understanding of end of life care and gaining GP co-operation.

*(Source: Hall S, et al. Implementing a quality improvement programme in palliative care in care homes: a qualitative study, BMC Geriatr. 2011 Jun 9;11:31)*

- 7.4 16% of people living in care homes who are in the last week of life die in hospital following an admission in their last week of life.

- 7.5 The proportion of deaths in hospital following an admission in the last week of life from care homes is higher in London than in other regions.

*(Source: Barclay, S., Preliminary research findings (unpublished) with analysis of patient transfers from home and care home to hospital in England. University of Cambridge working with SWPHO)*

- 7.6 The average length of stay in BUPA care homes was 801 days (2 years 9 months).

- 7.7 The median period from admission to the care home to death is 462 days. (15 months).

- 7.8 Around 27% of people lived in care homes for more than three years.

- 7.9 People had a 55% chance of living for the first year after admission, which increased to nearly 70% for the second year before falling back over subsequent years.

*(Source: Length of stay in care homes. Julien Forder and Jose-Luis Fernandez, PSSRU Discussion Paper 2769, 2011)*

## 8. What we know about different disease groups

- 8.1 The proportions of deaths that occur in hospital varies by disease group. The following figures report 2010 data unless stated:
- 73% of liver disease deaths (2001–09)
  - 65% of respiratory disease deaths
  - 57% of cardiovascular deaths
  - 50% of renal disease deaths
  - 50% of deaths from external causes
  - 42% of neurodegenerative disease deaths
  - 41% of cancer deaths
  - 25% of deaths from Alzheimer's Disease, dementia or senility occur in hospital.
- 8.2 Place of death varies within a disease group:
- 68% of acute respiratory deaths and 66% of chronic obstructive pulmonary disease deaths occur in hospital
  - 43% of lung cancer deaths were in hospital
  - 16% of deaths from lung cancer occur in hospices (16%) compared to deaths from other respiratory causes that occur in hospices (approximately 1%).

*(Source: End of Life Care Profiles, Deaths from Renal Disease in England 2001-2008, Deaths from Neurodegenerative Diseases in England 2001-2008, Deaths from Respiratory Diseases, Deaths from Alzheimer's disease, dementia and senility in England, NEOLCIN, with updated 2010 data)*

### Liver Disease:

- 8.3 There has been a 25% increase in liver disease deaths between 2001 (9,231) and 2009 (11,575):
- 90% of people who die from liver disease are under 70 years old. More than 1 in 10 of deaths of people in their 40s are from liver disease. When measured as 'years of life lost', liver disease is therefore much more prominent.
  - Alcohol-related liver disease is the most common type of liver disease and accounts for 37% of all liver disease deaths. However, the prevalence of deaths from alcohol-related liver disease varies greatly between males (41% of liver disease deaths) and females (30% of liver disease deaths).
  - Alcohol-related liver disease is also more common in the most deprived areas (44% of liver disease deaths) than the least deprived areas (28% of liver disease deaths).
  - The complex needs of many people who die from liver disease mean that more than two thirds die in hospital, compared to 55% of all deaths from any cause (2009).

*(Source: Deaths from Liver Diseases: Implications for end of life care in England. NEOLCIN, February 2012)*

- 8.4 Homeless people with liver failure are an important and growing group with palliative care needs that are largely unmet.

*(Source: Supporting homeless people with advanced liver diseases approaching end of life. May 2011. St Mungos and Marie Curie Palliative Care Research Unit)*

- 8.5 22% of people living at home with cancer and who are in the last two days of life die in hospital following an admission in their final two days of life.

*(Source: Barclay, S., Preliminary research findings (unpublished) with analysis of patient transfers from home and care home to hospital in England. University of Cambridge working with SWPHO)*



**Dementia:**

- 8.6 There are currently 750,000 people with dementia in the UK. This will rise to over a million by 2021.
- 8.7 60,000 deaths a year are directly attributable to dementia.  
*(Source: Alzheimer's Society)*

**9. What we know about costs of care**

- 9.1 If all people who die in hospital stayed only a maximum of eight days, then the total estimated cost to commissioners would be lower by approximately £357m pa.  
*(Source: Ian Blunt Analysis of Hospital Cost data – Nuffield Trust unpublished)*
- 9.2 The estimated total cost of acute admissions ending in death in 2010-11 was over £520m.
- 9.3 In England a 10% reduction in the number of hospital admissions ending in death could potentially result in a saving of £52m.  
*(Source: CMG42 Guide for commissioners on end of life care for adults. NICE, 2011)*

**Quality Innovation Productivity and Prevention (QIPP) data:**

- 9.4 The majority of people admitted as emergencies in the last of year of life have only one or two such admissions. However in the five year period between 2004 and 2008 an annual average of 83,760 people had three or more emergency hospital admissions in the last year of life, which is almost a quarter of all people with at least one such admission.
- 9.5 The price of an inpatient admission in the last year of life that ends in death is estimated to range from £2,352 - £3,779, with NICE estimating the cost to be £2506.
- 9.6 The cost of an inpatient bed day in the episode of care that ends in death is estimated to range from £200 - £425.
- 9.7 Whilst there is considerable difficulty in measuring the costs of community-based end of life care, it is estimated to range from £1,415 - £2,800 per person, per episode at the end of life.
- 9.8 Taking a midpoint of the estimated inpatient (£3,065.50) and community-based (£2,107.50) end of life care costs, there is an estimated potential net saving of £958 per person who dies in the community.
- 9.9 A 10% reduction in bed days for the cohort with a length of stay of more than eight bed days ending in death could yield savings of around £57m in hospital costs at £200 per bed day. However, any reduction in bed days must be based on clinical need, quality of care and individuals' preferences. Additional costs in the community would be anticipated.  
*(Sources: QIPP Indicator for End of Life Care. Proposal of a new indicator, NEoLCIN, unpublished  
QIPP End of Life Care. Hospital admissions in the last year of life, NEoLCIN, unpublished  
QIPP Reviewing end of life care costing information, NEoLCP, Apr 2012)*

**Palliative Care Funding Review:**

- 9.10 The total cost of hospital admissions in the last year of life for adults admitted with a primary diagnosis indicating a palliative care need is in the region of £1.3bn. The estimated cost for children is estimated to be in the region of £18.2m. These estimated costs to the NHS far outweigh the cost of providing palliative care as they take into account all types of care, not strictly palliative care.  
*(Source: Analysis by the Department of Health of ONS mortality data from 2009 linked with HES data)*

- 9.11 Delivering improved recognition of palliative care needs, as well as optimised provision of services outside the hospital setting, could potentially reduce deaths in hospital by up to 60,000 a year by 2021. Using the QIPP estimate of £3,000 per hospital death, this would translate to a potential reduction in hospital costs of £180m per annum.

*(Source: Hughes-Hallet, T. et al., Funding the Right Care and Support for Everyone: Creating a fair and transparent funding system: the final report of the Palliative Care Funding Review. July 2011)*

- 9.12 Short-term early palliative care for people with multiple sclerosis may reduce costs as well as lessening caregiver burden.

*(Source: Higginson JJ, et al., Is short-term palliative care cost-effective in multiple sclerosis? A randomized phase II trial. J Pain Symptom Manage. 2009 Dec;38(6):816-26. Epub)*

## 10. What we know about unexpected / unanticipated deaths

- 10.1 At least 25% of all deaths in England and Wales are unexpected deaths from sudden causes. In the past estimates have varied between 8% and 42%. Many people with chronic disease may die unexpectedly and this would increase the proportion of unexpected deaths and would account for some of the discrepancy with the 42% of deaths described as 'sudden' or 'unpredictable' in the 'Omega report: End of Life care in primary care 2009 national snapshot'.

- 10.2 The proportion of unexpected deaths increases with age.

*(Source: Predicting death: estimating the proportion of deaths that are unexpected. NEoLCIN Report. Feb 2011)*

## 11. What we know about public attitudes

- 11.1 People are most scared of:

- Dying in pain (83%)
- Dying alone (67%)
- Being told they are dying (62%)
- Dying in hospital (59%)
- Going bankrupt (41%)
- Divorce/end of a long-term relationship (39%)
- Losing their job (38%)

*(Source: ComRes Opinion Poll for Dying Matters' 'No Dress Rehearsals', Aug 2011)*

- 11.2 The study exploring the experiences and perceptions of adults with advanced lung cancer highlighted a need to focus on supportive strategies that do not force people into discussions about the future, recognising that discussing death and dying could make it harder to cope or take away their sense of hope and so cause suffering for some people.

*(Source: Gillian Horne, Maintaining integrity in the face of death, PhD thesis submitted to the University of Nottingham, confirmed Dec 2010)*

## 12. What we know about workforce

- 12.1 Baseline data has been collected by several parties in order to identify the current number of palliative medicine consultants:
- The NHS Information Centre census reports that there were 251 head count (218 FTE) palliative medicine consultants employed in the NHS, in England as of September 2010
  - The Royal College of Physicians 2010 workforce census (RCP, 2011a) identified 433 palliative medicine consultants across the UK, of which 359 were in England
  - The Association of Palliative Medicine / Specialist Advisory Council 2010 census recorded consultant figures of 362 head count (245.5 FTE)
  - The Royal College of Physicians estimates that the ratio of Palliative Medicine consultants to population should be 2 FTE to 250,000 population. In order to achieve this, 466 FTE consultants would be required across the UK by 2013 (RCP, 2011b).
- Note:** APM/SAC and RCP figures include consultants working outside NHS e.g. in hospices, which may account for the difference with the NHS Information Centre figures.
- (Sources: NHS Information Centre for health and social care (2011) NHS Medical and Dental Staff – detailed results, online, accessed Mar 2012*  
*Royal College of Physicians (2011a) Census of consultant physicians and medical registrars in the UK, online, accessed Mar 2012*  
*Royal College of Physicians (2011b) Consultant physicians working with patients – 5th edition, online, accessed Mar 2012)*
- 12.2 The National Council for Palliative Care workforce survey has provided vital baseline data across all areas of Specialist Palliative Care, enabling us to assess workforce levels within both the NHS and voluntary sectors by cancer network. The longitudinal analysis of survey data has enabled us to draw out key trends such as:
- There has been an increase in nursing FTE of 12.3% between 2005 and 2010. However, numbers have been in decline since a peak of 6155 FTE in 2008
  - Three of the largest AHP groups reported within the SPC workforce in 2010 were: Occupational Therapists, Physiotherapists and Social Workers
  - There has been an overall increase in the consultant workforce of 20.4% (FTE) between 2005 and 2010. However, APM data has shown an increase of 19% in consultant numbers from 2005 to 2010
  - The majority of consultant respondents were reported as working in voluntary SPC units and NHS hospital support services.
- (Source: National End of Life Care Intelligence Network (2011) National Council for Palliative Care Specialist Palliative Care Workforce Survey, online, accessed Mar 2012).*
- 12.3 Palliative medicine recruitment data at ST3, by Deanery (as at October 2010) indicates that recruitment may be difficult in some regions. The total fill rate achieved was 65%.
- (Source: Centre for Workforce Intelligence (2011) Medical specialty workforce factsheet – palliative medicine, online, accessed Mar 2012)*
- 12.4 Based on an analysis of the palliative medicine workforce for NHS England against Modified Index Values (M.I.Vs), there is evidence of wide variation among Strategic Health Authorities (SHAs) in terms of how the workforce is proportioned. For example, the analysis indicates London may be oversupplied in terms of junior doctors and consultants, whereas the North East SHA may be undersupplied.
- (Source: Centre for Workforce Intelligence (2011) Medical specialty workforce factsheet – palliative medicine, online, accessed Mar 2012)*

- 12.5 The number of specialist palliative care nurses fell by 6.9% from 2008 to 2010.
- 12.6 Average vacancy rate among specialist palliative care nurses of 8.7% and among specialist palliative care consultants of 7.8%.
- 12.7 Almost 4 out of 10 (39%) specialist palliative care nurses are over the age of 50, as are 44.7% of social workers, 36.3% of physiotherapists, 25.3% of occupational therapists and 27.5% of specialist palliative care consultants.
- (Source: National End of Life Care Intelligence Network (2011) National Council for Palliative Care Specialist Palliative Care Workforce Survey 2010, online, accessed Mar 2012)*

### 13. What we know about competences and training

- 13.1 While the knowledge of most GPs and community nurses is sound in some key areas of end of life care, there remain significant educational needs for both professional groups. The following educational needs were identified:
- Dose conversion of oral to subcutaneous opioids
  - Co-prescribing of laxatives and anti-emetics when commencing strong opioids
  - The use of a quick-acting opioid for the management of breakthrough pain
  - The use of radiotherapy and bisphosphonates in managing bone pain
  - The broad range of indications for use of a syringe driver
  - The availability of services out of hours to support people at the end of life at home.
- (Source: Momen N et al., Report of study to investigate the knowledge and prescribing habits of Peterborough and Cambridgeshire GPs and CNs, CLAHRC for Cambridge and Peterborough)*
- 13.2 A review of the literature concerning conversations about end of life care between people with heart failure and healthcare professionals found conversations focus largely on disease management and end of life care is rarely discussed. Clinicians are unsure how to discuss the uncertain prognosis and risk of sudden death, fearing causing premature alarm and destroying hope.
- (Source: S Barclay et al., End-of-life care conversations with heart failure patients: a systematic literature review and narrative synthesis. Br J Gen Pract 2011; DOI: 10.3399/bjgp11X549018)*

### 14. What we know about quality of care

#### Results of a pilot VOICES survey carried out in East Berkshire and the Isle of Wight during 2011:

- 14.1 Ratings of the quality of care varied between care sectors with care provided by hospices most consistently rated as excellent (79%) and care provided out of hours receiving the lowest ratings for excellent (23.8%).
- 14.2 Ratings of staff groups most likely to treat people with respect and dignity all the time varied with hospice doctors most likely (91.8%) to hospital nurses least likely (48.4%).
- 14.3 In the last two days of life, people with cancer were more likely to be treated with dignity and respect than those with other causes of death.

- 14.4 Those who died from cardiovascular disease were less likely to report that community services worked well together than those dying from other conditions.
- 14.5 Out of all care settings, hospices were most likely to relieve pain 'completely, all the time' (59.6%).
- 14.6 People who died in hospital were less likely to receive enough help with personal care than those who died at home, hospice or care home.
- 14.7 People dying from cancer were more likely to have a record of their preferences than those with other conditions.

*(Source: VOICES Redesign and Testing to Inform a National End of Life Care Survey. Final Report for the Department of Health, July 2011)*

- 14.8 A study exploring service user, clinician and commissioner views on continuity of care for adults with advanced cancer highlighted that systems for information transfer and for overseeing care were problematic. It found a lack of role clarity between generalists and specialists causing tensions and confusion. User led outcomes were suggested to measure continuity of care.

*(Source: Sean Hughes, Living with advanced cancer: an exploration of continuity of care. PhD thesis submitted to the University of Manchester, Dec 2009)*

## 15. What we know about need and trends in deaths

### Palliative Care Funding Review:

- 15.1 Up to 457,000 people need good palliative care services every year but around 92,000 people are not being reached.

*(Source: Hughes-Hallet, T. et al., Funding the Right Care and Support for Everyone: Creating a fair and transparent funding system: the final report of the Palliative Care Funding Review, July 2011)*

### Office for National Statistics:

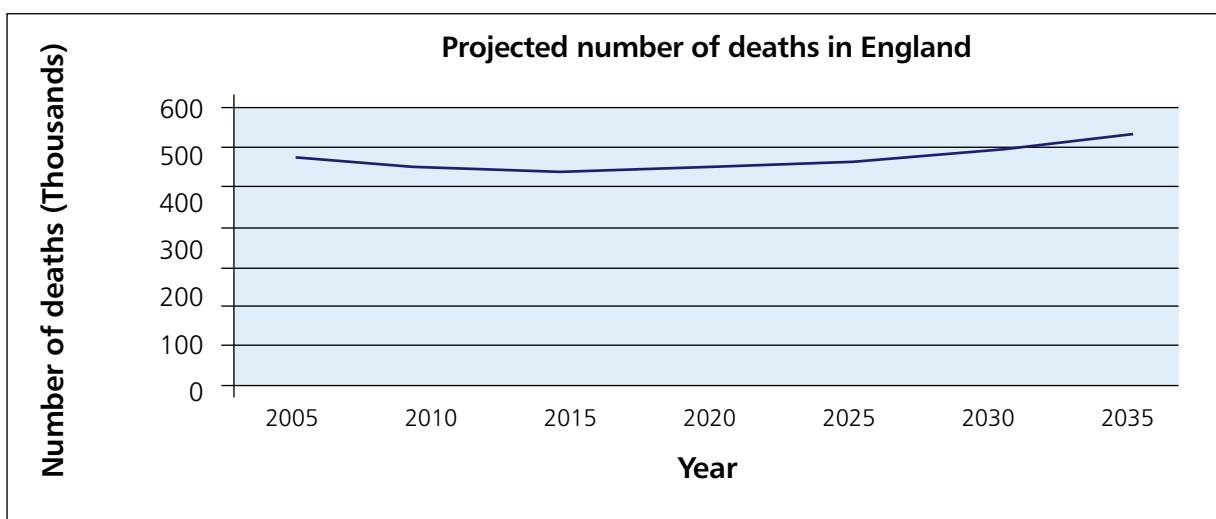


Figure 5: ONS projected number of deaths in England

*(Source: ONS 2008 based population projections)*

15.2 460,000 people die each year in England. This has fallen from 497,878 in 2001 to 461,016 in 2010 but predicted to rise to 499,000 per year by 2030.

(Source: *ONS 2008 based population projections*)

15.3 Two thirds of people who die are age 75 or over (66.9% in 2010).

15.4 More than one third of people who die are aged 85 and over (36.8% in 2010).

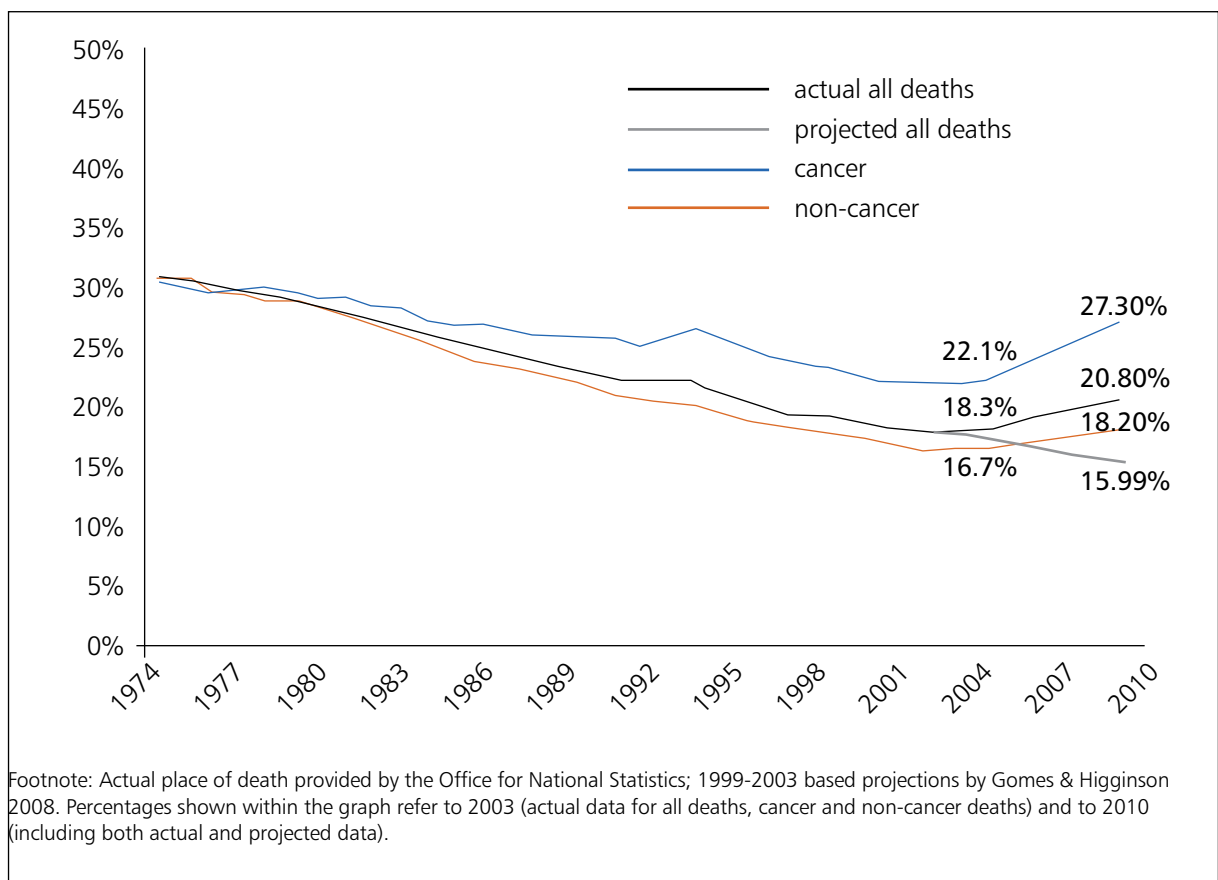
(Source: *Variations in Place of Death England 2010 and End of Life Care Profiles, NEO LCIN*)

15.5 The 2010 age-standardised mortality rates for both males and females were the lowest ever recorded in England and Wales.

(Source: *ONS Deaths registered in England and Wales in 2010, by cause*)

15.6 The proportion of deaths at home rose from 18.3% in 2004 to 20.8% in 2010. Absolute numbers of home deaths increased by 9.1%, while overall numbers of deaths decreased by 3.8%.

15.7 The rise in home deaths was more pronounced in cancer, happened for both genders and across all age groups, except for those younger than 14 years and for those aged 65–84, but only up to 2006. The rise was more evident when ageing was accounted for (age–gender standardised proportions of home deaths increased from 20.6% to 23.5%).



**Figure 6: Proportion of home deaths in England and Wales 1974-2010**

(Source: *Gomes B. et al., Reversal of the British trends in place of death. Time series analysis 2004-2010. Palliative Medicine, 2012 Jan 18 [Epub ahead of print]*)

## 16. What we know about other research relating to end of life care

- 16.1 Short-term palliative care is effective in reducing symptoms and caregiver burden in multiple sclerosis.  
*(Source: Higginson IJ, et al., Is short-term palliative care cost-effective in multiple sclerosis? A randomized phase II trial. J Pain Symptom Manage. 2009 Dec;38(6):816-26. Epub)*
- 16.2 Dignity therapy may be possible to implement to improve dignity in care home.  
*(Source: Hall S, et al., Feasibility, acceptability and potential effectiveness of Dignity Therapy for older people in care homes: A phase II randomized controlled trial of a brief palliative care psychotherapy. Palliat Med. 2011 Aug 22. [Epub ahead of print])*
- 16.3 There is some evidence on the effectiveness of hospice care in improving outcomes.  
*(Source: Candy B, et al., Hospice care delivered at home, in nursing homes and in dedicated hospice facilities: A systematic review of quantitative and qualitative evidence. International Journal of Nursing Studies 2011 Jan;48(1):121-33. Epub 2010 Sep 16. Review)*
- 16.4 Methylnaltrexone may work for constipation.  
*(Source: Candy B, et al., Laxatives or methylnaltrexone for the management of constipation in palliative care patients. Sao Paulo Medical Journal 2011;129(4):277)*
- 16.5 Interventions for carers should be well thought through and include carer views in their design.  
*(Source: Candy B, et al., Interventions for supporting informal caregivers of patients in the terminal phase of a disease. Cochrane Database Syst Rev. 2011 Jun 15;(6):CD007617. Review)*
- 16.6 Good psychological flexibility helps both psychological function and physical function.  
*(Source: Low J, et al., The Role of Acceptance in Rehabilitation in Life-Threatening Illness. Journal of Pain and Symptom Management. 2011 Aug 18. [Epub ahead of print])*
- 16.7 Early palliative care, alongside standard oncologic care, for people with metastatic non-small-cell lung cancer improves quality of life and mood and extends length of life when compared with those receiving standard oncologic care alone.  
*(Source: Temel J, et al., Early palliative care for patients with metastatic non-small-cell lung cancer, NEJM 2010)*
- 16.8 Impaired cognitive function is an independent predictor of mortality.  
*(Source: Sampson EL, et al., Survival of community-dwelling older people: the effect of cognitive impairment and social engagement. J Am Geriatr Soc. 2009 Jun;57(6):985-91)*
- 16.9 Palliative care in heart failure is important.  
*(Source: Low J, et al., Palliative care in advanced heart failure: an international review of the perspectives of recipients and health professionals on care provision. J Card Fail. 2011 Mar;17(3):231-52. Epub 2010 Dec 3)*

**People with learning disabilities:**

- 16.10 The support needs of people with learning disabilities who have a relative or friend with cancer are more important than their information needs:
- The most important support and information needs of this group are: (1) to be included and not protected from the situation; (2) to have someone who can listen to questions and concerns, and who can offer a supportive presence; (3) to have access to information that is easy to understand; and (4) to have sensitive bereavement support
  - People with learning disabilities tend to 'keep quiet', and often do not ask questions or express true feelings to those who might be able to help
  - People with learning disabilities lack access to easy-read information materials, even if they exist; they rely on others to enable them to access such materials.

*(Source: Tuffrey-Wijne, I., et al., Supporting people with learning disabilities who are affected by a relative or friend with cancer: Final Report. Macmillan Cancer Support, 2011)*

- 16.11 Existing models for breaking bad news are inadequate for people with learning disabilities:
- Breaking bad news to people with learning disabilities should be seen as a process, not a one-off event or series of events
  - Understanding of bad news is built gradually over time. Information needs to be broken down into singular chunks of knowledge that can be added over time to people's existing knowledge base
  - Breaking bad news to people with learning disabilities should involve health and social care professionals as well as (family) carers and paid care staff
  - A new model for breaking bad news that has been developed for people with learning disabilities may also have relevance for other client groups.

*(Source: Tuffrey-Wijne, I. A new model for breaking bad news to people with intellectual disabilities, Palliative Medicine published online Jan 2012)*

**Children with life-limiting and life-threatening conditions:**

- 16.12 There is poor awareness of services by families and professionals and a lack of co-ordination between those involved in delivering children's palliative care.
- 16.13 Key working is seen by families as a necessity for helping navigate the complex health, education and social care systems. There is a reported lack of a key worker/key contact to support children and families.
- 16.14 There are concerns about the availability of support for young people making the transition to adulthood.
- 16.15 Funding and the future sustainability of children's palliative care provision is a concern. Effective national leadership and partnerships were seen as vital to making the most of resources.

*(Source: The UK wide Square Table Programme, Report by Together for Short Lives published 2012)*

- 16.16 The number of children and young adults in England with life-limiting and life-threatening conditions who are surviving into adulthood is far higher than had previously been thought and is increasing year on year, particularly in the 16-19 age group.

- 16.17 It is estimated that there are about 40,000 children in England currently living with a life limiting condition. As numbers continue to rise, this will place a growing burden on paediatric palliative care providers and young adult services, particularly in deprived areas.

*(Source: L Fraser et al. Rising National Prevalence of Life-Limiting Conditions in Children in England, Pediatrics 2012;129:1-7)*

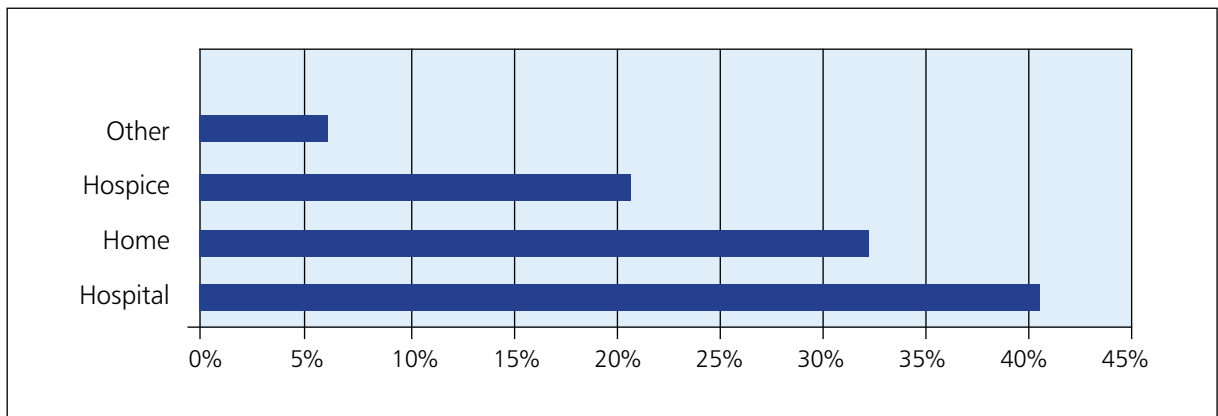


**Survey of Children's Hospice Providers in UK 2010/11:**

Data collected from 35 children's hospice providers in the UK, reporting on 46 hospice care services, including hospice at home services and community outreach teams.

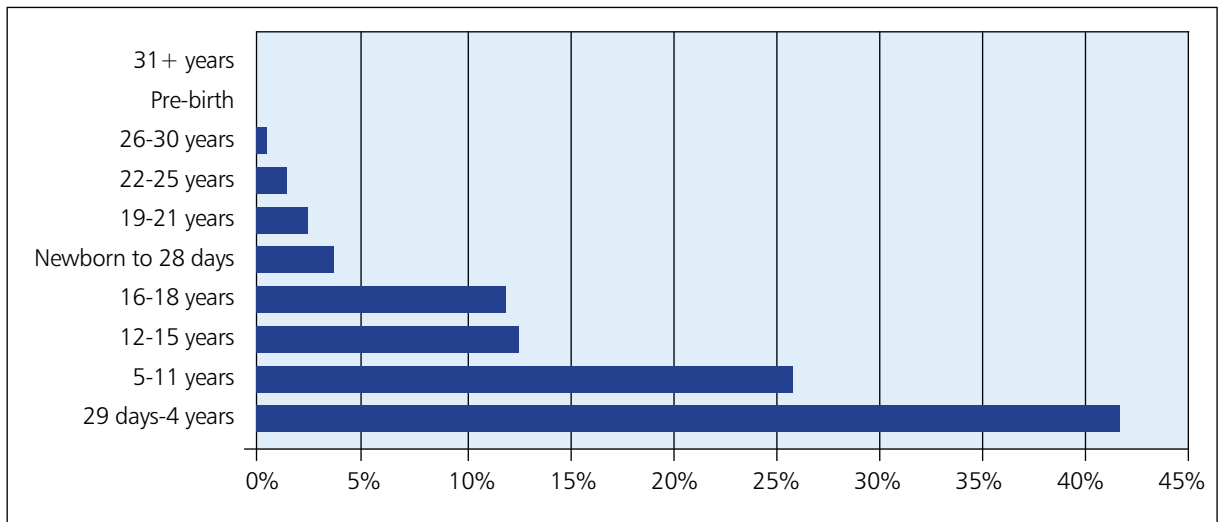
16.18 Services supported 7,101 children and young people and 9,182 families (includes support to 2,986 bereaved families).

16.19 The total number of deaths reported was 729:



**Figure 7: Percentage of deaths by location of death**

16.20 Of the 612 deaths reported by age band: 41% were in '29day-4years old' age band and 25% in the '5-11years old' age band.



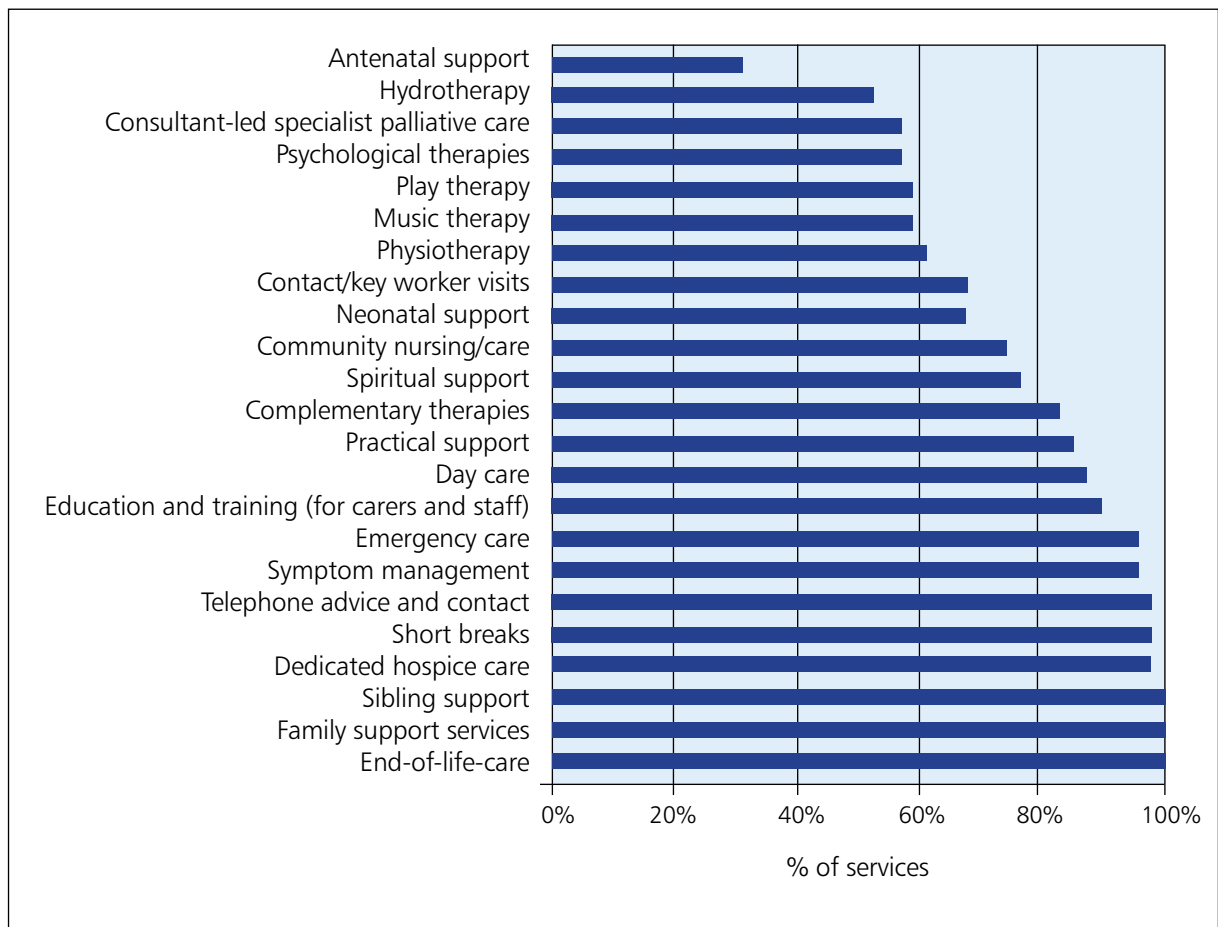
**Figure 8: Percentage of deaths by age band**

16.21 The direct care team in post reported was 1,482 FTE. Nurses made up 52% (767 FTE) of the workforce of which 32% were Registered Sick Children's Nurse/Registered Nurse (Child). NVQ qualified healthcare workers made up 21% and medical staff accounted for 1.4%.

16.22 In terms of provision, 11 of the 45 services (24%) reported a separate wing or building for young people and 39 of the 45 services (87%) has staff specifically trained to work with young people.

16.23 In terms of transition, 24 of the 45 services (53%) provided adult services within the same organisation. Of these 75% had internal arrangements for the transition of young people between their child and adult services and 72% had key worker arrangements in place to provide ongoing support into adult services. Of the 21 services whose organisations did not also provide adult services, 67% had arrangements in place for transition to adult services outside the organisation and 29% provided a key worker for ongoing support.

16.24 The 46 hospice care services reported providing a range of services:



**Figure 9: Types of hospice service provided by UK children's hospices (2010/11)**

*(Source: Children's Hospice Service Provision 2010/11. Durham University Mapping Unit with former Children's Hospices UK, June 2011)*

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[www.endoflifecare-intelligence.org.uk](http://www.endoflifecare-intelligence.org.uk)

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### **About the National End of Life Care Intelligence Network**

The Department of Health's National End of Life Care Strategy, published in 2008, pledged to commission a National End of Life Care Intelligence Network (NEoLCIN). The Network was launched in May 2010. It is tasked with collating existing data and information on end of life care for adults in England. This is with the aim of helping the NHS and its partners 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.

### **Key partners**

Key partners include the National Cancer Intelligence Network, which will work closely with the Network to improve end of life care intelligence; and the South West Public Health Observatory, lead public health observatory for end of life care, which hosts the NEoLCIN website. The SWPHO has been commissioned to produce key outputs and analyses for the Network, including the national End of Life Care Profiles.